Treatment Decision Making in Patients with Bladder Cancer

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Issues in Patient-centered Decision Making

• Varying treatment issues, concerns for each stage
  ▪ One of the most complex treatment discussions is that relevant to muscle-invasive, stages II and III bladder cancer with neoadjuvant chemotherapy, followed by cystectomy.
  ▪ Bladder reconstruction

• Counter-intuitive treatment decisions are sometimes made by the patient given the medical facts of the conditions.
Other Cancers and Decision Making

• Patient factors and characteristics influence the decision process and end results.\textsuperscript{1-3}

• Possible adverse outcomes, 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.\textsuperscript{2,4,5}
The Gap and the Purpose

• Individuals diagnosed with bladder cancer have not been studied as to the processes of treatment decisions.

• No evidence-based 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.
Methods

• Descriptive cross-sectional design
• An exploratory study using Grounded Theory\textsuperscript{6} methods of data generation and analysis
• Participants were recruited 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); all in Boston
Methods

• Eligible patients were:
  ▪ 18 years or older
  ▪ English or Spanish speaking
  ▪ a diagnosis of any stage bladder cancer
  ▪ making (or had made) a bladder cancer treatment decision within the past 6 months
Data Collection

• 60 individual, semi-structured interviews
  ▪ in person or by telephone
• Opening query: "Please tell me about your decision making with regard to treating the bladder cancer."
• Participants were prompted to address the following:
  ▪ Information sources, who had influenced the treatment decision, including the physician and others
  ▪ Worries, understanding the treatment options and anticipated side effects and outcomes
  ▪ Influence of work or family roles, lifestyle,
  ▪ How much the participant shared in decision making
Analysis

- Grounded Theory
  - Discovering the basic process involved in treatment decision making, including all aspects and influential people and factors.
  - Analysis begins with first set of data, continues with subsequent data and analysis builds
    - Purposive sampling
  - Team approach to coding led by principal investigator
    - Nvivo software
Qualitative Analysis

- Each substantive line of the interview was coded
- Codes were reviewed and major and minor categories/themes were derived
- Selected themes explored with demographic and clinical data using NVivo query functions
- Coded themes cross referenced with other coded themes
Qualitative Analysis, continued

• 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.

• Keeping with the Grounded Theory method, we derived a social process inherent in this sample's treatment decision making.
Results: Demographics N=60

<table>
<thead>
<tr>
<th>Age median (min- max)</th>
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<tbody>
<tr>
<td></td>
<td>66</td>
<td>(33-86)</td>
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<tr>
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<td>n (%)</td>
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</table>

| 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)   |

| Stage                | 0a-I               | 28(47) |
|                      | II-III             | 18(30) |
|                      | IV                 | 14(23) |
## Results

<table>
<thead>
<tr>
<th>Theme</th>
<th>Exemplar quotations</th>
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</thead>
<tbody>
<tr>
<td>My decision was based on…..</td>
<td>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)</td>
</tr>
<tr>
<td>Where to receive the best care and from whom</td>
<td></td>
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<td>What the physician recommended</td>
<td>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.” And, we decided to go along. (79 yo W, Stage II)</td>
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<td>Chance of survival</td>
<td>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)</td>
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</table>
## Results

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<tr>
<td><strong>My decision was based on…...</strong></td>
<td><strong>Chance of survival</strong></td>
</tr>
<tr>
<td><strong>Personal attributes (age, leisure and work activities)</strong></td>
<td></td>
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<td></td>
<td>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)</td>
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<td></td>
<td>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)</td>
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<td>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)</td>
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## Results

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<th>Exemplar quotations</th>
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<tbody>
<tr>
<td><strong>Decision control preference</strong>&lt;br&gt;Passive</td>
<td><em>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.</em> (58 yo M, Stage IV)</td>
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<td><strong>Shared</strong></td>
<td><em>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 we’re all in agreement</em> (52 yo M, Stage I)</td>
</tr>
<tr>
<td><strong>Active</strong></td>
<td><em>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.</em> (56 yo W, Stage I)</td>
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# Results

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<td>Surgery</td>
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<td>Primary</td>
<td><em>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.”</em> 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)</td>
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<tr>
<td>Reconstructive</td>
<td></td>
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<td><em>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, 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.</em> (59 yo W, Stage IV)</td>
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Results

• Secondary themes; Indirectly related to treatment decisions
  ▪ Physician communication
  ▪ Support from family members
• Relationships between clinical, demographic variables and patient decisions
  ▪ Stage 0-1: typically perceived only one treatment option and described simply following the physician's recommendation.
  ▪ Stage II-III: awareness of multiple options was clear. Descriptions of the physician's expertise were common
  ▪ Stage IV: balancing quality of life and outcomes was common to the decision process
Results

• Gender
  - Men began their decision making with the institution as a choice more often than women (60% vs 33%) and recommendation of the cancer center physician (62% vs 47%).
  - The only influential decision factor that women voiced more often than men (53% vs 36%) was expected recurrence/survival rates.
Strengths and Limitations

• Strengths
  ▪ “All comer” recruitment enabled a description of experience in various stages
  ▪ Multiple coders for consensus
  ▪ Saturation of categories
  ▪ Men/women ratio close to population incidence
    • 3:1 in our sample
    • ABCS statistics cite 3:1
    • Age-adjusted ACS statistics for 2007-2011 cite 4:1

• Limitations
  ▪ Lack of educational, racial and ethnic diversity
Conclusion

Patients with 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.
Acknowledgments

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References


