

## Research Report

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# Treatment Decision Making in Patients with Bladder Cancer

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### Abstract.

**Background:** Each stage of bladder cancer involves varying treatment issues and concerns that are discussed between patients and providers during the pre-treatment consultation. There is no documentation of how patients engage in decision making.

**Objective:** To describe aspects of treatment decision making perceived by patients with bladder cancer using qualitative analysis of data from individual interviews.

**Methods:** Patients with any stage bladder cancer were recruited from urology and medical oncology services at a comprehensive cancer center. A qualitative approach to data collection and analysis was applied. Individual, semi-structured interviews were conducted, recorded and transcribed. Coding of the transcripts was conducted by research team members, discussed for consensus and major themes derived.

**Results:** 45 men and 15 women, the majority college educated, were recruited. Where to receive care, including from whom, was the initial and major decision. Challenges of decisions regarding urinary reconstruction were dominant. Personal characteristics, including age and being active, were considered. Participants with early stage tumors ( $n=28$ ) typically perceived only one treatment option and followed the physician's recommendation. The 18 participants with stage II-III were aware of multiple options. In 14 stage IV participants, balancing quality of life and outcomes between treatments was common to the decision process.

**Conclusions:** For this educated sample with bladder cancer, recruited at a comprehensive cancer center, the major decision was to seek treatment at a location with the highest level of physician expertise. Personal preferences informed decisions surrounding bladder reconstruction. Further research will be conducted in a diverse sample of patients making decisions in a non-urban, community setting.

Keywords: Bladder cancer, shared decision making, qualitative evaluation

## INTRODUCTION

Of the approximately 74,000 individuals who are diagnosed with bladder cancer each year in the US [1], the majority present with non-muscle-invasive tumors, while an important minority present

with muscle invasive and/or advanced disease [2]. Each stage involves varying treatment issues and concerns that are discussed between patients and providers during the pre-treatment consultation. One of the most complex treatment discussions is that regarding muscle-invasive (stages II-III) bladder cancer for which there is evidence of survival benefit associated with neoadjuvant chemotherapy, followed by cystectomy, compared to cystectomy alone [3]. Additional decisions are discussed with

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patients regarding radiation therapy and bladder reconstruction.

Studies of treatment decisions for other cancers, notably breast [4] and prostate [5, 6], have revealed factors and characteristics that influence the patient's decision process and end results. Work, leisure activities and stories from friends and family members about cancer treatment are known to influence men making a decision about managing localized prostate cancer [5, 7, 8].

Individuals diagnosed with bladder cancer have not been studied as to the processes of treatment decisions. No support system exists to facilitate the decision process. The purpose of our study was to explore and understand the aspects and process of treatment decision making perceived by patients with bladder cancer. We began our exploration in an urban comprehensive cancer center and report the results here.

## **MATERIALS AND METHODS**

Due to the need to begin with an evaluation of the patients' experiences as reported in the patient's and caregivers' own words, a qualitative approach was most appropriate. With a descriptive cross-sectional design, an exploratory study using Grounded Theory [9] methods of data generation and analysis was conducted. Patient participants were recruited locally from a multi-disciplinary genitourinary oncology clinic (Dana-Farber Cancer Institute) and two urology clinics (Brigham and Women's Hospital and Beth Israel Deaconess Medical Center) in Boston. The study was approved by the Dana-Farber/Harvard Cancer Center Institutional Review Board. Eligible patients were 18 years or older, English or Spanish speaking, had a diagnosis of any stage bladder cancer and were making (or had made) a cancer treatment decision within the past 6 months. A study invitation letter and opt-out form was sent or the urologist provider directly asked the patient whether a study coordinator could call to introduce the study. If patients did not opt-out, they received up to two follow-up telephone calls or visits in clinic by the study coordinator to discuss participation. Recruited patient participants were invited to identify a caregiver (18 years or older; English or Spanish speaking) to participate in the interview. Based on our prior experiences with qualitative methods [5], a sample of up to sixty participants was planned in order to adequately describe the experiences of the participants.

Individual, semi-structured interviews were conducted in person or by telephone per participant

preference and convenience. The opening query for each interview was "Please tell me about your decision making with regard to treating the bladder cancer." Based on prior research with individuals with genitourinary cancers [10], participants were prompted, only if needed, to address the following topics: information sources, worries, understanding the treatment options and anticipated side effects and outcomes, others who had influenced the treatment decision, work or family roles, lifestyle, and how much the participant shared in decision making. The principal investigator (DB) conducted initial interviews and trained research team members to conduct subsequent interviews using open-ended prompts and active listening. Demographic information was collected by self-report at the end of the interview, and research staff abstracted clinical information from medical records (diagnosis, staging, and prior and current treatment options). All interviews were digitally recorded, processed to remove all protected health information and then transcribed; transcripts of interviews conducted in Spanish were translated to English by a professional, certified translator. All data were entered into NVivo 9© (QSR International, 2010) for analysis.

Two study team members (DB, BH) began coding sets of transcripts independently for the topics listed above. Line by line coding of new constructs and categories in the transcript data was conducted and then discussed at regular team meetings. Initial results were used to guide selection of remaining participants and the introduction of additional interview probes. After recruitment of 29 participants, purposive sampling [11] was initiated to recruit more participants with non-muscle-invasive cancers in order to approximate the ratio of non-muscle-invasive to muscle invasive in the US [2]. The final recruitment period targeted women. A coding framework was developed and two new team members (MN, SH) joined the coding efforts. All coding was reviewed by the principal investigator during 20 team meetings over eight months and then discussed for consensus with research team members. Major and minor themes were derived. Selected themes were explored with demographic and clinical data using NVivo query functions and coded themes cross referenced with other coded themes. As the recruitment goal neared, saturation of most categories and themes was achieved; in other words, coding of data collected later in the study revealed the same themes identified in earlier data. Finally, keeping with the Grounded Theory method, we derived a social

process [9] inherent in this sample's treatment decision making.

## RESULTS

Over 23 months, 212 eligible participants were identified, among whom 142 were targeted for recruitment following our purposive sampling procedure to recruit about 25% women and a majority of stage I as in national statistics [2]. Forty-four contacted patients (39%) declined to participate, and 29 were unable to be contacted. Sixty-nine (61% of those contacted) gave written consent to participate; nine of these were lost to follow-up or withdrew consent prior to the interview. Ten caregivers participated in the interviews, however the vast majority of description came directly from the patient participants. Thirty-two interviews were conducted by telephone and 28 in person. Interviews ranged from 8 to 54 minutes in length; two interviews were conducted in Spanish. Our analytic sample included 45 men and 15 women; 28 with non-muscle invasive tumors, 18 with muscle-invasive stage II-III and 14 with stage IV metastatic disease. Clinical and demographic characteristics are listed in Table 1.

Table 1  
Participant clinical and demographic information,  $N = 60$

Characteristics		
Age median (min- max)	66 (33–86)	
	n (%)	
Gender	Men	45 (75)
	Women	15 (25)
Education	High school or less	11 (18)
	Some college & above	49 (82)
Ethnicity	Hispanic/Latino	3 (5)
	Non-Hispanic/Non-Latino	57 (95)
Race	White/Caucasian	56 (93)
	Black/African American	2 (3)
	Missing	2 (3)
Marital Status	Single, never married	5 (8)
	Married or living together	47 (78)
	Separate, divorced, or widowed	8 (14)
Work Status	Working full-time	19 (32)
	Working part-time	9 (15)
	Retired	24 (40)
	Other	8 (13)
Diseases Type	New diagnosis	40 (67)
	Recurrent disease	20 (33)
Stage	0a-I	28 (47)
	II-III	18 (30)
	IV	14 (23)
Last time a bladder cancer treatment decision was made	Never	3 (5)
	Within past month	15 (25)
	Within 3–6 months	35 (58)
	1 or more years	6 (10)
	Missing	1 (2)

Major themes are discussed below and Table 2 lists themes with exemplar quotes. Taken together, we synthesized a new Grounded Theory basic social process [9] for patient treatment decision making in bladder cancer: *Finding the best place to have the best treatment for me.*

### *Decision based on: Where to receive the best care and from whom*

The initial and major decision was clearly focused on where, including from whom, to receive the best care. This theme was consistent across stage and also included patient and caregiver's statements that professed beliefs that certain physicians at high-volume hospitals had the best treatment regimens, skills and clinical trial options. Institutional operations were described as more efficient than experienced at other institutions. Often, participants traveled a significant distance for treatment.

### *Decision based on: "We decided to go along"*

The physician's recommendation was one main factor on which 20 participants based treatment decisions. Of these, 19 described a passive or shared control approach to the decision. Many participants took the physician's recommendation into account in context of other influences such as Internet searching or talking to others with knowledge, or personal history, of bladder cancer. Others described not hearing any options and taking the recommendation provided by the physician. Having faith in the physician was addressed by these participants.

### *Decision based on: "Better chance of a long life"*

Participants discussed the chance to survive and to survive in the long term, particularly related to neoadjuvant chemotherapy. Of the 23 who spoke of survival as a main feature of the treatment decision, 5 had stage 0-I tumors, 11 had stage II/III muscle invasive disease, and 7 had stage IV metastatic disease. Participants elaborated on the rationale behind balancing survival statistics and treatment toxicities.

### *Decision based on: Personal attributes*

Nine participants addressed their own age as a decision factor, in a few cases ruling out a certain option, but also feeling vulnerable as an elderly patient facing aggressive therapy. Recreational activities,

Table 2  
Dominant themes, sub-themes and exemplar quotes relevant to bladder cancer treatment decisions (N=60)

Theme	Sub-themes	Exemplar quotations
My decision was based on...	Where to receive the best care and from whom	<i>So when I have something that I think is amiss like cancer, I put on my due diligence hat and start analyzing what's happening. And one of the things that I've always kept as a reference point is, where are the centers of excellence for various treatments? (71 yo M, Stage III) I just liked the reputation and the doctors here better and just stayed here. That was it, very simple. (79 yo W, Stage II)</i>
	What the physician recommended	<i>We decided that—my husband was with me again—we decided that we preferred coming here to going locally. So [Dr] did say, "We've got to get the tumor out right away." So I had the TURBT surgery in December. And then he said, "I would like [you]to have a course of chemo before we proceed with the rest of the surgery." In the meantime, I had contacted, uh, someone we knew who had had bladder cancer. I spoke to a couple people, looked at some things on the Internet, um, checked the [hospital] and people here on—on the Internet, went to their sites. And, we decided to go along. (79 yo W, Stage II)</i>
	Chance of survival	<i>So that's why they decided to go this way with [patient]. They're going to remove it completely and give him—and that's going to give him the better chance of a long life because he won't be able to get bladder cancer again if he doesn't have a bladder. (Caregiver to 70 yo M, Stage III)</i>
	Personal attributes (age, leisure and work activities)	<i>I based it on the fact that, uh, I'm 59 so it's not like I'm 20 and have to live with this bag for, you know, a hundred years. If I were still a young woman... I might have considered doing a rebuilt bladder simply because it's a more natural in appearance and, uh, as long as nothing recurs I would think that it would be a good solution. (59 yo W, Stage III)</i> <i>I've always been a very active person; I go to the Y two or three days a week, and I fish and I play golf. And I just figured that it was worth it to go through the inconvenience of having a bag. And it is—sometimes it's an inconvenience, but for the most part I've adjusted, I think, very, very well to the fact that I'm wearing this thing. (81 yo M, Stage III)</i> <i>I've been an athlete my whole life. I have always exercised. I never had a period of my life where I was not exercising. Very active. So an ostomy bag really was not an option for me. (54 yo M, Stage II)</i> <i>I want to be able to move around and I want to be able to continue working. Um let's see. Yeah...because as far as my decision making it was really um life expectancy, quality of life, reproductive sexual function, third as far as importance on the list. (33 yo M, Stage II)</i>
Decision Control Preferences	Passive	<i>It's like, "No, you tell me what I'm supposed to do. I just want to live [laughs]." That was basically how I made my decision. When I met with him, and I did feel confident that he knew what he was doing. (58 yo M, Stage IV)</i>
	Shared	<i>I felt very involved... we even communicated with him prior to this last surgery what our desires were with respect to my bladder being so sensitive, we wanted to be a little bit more on the conservative side with surgery... because we understood things now, and we were all in agreement (52 yo M, Stage I)</i>

(Continued)

Table 2  
(Continued)

Theme	Sub-themes	Exemplar quotations
Surgery	Active	<i>At first I thought not to do anything, and then talking to them and talking to my husband, and obviously talking to [Dr] that we all agree that I needed to do something. I think that my children and my husband really felt relief when I decided I'm committing myself to do the six weeks, because at the end I was the only one who would make the decision. (56 yo W, Stage I)</i>
	Primary	<i>The bladder is out; prostate is out, a bunch of fat and lymph nodes and stuff because it had gone so far through [the bladder]; he's like, "It was pretty serious." I didn't have a whole lot of people to go to. I mean, a lot of people are "So-and-so had that twenty years ago, and they're fine," (58 yo M, Stage IV)</i>
	Reconstructive	<i>Back at the beginning when we found out I had the bladder cancer, it was like eventually it's going to be a removal of the bladder. And, um, so a decision had to be made whether I would have a stoma, a bag on the outside or a rebuilt bladder. And so that was probably one of the biggest decisions I made. And in talking to the doctor, I took a lot of what the doctor had to say because he's the expert, not me. And then I also – though I'm not very computer literate but my daughters are. (Laughs.) So they would pull information up online for me so that I could read about it at home, too, and, made the decision to go with the stoma, the bag on the outside. (59 yo W, Stage IV)</i>

Abbreviations: yo = year old; M = man; W = woman.

occupations and personal characteristics were addressed by 26 participants, with 10 explicit statements linking the personal attributes to a treatment decision. The impact of an ostomy bag was described negatively by physically active participants and those who worked in occupations that required physical abilities. Personality traits (e.g., faithful, happy) were discussed as relevant to getting through the treatment.

#### *Decision control preferences*

The sample participants spoke of various levels of participating in the treatment decision. Close to half ( $n = 28$ ) described simply accepting what the physician at the comprehensive cancer center recommended with little or no description of participating in the decision, while 22 participants spoke of a dialogue regarding making the decision including activities such as going to the Internet to confirm what the physician had said during a consultation. A smaller number ( $n = 10$ ) of participants described themselves as active decision makers, preferring to exert control over the treatment decision.

#### *Surgery choices*

Few participants with early stage tumors spent time addressing transurethral resection as something about which to make a decision. Those with muscle-

invasive disease discussed cystectomy decisions, mainly focused on selecting the best surgeon and the approach (robotic vs open). The better surgeon was one who communicated clearly about details and performed cystectomies on a regular basis. Only one participant (86 year old man) declined cystectomy and preferred radiation therapy for stage 3 disease, stating he did not have the resilience required for the surgery.

The dominant discussion of surgery focused on whether to have a reconstructed neobladder or urinary diversion to a stoma. The choice was characterized by participants as having "a bag" or not. The patient-reported pros and cons were thoughtfully balanced; bags were visible and likely to interfere with an active lifestyle, but did not require catheterization; neobladders were invisible, but sometimes had to be catheterized and had a risk of long-term incontinence. Age and lifestyle were integrated into these considerations of urinary diversion choices.

#### *Chemotherapy*

Participants with muscle-invasive disease described neoadjuvant chemotherapy as being the *best way to go* for eradicating the cancer; some cited their own research but most recounted the physicians' explanations that chemotherapy followed by radical cystectomy was best. Neoadjuvant chemotherapy often was described as aggressive, but necessary. One 78

year-old man described how his local urologist had cautioned not to let the cancer center physicians “do chemotherapy on you because it will ruin your life.”

Chemotherapy for stage IV disease often was described by participants as the only choice for treatment; the alternative was to do nothing and “wait for the end.” Positive lymph nodes after surgery prompted systemic chemotherapy and participants described the treatments as a way to “get all the cancer.”

#### *Secondary themes: Indirectly related to treatment decisions*

Participants described feeling confident in the physician resulted in feeling comfortable as a patient. Positive comments reflected how participants believed the physician communicated well: the physician had a “conversation with me” and “laid out the options,” gave out a personal phone number, knew the patient’s priorities and addressed quality of life issues. Aspects of communication with the physician that participants did not like included: the diagnosis disclosure was framed negatively, “being talked to instead of with,” being rushed, the surgeon had the “scalpel in his hand,” did not return phone calls and provided no preparation for side effects.

The majority of participants discussed family issues, related to the treatment decision, but primarily how family members were supportive or non-supportive. Participants relied on family members for information gathering, places to stay near treatment facilities, transportation and as a second person to attend clinical consultations. Conversely, a few participants described keeping family out of the decision and protecting family from the burden of knowing and helping.

#### *Relationships between clinical, demographic variables and patient decisions*

Participants with early stage tumors typically perceived only one treatment option and described simply following the physician’s recommendation. For those with stage II-III, awareness of multiple options was clear. Descriptions of the physician’s expertise were common for these patients with muscle invasive disease, 2-3 times more frequent than in other stages. In stage IV participants, balancing the impact on quality of life issues (e.g., chemotherapy side effects) and survival outcomes was common to the decision process. Men began their decision making more often than women with the institution as a choice (60% vs. 33%) and the recommendation of the cancer center

physician (62% vs. 47%). The only influential factor that women voiced more often than men (53% vs. 36%) was expected recurrence/survival rates.

## **DISCUSSION**

Our results suggest that decision making by patients diagnosed with bladder cancer, and receiving care at practices associated with a comprehensive cancer center, is driven by seeking the best care possible, described by our participants as cancer care at a center of excellence. Further decisions were based on selecting effective treatments that suited the patients’ lifestyles and personal attributes.

Other qualitative studies with similar methods have documented the influence of lifestyle and personal attributes on prostate cancer treatment decision making, particularly relevant to living with erectile dysfunction or incontinence in the context of active lifestyles and occupations [5, 12, 13]. Puts and colleagues [14] reviewed both qualitative and quantitative studies of cancer treatment decision making in older adults and, similar to our findings, reported that treatment success rates, fears of recurrence, quality of life and adverse outcomes impacted decisions to accept or decline physician recommendations. In contrast to our finding that participants were quite willing to face inconvenience and transportation issues in order to receive the best care, the review concluded that older adults chose to accept recommendations when convenient and declined when travel was required.

The use of neoadjuvant chemotherapy is supported by level I evidence demonstrating improved survival compared to surgery alone [15]. Yet, neoadjuvant chemotherapy has not had a rapid translation into practice, primarily due to lack of acceptance by surgeons and medical oncologists. As reviewed by Keegan and colleagues in 2014 [16], utilization of neoadjuvant chemotherapy now is increasing. In our study, patient factors associated with decision making around neoadjuvant chemotherapy focused on cure and long-term outcomes. However, patient satisfaction seemed most associated with clear conversations around the purposes and benefits of this chemotherapy. These data suggest that further gains in use of neoadjuvant therapy may be derived from improved patient–physician communication.

Surgical discussions revolved around the choice of urinary diversion (incontinent vs. continent) and surgical approach (open vs. robotic) for radical cystectomy. There is neither level I evidence nor consensus

regarding surgical or health-related quality of life outcomes after incontinent ileal conduit or continent orthotopic neobladder. Longitudinal studies have been small and/or single center, and limited by selection bias, especially for age, disease severity and functional status [17, 18]. Several small randomized trials have compared open and robotic surgical approaches, and have not demonstrated significant differences in lymph node yield [19] or complication rates [20]. Given this state of science, patient preferences must come to the forefront when sharing decisions regarding urinary diversion approaches.

Our data suggest misunderstanding on the part of certain participants for the goals of surgery and prognosis for stage II-III, as well as the outcomes of chemotherapy for stage IV disease. Inaccurate expectations for cure in those with metastatic, stage IV lung and colorectal cancers have been documented when receiving chemotherapy [21] or radiation therapy [22].

This study is limited primarily by lack of diversity in education and race/ethnicity and recruitment only from three institutions of a comprehensive cancer center. Certainly, the well-educated patients who dominated our sample were more likely to have the resources available to explore various institutions and garner transportation. We did not collect income or insurance data. In other studies of cancer treatment decision making, minority patients have described less self-preparation for the decision than majority patients [5, 23].

One goal of the Grounded Theory method is to recruit a sample with diverse experiences in order to solicit a detailed, comprehensive description of the process of interest [24]. For the next phase of our exploration into the aspects and processes of treatment decision making for bladder cancer, we will be recruiting patients of various demographic factors who chose care at non-urban and community settings. Further, we will seek samples in these settings in which the decision making of those with stage II-III is exhaustively described. As we plan future studies, we will consider the interaction of the physician consultant/provider and the patient/caregiver during the consultation visit and measure differing expectations for prognosis.

Our findings contain several implications for practice that are fairly easy to implement. Individuals with bladder cancer typically want input into the treatment and reconstruction decision. Personal attributes such as age, work and leisure activities are relevant, as well as a cure. Consulting clinicians are encouraged to solicit these attributes and help patients navigate the various aspects of bladder cancer treatment decisions.

## CONCLUSION

Patients receiving care at a multi-institution comprehensive cancer center for various stages of bladder cancer described a complex treatment decision process that began with seeking a cancer center of excellence. Combining the physicians' recommendations with treatment success rates and personal attributes resulted in various attitudes and choices, particularly relevant to bladder reconstruction. This process culminated in *finding the best place to have the best treatment for me*.

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## CONFLICTS OF INTEREST

The authors have no conflicts of interest to report.

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