Prostate Cancer Education and Decision Making

B. Joyce Davison, R.N., PhD.

www.usask.ca/nursing
Question

- What do we know about how men newly diagnosed with prostate cancer make a treatment decision and the information they want to make that decision?
Introduction

- Making a treatment decision at the time of a prostate cancer diagnosis is difficult
- No randomized clinical trials have shown that one treatment is superior
- Treatment decisions are often made based on biases of both patients and physicians
- Patients continue to have unmet information needs, and a significant proportion of men are not satisfied with the type and amount of information they receive to make a treatment decision
Introduction

- Information is essential for patients and their partners to make informed treatment decisions.
- Lack of consistency regarding the amount and type of information men receive, and treatment protocols vary across the country.
- More recent studies have shown that men with prostate cancer consider their personal characteristics and factors as important in deciding which treatment they will choose, however these are not being assessed.
- So, there is still a lot of work to be done in this area.
Objectives of Today’s Presentation

1. To identify how decision preferences have changed over the past 15 years
2. To identify the amount and types of information men and their partners have a preference for at the time of diagnosis to make a treatment decision
3. To identify factors having an influence on treatment decision making
4. To describe a project that aims to improve the treatment decision making experience of men newly diagnosed with PC through the use of an innovative internet based decision support intervention
Measurement of the Role Patients Want to Play in Treatment decision Making
Control Preferences Scale (Current Version)

Active:
• I prefer to make the final selection of the treatment after considering my doctor’s opinion.

Collaborative:
• I prefer that my doctor and I share responsibility for deciding which treatment will be best for me.

Passive:
• I prefer that my doctor makes the final decision about which treatment is best for me after considering my opinion.

# Decision Preferences

<table>
<thead>
<tr>
<th>Study (N)</th>
<th>Active</th>
<th>Collaborative</th>
<th>Passive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Davison et al. 1995 (N=58) MB</td>
<td>19%</td>
<td>23%</td>
<td>58%</td>
</tr>
<tr>
<td>Davison et al. 1997 (N=60) MB</td>
<td>25%</td>
<td>43%</td>
<td>32%</td>
</tr>
<tr>
<td>Davison et al. 2002 (N=80) BC</td>
<td>50%</td>
<td>43%</td>
<td>8%</td>
</tr>
<tr>
<td>Davison et al. 2007 (N=324) BC</td>
<td>53%</td>
<td>36%</td>
<td>11%</td>
</tr>
<tr>
<td>Davison et al. 2011 (N=150) BC &amp; SK</td>
<td>38%</td>
<td>53%</td>
<td>9%</td>
</tr>
<tr>
<td>Davison et al. 2012 (N=30) SK</td>
<td>32%</td>
<td>68%</td>
<td>0%</td>
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</table>
Comparison of Men and Partners’ Preferred and Assumed Roles

(Davison BJ, Goldenberg SL, Gleave ME, Degner LF. Provision of individualized information to men and their partners to facilitate treatment decision making in prostate cancer. Oncology Nursing Forum 2003:30:107-14)

<table>
<thead>
<tr>
<th>Preferred Role</th>
<th>Active</th>
<th>Collaborative</th>
<th>Passive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient with doctor</td>
<td>51%</td>
<td>42%</td>
<td>7%</td>
</tr>
<tr>
<td>Patient with partner</td>
<td>46%</td>
<td>54%</td>
<td>0</td>
</tr>
<tr>
<td>Partner with patient</td>
<td>3%</td>
<td>55%</td>
<td>42%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Assumed Role</th>
<th>Active</th>
<th>Collaborative</th>
<th>Passive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient with doctor</td>
<td>78%</td>
<td>14%</td>
<td>8%</td>
</tr>
<tr>
<td>Patient with partner</td>
<td>60%</td>
<td>40%</td>
<td>0</td>
</tr>
<tr>
<td>Partner with patient</td>
<td>0</td>
<td>16%</td>
<td>84%</td>
</tr>
</tbody>
</table>
Main Differences in Patient and Partner Preferences

- Major reason for partners reporting that they had assumed a less active role in selection of treatment was that they believed that the decision was up to their spouse (patient) as it was his body.
- Majority of men reported that they had made the decision with their partner. This was their perception of how the decision was made.
Information Preferences of Couples at Time of Diagnosis

**Prognosis** – Likelihood of cure or survival

**Stage of Disease** – Spread & extent of cancer

**Treatment Options** – Treatments available

**Side Effects**- Side effects of recommended treatments


Davison B.J. et al. (2007) Quality of life, sexual function and decision regret one year following surgical treatment of localized prostate cancer. BJUJ,100, 780-785.
Amount of Information Patients Want?

- This part was missing in my previous clinical assessments of patients
- Often had to guess how much detail patients wanted
- Following assessment was recently implemented. Comprised of 5 statements (with descriptions) that measure health information seeking behaviour or how much information men actually want to access
Statements of HISB

- **Intense:** *I am the type of person that is committed to get thorough, in-depth information.* This means that I want to learn ‘everything’ I can about prostate cancer and the available treatments. I also believe it is important to develop an expertise about prostate cancer so that I can make an informed treatment decision. I would like to access high quality, up to date, and detailed sources of information from a variety of sources.
Statements of HISB

- **Complementary** - *I am interested in receiving information about prostate cancer, but I want the amount of information to be restricted.* I want to have a basic level of knowledge about what is going on. I would like to access easy to understand overviews of prostate cancer or practical information to understand what I consider most relevant to me. I would also like to learn more about what to expect prior to and following treatment so that I can prepare myself to handle such events.
Statements of HISB

- **Fortuitous**- *I want to pick up information about prostate cancer as I go along.* I would like to talk with other patients who have been diagnosed with prostate cancer to see what their first hand experiences were with different treatments. I do not want to undertake in-depth information seeking. I want information on topics that are of interest to me and choose to identify the type of information I want as I go along.
Statements of HISB

- **Minimal**- I want little or no information about prostate cancer as I am sure that my specialist will take care of me and give me the information that I need. The type of information I do want should be general and not detailed. I would like to have some general information to deal with a specific problem if one should arise. I want to get the treatment done and move on with my life and achieve ‘normalcy’ as soon as possible. I want to minimize the effects of my prostate cancer on my family and job/leisure activities.
Statements of HISB

- **Guarded** - *I do not want additional information about prostate cancer as it tends to make me anxious and fearful.* I only want information that explains specific aspects of my situation. I am sure that my specialist will give me the information that I need to have. General information would not be helpful to me. I want my specialist to get the treatment done and get rid of the cancer. I do not want information that will distress me.
Findings of Recent Study (N=150)

- **Intense**- I am the type of person that is committed to get thorough, in-depth information. 52%

- **Complementary**- I am interested in receiving information about prostate cancer, but I want the amount of information to be restricted. 38%

- **Fortuitous**- I want to pick up information about prostate cancer as I go along. 4%

- **Minimal**- I want little or no information about prostate cancer as I am sure that my specialist will take care of me and give me the information that I need. 3%

- **Guarded**- I do not want additional information about prostate cancer as it tends to make me anxious and fearful. 3%
Health Information Seeking Behavior

- Majority of men had preference for intense/detailed (52%) or complementary/restricted (38%) HISB-
  (Randomizing statements to determine if this shows a difference)
- Men with university degree more likely to prefer intense (detailed information) (p=0.03) compared to other education categories
- Men in these two categories wanted access to more types of information resources compared to other patterns
Current Preferred Information Sources

Top Five from Recent Survey (2011)

- Internet sites (74%)
- General brochures (57%)
- Articles from medical journals (31%)
- Information on complementary and alternative medicine (CAM) (31%)
- How to access support groups (19%)
Factors Influencing Treatment Decision

Personal factors (9 factors) identified in literature and my clinical work over past 15 years

- Impact of treatment on: survival; urinary function; sexual function; bowel function; and work and leisure activities
- Invasiveness of the procedure
- Impact of a friend’s or acquaintance's experience with a treatment
- Specialist’s recommendation
- Spouse’s or family members opinion

<table>
<thead>
<tr>
<th>Factor</th>
<th>Total Z Score Mean (SD)</th>
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<tbody>
<tr>
<td>Survival</td>
<td>7.21 (0.80)</td>
</tr>
<tr>
<td>Impact of treatment on urinary function</td>
<td>4.26 (0.47)</td>
</tr>
<tr>
<td>Urologist’s opinion</td>
<td>3.65 (0.41)</td>
</tr>
<tr>
<td>Invasiveness of treatment</td>
<td>0.88 (0.10)</td>
</tr>
<tr>
<td>Impact of treatment on bowel function</td>
<td>0.70 (0.08)</td>
</tr>
<tr>
<td>Impact of treatment on work/leisure</td>
<td>-1.07 (-0.12)</td>
</tr>
<tr>
<td>Impact of treatment on sexual function</td>
<td>-2.27 (-0.25)</td>
</tr>
<tr>
<td>Spouse/family opinion</td>
<td>-6.43 (-0.71)</td>
</tr>
<tr>
<td>Friend’s experience with treatment</td>
<td>-6.94 (-0.77)</td>
</tr>
</tbody>
</table>
Association Between Personal Factors and Preferred Role in Decision Making

- No additional factors identified as having an impact on treatment decision

Top 5 factors common to all preferred roles were:

1. Survival
2. Urinary function
3. Bowel function
4. Urologist’s opinion
5. Invasiveness of procedure

- These factors similar based on level of education
- Men 60 years and younger more concerned about impact of work and leisure activities than invasiveness of procedure compared to other age groups
Comparing Sexual Function to Other Personal Factors

- Impact of treatment on sexual function on treatment decision declined with age
- Ranked least in importance by men > 71 years of age
- 7th in importance men age 61-70 years of age
- 6th by men 60 years of age or younger
What to do with this information?

- Currently the information from this previous body of research has been converted into an internet based program
- Decision Support Intervention- Prostate Cancer (DSI-PC)
- Funding from Canada Motorcycle Ride for Dad received in November 2011 to develop the initial version and pilot test with a group of men newly diagnosed with prostate cancer in SK
- Patients complete the program at home or in the clinic. Takes approximately 20 minutes to complete including the consent
What does program do?

A summary page is produced for the patient that provides:

1. Amount of information wanted (HISB)
2. Types of resources wish to access
3. Preferred role in medical decision making
4. Top four factors having an influence on treatment decision
5. Preferred treatment choice
Summary Sheet

- Patients asked to share this summary sheet with nurses, physicians at the time of treatment discussions
- Goal is to provide HCPs with a summary of the patient’s preferences and values so that the discussion can be tailored to provide patient centered care
Measures for Research Purposes

Outcomes being measured prior to treatment decision:
1. HISB- How much information wish to get
2. Preferred role in making a decision with physician
3. Decision conflict (how sure about your initial treatment choice)

Post Treatment Decision:
1. Role actually played in making the treatment decision with physician
2. Decision conflict (how sure you are about the treatment you chose)
3. Satisfaction with preparation in TDM
4. Satisfaction with type, amount and way information received to make a TD; role played in TDM; treatment choice
Future Work

- Changes will be made to the program based on the initial work.
- Extra Physician training will be done to make sure that they know how to use summary sheet during treatment discussions.
- A copy of the summary sheet will be sent to physician/s before treatment consultation.
- Study will now be conducted with 175 patients starting in January 2013. Funded by Saskatchewan Health Research Foundation.
Questions?