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Is “Active Surveillance” an Acceptable Alternative? A Qualitative Study of Couples’ Decision Making about Early-Stage, Localized Prostate Cancer

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Abstract

The objective of our study was to describe decision making by men and their partners regarding active surveillance (AS) or treatment for early-stage, localized prostate cancer. Fifteen couples were recruited from a Cancer center multispecialty clinic, which gave full information about all options, including AS. Data were collected via individual, semi-structured telephone interviews. Most patients were white, non-Hispanic, had private insurance, had completed at least some college, and were aged 49–72 years. Ten chose AS. All partners were female, and couples reported strong marital satisfaction and cohesion. All couples described similar sequences of a highly emotional initial reaction and desire to be rid of the cancer, information seeking, and decision making. The choice of AS was built on a nuanced evaluation of the man's condition in which the couple differentiated prostate cancer from other cancers and early stage from later stages, wanted to avoid/delay side effects, and trusted the AS protocol to identify negative changes in time for successful treatment. Treated couples continued to want immediate treatment to remove the cancer. We concluded that having a partner's support for AS may help a man feel more comfortable with choosing and adhering to AS. Using decision aids that address both a man's and his partner's concerns regarding AS may increase its acceptability. Our research shows that some patients want to and do involve their partners in the decision-making process. Ethical issues are related to the tension between desire for partner involvement and the importance of the patient as autonomous decision-maker. The extended period of decision making, particularly for AS, is also an ethical issue that requires additional support for patients and couples in the making of fully informed choices that includes AS.

Keywords

Active Surveillance; Couples; Decision Making; Prostate Neoplasm; Qualitative

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Introduction

Although there is growing recognition of active surveillance (AS) as a reasonable management option for many men with early-stage prostate cancer, it is selected by only 10% of U.S. men (Andriole et al., 2009). Factors identified as influencing patients' acceptance and adherence to AS are multidimensional and include personal preferences, physician recommendation, and the opinions of family and friends (Gorin, Soloway, Eldefrawy, & Soloway, 2011; Penson, 2012). Treatment decisions often occur within the context of social networks, with patients relying on their partners (e.g., wives, significant others) for support and help in making decisions (Emslie et al., 2009; Schumm, Skea, McKee, & N'Dow, 2010; Speice et al., 2000; Zeliadt et al., 2011). Partners also play important roles in information seeking (Boehmer & Clark, 2001; Davison, Goldenberg, Gleave, & Degner, 2003; Echlin & Rees, 2002; Resendes & McCorkle, 2006).

Studies of decisions about the treatment of prostate cancer have concentrated on immediate or active treatment options such as prostatectomy, brachytherapy, or external beam radiation (Chamie et al., 2012; Zeliadt et al., 2011). In particular, studies that examined decisions of couples have rarely included those who have considered active surveillance. Each type of treatment for prostate cancer has advantages and disadvantages that may be weighed differently by patients and by their partners. For instance, partners tend to be less tolerant of uncertainty and most often want to take care of the cancer right away (Davison, Oliffe, Pickles, & Mroz, 2009; Holmboe & Concato, 2000). Patients' partners (e.g., wives) also prefer for the patients (e.g., husbands) to receive curative treatment, especially prostatectomy, rather than active surveillance, expectant management, or watchful waiting (Pickles et al., 2007; Srirangam et al., 2003). In addition, patients and their partners may prioritize outcomes differently. Past research shows that patients prioritize quality of life while partners prioritize quantity of life when thinking about treatment (Srirangam et al., 2003; Volk et al., 2004).

Most studies looking at how prostate cancer treatment decisions are made have focused on the process between the patient and the health care provider (Davison et al., 2009; Ernstmann et al., 2012; Underwood et al., 2010; Zikmund-Fisher et al., 2010). Fewer studies have looked at the decision process of patients and their partners (Boehmer & Clark, 2001; Schumm et al., 2010; Zeliadt et al., 2011). To the best of our knowledge, no published studies have included couples who chose active surveillance as well as couples who chose treatment for early-stage, localized prostate cancer. This study describes the decision-making processes used by a convenience sample of couples who made a decision in a multispecialty clinic setting where information about all treatment options, including active surveillance, was available. Specifically based on individual interviews with men and their partners, we describe their recollections of initial reactions to the cancer diagnosis, their information seeking, and the process of making the treatment decision.

Participants and Methods

Setting and sample

Participants were recruited from the Multidisciplinary Prostate Cancer Clinic (MPCC) at The University of Texas MD Anderson Cancer Center. One of the goals of the MPCC is to educate men about their management choices based on a thorough assessment of their life expectancy, comorbidities, and other medical and psychosocial concerns such as anxiety. The clinic schedules a patient for several appointments in a single day with members of a multidisciplinary team including a urologist, a radiation oncologist, an advanced practice registered nurse, and a medical oncologist as necessary for more aggressive disease. The team makes a joint recommendation to the patient about treatment options, including AS. Patients make the final decision and are referred to a treatment team or to an AS protocol.

This article is based on a subsample of a larger qualitative study. MPCC patients who were eligible to participate in our study were: 1) diagnosed with localized prostate cancer, defined as cancer that had not spread beyond the prostate gland at the time of diagnosis, 2) English speaking, and 3) had a partner who was willing to participate in the study and to be interviewed separately. Patients were sampled to include those who selected AS or immediate treatment (T). The AS patients had no evidence of more aggressive disease on re-biopsy prior to initiating AS (a requirement of the AS protocol) and were within 6–18 months of their decision to be on the AS protocol. This time frame was selected because few men would have transitioned to active treatment due to disease progression, yet all would have several months' experience with the AS protocol, including returning for surveillance testing. Treated men had chosen some form of surgery or radiation and were within 6–18 months of completing treatment (the date of surgery or completion of a course of radiation) so that the acute recovery period would be over and most patients would have achieved continence.

An advanced practice registered nurse confirmed the eligibility of men based on review of medical records and contacted them about participating in the study. Of the 36 men who were contacted, 30 agreed to participate in the larger qualitative study. Men were asked if they were in a relationship (i.e., married or involved with someone they consider their partner) and, if yes, for permission to contact this person. This study of couples was limited to 17 men with partners who were also willing to participate. However, two couples were excluded from the analyses because the men were not offered AS, resulting in a study sample of 15 couples.

The project was reviewed and approved for use with human participants by the Institutional Review Board of The University of Texas MD Anderson Cancer Center and the Committee for the Protection of Human Subjects at The University of Texas School of Public Health..

Measures and interview procedures

A research coordinator scheduled men and their partners for separate telephone interviews, which took place between May and August 2011. All interviews were conducted by RV (health services researcher), YL (psychologist), or a research assistant. No interviewers had prior relationships with the patients. Interviewers telephoned most participants at home,

asking them to take the call in a private setting away from their partners. Participants were questioned by interviewers of the same sex, and the interviews were audio-recorded and transcribed. Each participant received \$50.00 as compensation.

Interviews were scheduled for one hour and included an informed consent process, close-ended questions about social characteristics, relationship attributes, and information about the treatments received, followed by semi-structured questions about the participants' decisions. The close-ended questions assessed: 1) age; 2) education; 3) race/ethnicity; 4) household income; 5) which treatment options, including active surveillance, had been offered; 6) which treatment option was selected; 7) the role each member of the couple played in the treatment decision; and 8) the couple's adjustment and coping. We used modified items from the Control Preferences Scale (Degner et al., 1997) to measure the participants' perceptions of the decision-making role that each member of the couple took in the treatment decision. Responses ranged from "preferred to make the decision on the patient's own," to "shared equally in decision making," to "preferred that the partner make the decision." Dyadic adjustment was measured using the 14-item Revised Dyadic Adjustment Scale with dyadic consensus, dyadic satisfaction, and dyadic cohesion (Busby, Christensen, Crane, & Larson, 1995). Sample items included "How often do you and your partner quarrel?" and "How often do you and your partner engage in outside interests together?" Responses ranged from "all the time" to "none of the time."

The semi-structured part of the interview included questions about the treatment options offered to the patient, how the patient and partner discussed and considered the choices, and how the respondent would describe AS. For example, we asked, "Could you tell me in your own words what active surveillance is all about?" We also asked about sources of information consulted—for example, whether patients or partners made use of the Internet, books, and other written materials or talked with others who have prostate cancer—what role each member of the couple played in making the treatment decision, and whether members of couples selecting AS had seen any pressure from others to consider immediate treatment. Questions were also included about the importance of specific treatment-related side effects (i.e., impotence, urinary incontinence, and bowel incontinence) and other quality-of-life issues that might have been related to the treatment choice.

The interviews concluded with a question about lessons for other patients and partners who are facing similar treatment decisions. Interviews lasted between 20 and 65 minutes. During the period when the interviews were being conducted, interviewers met weekly and discussed participants' responses and the similarities and differences in responses across participants. Based on the discussion, minor modifications were made to the interview schedule to improve the elicitation of respondents' accounts of decision making, but the questions remained essentially the same.

Data analysis

The analysis was conducted by four of the authors (TB, YL, PDM, SM), none of whom had a prior relationship with the study participants. We used the couple as the unit of analysis in identifying thematic patterns (Braun & Clarke, 2006) for the 15 patient-partner dyads. All interviews were reviewed independently by all analysts to identify broad themes. A coding

table was then devised with three main themes: 1) initial reactions to the diagnosis, 2) information seeking, and 3) making the decision. Each interview was then re-read and coded by at least two analysts. Disagreements in coding were resolved by discussion among all analysts. We looked for overlaps and contrasts across the individual accounts of the decision. Joint consideration of the answers of each partner added information and allowed us to identify areas of agreement or divergence within each couple (Eisikovits & Koren, 2010). Analyses also compared couples in which the man chose AS with those who chose immediate treatment. For the sample description, we compared the percentages in AS and treated groups. Although the sample size was not adequate for quantitative analysis, the purpose of the comparison was to provide information about the perceived quality of relationships in interviewed couples. We do not consider this a true mixed methods study because the sample size was too small for quantitative analysis.

Results

Ten men were being followed on an AS protocol and another five had completed treatment (T) (Table 1). Patients were somewhat older than their partners. Most participants had at least some college and were white. All partners were female and were married or viewed themselves in a marriage-like relationship (we will refer to all as “partners” regardless of marital status). Overall, couples reported high dyadic adjustment, finding their marital interactions satisfying and their relationships cohesive. Dyadic adjustment scores did not appear to differ between AS couples and treated couples. The majority of the couples perceived the decision making to be collaborative, although patients were more likely to describe shared responsibility and partners to say that the patient had made the decision after considering the partner's point of view. Six patients (5 AS, 1 T) reported making the decision themselves. Four patients said that they had made the decision after considering their partner's opinion (2 AS, 2 T), and five said that the decision was a shared responsibility (3 AS, 2 T). Men choosing AS were more likely to say that they had made the decision themselves than were men choosing active treatment. A larger proportion of partners in the T group (80%) than in AS (40%) said that the patient made the decision after seriously considering the partner's opinion (4 AS partners, 4 T partners).

Guided by the interview structure, both AS and T couples described their interactions in three periods: initial diagnosis, information seeking before and after enrolling as patients in the MPCC, and making the decision. Our analysis focused on their accounts of their decision-making process as well as advice that they would give to other couples. We identify quotations with an arbitrary couple number, with H for patient/husband and W for partner/wife, AS for active surveillance and T for treatment.

Initial reactions to the diagnosis

Some men had had a biopsy following an elevated or rising PSA test. Others received a biopsy in conjunction with treatment for a urologic condition. The initial news of the diagnosis took place in the office of a community-based urologist who communicated the biopsy results and presented information about treatment options. All respondents characterized the session as presenting a lot of information to be absorbed at a time of

heightened emotion. One partner explained, “not only are you told that you have cancer, but now you're being presented with so many options. So it is a lot to digest at one time” (3W, AS). Her husband expressed his reaction in this way: “I just heard the word ‘cancer’ and that was serious enough right there, so I was figuring I would get rid of it” (3H, AS). In a similar summary, a man treated with proton radiation told us, “My first thing was to get it out of there” (8H, T). His partner said, “We wanted to be aggressive with it and to put a stop to it” (8W, T). We see the heightened emotion expressed in statements about the importance of getting the cancer out of the body.

Even more than a year after diagnosis, the couples' accounts were highly expressive. One partner summarized her experience in this way: “When you hear the word ‘cancer,’ the first thing you think of is getting rid of the cancer.” She contrasted it with their later reactions, “. . . when we became more informed, we realized there were more options” (1W, AS). In the discussions about their initial reaction to the diagnosis, couples were in agreement about what had occurred and about how they had reacted to the news. This convergence was seen in both treated and AS couples.

We saw divergence, however, in the views of AS and treated couples regarding lessons they had for other couples facing this decision. The AS couples, both men and their partners, counseled the importance of not getting too upset, of staying calm and not succumbing to panic. This was coupled with the message not to rush into a choice, that there is “no need to run off and get treatment” (29H, AS). Although they may not have initially reacted in this way, it is the advice they wished to convey to others facing a similar decision. Their recommendations indicated that their perspectives on the sense of imminent threat had changed over time and that some men had changed faster than their partners. For treated couples, the sense of urgency did not change.

Information seeking

Couples in this study, none of whom made a treatment decision in the session in which they learned of the diagnosis, began an information-seeking phase that lasted from two weeks to several months. During this time, couples often sought information from the Internet, physicians, support groups, and friends and family members who had experienced cancer. Generally, they sought information from multiple sources. AS and treated couples provided similar descriptions of the process of information seeking, although they differed with respect to their relative emphasis (or lack of emphasis) on AS. Some AS couples spent a longer time in the information-seeking phase because they lived in places where AS was not readily available, and they had to actively seek out and travel to treatment centers offering it as a treatment option.

Both men and their partners reported that the partner was involved in information seeking. One exception was a treated couple in which the man enlisted his brother in his research on prostate cancer; however, he did discuss what he found with his wife. Respondents often described playing a specialized role in information seeking based on such skills as facility with computers and the Internet, processing or understanding statistical or scientific information, or note taking and organizing information. Another specialized skill was

networking with friends and community members to learn about the experiences of others who had been treated for prostate cancer.

Making the decision

In general, patients described their partners as being very involved in decision making. Similarly, partners described themselves as having been very involved in making the decision regarding the patients' treatment choice: that is, we heard much "we" talk in discussions of the decision. This is consistent with findings from the close-ended question about the role the partners played (see table 1). Both AS and treated couples described the decision as being ultimately up to the man, as the person with cancer. As one partner said, "We agreed that whatever he decided on, that we would do it as a team" (10W, AS). Another partner summarized, "We went to all the doctors together, got all the information together and then we would discuss it, but the ultimate decision was his" (8W, T). Although both the men and their partners talked about the importance of partner involvement, partners provided more detailed accounts of how they participated.

The decision for treatment or AS is one of fundamental trade-offs. For localized prostate cancer the difference in terms of benefit in survival is small, and all the active treatments present the risk of side effects including impotence and urinary incontinence. AS and treated couples evaluated the trade-offs differently.

Selecting AS—The AS couples tended to move quickly to a position of reconsidering the gravity of this cancer diagnosis. This process took a variety of forms, which were often combined. For example, at a general level, couples would refer to prostate cancer as being a condition that a man dies *with*, rather than dies *from*, or would emphasize that prostate cancer is frequently a slow-growing or less aggressive type of cancer. Regarding their specific situation, they characterized the cancer as being "low grade," referring to the Gleason scores of the biopsy samples. The men, in particular, numerically described their biopsy results in a fashion that pointed out that their condition should not be seen as highly risky. As one man described his results, "of the 12 samples, there were cancer cells found in only 5% of the tissue in one of the 12 samples" (17H, AS). His partner echoed that language in referring to "the minor part of the biopsy that was cancerous" (17W, AS).

The AS couples also considered the possible side effects of active treatment (i.e., urinary incontinence, fecal incontinence, sexual dysfunction) when making a decision. The men, and sometimes the partners, discussed the importance of avoiding treatment-related side effects. As one man said,

Well, the advantages are not having to worry about incontinence and sexual dysfunction. I feel fine. My health is—if it weren't for the biopsy, I would have no way of knowing that I have cancer because my health is excellent, and it just seemed to me that why endure these side effects of treatment when if I—as long as I'm keeping a close eye on it with my doctors, I can possibly prolong this for a number of years. (12H, AS)

Similarly, his partner talked about the patient's desire to avoid side effects and her conclusion that the low-risk features of his condition would permit him to avoid the risk of side effects:

Well, the advantages were that he wouldn't have to have the surgery, of course, and the recovery from that. And he was concerned about incontinence and things like that with surgery, or even with the radiology. So it felt like this was a good thing for him with his low scores and just the one sample having cancer. (12W, AS)

The acceptance of AS was also supported by the couples' confidence in it as a system of regular surveillance activities. One partner defined the AS program as a "regimen of testing at periodic times to make sure that the amount of cancer has not grown. Keeping on top of his situation so that if anything gets worse, then he can choose a different treatment" (1W, AS). Several important elements are expressed in that remark. First, that AS is not just waiting, but being tested at specific times and using the results to judge how the man's condition has changed. This statement also echoed the position that there would be additional opportunities to choose to be treated, and that they would not have missed their chance at effective treatment by waiting. Because AS was presented as a system with a defined protocol, the couple do not feel as if they are alone in the decision but that they are supported by the monitoring and the structured opportunities to evaluate the man's condition and life circumstances. Having learned that the risk was smaller than first perceived, that the couple would have support in monitoring the man's condition in the AS protocol, and that there would be additional opportunities to opt for treatment, provided support for the decision for AS. One wife said, "If we ended up with not so great numbers or yucky dirty looking biopsies, he agreed to come off study [AS protocol] and have it removed" (16W, AS).

Selecting immediate treatment for prostate cancer—The couples who ultimately chose treatment faced the same central trade-offs. Unlike AS couples, they continued to emphasize the importance of getting the cancer out, to have a cure and to be done with the process. Both men and their partners articulated the risks of side effects from treatment but considered them secondary to eradicating the cancer:

We knew about the side effects—about the erectile dysfunction and about the bladder control issue. But, to me, those were only secondary problems; they could be overcome. You can always make adjustments in your life to overcome those or adjust to them. Our main factor was his survival rate. (27W, T)

A man treated with robotic surgery summarized,

The urinary incontinence was probably the biggest concern that I had, followed by the sexual side effects. But bottom line is, having surgery, being alive, being viable—overrode all of those concerns . . . If the surgery is a success, and I'm going to live, then I'll deal with the other issues. (23H, T)

In general, these couples described making a decision among various treatments, rather than between AS and one or more treatments. For example, in describing treatments, they related them to features of their own lives; the man quoted above described himself as being young

and able to recover from surgery, while other men cited their ages or other health conditions that would make surgery more risky. Other men, particularly those still employed, did not want to take on a radiation treatment regimen stretching over weeks.

The idea of keeping the decision open, of being able to delay having treatment, which appealed to the AS couples, was not attractive to the couples who chose treatment. They were selecting a “final” solution. As one partner said, “They told us about it [AS] but I said that we did not want to wait. We did not want him to have cancer anymore. And the thought of waiting to see if it was going to spread more rapidly was not an option for us. We couldn't deal with that. We wanted him well” (21W, T).

Discussion

This study describes couples' recollections of their initial reactions to the diagnosis of prostate cancer, their information seeking, and the process of making the treatment decision for early-stage, localized prostate cancer at a multispecialty treatment clinic. What is unique about our study is the inclusion of couples who selected AS, because partners have generally not been supportive of AS (Penson, 2012; Schumm et al., 2010). We found that the decision-making process of these couples, resulting in the man choosing AS, shared similarities with that of couples with the man choosing treatment. In line with previous studies of treated couples (Zeliadt et al., 2011), we found that partners of men who chose AS and treatment often attended clinic visits and were involved in discussing treatment options with their husbands and with providers. Partners of men who chose AS as well as those of men who chose treatment were also often involved in information seeking (Davison et al., 2009; Srirangam et al., 2003).

In this sample, most men and their partners were in agreement about the partner's level of involvement in the information-seeking and decision-making process. Couples in the treatment (T) group generally reported that the final decision was shared or was the man's to make, after seriously considering his partner's opinion. This finding was in line with other studies of treated couples (Schumm et al., 2010; Srirangam et al., 2003; Zeliadt et al., 2011).

So how did partners come to support the patient's decision about AS? We know that AS is not a common choice. In fact, when Srirangam and colleagues (2003) asked partners about their treatment preferences, none of the 82 partners surveyed chose AS. Couples choosing AS found that the presence of the AS protocol was reassuring. They saw that the protocol would provide systematic and close monitoring of the patient's condition. This increased their comfort with selecting AS, particularly among the partners. As in other studies (Volk et al., 2004), the partners were more concerned about maximizing the man's length of life than about possible side effects, but once the AS protocol was understood, the AS partners were willing to accept that with this particular cancer, and given their husbands' early-stage disease, AS would be a viable option. In this study, some AS partners described how they were at first reluctant to select AS, but then moved to supporting their husbands' decisions after information seeking and discussion. The couples choosing treatment were also informed about the AS protocol, but did not select it because they felt it important to remove the cancer as soon as possible.

This study has both strengths and limitations. One strength is that all of the men surveyed were drawn from the same clinic population and were all offered both AS and immediate treatment by relevant specialists in a balanced way on the same day. They were also able to discuss treatment options and to consult with a variety of specialists, a benefit available to those receiving treatment in a multidisciplinary prostate cancer clinic. While primary care or urology clinics may encourage patients to seek second opinions, they are not able to offer the convenience in scheduling of multidisciplinary consultations that is available at the MPCC. In this clinical setting, some men and their partners changed their view of the immediate threat of cancer, and of the need to be treated immediately, and selected AS. However, the lack of availability of multidisciplinary clinics outside of academic centers and large metropolitan areas may limit the number of men who will have access to this resource.

Other limitations of this study include the homogeneity of the participants (i.e., mostly white, highly educated, privately insured), and high dyadic adjustment of these couples. There were limitations in the qualitative analysis method. The analysis was mostly conducted following the completion of data collection so that lessons from the data could not guide decisions such as whether theoretical saturation had been reached. The small sample size may also be seen as potentially limiting the conclusions reached. These factors may limit the generalizability of our findings. Nevertheless, participants' perspectives suggest messages that may be helpful in bringing AS into more serious consideration.

One of the ethical issues raised by this study concerns the principle of the patient as an autonomous decision-maker. The patients studied wanted to involve their partners, and physicians have viewed this as important in making decisions about prostate cancer. However, although our study participants were generally concordant in their preferences for shared decision making, not all couples may agree. Ethical issues may arise in cases where partners want to be more involved in the decision-making process than is wanted by the patients. In these circumstances, the patient's care team may need to advocate for his wishes and provide him with additional support. Providers will need to consider how to provide information for both patient and partner while clarifying that the choice is the patient's.

A second ethical concern is the conditions under which information is provided, such that the full range of alternatives, including AS when appropriate, is described. Our study shows that the decision-making process is lengthy. The extended period of information seeking used by couples selecting AS suggests that a single encounter in which the physician outlines features of the diagnosis and prognosis may not be adequate. The cancer center multispecialty clinic provided a thorough and balanced opportunity to explore features of both treatment and AS. However, since this setting is not available to all, some alternative support must be developed. Designing educational and value clarification materials that can be used by couples in conjunction with physicians and other providers is one way to address the ethical issues of fully informed decision making. Providers may need to check in periodically with the patient to see whether he is still comfortable with including the partner in office visits and decision making.

Given that partners are often less accepting of AS as a treatment option for men with localized prostate cancer (Penson, 2012; Srirangam et al., 2003) and are influential in men's

treatment decision making, our study adds to the literature by describing how couples who do decide on AS make that decision. Further research including men and their partners from different ethnic and socioeconomic groups and those from a variety of practice settings (e.g., private clinics and federally qualified health centers for underserved populations) would be informative. Men who are considering AS may require additional support from their care team to better communicate their choice of AS to partners as well as to other family members. Health care providers could perhaps structure office visits so that patients and their partners have ample opportunities to discuss treatment options with the provider and with each other. In addition, the development of decision aids that might be effective in helping men and their partners understand that not all types of cancer need to be treated immediately would be useful. These decision aids might be developed to help men personalize their own risk, as well as to discover their values and their partner's values related to treatment, side effects, and their tolerance for the systematic protocol of AS. It may also be beneficial to design decision aids for the partners of men who are eligible for AS. These decision aids for couples could frame messages about AS in terms of the benefit of maintaining both the man's quantity and quality of life as well as the reversibility of the decision when symptoms appear or worsen.

In summary, our study provides a glimpse into the decision-making processes of couples, including those who choose AS. Although some partners place great value on the removal of cancer through immediate treatment, they recognize that the ultimate decision lies with the patients. Decision aids that address both patients' and partners' concerns could help couples to better cope with the decision-making process.

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References

- Andriole GL, Crawford ED, Grubb RL III, Buys SS, Chia D, Church TR, Berg CD. Mortality results from a randomized prostate-cancer screening trial. *New England Journal of Medicine*. 2009; 360(13):1310-1319. [PubMed: 19297565]
- Boehmer U, Clark JA. Married couples' perspectives on prostate cancer diagnosis and treatment decision-making. *Psychooncology*. 2001; 10(2):147-155. [PubMed: 11268141]
- Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006; 3(2):77-101.
- Busby DM, Christensen C, Crane DR, Larson JH. A revision of the Dyadic Adjustment Scale for use with distressed and nondistressed couples: Construction hierarchy and multidimensional scales. *Journal of Marital & Family Therapy*. 1995; 21(3):289-308.
- Chamie K, Kwan L, Connor SE, Zavala M, Labo J, Litwin MS. The impact of social networks and partnership status on treatment choice in men with localized prostate cancer. *BJU International*. 2012; 109(7):1006-1012. [PubMed: 21895934]
- Davison BJ, Goldenberg SL, Gleave ME, Degner LF. Provision of individualized information to men and their partners to facilitate treatment decision making in prostate cancer. *Oncology Nursing Forum*. 2003; 30(1):107-114. [PubMed: 12515988]

- Davison BJ, Oliffe JL, Pickles T, Mroz L. Factors influencing men undertaking active surveillance for the management of low-risk prostate cancer. *Oncology Nursing Forum*. 2009; 36(1):89–96. [PubMed: 19136342]
- Degner LR, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O'Neil J, Mueller B. Information needs and decisional preferences in women with breast cancer. *Journal of the American Medical Association*. 1997; 277(18):1485–1492. [PubMed: 9145723]
- Echlin KN, Rees CE. Information needs and information-seeking behaviors of men with prostate cancer and their partners: A review of the literature. *Cancer Nursing*. 2002; 25(1):35–41. [PubMed: 11838718]
- Eisikovits Z, Koren C. Approaches to and outcomes of dyadic interview analysis. *Qualitative Health Research*. 2010; 20(12):1642–1655. [PubMed: 20663940]
- Emslie C, Browne S, Macleod U, Rozmovits L, Mitchell E, Ziebland S. “Getting through” not “going under”: A qualitative study of gender and spousal support after diagnosis with colorectal cancer. *Social Science & Medicine*. 2009; 68(6):1169–1175. [PubMed: 19195750]
- Ernstmann N, Ommen O, Kowalski C, Neumann M, Visser A, Pfaff H, Weissback L. A longitudinal study of changes in provider-patient interaction in treatment of localized prostate cancer. *Supportive Care in Cancer*. 2012; 20(4):791–797. [PubMed: 21479989]
- Gorin MA, Soloway CT, Eldefrawy A, Soloway MS. Factors that influence patient enrollment in active surveillance for low-risk prostate cancer. *Urology*. 2011; 77(3):588–591. [PubMed: 21215429]
- Holmboe ES, Concato J. Treatment decisions for localized prostate cancer: Asking men what's important. *Journal of General Internal Medicine*. 2000; 15(10):694–701. [PubMed: 11089712]
- Penson DP. Factors influencing patients' acceptance and adherence to active surveillance. *Journal of the National Cancer Institute Monographs*. 2012; 2012(45):207–212. [PubMed: 23271775]
- Pickles T, Ruether JD, Weir L, Carlson L, Jakulj R, SCRN Communication Team. Psychosocial barriers to active surveillance for the management of early prostate cancer and a strategy for increased acceptance. *BJU International*. 2007; 100(3):544–551. [PubMed: 17532857]
- Resendes LA, McCorkle R. Spousal responses to prostate cancer: An integrative review. *Cancer Investigation*. 2006; 24(2):192–198. [PubMed: 16537189]
- Schumm K, Skea Z, McKee L, N'Dow J. “They're doing surgery on two people”: A meta-ethnography of the influences on couples' treatment decision making for prostate cancer. *Health Expectations*. 2010; 13(4):335–349. [PubMed: 20860778]
- Speice J, Harkness J, Laneri H, Frankel R, Roter D, Kornblith AB, Holland JC. Involving family members in cancer care: Focus group considerations of patients and oncological providers. *Psychooncology*. 2000; 9(2):101–112. [PubMed: 10767748]
- Srirangam S, Pearson E, Grose C, Brown SC, Collins GN, O'Reilly PH. Parmer's influence on patient preference for treatment in early prostate cancer. *BJU International*. 2003; 92(4):365–369. [PubMed: 12930420]
- Underwood W III, Orom H, Poch M, West BT, Lantz PM, Chang SS, Fowke JH. Multiple physician recommendations for prostate cancer treatment: A Pandora's box for patients? *Canadian Journal of Urology*. 2010; 17(5):5346–5354. [PubMed: 20974025]
- Volk RJ, Cantor SB, Cass AR, Spann SJ, Weller SC, Krahn MD. Preferences of husbands and wives for outcomes of prostate cancer screening and treatment. *Journal of General Internal Medicine*. 2004; 19(4):339–348. [PubMed: 15061743]
- Zeliadt SB, Penson DF, Moinpour CM, Blough DK, Fedorenko CR, Hall IJ, Ramsey SD. Provider and partner interactions in the treatment decision-making process for newly diagnosed localized prostate cancer. *BJU International*. 2011; 108(6):851–856. discussion 856-857. [PubMed: 21244609]
- Zikmund-Fisher BJ, Couper MP, Singer E, Ubel PA, Ziniel S, Fowler FJ Jr, Fagerlin A. Deficits and variations in patients' experience with making 9 common medical decisions: The DECISIONS survey. *Medical Decision Making*. 2010; 30(5 Suppl):85S–95S. [PubMed: 20881157]

Table 1

Characteristics of Men and Partners

	Men (Patients) n=15	Partners n=15
Treatment		
Active Surveillance	10	
Radiation	3	
Surgery	2	
Age		
Mean (SD)	61.5 (7.5)	59.3 (7.0)
Minimum, Maximum	49, 72	45, 71
Education		
High school graduate or less	3	2
Some college or college graduate	6	10
Postgraduate education	6	3
Decision Role*		
Preferred man to make treatment decision	6	3
Man made decision after considering partner's view	4	8
Shared responsibility for decision	5	1
Partner made after considering the man's view	0	1
Dyadic Adjustment		
Mean (SD)	52.47 (5.16)	52.82 (4.08)

Note: RDAS cutoff score for non-distressed couples is >48.

* Missing data from 2 partners on decision role.