Uncertainty and Quality of Life of Older Men Who Undergo Watchful Waiting for Prostate Cancer

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Purpose/Objectives: To explore uncertainty, anxiety, and the personal manner in which uncertainty is understood, and explain the health-related and affective quality of life (QOL) of men who undergo watchful waiting for prostate cancer.

Design: Descriptive, quantitative, survey approach.

Setting: United States.

Sample: A national sample of 21 men diagnosed with prostate cancer (X age = 76 years) who had elected to receive no treatment for their disease.

Methods: 19 subjects who met the criteria contacted the researcher and completed the mailed questionnaire.

Main Research Variables: Uncertainty and QOL.

Findings: Moderate yet significant relationships were found between each of the independent variables. Significant relationships were found among uncertainty, anxiety, and the perception of danger (a dimension of QOL). Using hierarchical multiple regression, a model was built to explain 60% of the variance in this QOL dimension.

Conclusions: This study supports that men who undergo watchful waiting are uncertain and that this uncertainty results in their perception of danger and influences their affective health-functioning QOL. This study lends further support for the Uncertainty in Illness Model in the watchful waiting population.

Implications for Nursing: The findings of this study imply that increased teaching and patient care management regarding watchful waiting are needed both before and after the treatment decision has been made. This study provides the framework for further study on interventions to improve the QOL of this population.

Key Points . . .

➤ Watchful waiting is an appropriate management option for certain men with prostate cancer.

➤ As men’s uncertainty increases, so does their perception of that uncertainty as a danger.

➤ Uncertainty explains a significant amount of the variance in affective health functioning quality of life.

➤ Nurses should target their efforts to reduce uncertainty through teaching and patient care management, which likely will reduce the perception of danger and the effects of this perception and uncertainty on the quality of life of the watchful waiting population.

Prostate cancer is the sixth most common cancer in the world and the fourth most common cancer among men (Parkin, Pisani, & Ferlay, 1999). In the United States, prostate cancer is the most prevalent cancer in men, with 220,900 new cases estimated for 2003 (American Cancer Society, 2003). Low death rates and the high risks and costs associated with treatment have led some patients and physicians to choose not to aggressively treat prostate cancer but rather to periodically observe its progression. Watchful waiting is defined as “initial surveillance followed by active treatment if and when tumor progression produces symptoms” (Adolfsson, 1995, p. 333). Watchful waiting takes into consideration factors such as age, other medical conditions, and tumor qualities (organ-confined disease and total Gleason score of seven or less) in the decision of how to manage prostate cancer. From 3%–13% of urologists consider watchful waiting to be as appropriate as aggressive therapy (Fowler et al., 1998). In a study of patients with prostate cancer over the age of 40 in a suburban general practice, 31% underwent watchful waiting (Brett, 2001).

Men who receive watchful waiting as a treatment are likely to be older than most men diagnosed with prostate cancer and have other medical conditions and low-grade tumors. Watchful waiting is most appropriate for men whose life expectancy is less than 10–15 years. Naitoh, Zeiner, and De Kornion (1998) found watchful waiting to be an appropriate management option for older men with prostate cancer or men with other serious illnesses that could threaten their lives more quickly than the cancer. Koppie et al. (2000) conducted a study to determine the demographic and clinical profile of men who elect watchful waiting as a management option by analyzing a database of 329 watchful waiters from the Cancer of the Prostate Strategic Urological Research Endeavor. Chi-square analysis revealed that patients treated with watchful waiting were more likely to be 75 years old or older and have a low serum prostate-specific antigen, organ-confined disease, and a total Gleason score of seven or less. In another study of 199 men who were undergoing watchful waiting for prostate cancer (1999).
cancer at several urology practices, 56% of patients remained free from treatment after five years (Zeitman, Thakral, Wilson, & Schellhammer, 2001).

Uncertainty has been determined to be a major stressor for patients coping with life-threatening illnesses such as prostate cancer (Germino et al., 1998). In addition, the quality of life (QOL) of older patients with cancer has gained increased attention as a significant factor in the management of cancer and cancer-related problems. Uncertainty has been shown to affect QOL (Padilla, Mishel, & Grant, 1992).

The absence of organizing frameworks showing the relationship among illness variables and QOL is evident in nursing knowledge and clinical practice. The lack of a clear understanding of what influences QOL in patients with prostate cancer and a framework to guide patients from diagnosis to an outcome may encourage clinicians to use morbidity and mortality rather than QOL to make decisions about prostate cancer treatment. Therefore, the purpose of the current study was to explore uncertainty, anxiety, and the manner in which uncertainty is understood, as well as to explore the health-related and affective QOL of men who undergo watchful waiting for prostate cancer.

**Theoretical Framework**

The theoretical framework for this study was adapted from Mishel’s Uncertainty in Illness Model (Mishel, 1988) (see Figure 1). Mishel viewed uncertainty as the greatest psychological stressor for patients coping with life-threatening illnesses such as cancer. The model proposed that uncertainty evolves from several life factors (structure providers, stimuli frame, and cognitive capacity), is influenced (or mediated) by personality characteristics and the personal manner in which uncertainty is understood (primary appraisal), and results in an outcome.

The influences of many personality characteristics have been tested as mediators of the relationships among uncertainty and outcomes, including optimism (Christman, 1990; Mishel, Hostetter, King, & Graham, 1984; Mishel & Sorenson, 1991), hope (Hilton, 1994), mastery (Mishel, Padilla, Grant, & Sorenson, 1991), and learned resourcefulness (Rosenbaum, 1983). The presence of anxiety was suggested in the current study to mediate the relationship between uncertainty and the personal interpretation of uncertainty. Anxiety was not used previously as a mediator in the model between uncertainty and QOL. However, theoretical support can be derived from the literature about fear of cancer manifested as anxiety among older adults (Berman & Wandersman, 1990; Burman & Weinert, 1997; Lauver & Angerame, 1993; Sutton, Eisner, & Burklow, 1994). Primary appraisal, derived from the work of Folkman and Lazarus (1985) with stress and coping, functions to process the uncertainty and acts as a mediator between uncertainty and QOL. Primary appraisal may result in the perception of uncertainty as either danger or opportunity.

**Literature Review**

The personal nature of QOL and the great variability inherent in individual values make defining the concept difficult. QOL definitions usually include physical, psychological, social, and spiritual aspects of function and well-being (Muldooon, Barger, Flory, & Manuck, 1998). Function primarily is measured as health-related QOL, and well-being generally is evaluated with affective measures of the concept. The current study determined function using a health-related QOL measure and well-being using an affective measure of QOL.

Studies have demonstrated that prostate cancer and its treatment choices have a pervasive impact on QOL of older men (Borghede, Karlsson, & Sullivan, 1997; Kornblith, Herr, Ofman, Scher, & Holland, 1994; Litwin et al., 1995). The two main side effects of treatment, incontinence and impotence, affect the physical, psychological, social, spiritual, and overall QOL of older men (Keister & Blixen, 1998).

Although some studies have identified QOL dimensions for patients with prostate cancer, few of these studies included men who have undergone watchful waiting. In addition, all of the studies focused on health-related QOL to the exclusion of other QOL dimensions.

Bacon, Giovannucci, Testa, and Kawachi (2001) conducted a survey of 842 men diagnosed with prostate cancer. The survey, which was mailed to participants, was completed during a five-year period. Using several QOL instruments with reported reliability and validity, a study group undergoing watchful waiting and another study group undergoing hormone therapy reported the lowest total QOL scores. The low QOL scores occurred despite the absence of urinary incontinence, impotence, and bowel side effects in these populations. Differences among treatment groups were apparent on specific QOL dimensions. Galbraith, Ramirez, and Pedro (2001) used a longitudinal design to demonstrate QOL differences among five treatment groups (watchful waiting, surgery, conventional radiation, proton-beam radiation, and a combination of both radiation types). One hundred eighty-five men with localized prostate cancer were sent a QOL questionnaire with supported reliability and validity at 6-, 12-, and 18-month intervals; the researchers found that although the treatment groups varied on QOL dimension scores, no differences in overall QOL scores were seen. Litwin et al. (1995) used a mail survey to determine how health-related QOL was affected in 214 subjects receiving radiation, radical prostatectomy, or watchful waiting for prostate cancer, and a control group (n = 273). Analysis of covariance, controlling for age and comorbidity, revealed differences in various dimensions of QOL. However, no differences were found in overall QOL among the three treatment groups and the comparison group. In another study by Kornblith et al. (1994), the effect of androgen ablation treatment (n = 94), radical prostatectomy (n = 48), or watchful waiting (n = 31) on the health-related QOL of men.

**Figure 1. Uncertainty in Illness Model**

*Note: Based on information from Mishel, 1988.*
and their spouses or partners was explored. Multivariate analysis of variance revealed no significant differences in overall QOL among the three treatment groups. However, once again, differences were seen among treatment groups on specific QOL dimensions. The investigators did not report the individual score reports but stated that all three groups experienced distress that affected their QOL.

These outcome studies revealed that QOL concerns transcend treatment groups. The researchers found support for the notion that total QOL in the watchful waiting group was lower or no different than the total QOL of treatment groups experiencing the side effects of treatment, despite domain-specific differences in QOL. In other words, the results of the current study indicated that QOL is affected fairly equally by all men with prostate cancer, regardless of treatment choice.

Only one study has been conducted on the role of uncertainty in prostate cancer. However, only Caucasian (n = 132) and African American (n = 69) men who received radical prostatectomy or radiation treatment for prostate cancer and their families were included in the sample (Germino et al., 1998). After controlling for age and education, no difference in uncertainty was found between the radical prostatectomy group and the radiation treatment group. Low yet significant correlations were apparent among uncertainty and coping, psychological adjustment, and perceptions of health and illness in all four groups. Role and spiritual variables were correlated with uncertainty in Caucasian patients and family members. Although QOL was not measured directly, domains that are considered to be important to QOL, including psychological adjustment, social support, and spirituality, were shown to be negatively related to uncertainty in this sample of patients with prostate cancer. Based on this information, two hypotheses were developed to guide the current study’s research.

1. Uncertainty, anxiety, and primary appraisal significantly will explain the health-related and affective QOL among older men who undergo watchful waiting for prostate cancer.
2. Anxiety and primary appraisal will have a mediating effect on uncertainty and affective and health-related QOL in older men who undergo watchful waiting for prostate cancer.

**Methods**

Approval for this study was obtained from the respective institutional review boards. To be included in the study, participants had to be male, aged 65 and older, fluent in English, and able to give informed consent. Participants in the study must have been diagnosed with prostate cancer but could not have received surgical, radiation, or other treatment for the disease.

Participants were recruited through their urologists, a newspaper advertisement, or Web site announcement. A total of 31,500 flyers, accompanied by a letter, were mailed to 4,500 urologists identified through a purchased database from the American Urological Association. This sample represented diverse geographical areas throughout the United States. In addition, five urologists in Connecticut were contacted by telephone and through subsequent personal meetings. The subject recruitment flyer also was posted on eight prostate cancer Web sites and distributed at local supermarkets and libraries, and an advertisement was placed in the “Healthy Living” section of *The New York Times*.

Along with the flyers, urologists were sent a letter specifically discussing the inclusion criteria and the focus of the study on the QOL of men who were watchful waiting. The urologists were instructed to distribute the flyers to their patients that met the inclusion criteria. The flyers and advertisements listed the study inclusion criteria and the investigator’s identification and telephone number, notified participants of a $10 token of appreciation, and requested participants to call the researcher if they met the criteria, had questions, or were interested in participating.

**Instruments**

The Mishel Uncertainty in Illness Scale-Community Form (MUIS-C) (Mishel, 1997) was used to measure uncertainty in this study. The MUIS was developed in 1986 as an adaptation of the original MUIS (Mishel, 1981). MUIS-C contains the same 28 Likert scale items as the original MUIS, except the items pertinent to treatment and communication with physicians and healthcare personnel that were not appropriate to individuals residing in the community were not included. Because the items on the MUIS-C are highly similar to those on the original MUIS, the extensive reliability and validity results from the original MUIS are used to support the MUIS-C.

The State-Trait Anxiety Inventory (Spielberger, 1983) was developed in 1964 in response to the need for a valid and reliable instrument to measure anxiety. The inventory has been used extensively in research and clinical practice. The Trait Anxiety Scale used in the current study consisted of 20 statements asking respondents to choose the degree to which they possess anxiety descriptors on a four-point Likert scale. The scores can range from 20–80, with higher scores indicating greater anxiety.

The Appraisal Scale, used to measure the manner in which the participants perceive the uncertainty associated with prostate cancer, originally was designed by Folkman (1982) to assess a number of psychological variables related to stress and coping during college examinations, including cognitive appraisal, emotion, and coping. The scale later was divided into two components: the appraisal scale and the coping scale, for use in a later study (Folkman & Lazarus, 1985). The appraisal scale consists of 15 questions on a five-point Likert scale (0 = not at all to 5 = a great deal). Respondents are asked to rate the extent to which they felt each of 15 emotions regarding a stressor. In this case, the scale was adapted to query participants regarding their feelings about the uncertainty associated with prostate cancer.

Two instruments were used to measure QOL in this study. The University of California, Los Angeles, Prostate Cancer Index (UCLA-PCI) was developed by Litwin et al. (1995) to measure specific changes in health-related QOL experienced by patients with prostate cancer. The instrument contains a total of 28 items presented in a three- to five-point Likert format. The first 11 items (containing subitems for a total of 36 questions) of the questionnaire are taken directly from the Short Form-36 (SF-36) Health Survey (Ware & Sherbourne, 1992). The SF-36 has been used widely to assess the QOL of multiple populations. Validity of the SF-36 was supported using the data collected from 4,842 patients in the original medical outcomes study. In addition to the 11 items of the SF-36 scale, the prostate-specific module consists of 14 items in a Likert scale format, focusing on urinary, sexual, and bowel function (Litwin, Hays, Ganz, Leake, & Brook, 1998).
The Quality of Life Index (QLI) was designed by Ferrans and Powers (1985) to measure satisfaction with various domains of life and the importance of such domains to individual participants. The initial development of the instrument included 32 questions on a six-point Likert scale with QOL anchors on either side. The scale consists of two parts. The first part asks subjects about their satisfaction with the various domains of life. The second part asks respondents to rate the importance of those domains. Reliability and validity testing repeatedly has supported the psychometric properties of this instrument in numerous populations. Although previous results of reliability testing were found on all instruments in the literature, internal consistency reliability was measured again for instruments with multiple scales used in this research, resulting in internal consistency reliability range of alpha = 0.78–0.88.

A demographic data form was used to gather information on subjects’ age, date of diagnosis, educational level, socioeconomic status, religious or spiritual practice, marital status, presence or absence of diagnosed dementia, and comorbidity.

Statistical Analyses

Data were hand-entered into SPSS® version 8.0 (SPSS Inc., Chicago, IL). Data were double-entered and reviewed for accuracy, missing data, and adherence to the assumptions of correlational and multiple regression analyses. Transformations to reduce skewness were performed as necessary to meet these assumptions. Descriptive statistics were calculated on all demographic variables. Cronbach’s alpha coefficients for internal consistency were computed on all measures with multiple scales used in this research, resulting in internal consistency reliability range of alpha = 0.78–0.88.

A hierarchical multiple regression was chosen to address the first hypothesis. This method of analysis was appropriate because the order of the variables had been supported through prior use of the Uncertainty in Illness Model (Mishel, 1988). Pearson correlations were conducted among all variables to determine the best variables to be used in the regression analyses. A hierarchical model was built using uncertainty, anxiety, and “danger” as predictors and affective health functioning as the outcome. None of the 14 health-related QOL measures had significant relationships with all three variables. Therefore, a significant hierarchical model unlikely could be built with uncertainty, anxiety, and appraisal to predict health-related QOL.

Four blocks of variables were entered into the regression model. The first block contained uncertainty, the second block contained uncertainty and anxiety, and the third block contained uncertainty, anxiety, and appraisal of uncertainty as danger. The fourth block contained the interactions among the variables. Table 1 displays the summary of findings of the general linear model and the multiple regression analyses, and it reveals that the total R² accounted for by uncertainty in block one was 36%. This statistic demonstrates a significant ability of uncertainty in the first block to explain 36% of the variance in this QOL measure (R² change = 0.361, F(1, 16) = 9.025, p = 0.008). The addition of anxiety to the model increases the variance explained in QOL to 39%, a change of only 3%. This was not a significant increase in the explained variance (R² change = 0.031, F(2, 15) = 4.822, p = 0.024). However, the addition of danger increased the variance explained by 21%, increasing the total variance explained in QOL significantly over and above uncertainty and anxiety (R² change = 0.209, F(3, 14) = 6.998, p = 0.004), to 60%. The addition of the interaction effects to the fourth block of the model did not significantly increase the explained variance in QOL (R² change = 0.123, F(6, 11) = 4.795, p = 0.012). The combination of all independent variables explains the total of 72% of the variance in the affective health function measure of QOL.

To develop a rigorous model composed only of the significant variables, the regression analyses were repeated with only the variables that resulted in a significant ability to increase the explained variance in QOL. When anxiety and the interaction effects were removed, the total variance explained in QOL remained 60%. Uncertainty continued to predict 36% of the variance, and danger increased the total variance explained to 60% (see Figure 2). Post hoc tests verified that none

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of the assumptions of regression were violated. Therefore, the hypothesis was supported.

As a final analysis in this case, the ability of danger appraisal to function as a mediator between uncertainty and QOL was evaluated. Analysis of covariance was used to examine the mediator effects of danger appraisal. Danger appraisal would be considered a mediator if the relationship with QOL was significant; however, when statistically controlling for the paths of these variables, a previously significant relationship between uncertainty and QOL became nonsignificant (Baron & Kenny, 1986). As seen in Table 1, the direct path between uncertainty and the affective health function of QOL was significant. The direct relationship between danger appraisal and affective health function QOL also was significant ($F = 12.896, p = 0.002$). When controlling for danger appraisal, the ability of uncertainty to predict this domain of QOL became nonsignificant ($F = 0.389, p = 0.890$), substantiating the role of danger appraisal as a mediator of uncertainty.

### Discussion

One of the most fascinating and disturbing findings in the literature among men with prostate cancer is the low QOL scores experienced across treatment groups (Bacon et al., 2001; Borghede et al., 1997; Litwin et al., 1995; van Andel, Kurth, & de Haes, 1997). Although alterations in QOL might be expected among men who are experiencing post-treatment urinary incontinence, alterations in libido and sexual function, and diarrhea (Borghede et al.; Litwin et al., 1995; van Andel et al.), such QOL alterations as found in the literature were not expected in men who do not experience these side effects of treatment. The affective QOL scores in the current study were similar to those reported by Yarbro and Ferrans (1998) in their study of men receiving radical prostatectomy and radiation treatment for prostate cancer. The scores also were similar to Yarbro and Ferrans and Litwin et al. (1998) with the health-related QOL of patients who received radiation and radical prostatectomy.

The current study tested a model for use with men who were undergoing watchful waiting for prostate cancer and determined that uncertainty and danger significantly predicted the affective health functioning domain of QOL. Interestingly, 19 measures of QOL were taken, yet only the affective health function measure had significant correlations with all three predictor variables and could be used to build a significant model. Although finding a significant ability of the predictors to explain the variance in all dimensions of QOL would have been ideal, the health-functioning domain that was significantly predicted in this study has been supported as a representative domain of QOL in several prostate cancer studies (Albertsen, Aaronson, Muller, Keller, & Ware, 1997; Altwein et al., 1997; Borghede et al., 1997; Kornblith et al., 1994; Litwin et al., 1995). Health functioning is the focus of several health-related QOL instruments, which further supports its importance as a measure of QOL. Furthermore, Aaronson (1991), in his discussion of the QOL of patients with cancer, suggested that QOL should be limited to health-related and health-sensitive domains.

In the current study, the inability of anxiety to explain more of the variance than uncertainty alone may result from the possible multicollinearity between the two variables. The relationship between uncertainty and anxiety was moderate yet significant in this study ($r = 0.544, p = 0.020$). The correlation as presented appears to support a relationship. But, the moderate nature appears to support some distinctiveness of the concepts. The small sample size of the study may play a role in this relationship. In other words, if the sample size was larger, a stronger relationship may have been seen to negate the distinctiveness of the concepts. Further study is needed about the relationship between uncertainty and anxiety and the way in which the two concepts are measured to determine the extent of the relationship.

This study supports the role of danger as a mediator between uncertainty and QOL. The addition of this variable significantly increased the explained variance in QOL from 36%–60%. This increase in explained variance is considerable and has extensive implications for nurses caring for this population of men. The findings of this study indicate that uncertainty often results in the perception that living with prostate cancer is dangerous, and this perception of danger may alter QOL. Thus, the effect of uncertainty and perception of danger on QOL may be anticipated in this population and appropriate teaching and patient care management interventions implemented to reduce this perception and promote the highest possible QOL.

### Limitations

The small sample size of this study was a significant limitation to the generalizability of the study findings beyond the current sample. However, the small sample size occurred despite substantive subject recruitment efforts. These efforts included the mailing of flyers to 4,500 urologists nationwide, a subject recruitment advertisement in a major newspaper, and numerous visits and phone calls by the researcher to urology practices. The small sample size may be a product of the infrequent use of watchful waiting as an option for the chronic management of prostate cancer.

### Implications for Nursing

The presence of uncertainty in this study explained 36% of the variance in the affective health function measure of QOL. The explained variance is considerable and has implications for nurses caring for men undergoing watchful waiting for prostate cancer. This study provides further information to support the role of uncertainty as a significant factor in the lives of men who undergo watchful waiting for prostate cancer, and the effect of that uncertainty on the QOL of this population. From the results of this study, information is added to the literature on the effect uncertainty has on QOL in men undergoing watchful waiting for prostate cancer. These findings imply the need for increased teaching and appropriate patient care management regarding watchful waiting both before and after the treatment decision has been made, and the results provide the framework for further study on interventions to...
improve the QOL of this population. Future research is necessary to substantiate the findings of this study and to explore patient teaching and management interventions needed to promote the highest possible QOL in this population. A study by Feldman-Steward, Brundage, Nickel, and MacKillop (2001) indicated that although much disagreement occurred in the type and amount of information needed in early-stage prostate cancer, this information need did not vary according to demographic characteristics. Apart from the clinical implications of the ability of uncertainty and danger to predict QOL, the significant findings herein provide further strength for the application of the Uncertainty in Illness Model to the watchful waiting population.

Summary

A prevalent belief exists in society that people cannot live quality lives with cancerous growths in their bodies. This belief is perpetuated by a lack of understanding regarding the chronic character of prostate cancer. Watchful waiting is an appropriate option for selected men with localized prostate cancer who are older than 70. Yet, the findings of this study indicate that uncertainty existed among this group of men undergoing watchful waiting, and this uncertainty results in the perception of danger and a subsequent alteration in QOL. With this information, nurses may enhance teaching and patient management interventions regarding watchful waiting (Wallace, 2002). The current study contributes initial work to the field of knowledge on the QOL of older men undergoing watchful waiting for prostate cancer.

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References


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For more information . . .

- Prostate.com: Watchful Waiting for Prostate Cancer  
  [www.prostate.com/watchwaitingpc_e.htm](http://www.prostate.com/watchwaitingpc_e.htm)

- Watchful Waiting: The Preferred Option for Many Men  
  [www.prostatepointers.org/ww/wwopt.htm](http://www.prostatepointers.org/ww/wwopt.htm)

- When Is Watchful Waiting Appropriate for Prostate Cancer?  

  
  *Links can be found using ONS Online at [www.ons.org](http://www.ons.org).*