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Abstract

Background and Purpose—Uncertainty is an aversive experience and plays an important role in the lives of men undergoing active surveillance (AS) (earlier referred to as watchful waiting) for early-stage prostate cancer. Yet reliable and valid measures of uncertainty have not been fully tested in this population. This secondary analysis therefore tested the reliability of the Mishel Uncertainty in Illness Scale – Community Form (MUIS-C; Mishel, 1997b) for use with a population of men undergoing AS for prostate cancer.

Methods—Item-to-total correlations were conducted on the 23 items of the MUIS-C with four samples of men undergoing AS.

Results—Cronbach's alpha for the full MUIS-C was .908; 22 of 23 items showed significant positive correlations with the total score. Removing the item without a significant correlation from the reliability analysis increased Cronbach's alpha to .913.

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Conclusions—The Mishel Uncertainty in Illness Scale – Community Form for Active Surveillance (MUIS-C-AS) is a reliable and valid tool for measuring uncertainty with men undergoing AS for prostate cancer.

Keywords

active surveillance; illness uncertainty; measurement; prostate cancer

1. Introduction

Illness uncertainty, which occurs when patients are unable to define the meaning of illness-related events, is a major psychological stressor (Mishel, 1997a). Prior research has described the effects of illness uncertainty in men undergoing active surveillance (AS) (earlier referred to as watchful waiting) for localized prostate cancer (Bailey & Wallace, 2007; Bailey, Wallace, & Mishel, 2007; Wallace, 2003). Initially, the watchful waiting management strategy for prostate cancer was defined as surveillance followed by active treatment when symptoms progress (Adolfsson, 1995). Unfortunately, however, many patients and healthcare providers viewed this as a do-nothing approach, and few considered it a reasonable strategy for disease management. Clinicians have developed a formal protocol for active surveillance with constant evaluation of disease state (Warlick, Trock, Landis, Epstein, & Carter, 2006). Although men undergoing monitoring may eventually need traditional therapy, the delayed time to treatment leaves quality of life intact and may result in improved treatment used in future therapies. However, men who undergo this option may also experience illness uncertainty, which can be associated with increased emotional distress and decreased satisfaction with activities, and can have a negative effect on marital relations and quality of life (Bailey et al., 2007, Litwin et al., 1995; Kronenwetter et al., 2005; Wallace, 2003).

Men undergoing AS live every day with the knowledge that they have cancer in their bodies (Hedestig, Sandman, & Widmark, 2003). When they are asymptomatic or experience only occasional signs that cancer is present, their uncertainty about the state of the cancer may be intense. A defining characteristic of that uncertainty is the fact that prostate cancer offers few signals for men as they try to monitor the progression of their illness. Without markers of disease, some men incorrectly attribute benign physical changes to disease progression (Bailey et al., 2007). For example, they may associate common arthritic pain with bony metastases, or attribute a change in sexual function to advancing disease. Others, who experience no physical discomfort, may find it hard to believe that the cancer really exists (Bailey et al., 2007). If AS is to succeed as a viable treatment alternative, researchers and clinicians must have adequate tools to measure the effect of uncertainty during the AS process, as a basis for developing and evaluating of interventions to manage the uncertainty. This article reports secondary analysis of pooled data from four separate studies testing the reliability and validity of the Mishel Uncertainty in Illness Scale Community form (MUIS-C; Mishel, 1997b) instrument for use with men undergoing AS for prostate cancer and its potential for serving as a measure of intervention effectiveness.

1.1 Theoretical Framework

Mishel's Uncertainty in Illness Theory (Mishel, 1988) was the theoretical framework for this analysis. Uncertainty is defined as the "inability to determine the meaning of illness-related events which occurs in situations where the decision maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes because sufficient cues are lacking." (Mishel, 1988, p. 225). The framework describes how patients process illness-related stimuli and then, through the primary appraisal of uncertainty, derive

meaning from the illness event. According to the theory, uncertainty evolves from several antecedent variables (structure providers, stimuli frame and cognitive capacity), is mediated by personality characteristics and primary appraisal, and results in an outcome. Mediators between uncertainty and outcomes of uncertainty include: 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).

When an event is perceived as uncertain, the event is either not recognized, recognized but not classified, or recognized but not correctly classified (Mishel, 1988). The role of primary appraisal in the Uncertainty in Illness theory functions to process the uncertainty and acts as a mediator between uncertainty and an outcome, as suggested by the work of Folkman and Lazarus (1985) with stress and coping. Folkman and Lazarus identified primary appraisal as the cognitive ability to classify the stressor as: irrelevant, benign or as a threat. Mishel and Sorenson (1991) have further evaluated these constructs, empirically demonstrating that the primary appraisal process results in the view of the prostate cancer as either a danger or an opportunity.

Outcomes that have been measured using the uncertainty model include: psychosocial adjustment (Hilton, 1994; Mishel & Braden, 1987; Mishel et al., 1984), satisfaction with medical care and knowledge about disease (Richardson et al., 1987); and quality of life (Hawthorne & Hixon, 1994; Padilla, Mishel, & Grant, 1992). Mishel has developed and tested a theoretically derived uncertainty management intervention (UMI) and found that patients who receive UMI report a decrease in illness uncertainty; improvement in two uncertainty management methods, cognitive reframing and problem solving; and improvement with symptom management and coping (Gill et al., 2006, Mishel et al., 2002, Mishel, Germino, Gil, et al., 2005). Bailey, (2004) modified this strategy for men undergoing watchful waiting and also found significant effects in the areas of view of life, level of confusion and quality of life (Bailey et al., 2004). However, measurement of illness uncertainty in men undergoing active surveillance may need further refinement. Therefore, this secondary analysis tested the reliability of the Mishel Uncertainty in Illness Scale – Community Form (MUIS-C; Mishel, 1997b) for use with men undergoing AS for prostate cancer.

2. Background

Several studies have been focused on measuring the psychometric properties and thus enhancing the use of the MUIS instruments in specific populations (Bailey et al., 2009. Reich, Johnson, Zautra, & Davis, 2006; Wineman, Durand, & Steiner, 1994). Santacroce (2003) has observed that the original measures may underestimate current levels of illness uncertainty because of significant changes in our health care system and the increasing complexities of therapy. Mishel herself has noted that uncertainty scales can and should be developed for specific diagnostic groups (Mishel, 1983).

Measuring illness uncertainty is important for many populations with chronic illness -- including men undergoing active surveillance for localized prostate cancer -- as a basis for developing interventions to help these patients manage uncertainty. However, in view of the Mishel's recommendation for the development of uncertainty scales tailored to specific diagnostic groups, it was not clear whether the MUIS-C would be applicable to active surveillance patients. Therefore this analysis was conducted to provide support for the MUIS-C as a reliable and valid instrument for use in measuring uncertainty in illness in men with prostate cancer undergoing active surveillance.

2.1. Mishel Uncertainty in Illness Scale (MUIS-C)

The 23-item MUIS-C was developed in 1986 as a modification of the 33-item Mishel Uncertainty in Illness Scale (MUIS-A). While the original instrument was designed to assess uncertainty in hospitalized or acutely ill adults, the MUIS-C is intended for use with community-dwelling chronically ill adults who are not hospitalized and may not be receiving treatment, or living with their families (Mishel 1997b). Items from the MUIS-A relating to hospitalization of acutely ill patients were therefore removed from the MUIS-C (Mishel 1997b). Although validity of the MUIS-C has not been directly measured, its items are highly similar to those of the original MUIS-A and the validity results from that instrument have been used to support the MUIS-C (Mishel, 1997b).

Content validity of the MUIS-A was determined through expert analysis of the items during the development of the original scale (Mishel, 1981). Construct validity was supported through a factor analysis conducted in 1982, indicating a four factor structure originally labeled: ambiguity, complexity, lack of information, and unpredictability (Mishel, 1997b. However, the reliability of the third and fourth factors were low and unstable across populations. In 1986, a principle components factors analysis of 616 participants again showed four factors (Mishel, 1997b). Attempts to reduce the scale to two factors resulted in all items loading .39 or higher on one of the two factors (ambiguity and complexity). In 1989, a sample of 1,199 participants was again used in attempts to determine the four factor structure. Four factors emerged from the 32 item questionnaire with loadings of .38/.39 on at least one of the four factors (Mishel, 1997b). The difference between the loadings of each item was not reported. The four factors were relabeled ambiguity (13 items), complexity (7 items), inconsistency (7 items) and unpredictability (5 items) and these are the factors currently recognized by the Mishel (Mishel, 1997b). Because of the lack of support for a multi-factorial scale of the MUIS-C, this scale remains uni-dimensional (Mishel, 1997b). In analyses of MUIS-C scores from 18 samples of chronically ill adults (total n=1068), Cronbach's alpha ranged from 0.53 to 0.92, with values exceeding 0.85 in a large majority of the samples (Mishel, 1997b), suggesting that the reliability of the MUIS-C is generally comparable to the alpha of 0.87 reported for the MUIS-A (Mishel, 1997b).

The 23 MUIS-C items are scored 1-5 on a Likert scale, where 1 = *strongly disagree* and 5 = *strongly agree*. Respondents are asked to complete all items based on their perception of their condition. Some respondents who have difficulty with a particular item may find that if they evaluate the item in the context of a true or false strategy, they can then respond using the Likert format. If an item does not apply, they may write "not applicable" and this item is scored as a 0 on the Likert scale. All 23 items are summed to calculate a total score, with a range 23 – 115; the higher the score, the greater the uncertainty. The mean scores of the MUIS-C ranged from 42.5 to 85.5 in 18 samples of chronically ill adults (n=1068) (Mishel, 1997b).

3. Methods

3.1 Samples

The MUIS-C was administered to four convenience samples of men with localized prostate cancer who were undergoing AS and participating in studies. The small number of men in these samples highlights the difficulty of recruiting research participants to explore the experiences and outcomes of men whose prostate cancer is being treated with the AS management option. Active surveillance is a responsible approach to managing what for many men is a slow-growing cancer, but it conflicts with the dominant cultural preference (particularly in America) for aggressive treatment to eradicate disease (Kaufman, Shim & Russ, 2004).

Sample 1—Hegarty, Wallace, and Comer (2007, in press) administered the MUIS-C in 2005-2006 to a sample of 10 men from southern Ireland who were undergoing AS. The men were recruited with the assistance of the National Cancer Registry Ireland (NCRI) and family physicians. The NCRI sent a letter to the potential participant's family physician who determined eligibility and invited the man to participate. Each participant signed a consent form, completed the questionnaire, and returned it by mail to the researchers.

Sample 2—Wallace (2003) assessed a sample of 19 U.S. men undergoing AS in 1999-2000. Participants resided in the states of Arizona (1), California (2), Connecticut (1), Florida (11), New Hampshire (1), New York (2) and Texas (1). They were recruited with the assistance of community urologists or responded to recruitment fliers posted on prostate cancer websites and distributed at local supermarkets and libraries, or to an advertisement placed in the Healthy Living section of the New York Times. Verbal consent was obtained during an initial telephone call and participants received a copy of the consent form with the questionnaire packet, completed the questionnaire at home and mailed it to the investigator.

Sample 3—Bailey (unpublished data) assessed a sample of five North Carolina men undergoing AS in 1998. Potential participants were identified from a database of physicians caring for patients at two tertiary care medical centers in North Carolina, and were recruited by sending them a letter from the physician and the investigator. Participants responded to the MUIS-C in their homes at baseline and again 4 weeks after completing a telephone uncertainty intervention.

Sample 4—The MUIS-C was administered as part of a descriptive study of eight North Carolina men undergoing AS, who were recruited using the same procedures as Sample 3. Data were collected between 2003 and 2005 (Bailey et al, 2009). Participants responded to the MUIS-C in their homes at baseline, and at 6, 12, 18 and 24 months post baseline.

3.2 Procedures

After approval by the respective Committees for the Protection of Human Subjects, participants in each study completed the questionnaire either at their home or in the clinic. They answered demographic questions about their age, race, marital status, educational level, and income, indicated the number of months that had elapsed since their prostate cancer diagnosis, and completed the Mishel Uncertainty in Illness Scale–Community Form (MUIS-C).

3.3 Data Analysis

Approval for analysis of secondary data was granted by the Committee for the Protection of Human Subjects by the first author's institution. For each sample, univariate statistics were calculated for demographic variables and the number of months since prostate cancer diagnosis. Preparation for analysis of MUIS-C data included reverse-coding six of the 23 items on the MUIS-C and calculation of the total score for each participant. Univariate statistics for the total MUIS-C score were then calculated for Samples 1-4 and for a pooled sample comprised of the men in all four samples (n=42). For selected variables (number of months since diagnosis, total MUIS-C score), the significance of differences among samples was evaluated using the Kruskal-Wallis test with three degrees of freedom.

3.4 Reliability assessment

The psychometric properties of the MUIS-C were tested using the pooled data. Item-to-total correlations were calculated for the 23 items and significance was assessed using a one-tailed test, because all predicted relationships were positive. Reliability of the MUIS-C was

analyzed by determining Cronbach's alpha for the total scale, removing any items for which the item-to-total correlation was not significant at $p<.05$, and then determining Cronbach's alpha for the reduced scale.

4. Results

Demographic characteristics of the participants in each sample are shown in Table 1. The ages of the men were similar across all four samples. The men in Samples 3 and 4 reported greater numbers of co-morbidities and had been undergoing active surveillance for a much shorter period of time (8.2 and 5.6 months, respectively, than samples 1 and 2, who had been followed for 28 and 49 months, respectively).

Univariate statistics for the MUIS-C total score are given for each of the four samples and for the pooled sample in Table 2. Sample means on the MUIS-C ranged from a low of 52.8 (Group 1-Ireland sample) to a high of 80.6 (Group 4-U.S., North Carolina sample). Hegarty and Wallace (2007) offered a possible reason for this difference noting that there may be a higher expectation for active treatment in the U.S than in Ireland, resulting in greater uncertainty among U.S. men being directed toward a less active approach to disease management. Consistent with this explanation, statistics indicate that only 8.66 % of U.S men undergo active surveillance (National Cancer Data Base, 2003) compared to 23% of Irish men (National Cancer Registry, 2006).

Item-total correlations were positive for all 23 items of the MUIS-C; the correlations were significant at $p<.05$ for 22 of the 23 items. Table 3 shows a representative sample of 12 items from the scale. Cronbach's alpha for the total scale was .908. Item 19 ("I'm certain they will not find anything else wrong with me") was the only item that was not significantly correlated ($r=.023$, $p=.442$) with the total MUIS-C score. Removing the item from the reliability analysis increased the total Cronbach's alpha reliability only slightly to . 913.

Nonparametric tests identified significant differences among the four groups for both the time elapsed since prostate cancer diagnosis and the total MUIS-C score (Table 4). P values on the Kruskal-Wallis test were <0.001 for both time elapsed since diagnosis and total MUIS-C score (Table 4), indicating that for each variable there was greater than expected variation among the groups. However, due to small sample size, we chose a nonparametric analysis approach that does not provide the same opportunities for post-hoc comparisons that parametric analyses of a larger sample would allow.

5. Discussion

The slow-growing and often indolent nature of prostate cancer differentiates this cancer from others, and makes it more amenable to an active surveillance protocol than more aggressive tumors. However, prostate cancer is still a "cancer", and this word produces fear and substantial illness uncertainty in diagnosed men. In men with early stage prostate cancer, "cancer"-related uncertainty is compounded by a lack of disease symptoms, and uncertainty may become so intolerable that radical (and perhaps unnecessary) treatment is selected simply to end the constant worry (Patel et al., 2004). Despite the critical need for nursing intervention, little research has measured uncertainty in this group of men, and few researchers have developed strategies to help these men self-manage the problem.

Effective measurement of illness uncertainty is dependent on valid and reliable uncertainty measures. This article describes an attempt to evaluate the reliability and validity of the MUIS–C for use with men undergoing active surveillance for prostate cancer. With the elimination of one item, all items showed significant positive item-total correlations, with

excellent reliability of α = .91 for the instrument. The MUIS-C, with its well supported theoretical model (Mishel, 1988), is a potentially robust instrument to measure illness uncertainty at baseline and to track improvements in uncertainty as a result of uncertainty management interventions. The results of this secondary analysis the MUIS-C may be suitable for use in men during the early diagnostic period and for men who have been living with prostate cancer for four or more years.

This composite sample of men undergoing AS for prostate cancer, although geographically and educationally diverse, was small (n=42), and severely limits interpretation of the data obtained in this analysis of the MUIS-C or the use of more sophisticated psychometric testing. As evidence continues to mount regarding the over-treatment of prostate cancer, opportunities for future evaluation of the MUIS-C using larger and more homogenous sample sizes will permit more comprehensive psychometric evaluation. The results of this analysis indicate significant item-total correlations and adequate reliability among sample data from four different studies and support the use and continued testing of the MUIS-C in men undergoing AS. However, interpretation of these results must be viewed with caution due to the small sample sizes and variations among inclusion and exclusion criteria of the data reported in this article. Although Mishel (1983) has proposed the development of uncertainty scales tailored for specific populations, the MUIS-C can be used for men undergoing As with minor modifications of the item wording. Specifically, six items will be revised by substituting the term “active surveillance” for “treatment” in order to accurately represent the experiences of men undergoing active surveillance for prostate cancer.

Several qualitative studies of men on AS indicate that the AS process can generate substantial illness uncertainty (Hedestig et al., 2003; Kronenwetter et al., 2005). Accurate measurement of illness uncertainty in this group of men is important and necessary for the development of theoretically based nursing interventions. An adaptation of the Mishel Uncertainty Management Intervention (UMI) (Mishel et al., 2002) is currently being developed for the AS population, and studies are planned to measure changes in uncertainty from pre- to post-intervention. We hope that effective nurse-delivered interventions may result in decreased uncertainty, improved quality of life, and deferral of active treatment until needed. The first step in this endeavor is to develop methods with which to evaluate the effectiveness of psychosocial interventions for men undergoing AS for localized prostate cancer. This study indicates that the MUIS-C is a valid and reliable tool based upon a substantive theoretical and empirical background that is directly applicable to future research on the assessment and management of illness uncertainty in the active surveillance population.

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Table 1

Demographic and Clinical Characteristics of Four Samples and Pooled Sample

Variable	Sample 1 Ireland (n = 10)		Sample 2 U.S (n = 19)		Sample 3 U.S. (n=5)		Sample 4 U.S. (n= 8)		Pooled Sample (n=42)	
Age (years)										
Mean (SD)	76.5 (4.4)		76.0 (6.7)		72.4 (4.2)		75.4 (4.8)		75.6 (5.6)	
Median	76		74		73		74		74	
Range	72 - 85		65 - 85		67 - 78		71- 83		65-85	
	n	%	n	%	n	%	n	%	n	%
Marital status										
Married	6	60	9	47	4	80	5	63.5	24	57.1
Living with partner	0	0	0	0	1	20	0	0	1	2.4
Divorced	0	0	3	16	0	0	1	12.5	4	9.5
Widowed	4	40	7	37	0	0	2	25	13	31.0
Educational level										
Grade school or less	4	40	1	5	2	40	4	50	11	26.2
High school or equivalent	5	50	8	42	1	20	2	25	16	38.1
College or technical school	0	0	3	16	0	0	1	12.5	4	9.5
Graduate/professional	1	10	5	26	2	40	1	12.5	9	21.4
Not reported	0	0	2	11	0	0	9	0	2	4.8
Annual income, US $										
< $20,000	5	50	9	47	2	40	4	50	20	47.6
$20,000 - $40,000	3	30	4	21	0	0	2	25	9	21.4
> $40,000	2	20	6	32	3	60	2	25	13	31.0
Number of co-morbidities										
Mean (SD)	1.3 (1.1)		2.9 (1.6)		5.6 (2.7)		5.0 (3.5)		3.2 (2.6)	
Median	1		3		5		5		3	
Range	0 - 3		1 - 7		3 - 10		0 - 10		0 - 10	
Months since prostate cancer dx.										
Mean (SD)	28 (10.3)		49 (33.5)		8.0 (1.9)		5.6 (2.3)		30 (28.8)	
Median	26		39		8		5.5		22	
Range	14 - 52		13-120		5-10		2-9		2-120	

Table 2

Total Scores on the Mishel Uncertainty in Illness Scale – Community form (MUIS-C) in Men with Localized Prostate Cancer Undergoing Active Surveillance, for 4 Samples and Pooled Sample

Sample	n	Mean	Standard Deviation	Median	Range
1	10	52.8	12.90	55.0	27 - 68
2	19	59.2	12.45	57.0	41 - 80
3	5	78.4	10.74	74.0	70 - 96
4	8	80.6	14.72	81.5	59 - 102
Pooled	42	64.1	16.53	64.1	27 - 102

Table 3

Item-total Correlations for Selected MUIS-C Items, Pooled Sample (n=42)

Item No.	Item	Correlation coefficient (r)	Significance (p)
16	The results of my tests are inconsistent.	.822	.001**
18	Because of the treatment, what I can do and cannot do keeps changing.	.795	.001**
2	I have a lot of questions without answers.	.792	.001**
7	My symptoms continue to change unpredictably.	.728	.001**
10	My treatment is too complex to figure out.	.727	.001**
1	I don't know what is wrong with me.	.689	.001**
9	The doctors say things to me that could have many meanings.	.677	.001**
3	I am unsure if my illness is getting better or worse.	.608	.001**
23	The doctors and nurses use everyday language so I can understand what they are saying.	.598	.001**
6	The purpose of each treatment is clear to me.	.453	.001**
20	The treatment I am receiving has a known probability of success.	.318	.020*
22	The seriousness of my illness has been determined.	.317	.020*

Significance:

* p <.05,

** p<.01

Table 4

Description of Differences in Time Elapsed Since Diagnosis and Total MUIS-C Score among the 4 Samples: Ireland (1), US (2), USNC (3), and USNC (4).

Sample	Time elapsed since diagnosis (months)[a]				MUIS-C total uncertainty score[b]			
	Mean	SD	Median	IQR	Mean	SD	Median	IQR
Ireland (1)	27.6	10.3	25.5	22-32	52.8	12.9	55	43-64
US (2)	48.9	33.5	39	22-70	59.2	12.4	57	48-70
USNC (3)	8.0	1.9	8	8.9	78.4	10.7	74	71-81
USNC(4)	5.6	2.3	5.5	4-7.5	80.6	14.7	81	69-91

[a] $P<0.0001$ for Kruskal-Wallis test of time elapsed since diagnosis.

[b] $P<0.0004$ for Kruskal-Wallis test of total uncertainty scores.