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Designing normative messages about active surveillance for men with localized prostate cancer

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Abstract

Active surveillance (AS) is increasingly recognized as a reasonable option for men with low-risk, localized prostate cancer, yet few men who might benefit from conservative management receive it. We examined the acceptability of normative messages about AS as a management option for

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Conflict of Interest

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patients with low-risk prostate cancer. Men with a diagnosis of localized prostate cancer who were recruited through prostate cancer support organizations completed a web-based survey ($N=331$). They rated messages about AS for *believability*, *accuracy*, and *importance* for men to hear when making treatment decisions. The message “you don’t have to panic...you have time to think about your options” was perceived as believable, accurate, and important by over 80% of the survivors. In contrast, messages about trust in the AS protocol and “knowing in plenty of time” if treatment is needed were rated as accurate by only about 36% of respondents. For AS to be viewed as a reasonable alternative, men will need reassurance that following an AS protocol is likely to allow time for curative treatment if the cancer progresses.

Keywords

cancer; oncology; prostate neoplasms; decision making

Introduction

At the heart of the current prostate cancer screening controversy is the accompanying and significant risk of overdiagnosis and overtreatment that can prove costly to both the patient’s quality of life and the healthcare system (Sandhu & Andriole, 2012). Recently, the National Cancer Institute in the United States has argued that physicians and patients need to recognize that overdiagnosis is a common result of cancer screening (Esserman, Thompson, & Reid, 2013). For men at low risk of dying from prostate cancer, treatment is not likely to improve prognosis and may instead leave these patients with significant adverse effects (e.g., impotence and incontinence) that negatively affect quality of life (Carter, 2012). According to current UK National Institute for Health and Clinical Excellence (NICE) guidelines (issued in 2008), active surveillance (AS) should be the preferred treatment for low-risk patients (Branney, White, Jain, Hiley, & Flowers, 2009). Nevertheless, active treatment for low-risk patients has increased in recent years (Jacobs et al., 2013). In the US, fewer than one in five patients with low-risk prostate cancer select AS (Cooperberg, Broering, & Carroll, 2010), suggesting a missed opportunity for conservative management and reducing treatment-related harms (Carter, 2012).

Because of the discrepancy between guidelines and treatment choice for patients with low-risk prostate cancer, we studied the effect of normative messages to address underutilization of AS. Normative messages effectively promote desirable behaviors through expression of the behavior as a social norm, an expectation or rule that governs behavior within a group (Bicchieri & Muldoon). Psychologists, as well as other researchers, have determined that norms are powerful influences on decision making and behavior. For example, in one study, researchers tested whether descriptive norm information (e.g., the proportion of other people choosing a particular treatment) would influence people’s hypothetical choices about cancer treatment and found that patients had more interest in chemotherapy when the norm information suggested that it was popular (Zikmund-Fisher, Windschitl, Exe, & Ubel, 2011). In another example, researchers found that rural mothers were more than twice as likely (45% vs. 20%) to comply with a nutritionist’s recommendation to administer cod-liver oil to infants when they received this recommendation in six-person discussion groups as opposed

to individual consultations (Bertrand, Mullainathan, & Shafir, 2006; Ross & Nisbett, 1991). Our normative intervention followed a similar rationale—to create a new norm for prostate cancer treatment decisions rather than attempt to isolate men from the expectations of their groups, which could range from friends and family to fellow patients to physicians.

In the context of decision making about management for clinically localized prostate cancer, normative behaviors are currently informed by conventional wisdom that a cancer diagnosis should be followed by immediate treatment and that delaying treatment puts the patient at greater risk of progression, need for more aggressive treatments, and perhaps death. We attempted to create messages that depict AS as a reasonable choice for men and to *slow* the decision-making process by communicating that patients have time to weigh their values and preferences and do not need to make a decision immediately. These messages took the form of quotations from men about the decision-making process. An example of a quotation about the non-acute nature of the decision follows: “Deciding about prostate cancer is a decision you make in weeks, not days.”

The goal of this study was to test the acceptability of normative messages about AS (in contrast to immediate treatment) as a management option for men with clinically localized prostate cancer from the perspectives of men who have made a treatment decision. This group of men was selected because they benefit from the experiences of going through the decision-making process, selecting a management option, and living with the consequences of their management decisions. We developed messages that might help men to consider AS as a reasonable option for managing prostate cancer and then tested these messages in a sample of men who had a previous diagnosis of early-stage prostate cancer.

Methods

A Framework for Evaluating the Acceptability of Normative Messages in Decision Making

The following framework for assessing the acceptability of a message about management options for localized prostate cancer (including AS) was adapted from similar studies of normative messages related to prevention of behaviors with adverse consequences such as disordered eating, cigarette smoking, and unhealthy weight loss dieting (Durkin, Paxton, & Wertheim, 2005; Flynn et al., 2007; Paxton, Wertheim, Pilawski, Durkin, & Holt, 2002). In this study, our normative messages support AS.

We suggest that an effective message about AS for men considering management options for localized prostate cancer should meet the following criteria:

1. The message should be perceived as credible, that is, “something a man would say” (believability).
2. The message should be perceived as providing accurate information (accuracy).
3. The message should be seen as important to men facing a decision about treatment (utility).

Within this framework it is possible to identify several problem areas or gaps in information needs that can be used to inform the design of effective messages. For a message to be

accepted, it must be believable to the target audience. Messages perceived as not believable will have little effect on decision making and may hurt the credibility of the overall educational materials. It would seem likely that a message perceived as believable would also be seen as accurate. However, if messages challenge widely held beliefs or reinforce misinformation, factual messages may be seen as less accurate or believable. Finally, messages may be seen as being more or less important in the decision. We anticipate that utility or importance should be less strongly related to the other two dimensions. As suggested, the joint examination of the three dimensions may reveal important gaps for the provision of messages. We have seen that there may be interesting juxtapositions of believability and accuracy that may suggest the need for message strategies to counteract misconceptions or to reinforce factually correct messages that are poorly accepted (viewed as not believable).

Additional criteria should be met for a message to be viewed as acceptable. Effective messages should not be affected by biases, that is, acceptability of the message should be invariant across characteristics of the men viewing it. In this case, ratings of acceptability of the message should not differ for younger and older men, for men who chose to be treated compared with those who chose observation, and across other factors such as marital status. Finally, ratings of the normative messages should be associated with overall attitudes about AS serving as a check of the validity of the messages.

Designing the Messages

Our approach to designing the messages was to select key themes reflecting men's perceptions of AS from a variety of sources, identify a change objective related to the theme, and rate the messages based on how strongly they favored AS over immediate treatment. The goal was to have a series of messages, varying in the degree to which they favored AS or immediate treatment and representing different change objectives. A change objective is a statement of what must change so that a person may adopt a certain behavior such as active surveillance (Bartholomew, Parcel, Kok, Gottlieb, & Fernández, 2011). Examples are: "A man sees himself as having time to make a decision" and "A man recognizes that choosing AS may require additional explanation to others." Each message was written as a quote along with a man's name (fictitious identity) and identification of the source of the message as either a prostate cancer survivor (eight messages) or a surgeon (one message).

In designing messages about AS we used three primary sources of information: 1) personal interviews with men who were treated for prostate cancer or who chose AS, 2) review of the literature on treatment decision making in prostate cancer, and 3) other sources such as blogs and survivor websites. Personal interviews, the main source of messages, were conducted with prostate cancer patients 6–18 months after completing treatment or the decision to follow an AS protocol. Details of the methods and findings from the patient interviews can be found elsewhere (Volk et al., 2013). We began by abstracting quotes from the interviews or drafting quotes based on the literature review or survivor websites. With intervention development in mind, a performance objective associated with each message was assigned. From there, we identified redundant messages and reduced the number of candidate messages. Each message was then rated independently by three members of the research

team (JBB, TLB, RJV) for valence related to favoring AS. The final nine messages reflected key themes and performance objectives related to AS decisions and varied in the degree to which they favored AS or immediate treatment. The messages tested in this study and their sources can be found in Table 1.

Participants and Procedures for Rating the Messages

Participants for the study were recruited through prostate cancer support organizations over a period of four months (September 2012 to January 2013). Organizations were identified through Google and Facebook, as well as referrals from colleagues. Seven organizations (American Cancer Society Survivors' Network, 50 Hoops, Malecare, Prostate.net, Prostate Cancer Research Institute, Urology Research and Education Foundation, and US Too) agreed to describe the survey and eligibility criteria to their members and provide them with a hyperlink to the study website using a variety of media (i.e., organizational newsletters, direct email, announcements on their websites). Organizations received a \$25 contribution for every survey completed under their auspices.

Interested participants followed the hyperlink to an informed consent statement that ended with an invitation to give their assent by selecting the "I consent and agree to participate" option to begin the study. After participants consented, they answered several questions to assess eligibility. Eligible participants (able to read English, received diagnosis of prostate cancer 6 months to 5 years previously, cancer not spread beyond the gland at the time of diagnosis) then completed the web-based study survey. To minimize burden during data collection, participants were randomly assigned to receive only three of the nine messages. For each message, participants were asked the following questions: 1) Do you believe this is something a man (a doctor) would say? 2) Do you believe this statement is accurate? 3) How important is it that men with prostate cancer hear this statement when making a decision about treatment? Response options for questions 1 and 2 were "yes," "no," and "I'm not sure." Response options for question 3 were "very important," "somewhat important," and "not important." A fourth question was included to provide an indicator of the perceived effect of the message on men's decisions about AS: What impact would this statement have on men deciding about prostate cancer treatment? For this question, response options were "men would be more likely to choose active surveillance," "men would be more likely to choose immediate treatment," and "the statement would have little or no impact on men's decisions." Participants were able to review and change their responses before submitting the survey. The study questionnaire was designed and maintained using the Qualtrics® survey software system. To prevent multiple entries from the same individual, parameters were set so that duplicate entries were not allowed from the same Internet Protocol (IP) address.

The protocol was approved by the Committee for the Protection of Human Subjects at The University of Texas Health Science Center at Houston and the Institutional Review Board at The University of Texas MD Anderson Cancer Center.

Data Analysis

Incomplete questionnaires were excluded from data analysis. The message ratings were tabulated and reported as percentages. We tested for bias of the messages by examining correlations of the message ratings with the participants' age, treatment received (self-reported receipt of AS or watchful waiting compared with all other treatments), and marital status. To test the validity of the normative messages, we examined correlations of each message with a broad measure of attitudes towards acceptability of AS developed for this study. The attitudes measure was adapted from a measure of perceived attributes of eHealth innovations (Atkinson, 2007). A positive correlation would indicate that acceptability of the message was associated with more favorable attitudes toward AS in general. Because of the large number of correlations, we used a Bonferroni adjustment of the type I error rate of $0.05/36$, or $P < 0.0014$.

Results

We followed the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) in reporting the methods and results of the study (Eysenbach, 2004). The study website was visited by 1,084 unique site visitors. Of those, 947 consented to study participation. Approximately 56% ($n=533$) of those who consented to participate did not meet eligibility criteria. Three hundred thirty-one of the 414 eligible participants who began the study completed the full questionnaire.

Characteristics of the Participants

The 331 respondents with completed questionnaires had an average age of 64.9 ± 8.4 years (range 45–96 years). Of the 331 respondents, 88% classified themselves as white, 82% were married, and 93% were college educated. Treatment history included surgery (37%), AS (24%), radiation (26%), and other (13%). Demographic characteristics of the included respondents are shown in Table 2.

Ratings of Normative Messages for Acceptability

For the believability dimension, ratings of messages largely ranged from 65.1% (message 4, representing trust in the AS protocol to catch any progression in time for curative treatment) to 90.1% (message 8, regret over not giving AS a second thought) (see Table 3). Message 9, a favorable quote about AS attributed to a surgeon, was a negative outlier on the believability dimension. Ratings of message accuracy varied more widely, with 35.8% (message 4) to 85.6% (message 1, having time to think about options) of respondents judging the various messages to be accurate. Men's ratings of the utility of different messages ranged from 36.0% (message 9) to 82.9% (message 1). Again, message 4 about trusting the AS protocol fared poorly.

We also examined the ratings for the messages across the three dimensions, contrasting messages high on all dimensions with one that was low on the multiple dimensions. The message "you don't have to panic...you have time to think about your options" (message 1) was perceived as believable, accurate, and important for men to hear by more than 80% of the respondents. Similarly, more than 75% of respondents rated as believable and accurate a

message about having low-risk prostate cancer and “not wanting to rush into getting something done right away,” (message 3) and 66% rated it very important for men to hear. In contrast, messages about trust in the AS protocol and “knowing in plenty of time” if treatment is needed (message 4) were rated as accurate by only about 35% of participants. Message 9, in which a surgeon describes men who chose AS as “jubilant” and “delighted” with their lack of side effects, received consistently low ratings in every dimension: believability, 13.5%; accuracy, 36.9%; utility, 36.0%.

Effect of Messages on Decision Making, Tests for Bias, and Validity

Perceptions of the impact of each message on men’s likelihood of choosing AS ranged from 60.4% (message 1) to 77.3% (message 6, prolonging the decision until treatment options have improved) with one exception. The outlier was message 8 (regret over not giving AS a second thought), which was viewed as favoring an AS decision by 45.1% of respondents. About 1/3 of respondents reported that message 1, addressing time to think about the options, would have little or no effect on men’s treatment decisions. In our tests for bias of the messages, we found no evidence of any association with the man’s age, the treatment received, or marital status. Finally, seven of the nine messages were correlated with overall attitudes about the acceptability of AS, with messages 1 and 8 not being associated (see Table 3).

Discussion

This study evaluated the acceptability of normative messages about AS among men diagnosed with localized prostate cancer. Generally, participants gave higher ratings to messages about the slow progression of prostate cancer paired with the idea that an immediate decision was not necessary. Messages such as “You don’t need to panic” (message 1), “Prostate cancer is one of the slowest growing cancers of all” (message 2), and “It’s at such a low level, I’ve got a little time” (message 3) were highly rated in all three metrics.

Messages that more strongly favored AS, on the other hand, received mixed ratings. Messages that presented AS as a way of living normally “until I absolutely have to do something else” (message 5) or “until the treatment options have improved” (message 6) were perceived as highly believable but received only moderate accuracy and importance ratings. Messages that suggested that under AS men could “see if [cancer] spreads and then... make that decision” (message 7) and still “know in plenty of time” fared still worse. While these statements were plausible as something a man might say, they received low ratings on accuracy and importance for other men to hear, suggesting an underlying discomfort with not treating a cancer immediately.

The dichotomy between the evidence-based effectiveness of AS as a viable treatment strategy for low-risk prostate cancer (Wilt, 2012) and the societal bias in favor of radical treatment (Jacobs et al., 2013) creates the need for a new type of decision support intervention, including patient decision aids, that highlights AS as a reasonable option. Despite the challenges of supporting informed decision making for patients, their families, and their health care providers (including setting expectations for quality indicators),

decision aids can be a useful method for providing balanced information about choices. Using narratives in patient decision aids may be a powerful strategy for enhancing the acceptability of AS (Bekker, 2010; Shaffer & Zikmund-Fisher, 2013). This analysis of normative messages in relation to prostate cancer treatment options suggests that message themes that stress treatment as a decision that requires careful consideration rather than immediate action may be most helpful in nudging men with localized disease to consider AS. However, convincing men to wait and be assured that a cure is still possible is more difficult and is a task in which our normative messages fared poorly. Further intervention may be needed with these low-risk patients to modify their belief that cancer should always be addressed with immediate, aggressive treatment. Men must be assured that AS is a proactive treatment and educated that AS does not inherently signify waiting to treat or take action until the cancer has done irreparable damage.

Our results are consistent with those of the ProtecT prospective trial as reported by Donovan (Donovan, 2012). When consenting to randomization, potential participants in ProtecT were at first confused and frightened by the apparent passivity of what was at first termed “watchful waiting.” However, after the treatment option was renamed “active monitoring” and presented with greater clarity and with enthusiasm equal to that shown for the other treatment options, agreement to randomization rose from 40% to 70%, signifying greater acceptance for active monitoring. Patients in the ProtecT trial, like those in our study, were similarly disinclined to accept waiting rather than undergoing immediate curative treatment, but after their fears and doubts about delaying radical treatment were assuaged they accepted AS more readily.

This study has several limitations. Men in this study were highly educated and most were Caucasian. The participants were members of online support groups and may have had a greater interest in treatment decision making about prostate cancer than other men. Finally, we chose prostate cancer survivors for this study. These men benefit for the experience and knowledge gained in going through the decision making process about management of their diagnosis. We do not know how men facing a decision about management would rate the messages.

Inclusion of normative messages in decision aids is controversial largely because when making healthcare decisions, patients tend to give greater consideration to information in a narrative format than information in a statistical format (Shaffer & Zikmund-Fisher, 2013). Thus, decision aids including these messages have the potential for imbalance in favor of AS. However, the existing bias against AS should also be considered. Patients may fear that any delay in even unnecessary treatment will negatively affect health outcomes, and physicians may prefer to treat with the potential for cure rather than promote AS as an equally appropriate option in low-risk cancer (Jacobs et al., 2013). Therefore, quality decision aids may use narrative framing ethically to promote AS and truly balance the informed decision-making process by affording this strategy due consideration (Blumenthal-Barby, Cantor, Russell, Naik, & Volk, 2013). Normative messages may be a viable method to facilitate informed decision making with respect to AS for men, their families, and their medical providers. Further, they might help right the larger imbalance toward overtreatment for other cancer diagnoses.

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Table 1

Normative messages about active surveillance (AS) for localized prostate cancer tested in the study.

Normative Message	Theme (change objective)	Source of message*
1. "A diagnosis of cancer is frightening, but you don't need to panic. You have time to think about your options."	Sees himself as having time to make a decision.	Interviews with treated and AS prostate cancer patients.
2. "Prostate cancer is one of the slowest growing cancers of all and most men die with prostate cancer, not because of it."	Sees prostate cancer as often slow growing.	Commonly cited quote about non-aggressiveness of some prostate cancers.
3. "...but I just felt like it's at such a low level, I've got a little time on my side. I just didn't want to rush into getting something done right away."	Understands that there is a spectrum of risk for localized prostate cancer and knows where he falls on that continuum.	Interviews with treated and AS prostate cancer patients.
4. "Well, I just think they're sufficiently on top of it. If some more active treatment is needed, we would know in plenty of time."	Trusts the AS protocol would catch disease progression in time.	Interviews with treated and AS prostate cancer patients.
5. "With active surveillance, my life goes on in a perfectly normal fashion, and I'm interested in continuing that until I absolutely have to do something else."	Recognizes the potential burden (includes likelihood) of adverse effects (e.g., urinary incontinence, impotence) from active treatment (e.g., surgery, radiation).	Interviews with treated and AS prostate cancer patients.
6. "...as long as I'm keeping a close eye on it with my doctors, I can possibly prolong this for a number of years until	Regards active surveillance as a reversible decision.	Interviews with treated and AS prostate cancer patients.

Normative Message	Theme (change objective)	Source of message*
the treatment options have improved.”		
7. “It depends on your age. If you’re young and you have a sexual life, I would definitely wait and just watch and see if it spreads, and then you can always make that decision, but I just wouldn’t jump into it.”	Sees AS as a decision that varies by characteristics of the man.	Interviews with treated and AS prostate cancer patients.
8. “Regretfully, I never gave “Active Surveillance” a second thought when I was considering my treatment options. I was from the old school of thinking that says, “If it’s cancer, I want it out!”	Recognizes that some men want immediate treatment.	Adapted from http://www.healthboards.com/boards/cancer-prostate/541701-active-surveillance.html
9. “Men on active surveillance are jubilant after being on AS for a few years. They look at the side effects their friends are enduring who had treatment, and they are delighted they had not gone that route.”	Understands that doctors recognize that men may want to avoid treatment side effects.	Adapted from an interview with a doctor, http://www.healingwell.com/community/default.aspx?f=35&m=2358857&p=5

Messages 1–8 are from the perspective of a prostate cancer survivor. Message 9 is from the perspective of a doctor/surgeon.

* Interviews with prostate cancer patients who received immediate treatment (n = 15) or selected active surveillance (n = 15) were completed by the research team and served as the source for several quotes.

Table 2

Sociodemographic characteristics of the 331 men with localized prostate cancer.

Characteristic	No.	%
Age, years (mean)	64.94	—
Education		
High school graduate or less	19	5.7
Some college or college graduate	163	49.2
Postgraduate	146	44.1
Not stated	3	0.9
Ethnicity		
White, non-Hispanic	291	87.9
Other	37	11.2
Not stated	3	0.9
Relationship status		
Married	271	81.9
Unmarried	57	17.2
Not stated	3	0.9
Treatments received		
Surgery (laparoscopic)	12	3.6
Surgery (robotic)	110	33.2
External beam radiation therapy	86	26.0
Brachytherapy	20	6.0
Active surveillance	79	23.9
Other	11	3.3
None	13	3.9

All percentages may not add to 100% due to rounding.

Table 3

Ratings of normative messages, tests for bias, and correlations with attitudes about acceptability of active surveillance (AS).

Normative message	Criteria for rating normative messages about AS				Message validity (correlation of utility rating with attitudes about acceptability of active surveillance [<i>P</i> -value])
	Believability (% rated "yes")	Accuracy (% rated "yes")	Utility (% rated "very important")	Impact on decision (% rated "men more likely to choose AS")	
1. "A diagnosis of cancer is frightening, but you don't need to panic. You have time to think about your options."	84.7	85.6	82.9	60.4	0.29
2. "Prostate cancer is one of the slowest growing cancers of all and most men die with prostate cancer, not because of it."	80.2	74.8	54.1	73.0	0.40*
3. "...but I just felt like it's at such a low level, I've got a little time on my side. I just didn't want to rush into getting something done right away."	87.2	74.3	64.2	70.6	0.46*
4. "Well, I just think they're sufficiently on top of it. If some more active treatment is needed, we would know in plenty of time."	65.1	35.8	37.6	66.1	0.37*
5. "With active surveillance, my life goes on in a perfectly normal fashion, and I'm interested in continuing that until I absolutely have to do something else."	73.6	56.4	52.7	75.5	0.55*
6. "...as long as I'm keeping a close eye on it with my doctors, I can possibly prolong this for a number of years until the treatment options have improved."	82.7	62.7	53.6	77.3	0.43*
7. "It depends on your age. If you're young and you have a sexual life, I would definitely wait and just watch and see if it spreads, and then you can always make that decision, but I just wouldn't jump into it."	77.5	46.9	43.2	73.9	0.50*
8. "Regretfully, I never gave "Active Surveillance" a second thought when I was considering my treatment options. I was from the old school of thinking that says, "If it's cancer, I want it out!"	90.1	55.0	55.0	45.1	0.14
9. "Men on active surveillance are jubilant after being on AS for a few years. They look at the side effects their friends are enduring who had treatment, and they are delighted they had not gone that route."	13.5	36.9	36.0	69.4	0.54*

Messages 1–8 are from the perspective of a prostate cancer survivor. Message 9 is from the perspective of a doctor/surgeon.

Sample size ranges from 109 to 111 participants.

* Significant at $P < 0.0014$ after Bonferroni adjustment.