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## “It’s not like I can change my mind later”: Reversibility and decision timing in prostate cancer treatment decision-making

**Nora B. Henrikson,**

University of Washington School of Public Health and Community Medicine, Institute for Public Health Genetics

**William J. Ellis,** and

University of Washington School of Medicine, Department of Urology

**Donna L. Berry**

University of Washington School of Nursing, Biobehavioral Nursing and Health Systems

### Abstract

**OBJECTIVE**—To explore whether reversibility, decision timing, and uncertainty are relevant to men deciding on treatment for **localized prostate cancer (LPC)**.

**DESIGN**—Secondary qualitative data analysis of unstructured interviews.

**METHODS**—Content analysis of previously collected qualitative data (31 individual interviews, 5 focus groups). We identified the frequency of references to reversibility, decision timing, and uncertainty and related subthemes.

**RESULTS**—We identified eight themes: reversibility, timing of decision, number of options, “getting it over with,” “the way I make decisions,” uncertainty among experts, desire for certainty, and probability. Fifteen men mentioned reversibility in individual interviews; 13 mentioned the importance of the timing of their decision. Eleven mentioned the importance of the number of options; twelve “the way I make decisions.” Eleven men mentioned the uncertainty of experts, fourteen the desire to “get it over with,” and six a desire for certainty.

**CONCLUSION**—This study provides compelling preliminary data suggesting that men consider the reversibility, decision timing, and uncertainty in the prostate cancer treatment decision.

**PRACTICE IMPLICATION**—These findings may be helpful in enhancing support for men facing the treatment decision.

### Keywords

prostate cancer; decision-making; reversibility; qualitative research

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**Corresponding author:** Nora B Henrikson University of Washington Box 357236 Seattle, WA 98195 P 206-354-9295 F 206-667-7264 nhenriks@u.washington.edu.

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**CONFLICT OF INTEREST** None to report.

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

## 1. Introduction

Prostate cancer is the most common incident cancer in men in the United States [1]. Unlike many cancers where one treatment choice has clear benefit and is initiated as soon as possible, men with localized prostate cancer (**LPC**) are often asked to take time to choose a treatment considering their preferences, values, and perceptions of risk. Treatment can involve significant side effects, such as urinary incontinence and erectile dysfunction, for incremental or unknown reductions in risk of cancer progression. Avoiding pain, prolonging survival, and avoiding side effects have been documented as factors in decision-making; personal factors vary and are not fully understood [2-5].

We have identified constructs from an economic theory of decision-making that may be useful in understanding the prostate cancer treatment decision: reversibility of the treatment, the conditions of uncertainty associated with the decision, and their possible associations with decision timing and importance of number of options available. The theory of option value or option pricing was originally developed to model financial investments under conditions of uncertainty. Three characteristics of the decision at hand must be present for a decision to be considered a “real options” problem: (1) a decision has an uncertain outcome, (2) the choice is irreversible (defined as restricting the number of future options available), and (3) there is flexibility in decision timing. Under these conditions, there may be a value in the “decision” to take time to decide. Economic modeling is concerned with determining a precise value of the option to wait or to estimating thresholds, for example, the threshold at which the benefits of the information gained from deferring a decision are greater than the benefits from making an immediate decision [6, 7].

We suspected that the treatment decision for LPC met the three criteria of an options problem. Men make treatment decisions under conditions of uncertainty about outcome; some treatment options are irreversible (either in the sense of “can’t be undone” as in surgery, or in restricting future treatment options as in radiation); and in many cases there is no clinical urgency around decision timing so patients can take time to make an informed decision. In addition, we found that this theory’s emphasis on decision timing represented a compelling construct that could enhance the LPC treatment decision literature. Individuals who have trouble with irreversible decisions may seek to keep their options open or control the timing of decision-making which may take the form of deferring decision-making or even complete decision avoidance [8]. We reasoned that if some men are at risk for either decision avoidance or choosing a treatment based primarily on its reversibility then we could potentially enhance support for men facing the treatment decision. This analysis represents a unique opportunity to examine open-ended interviews with newly diagnosed prostate cancer patients.

The objective of this project was to examine how men with newly diagnosed **LPC** refer to the uncertainty surrounding their choice, the reversibility of the treatment options they are considering, and the potential importance of decision timing. We approached our analysis with two main goals: first, to qualitatively explore evidence for these three constructs from a patient perspective, and second, if we found it, to suggest how it might enhance efforts to assist men in making informed treatment decisions.

## 2. Methods

We conducted an exploratory secondary analysis of previously collected qualitative data, informed primarily by content analysis methodology [9, 10]. Our sample included 44 men with **LPC** who had (n=37) or had not (n=7) made treatment decision in the previous six months conducted in 1999-2000 during focus groups and individual unstructured interviews.

Participants were recruited through clinician invite from three Seattle-area urology clinics and media outreach; the study was not connected to any treatment clinical trials. The aim of the original study was to systematically document meaningful aspects of the treatment decision. The interviews and focus groups were unstructured and men were simply asked the following question: “Tell me about your decision for treatment of the prostate cancer, including all aspects and concerns you are considering or have considered.” The primary analysis of these interviews has been reported previously [4].

For the current analysis we used a focused coding technique to explore the data for evidence of specific constructs. Three main constructs of theoretical interest guided our analysis: reversibility, decision timing, and uncertainty. We used a lean coding technique, beginning with theoretical constructs, expanding these to smaller subsets, then grouping back to the larger themes [11]. Two investigators coded a pilot sample of five interviews, then verified and agreed on a list of approximately 30 codes as subsets of the three main categories. Disagreements were resolved by consensus. Using Atlas.ti qualitative analysis software (Berlin Germany, [www.atlasti.com](http://www.atlasti.com)), we assigned codes to the text of the complete set of transcripts. After coding was complete we grouped codes back into larger conceptual groups, identified exemplar quotes, and recorded frequency of the appearance of each code group.

We received approval for this analysis from the University of Washington Human Subjects Division. In accordance with that approval, we analyzed anonymized transcripts containing no protected health information and report only paraphrased quotes.

### 3. Results

We conducted secondary analysis of transcripts from five focus groups (15 men) and 31 individual unstructured interviews. The sample is described in Table 1. The mean age of the sample was 68.4 (SD=9.3). The majority of the men (84.5%) were white/Hispanic/non-Hispanic, and half reported earning more than \$50,000 per year. Most (70.5%) were married/partnered, and 43.2% were college graduates.

We identified eight sub-themes relating to the larger themes of reversibility, uncertainty, and decision timing (Table 2). Themes related to reducing uncertainty were uncertainty among experts, desire for certainty, and probability. Related to reversibility, the themes we identified were reversibility (either the idea of a decision that cannot be undone or one that limits future options) and the number of options. Themes related to decision timing involved taking more time, “getting it over with”, and discussions of “the way I make decisions” that often explicitly stated timing preferences around decision-making. Below are more detailed descriptions of the themes, with exemplar quotes provided for each theme.

#### 3.1 Theme 1: Uncertainty

**3.1.1 Uncertainty of experts**—Eleven men in individual interviews and one focus group identified the lack of consensus on a recommended treatment a source of uncertainty in their decision-making. Some comments of this type focused on the lack of conclusive research on a clear treatment recommendation:

With the years and years of men over forty or fifty having cancer of the prostate, you would think they would have some sort of data, be able to come up with some stored-up stats, and yet the doctors tell you it’s your own decision to make. ...you would think that they would have enough data by now to figure out at least results of which treatment would be the best.

Others mentioned a perceived bias by subspecialty of doctors they had consulted with:

[At the conference] they had all these different people, one used cryosurgery and one surgery, and the internal radiation, external, so forth. They're all sitting up on the stage, but none of them agreed to anything. ... Think of being in this position, who do you believe?

**3.1.2 Desire for certainty**—Six men in individual interviews and participants in two focus groups mentioned behaviors consistent with a desire for certainty. Behaviors included asking the doctor what they would do if it were them, choosing an aggressive treatment to be sure the cancer will be gone, and seeking extra tests or opinions.

I would much rather know what the deal is at first. It seems to me you have a better chance of stopping it. The other therapies treat cancer--they don't cure it, they treat it. The only thing that cures it; that says 'Now you've got it and now you don't' is surgery.

But then when I asked him directly, he said he would suggest surgery. And then his reasoning made logical sense because they know that surgery is effective. They're not as certain that seed implantation is effective yet. It hasn't been around long enough to get the information, the data.

**3.1.3 Probability**—Thirteen men in individual interviews reported considering the numeric or statistical probabilities associated with success of a treatment option. For example:

I said, do you think it's encapsulated? He said, about eighty percent chance it's encapsulated. By the way, the first doctor told me he'd have to remove the left bundle because it's the left [apex]. And he said, I'll bang around the right bundle and there'll be about a twenty five percent chance of being- it's be a seventy five- it'd be a twenty five percent chance of not being impotent.

## 3.2 Theme 2: Reversibility

**3.2.1 Reversibility**—Fifteen men in individual interviews and discussion in two focus groups referred to reversibility of the treatment they had or were considering. Both men in the sample who chose watchful waiting mentioned reversibility. Some remarks described concern over a general inability to undo a decision once it is made, for example:

So I decided that I want to get rid of it, I want to get [the prostate] out...so I basically made up my mind, and for me it's not like I can change my mind later, like if you buy shoes, you know what I'm saying.

You know, there's no reversing, like if I go through the treatment and for some reason my quality of life is shot, there's nothing you can do to correct things...it's irreversible.

Others were specifically about permanent damage or irreversible side effects:

Once survival to me was not an issue, they seemed to be equal, then it turned into quality of life ... it seemed like the main side effects are incontinence and impotence. And the prostatectomy certainly seemed to have worse long term or permanent possibilities of either of those. ...The brachytherapy was very attractive on that basis.

**3.2.2 Number of options**—The economic definition of an irreversible decision is one that reduces the number of future options, so we looked for references to the importance of a variety of options or to keeping one's options open. We identified references to options in

11 individual interviews and two focus group discussions. Many comments of this type included considering the ordering of treatments to maintain the most choices in the future, for example:

[I asked the doctor] what would you do? And he said surgery... I asked why don't we do the radiation first, and if that doesn't work then we'll have the surgery? He says, well, we can do that, in that case the surgery would be salvage something or other...you know, just the choice of words there does not sound too good. Like it doesn't sound like there'd be much to salvage, and he said, well in a lot of cases that's right... and [with surgery] if something does develop a year or two later you still have the option of radiation or all that other stuff.

One man used a rich example to explain the importance of keeping options open:

For me it's almost as if the decision is still open because I'm watchful waiting unless it really accelerates and I just come up totally wrong. It's not that I can't do an intervention further down the road. There's a scene of a play once, a very weird play, these two guys got plucked off the street and stuck in a cellar, and one of them talked about leaving, and the other guy said well, but you'd give up your freedom. He said as long as you're here you can decide to leave or decide to stay, if you decide to leave then you can't decide to stay. And as they're thinking about that, the door slammed shut so that, you know I think there's an aspect of, there may be an illusion of freedom that I have ... it seems to me that I can still down the road make a decision about my treatment.

Several men also mentioned reversibility more indirectly, such as expressing the preference to choose a treatment that would allow them to remain eligible for emerging new treatments or trials should they become available, or expressing disappointment if age or other illness made a given treatment option or trial not available to them.

### 3.3 Theme 3: Decision timing

**3.3.1 Taking more time**—Related to the **notion** of irreversibility, controlling the timing of a decision can have value to a decision-maker, usually because deferring a decision might allow the gathering of information that can subsequently help reduce the uncertainty around a decision. We found that 13 individual men and men in three focus groups referred to decision timing. Most often these comments were described in terms of the importance of taking the time they needed to make a decision:

I said, well how long do I have? Do I have a few months to put this off? He says, oh yeah, these tumors take three years to double. I said ...OK, I can hold it off in my mind so I can sort it out. I don't think anybody should rush into these things. It's like buying a car...you get buyer's remorse.

Other men described having been urged by others to decide or take action quickly, either because of a presentation of clinical urgency by the doctor:

I guess I would have had as long as I wanted [to decide] but [the doctor] seemed to think that it was an emergency; that I make up my mind like right now.

Or from loved ones:

The kids--I didn't want to say anything to them until I knew and they wanted me to do something immediately.

**3.3.2 "Getting it over with"**—We identified references in 14 individual interviews and two focus group discussions to the idea of wanting to make a decision quickly and stick to it.

We also included references to the importance of avoiding regret in this group. Some men talked about the importance of sticking to their decision once they had made it:

Whether I made the right decision, I'm not going to worry about that. I'm just going to go forward.

Several men also commented about the importance of avoiding regret:

Many people will marshal their facts to support their beliefs, marshal their beliefs to support their behavior. ... There are those people who when they buy a Ford stop reading Chevy ads all together, just read Ford ads. And there are those people who, once they've bought a car, start reading all the other ads just to convince his family he made a terrible mistake. And I think that's applicable all across the whole realm of decision making.

**3.3.3 “The way I make decisions”**—In twelve individual interviews and one focus group, men referred to their personality, profession, or how they tend to make decisions as a part of their treatment decision. Some men referred to their profession as a way to describe their decision-making processes:

I'm a scientist, by the way...very analytical.

Others talked more generally about how they had made previous decisions, often with explicit reference to preferences around timing, either in deciding quickly:

I've just always been the type of person that whatever it is, I want to take care of it right then and there, I don't want to sit and wait.

Or in taking time:

I have a tendency to look back and say, Why in the hell did I do that?...But that's why I've spent all this time and talked to all these people and read all this stuff so that I don't have regret.

## 4. Discussion and Conclusion

### 4.1.1 Discussion

Behavioral economics suggests that economic theory can be fruitful in examining human behavior [12]. We undertook this secondary data analysis because economic theory suggested several constructs that we suspected were relevant to the prostate cancer treatment decision, notably the reversibility of a treatment, the value in keeping options open, decision timing, and the conditions of uncertainty under which the decision takes place. Our findings confirm previous studies and suggest that these ideas are indeed relevant to men with LPC facing a treatment decision.

Economic theory defines an irreversible decision as one that reduces the number of subsequent choices, such as clear cutting an old growth forest, and suggests that in the face of an irreversible decision with uncertainty about the outcome deferring a decision until more information can be gathered can itself have value [6, 7, 13]. Irreversibility and timing of decision-making have been incorporated with success into economic studies of environmental resource management, AIDS therapy, and watchful waiting [14-16]. Investigators have examined the idea of finality, which could also be called irreversibility, of surgery, especially sterilization, in studies of anticipated regret and post-decision regret, finding that some voluntarily childless couples avoided or postponed sterilization because of the finality of the procedure [17, 18]. Few studies have examined these constructs specifically in the setting of the LPC treatment decision.

It is well-documented that men consider the possibility of cure, complete tumor removal, and the quality of life implications of treatment side effects in deciding on treatment [2, 19, 20]. Other studies have found that the prostate cancer treatment decision is far more complex than reasoning or considering clinical factors only; men also consider personal factors, prior beliefs about health and illness, emotion, and anecdote [3, 4, 21]. In the primary analysis of the data used for this study, we concluded that personal factors were important along with medical factors to men in making their own ‘best choice’ about cancer treatment [4]. In subsequent work, our group also found that marital status and age were the strongest predictors for treatment choice, and that factors contributing to uncertainty were a main predictor of satisfaction with treatment decision [22]. Denberg and colleagues found that reducing uncertainty and getting treatment quickly were important drivers in decision-making for men with LPC [21]. Gwede reported that men choosing seed implants reported doing so because it was the ‘least invasive’ and to ‘avoid surgery’ [2]. Another study found that tumor removal was a main factor in patient preferences for surgical treatment [23]. Previous work has also shown that information on several timing- or options-related ideas are considered essential or necessary by a majority of men, such as options in the case of unsuccessful treatment, consequences of delaying treatment, and how much time one can safely take to make a decision [24-26].

Our results build on these previous studies and indicate that many men consider the reversibility of a **specific** treatment in their decision-making process as well as the availability of treatment options and decision timing. We were struck by the richness of the narratives around these ideas, including the use of metaphors—shutting a door, buying shoes, buying a car—and references to these ideas in close proximity to their mention of the actual treatment decision. We had to make some judgment calls about whether a quotation “really” fit into one of our categories, but in most cases the references were obvious once we were looking for them, as in the title quote, “it’s not like I can change my mind later.”

This study adds to our understanding of the processes that influence the treatment decision in several unique ways. First, our probing for, and finding, references to the importance of more than one option and of reversibility both suggest that some men find it important to have a ‘backup plan’ in place or to keep their options open when choosing treatment, a construct that we have not seen explicitly identified in other studies.

Second, the frequency of references to the importance of decision timing, either in taking the time one needs or in getting the decision “over with” highlight the importance of individual preference around timing and may help us assist men in considering their own preferences around timing and potentially identify men at risk for deferring treatment. The frequency of mentions of “how I make decisions,” very often including explicit references to timing (eg always taking a lot of time, always wanting to make a decision quickly) may also have potential direct applications to treatment decision support through assisting men with identifying their own decision-making style.

Third, the frequent references to the importance of uncertainty in the treatment decision confirms previous studies of uncertainty in treatment decision making and suggests several specific sub-domains that may be of interest, such as desire for certainty, uncertainty of experts, and the bias of medical recommendations from different subspecialties. Desire for certainty may be the most likely describe an innate characteristic and therefore have the most direct potential for influencing decision support; the reflections on potential bias in treatment recommendation according to specialty may reflect conditions of the health care environment more than the individual.

Our study also shows that transdisciplinary inquiry can yield rich results. In this case, a quantitative economic theory that originally helped explain the importance of timing and reversibility in making financial investments inspired a qualitative inquiry whose results suggests that the same constructs may be useful in explaining the 'investment' in a cancer treatment. Guided by the work of health economists who noted that these constructs might be useful in health-related decisions and in watchful waiting specifically [7, 16], we were inspired to conduct the present study.

We consider this analysis to be intriguing preliminary work, and recognize some limitations. We could not place the constructs of interest in the context of other motivators of decision-making so we do not know the relative importance of these constructs for the men we interviewed. Nor does our study design permit a quantitative examination of potential covariates or predictors of the constructs in question. As a study designed to probe existing data for specific constructs, there is of course a possibility of bias in our theme definitions and interpretations. However, the interviews were designed to be a participant-led, not investigator-led, discussion of influential factors in decision-making; as such we can be reasonably confident that the ideas mentioned were influential enough for the men to note out loud. Indeed, a strength of our study is that we could detect obvious and unprompted references to reversibility, timing, and uncertainty in open-ended interviews.

While new variations of surgery and radiation therapy have been marketed, there remains no definitive trial result to suggest superiority of one therapy and lay publications have addressed the controversial state of LPC treatment decision-making [27, 28]. Thus it is possible that treatment decision culture may have changed since the interviews were conducted in 1999-2000, but consistent with evidence that men's information needs are stable over time [29] our findings likely remain relevant. That said, our study design prohibits a definitive assessment of which constructs we have suggested here are likely to be innate characteristics, such as tolerance of uncertainty or tolerance of irreversibility. Some ideas may reflect environmental influences such as being rushed into a treatment decision. Innate patient characteristics may have more direct impact on treatment decision support through the identification of individual needs in decision-making; but education on environmental influences such as potential bias according to specialist training may also be helpful in aids that support the decision process.

## 4.2 Conclusion

Our study provides compelling preliminary data to suggest that men with **LPC** consider uncertainty, reversibility, and decision timing relevant to the treatment decision. Future research could explore in more detail the relative importance of the reversibility of treatment options, keeping options open, and decision timing in the choice and timing of cancer treatment in the context of other established motivators and covariates such as survival, treatment side effects, and age. Determination of whether men for whom these topics matter more based on existing measures (e.g., tolerance for uncertainty) may also be of interest. Future study would ideally include prospectively collected data with a socially, economically, and geographically diverse population that could probe for these constructs in the current climate of treatment choices for LPC, and may be designed to aid the development of new measures that could be validated in wider use. We focused our study on LPC treatment because of the unique role of patient preference in treatment choice, but exploration of reversibility, timing, and uncertainty may also be fruitful in other disease areas that share these characteristics.



### 4.3 Practice implications

Interventions to assist men with decision-making may want to address the constructs reported here. This study offers evidence for a number of constructs that could add to evolving theories of patient decision-making and help us learn how best to help men with the treatment decision. If confirmed by subsequent research, decision aids might include questions to assist men in considering their own preferences around controlling decision timing, managing irreversibility, and uncertainty and potentially help identify men at risk for difficulty with decision timing or even deferring treatment.

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**Table 1**

## Sample characteristics

Characteristic	N(%)
<b>Age</b>	<b>Mean 64.8</b>
(SD=9.3)	
Employment	
Retired	23(51.1 )
Working full- or part-time	21(47.7)
Missing	1(2.3 )
Partner status	
Single/divorced/widowed	13(28.9)
Partnered/married	32(71.1 )
Education	
Less than four year college	14(31.1)
Four year college	12(26.9)
Graduate degree	19(42.2 )
Income (1999 USD)	
<\$30,000	9(20.0)
\$31,000-\$50,000	9(20.0)
Over \$50,000	23(51.1 )
Missing	4(8.9)
Ethnicity	
White/Hispanic/non-Hispanic	37(84.1 )
African American	6(13.6 )
Asian American/Pacific Islander	1(2.3 )
Religion	
Catholic	6(13.6 )
Protestant	20(45.5 )
Jewish	1(2.3 )
Other	16(36.4 )
Missing	1(2.3 )
Treatment choice	
Surgery	15(34.1)
Brachytherapy	15(34.1)
Watchful waiting	2(4.5)
Undecided	9(20.5)
Other	3(6.8)

**Table 2**

Themes and frequency of appearance in interviews and focus groups

Theme	Description	Mentioned in interview (n=31)	Mentioned in focus group (n=5)
<b>UNCERTAINTY</b>			
Desire for certainty	Asking doctor what they would do in same position	6	0
	Seek aggressive treatment to be sure cancer is gone		
	Seek extra tests/opinions		
Probability	Of surviving without treatment	13	1
	Of success of treatment		
	Of treatment side effects		
Uncertainty of experts	Conflicting opinions from doctors	11	1
	Research should be more conclusive		
	Bias of doctors by specialty		
<b>REVERSIBILITY</b>			
Reversibility	General "can't undo" decision	15	2
	Irreversible damage of treatment		
	Permanent side effects		
Number of options	Desire to maximize number/order of future options	11	2
	Interest in keeping eligible for new treatments available later		
	Age or illness eliminating options		
<b>TIMING</b>			
Decision timing: taking more time	Want to take the time to decide	13	3
	Urged to decide quickly		
Get it over with: deciding quickly	Stick with decision once it is made	14	2
	Want to decide quickly		
	Avoid regret		
The way I make decisions	Related to profession	12	1
	Personality: "always" make decisions quickly or slowly		