Survivorship: Maintaining a high Quality of Life while Living with Prostate Cancer

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Is it over when it’s over?
Uncertainty

- Uncertainty “may range from a falling short of certainty to an almost complete lack of conviction or knowledge especially about an outcome or result.” (Merriam-Webster Inc. 1997)
- Uncertainty in illness – a cognitive state resulting from insufficient cues with which to form a cognitive schema, or meaning of a situation or event. (Mishel, 1988)
Consequences

- Depression
- heightened anxiety and tension
- Decreased coping & adjustment
- Less optimism and hope
- Tension in family relationships, work, and recreation
- Weakened sense of mastery
- Heightened sense of threat and danger
Appraisal

- Primary appraisal in the model functions to process the uncertainty and acts as a mediator between uncertainty and an outcome.
- Suggested by the work of Folkman and Lazarus (1985) with stress and coping and defined it as the cognitive ability to classify the stressor as: irrelevant, benign or as a threat.
  - danger
  - opportunity
Active surveillance or Watchful waiting

- Active surveillance [AS] has been supported as an appropriate management option for prostate cancer in men
  - Over the age of 65
  - Low grade and stage disease
  - Low and stable serum prostate specific antigen (PSA) levels.
- Used by about 10% of eligible patients
Uncertainty & Active Surveillance

- AS has been associated with illness uncertainty consistent with that of other chronic illness populations and reduced quality of life.
- Older men who undergo active surveillance live every day with the knowledge that they have cancer in their bodies and associated uncertainty that this cancer may grow, spread and kill them.
A correlational study, consisting of questionnaires, self-completed by a national convenience sample of 19 older men who were receiving the active surveillance treatment for prostate cancer, throughout the United States found significant relationships were found between uncertainty, anxiety and appraisal of danger and the affective physical function domain of QOL ($r = .553; p = .014$ [Wallace, 2003]).
Uncertainty Management

- The Uncertainty Management Intervention (UMI) has been used in other populations and piloted in two samples of men undergoing AS (Bailey et al., 2004).

- The traditional approach involves a process of rethinking about prostate cancer as a chronic illness rather than an instant killer (cognitive reframing)
Considerations

- Men need to “do something” to combat their prostate cancer (Holmboe & Concato, 2000).

- Ornish et al., (2005) and Daubenmeier et al (2006) have found positive preliminary results supporting the relationship between self-management – particularly diet and exercise - on PSA levels and quality of life among AS participants.

- Need for anonymity - Not inclined toward support groups (Wallace & Storms, 2007)
Design & Methods

- An iterative intervention development process was used beginning with a focus group study of psychosocial and educational needs of AS patients.
- A structured interview guide was used to collect data regarding the types educational and psychosocial content the men desired.
- A prototype of the web-based intervention was then developed collaboratively with technology experts and an APRN expert and evaluated with a small sample of AS patients.
Measures

- **Focus Group:** A structured interview guide was used to collect data regarding the types of educational and psychosocial content the men desired.

- **Prototype Evaluation:** A structured questionnaire was used to determine older men’s perspectives and opinions on web prototype.
Data Analysis

- fundamental qualitative analysis method “entails the presentation of the facts of the case in everyday language.” (Sandelowski, 2000, p. 336).
- investigators read the transcription, coded into possible categories and through mutual consensus, categories were clarified and changed.
- categories were then verified by an expert in qualitative data analyses.
- five categories were determined.
Demographics

- Seven AS participants attended 1 of the 2 focus groups and three returned to evaluate the web prototype.

- Participants were all Caucasian and ranged in age from 64 to 79 years.
Focus group findings

- **Sources of Support:** It’s just part of my nature. I don’t like to be telling all sorts of personal war stories and agonizing over one thing or another. I just try to weather it on my own but I think your possible suggestion of being able to correspond or have another source of information via discussions or phone is very good also.
Findings

**Sources of Information:** I have a problem finding the Watchful Waiting areas in the websites. It seems like there’s more and more that are getting into the Watchful Waiting mode. So, I’m encouraged by that because I’m constantly searching... I’d like to see a couple of articles by Doctors who are old enough to have had Prostate Cancer...
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- **Myths/Mis-Information:** There is one thing that is very, very important and that is that PSA results can vary depending on who’s doing the analysis, who’s doing the testing.
Health Promotion and Taking Charge:
And then the exercising was also on a website, I mean, exercising, I now joined a gym and I go to the gym two or three times a week and work out for about an hour.
FAQ’s: Frequently Asked Questions

Can I pass prostate cancer onto my partner through sexual intercourse?

Let’s first address the idea of cancer being contagious. According to the American cancer society and scientists who have done extensive research on this topic, cancer CANNOT be passed from the patient to their partner. All cancers are diseases that begin in cells within the body; therefore it cannot be passed from one individual to another. Furthermore, prostate cancer can only occur in men, because women lack the prostate gland. This means that prostate cancer can’t be passed during sexual intercourse, oral-genital sex, or even kissing.

Can aspirin prevent prostate cancer?
Introduction

The American Cancer Society estimates that in 2008, approximately 186,320 men were diagnosed with prostate cancer. Surgery and radiation are the primary treatments for prostate cancer, yet Active Surveillance (sometimes referred to as watchful waiting) is an alternative approach to managing more low-risk forms of prostate cancer, with approximately 10% of all low-risk prostate cancer patients undergoing this management option. Candidates for Active Surveillance...
# Useful Resources & Links

**American Cancer Society**  
http://www.cancer.org/docroot/ln/ln_0.asp

**National Cancer Institute**  
http://www.cancer.gov/cancertopics/types/prostate

**Us Too**  
http://www.us TOO.org/

**John Hopkins Prostate Health Alerts**  
http://www.johnshopkinshealthalerts.com/alerts_index/prostate_disorders/25-1.html
Prototype Evaluation

- Participants liked the title, content and the idea of a website specifically devoted to AS.
- They found that it was visually appealing, easy to understand and navigate and specifically appreciated the frequently asked questions (FAQ) page.
- Participants found that some of the information was too clinical and thus "confusing". They requested further information on normal PSA ranges and rate of change, how often a biopsy should be taken and more specifics on diet and exercise recommendations.
Conclusions

- prostate cancer may result in intolerable uncertainty that impacts quality of life.

- Uncertainty management interventions have great potential in reducing the uncertainty associated living with prostate cancer.
Limitations

- No ethnic diversity
- Participants recruited from a single practice
- One time interview
Next Steps

- Pilot of intervention in 20 men undergoing AS with measurement of uncertainty and QOL as outcomes.
- Adapted internet intervention provides the groundwork for a larger clinical trial in a representative patient sample.