

# Illness Uncertainty and Its Antecedents for Patients With Prostate Cancer and Their Partners

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**OBJECTIVES:** Guided by Mishel's uncertainty in illness theory, patterns of change in uncertainty were explored over time for patients with prostate cancer and their partners. In addition, the relationships between uncertainty and its antecedents were examined, and the role effects (patient versus partner) on these relationships were assessed.

**SAMPLE & SETTING:** This study is a secondary analysis of the longitudinal data collected from a randomized clinical trial.

**METHODS & VARIABLES:** The current authors fitted multiple-level models that included time-invariant baseline variables (sociodemographics and cancer factors) and time-varying variables (uncertainty, symptoms, and social support) measured at baseline and at 4, 8, and 12 months thereafter.

**RESULTS:** No statistically significant patterns of change in uncertainty over time were detected. Partners reported greater uncertainty than patients. Higher uncertainty was associated with more general and prostate cancer-specific symptoms, recurrent and advanced prostate cancer, higher prostate-specific antigen level, and lower social support. More urinary symptoms were associated with greater uncertainty in patients than in partners.

**IMPLICATIONS FOR NURSING:** Uncertainty management can be tailored for and target symptom management and social support.

**KEYWORDS** illness uncertainty; prostate cancer; symptom management; social support

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Despite the encouraging average five-year survival rate, patients with prostate cancer can experience illness uncertainty related to treatment decision making and to the meaning and management of symptoms (e.g., sexual dysfunction) attributable to their prostate cancer and treatment exposures (Yu Ko & Degner, 2008). Illness uncertainty is defined as the inability to determine the meaning of illness-related events (Mishel et al., 2002). Illness uncertainty is a cognitive state that occurs when illness-related events are inconsistent with patient expectations, occur unpredictably, or have unclear causes, triggers, or patterns (Mishel, 1988). Illness uncertainty can negatively affect psychological adjustment (Eisenberg et al., 2015), quality of life (Parker et al., 2016), and satisfaction with treatment outcomes for people who are ill (Kazer et al., 2013).

Changes over time regarding illness uncertainty can be expected as patients with prostate cancer move from diagnosis, treatment, and post-treatment recovery to long-term survivorship, when they experience lingering or worsening symptoms and functional impairments. In addition, for patients with prostate cancer in an intimate relationship, symptoms and functional impairments, such as fatigue and sexual dysfunction, also affect their partner's psychological state and quality of life (Lehto et al., 2018). However, to the current authors' knowledge, no published study has used longitudinal data to examine how illness uncertainty changes over time for patients diagnosed with prostate cancer and their partners as they move through the cancer trajectory. The purpose of this study was to examine the patterns of change over time in illness uncertainty for patients with prostate cancer and their partners, as well as to verify relationships between uncertainty and its antecedents, as suggested by Mishel's (1988) uncertainty in

illness theory and previously published studies guided by uncertainty in illness theory (see Figure 1).

### Theoretical Framework and Literature Review

According to Mishel's (1988) uncertainty in illness theory, the antecedent component includes stimuli frame and structure providers. Stimuli frame refers to "the form, composition, and structure of the stimuli" that encompass the illness-related event and is composed of symptom pattern, event familiarity, and event congruency (Mishel, 1988, p. 225). Symptom pattern denotes the degree to which symptoms are consistent with recognizable characteristics of number, frequency, intensity, and duration (Mishel, 1988). Extant studies of prostate cancer symptoms and their relation to illness uncertainty would benefit from a framework that assessed the patterns (or lack thereof) in these symptoms. Findings about the association between symptoms and illness uncertainty have been inconsistent. For example, Parker et al. (2016) identified significant associations between illness uncertainty and prostate cancer-specific symptoms reported by patients undergoing watchful waiting or active surveillance for prostate cancer, which is inconsistent with Wallace's (2005) findings. Although patients' symptoms have been shown to change over time (Zelevsky et al., 2016), studies of how variations in symptoms over time

influence change in illness uncertainty are lacking, which means that a potentially important source of illness uncertainty for patients with prostate cancer is being overlooked.

Event familiarity describes a person's degree of understanding of the illness affecting them, its treatment, and the system of care (Mishel & Braden, 1988). Over time, as patients and their caregivers gain experience with and understanding of what to expect and how to manage illness-related challenges, their illness uncertainty can decrease. Indeed, greater length of time since diagnosis has been associated with lower levels of illness uncertainty in patients with prostate cancer (Wallace, 2005). In addition, research has shown that patients with biochemical recurrent and advanced prostate cancer reported greater illness uncertainty than patients with localized prostate cancer (Northouse, Mood, Montie, et al., 2007); this finding suggests that when the prostate cancer is more advanced, the prognosis more dire, and the treatment regimens more intensive and complex, patients have more difficulty comprehending the details and implications of their situation, therefore developing familiarity with illness-related events.

Event congruency refers to "consistency between what is expected and what is experienced" (Mishel, 1988, p. 227). When patients' experiences contradict their expectations, they can have difficulty interpreting their symptoms and clinical indicators of their health, which creates illness uncertainty (Mishel, 1988). For example, a rapid rise in prostate-specific antigen (PSA) soon after completion of cancer treatment would elevate illness uncertainty.

Structure providers refer to personal and environmental resources that can aid in stimuli frame formation (Mishel, 1988). Structure providers include social support and education (Mishel & Braden, 1988). Although the influence of internal (e.g., a couple's open communication about cancer) and external (e.g., assistance from friends and relatives) social support on illness uncertainty among patients with prostate cancer remains under-researched, studies of patients with other types of cancer have found that a higher level of social support was associated with a lower level of illness uncertainty (Hagen et al., 2015). Uncertainty in illness theory further speculates that level of formal education, a proxy of patients' knowledge about the illness, provides a cognitive resource for comprehending illness-related information and constructing the meaning of illness-related events, therefore reducing illness uncertainty (Mishel, 1988). Previous studies have found that patients with prostate cancer with lower

### FIGURE 1. Antecedents of Illness Uncertainty for Patients and Partners

#### Stimuli Frame

Symptom pattern

- General symptoms<sup>a</sup>
- Prostate cancer-specific symptoms<sup>a</sup>

Event familiarity

- Length of time since diagnosis<sup>a</sup>
- Phase of illness

Event congruency

- Prostate-specific antigen<sup>a</sup>

#### Structure Providers

Social support

- Internal social support<sup>a</sup>
- External social support<sup>a</sup>

Education

#### Covariates

Age, race, family income, length of relationship

<sup>a</sup>Time-variant variables

**Note.** Based on information from Mishel, 1988.

levels of education were more likely to report higher levels of illness uncertainty (Kazer et al., 2013).

Guided by the uncertainty in illness theory framework, this study aimed to (a) explore patterns of change in illness uncertainty for patients with prostate cancer and their partners over time, (b) examine relationships between uncertainty and time-invariant and time-varying antecedents for patients and partners, and (c) assess whether the effects of these antecedents differed between patients and partners. The results will provide evidence to enhance the development of nursing interventions to ameliorate the adverse effects of prostate cancer-related illness uncertainty on patients' and partners' quality of life.

## Methods

### Design and Sample

This study is a secondary analysis of the longitudinal data collected from a randomized clinical trial (RCT) (Ro1CA090739, ClinicalTrials.gov: NCT00708968) that examined the effects of a couple-focused psychoeducational intervention on quality of life among patients diagnosed with prostate cancer and their partners (Northouse, Mood, Schafenacker, et al., 2007). The original study was approved by the institutional review boards at the study sites. Patients with prostate cancer were eligible for the study if they (a) had been newly diagnosed with localized disease and were undergoing primary treatment, (b) had been diagnosed with recurrent disease based on two consecutive increases in PSA levels after completion of primary treatment, or (c) had been diagnosed with advanced cancer based on metastatic disease or progression. Patients also had to be aged 30 years or older, have a life expectancy of at least 12 months, and have a spouse or cohabitating partner. Patients could not participate in the study if they had a second primary cancer.

At entry to the study, patient-partner dyads were randomly allocated to either the intervention condition ( $n = 112$  dyads) or the usual care comparison condition ( $n = 134$  dyads). After providing written informed consent, patients and their partners independently completed questionnaires during in-person interviews in their homes with a research nurse at baseline (time 1 [T1]) upon recruitment, and at 4 (time 2 [T2]), 8 (time 3 [T3]), and 12 (time 4 [T4]) months after baseline.

The analytic sample for this study consisted of data provided by the dyads assigned to the usual care comparison group to minimize the effects of the intervention on illness uncertainty. This secondary analysis of the extant deidentified data involved no

direct contact with participants and, therefore, was exempted by the institutional review board at the University of North Carolina at Chapel Hill.

### Measurement

Study measures included time-invariant and time-varying variables collected from patients with prostate cancer and their partners (unless indicated otherwise). Time-invariant variables measured at baseline (T1) included sociodemographic characteristics (role [patient versus partner], age, race, family income, and length of the patient-partner relationship) and clinical factors (prostate cancer stage). These factors have been identified in prior research to be associated with higher levels of illness uncertainty among patients with prostate cancer (Kazer et al., 2013; Kershaw et al., 2008). Time-variant variables, measured at T1 and follow-ups (T2-T4), included the outcome of interest (illness uncertainty), stimuli frame variables (general symptoms, prostate cancer-specific symptoms, time since diagnosis [months], patient-reported PSA level), and structure provider variables (internal and external social support, level of education).

**Outcome variable:** Illness uncertainty was measured by the Mishel Uncertainty in Illness Scale, which consists of 28 items that are each rated using a five-point Likert-type scale that ranges from 5 (strongly agree) to 1 (strongly disagree) (Mishel & Epstein, 1990). Six items were reverse-scored. Scores were summed to reflect patients' and partners' levels of uncertainty. Total possible scores ranged from 28 to 140, with higher scores indicating greater uncertainty. In the current study, internal consistency reliability, as indicated by Cronbach's alpha, ranged from 0.92 to 0.94 for patients and from 0.91 to 0.92 for partners at T1-T4.

**Stimuli frame variables:** General symptoms were measured with the 16-item Symptom Scale, a subscale of the Risk of Distress Scale (Mood et al., 2007). Patients and partners each rated the severity of their own general symptoms, such as fatigue, pain, and sleeping problems. Possible total scores ranged from 0 to 32, with higher scores indicating more general symptoms. Internal consistency reliability, as indicated by Cronbach's alpha, ranged from 0.8 to 0.85 for patients and from 0.76 to 0.84 for partners at T1-T4.

Patients' prostate cancer-specific symptoms were measured using the 50-item Expanded Prostate Cancer Index Composite (EPIC), which measures patients' bowel, sexual, urinary, and hormonal symptoms and burden (Wei et al., 2000). Partners completed a four-item partner version of EPIC that

assessed how much of a problem the patients' bowel, sexual, urinary, or hormonal symptoms were for the partners in terms of symptom severity. For both the patient and partner versions, higher scores represented fewer symptoms and lower symptom burden for the patients and less of a problem for the partners; possible patient scores ranged from 0 to 400, and possible partner scores ranged from 4 to 20. The Cronbach's alpha for patients ranged from 0.74 to 0.9 across the four time points. Data concerning phase of illness, time since diagnosis, and PSA level were obtained from patients' medical records.

**Structure provider variables:** Two types of social support were measured for patients and partners: (a) internal social support between patients and partners and (b) social support from others (e.g., friends, relatives). Social support between the patient and his partner was measured based on their perceived level of open dyadic communication about prostate cancer, assessed using the 32-item Mutuality and Interpersonal Sensitivity Scale (Lewis, 1996). Possible scores ranged from 32 to 160, with higher scores

indicating that patients and partners perceived more open communication about cancer-related issues. Internal consistency, as indicated by Cronbach's alpha, ranged from 0.9 to 0.92 for patients and from 0.91 to 0.94 for partners across T1–T4.

Social support from others was measured with a 15-item Personal Resource Questionnaire (Weinert & Brandt, 1987). Possible scores ranged from 15 to 105, with higher scores indicating more general support from others. Internal consistency reliability, as indicated by Cronbach's alpha, ranged from 0.88 to 0.92 for patients and from 0.91 to 0.93 for partners at T1–T4. Level of education was measured as years of school completed.

### Data Analysis

Preliminary descriptive analyses were conducted for patients' and partners' sociodemographic and medical characteristics, illness uncertainty levels, and the theoretical antecedents of illness uncertainty. Frequencies and percentages were used for nominal- and categorical-level measurements. Means and standard deviations were used for continuous-level measurements.

The current authors fitted a series of multiple-level models using open-source R software, version 3.5.2. The authors first built the full model that included the sociodemographic variables (age, race, length of relationship, family income), concurrent time-variant variables (general symptoms, prostate cancer-specific symptoms, time since diagnosis, PSA levels, social support from partners, social support from others), and time-invariant factors (phase of illness, education, role [patient versus partner]). EPIC measures for patients and partners were standardized within individuals across time to control for the sizable discrepancy in their scores. The authors included interactions between role and the other antecedents in the full model to examine whether the effects of the antecedents on illness uncertainty differed between patients and partners. Next, to identify antecedents that influenced changes in patients' and partners' illness uncertainty over time, the authors used stepwise approaches to eliminate nonsignificant interactions and variables in the full model to identify a parsimonious model.

## Results

### Sample Characteristics

In this study, 134, 124, 123, and 114 patient-partner dyads completed the assessments at T1–T4, respectively. Table 1 presents sociodemographic and clinical

**TABLE 1. Sample Characteristics by Group at Baseline**

Characteristic	Patients (N = 134)		Partners (N = 134)	
	$\bar{X}$	SD	$\bar{X}$	SD
Age (years)	62.57	9.22	58.92	9.65
Education (years)	16.13	3.63	14.68	2.68
Length of relationship (years)	31.75	14.26	-	-
Time since diagnosis (months)	28.96	39.66	-	-
Characteristic	n	%	n	%
<b>Family income (\$)</b>				
50,000 or less	33	25	-	-
50,001 or greater	88	66	-	-
Missing data	13	10		
<b>Phase of illness</b>				
Localized	87	65	-	-
Biochemical recurrent	16	12	-	-
Advanced	31	23	-	-
<b>Race</b>				
White	114	85	111	83
Non-White	19	14	23	17
Missing data	1	1	-	-

**Note.** Because of rounding, percentages may not total 100.

characteristics at T1. Patients and their partners were mainly working age and White, with some college education and a middle-class household income. Tables 2 and 3 present the results of the descriptive analyses at T1–T4 for patients and partners, respectively.

#### Patterns of Change in Illness Uncertainty Over Time

Table 4 presents the results of the full model and the parsimonious model. No statistically significant change in illness uncertainty was found over time for patients or partners, after controlling for the effects of demographics, as well as for time-invariant and time-varying factors. However, partners reported significantly higher levels of illness uncertainty than

patients ( $p < 0.01$ ). The effects of race on illness uncertainty differed significantly between patients and their partners; non-White patients (about 90% of whom were African American) reported the highest levels of illness uncertainty, whereas non-White partners reported the lowest levels.

#### Antecedents of Illness Uncertainty for Patients and Partners

The parsimonious model indicated that greater illness uncertainty for patients and partners was associated with more general symptoms ( $p < 0.001$ ); greater prostate cancer-specific sexual ( $p < 0.05$ ), urinary ( $p < 0.001$ ), and hormonal symptoms ( $p < 0.01$ ); higher PSA

**TABLE 2. Descriptive Analysis Results of Illness Uncertainty and Potential Antecedents Over Time in Patients**

Variable	T1			T2			T3			T4		
	N	$\bar{X}$	SD	N	$\bar{X}$	SD	N	$\bar{X}$	SD	N	$\bar{X}$	SD
Illness uncert <sup>a</sup>	134	60.54	15.53	124	60.31	17.16	122	58.78	14.91	114	57.08	15.62
General symptoms score <sup>a</sup>	134	7.07	4.34	124	6.43	4.24	122	6.3	4.55	114	5.82	4.08
EPIC bowel <sup>b</sup>	131	88.71	12.01	122	90.05	12.73	120	89.96	12.39	112	90.63	11.13
EPIC sexual <sup>b</sup>	130	27.76	21.92	123	29.13	23.04	119	29.63	23.65	112	32.43	24.49
EPIC urine <sup>b</sup>	133	77.29	16.01	124	81.19	15.85	120	82.79	14.15	113	83.57	13.93
EPIC hormonal <sup>b</sup>	134	82.16	15.01	124	83.09	15.13	122	85.02	14.53	111	85.71	13.75
PSA <sup>a</sup>	129	16.23	63.95	124	14.8	65.27	122	25.57	129.1	114	26.33	165.34
Levels of dyadic comm <sup>b</sup>	130	3.72	0.66	120	3.63	0.73	119	3.73	0.64	111	3.64	0.68
Social support <sup>b</sup>	134	88.18	12.12	124	86.69	13.13	122	86.99	12.02	114	87.34	13.5

<sup>a</sup> Higher scores indicate more negative results: greater illness uncertainty; more general symptoms, such as fatigue, nausea, and increased difficulty in sleeping; and higher risk of prostate cancer.

<sup>b</sup> Higher scores indicate more positive results: more support from others, more communication, and fewer prostate cancer-specific symptoms. comm—communication; EPIC—Expanded Prostate Cancer Index Composite; PSA—prostate-specific antigen; T1—baseline; T2—4-month follow-up; T3—8-month follow-up; T4—12-month follow-up; uncert—uncertainty

**Note.** Illness uncertainty was measured with the Mishel Uncertainty in Illness Scale (range = 28–140); general symptoms were measured with the Symptom Scale, a subscale of the Risk of Distress Scale (range = 0–32); patients' prostate cancer-specific symptoms were measured with EPIC (range = 0–400); open dyadic communication was measured with the Mutuality and Interpersonal Sensitivity Scale (range = 32–160); social support was measured with the Personal Resource Questionnaire (range = 15–105).

levels ( $p < 0.01$ ); and lower levels of internal (dyadic communication about prostate cancer) and external social support (support from others) ( $p < 0.001$  for both). Compared to patients with localized prostate cancer and their partners, patients with advanced or recurrent prostate cancer and their partners reported higher levels of illness uncertainty ( $p < 0.001$ ).

#### Role Differences in the Relationships Between Antecedents and Illness Uncertainty

As shown in the parsimonious model, the effects of urinary symptoms on illness uncertainty differed between patients and their partners. Compared to partners, patients' illness uncertainty was more adversely affected by more prostate cancer-specific urinary symptom and burden ( $p < 0.05$ ).

#### Discussion

From what the current authors have been able to ascertain through computerized database searches, this study, guided by Mishel's uncertainty in illness theory, is the first to systematically examine longitudinal change in illness uncertainty and to verify its antecedents in patients with prostate cancer and their partners using measurements taken at four time points. Findings from the current study also extend application of this portion of uncertainty in illness theory beyond patients to their partners. The authors found that the level of illness uncertainty was stable over time among patients with newly diagnosed localized, recurrent, or advanced prostate cancer and their partners. Overall, partners reported significantly greater illness uncertainty over time

**TABLE 3. Descriptive Analysis Results of Illness Uncertainty and Potential Antecedents Over Time in Partners**

Variable	T1			T2			T3			T4		
	N	$\bar{X}$	SD	N	$\bar{X}$	SD	N	$\bar{X}$	SD	N	$\bar{X}$	SD
Illness uncert <sup>a</sup>	134	61.84	16.05	124	62.9	16.91	121	61.66	16.98	114	59.95	16.69
General symptoms score <sup>a</sup>	134	5.5	3.82	124	6.23	4.48	122	6.19	4.31	119	6.04	4.55
EPIC bowel <sup>b</sup>	134	4.58	0.87	124	4.65	0.82	121	4.62	0.82	114	4.61	0.82
EPIC sexual <sup>b</sup>	132	3.3	1.49	123	3.16	1.6	120	3.23	1.57	112	3.21	1.58
EPIC urine <sup>b</sup>	134	4.08	1.18	124	4.18	1.13	121	4.22	1.1	114	4.3	1.05
EPIC hormonal <sup>b</sup>	134	4.08	1.19	124	4.07	1.27	120	4.12	1.2	114	4.07	1.17
Levels of dyadic comm <sup>b</sup>	132	3.7	0.63	122	3.51	0.78	120	3.5	0.73	116	3.45	0.76
Social support <sup>b</sup>	134	85.24	14.25	124	84.52	15.12	122	83.98	14.41	119	84.1	16.05

<sup>a</sup> Higher scores indicate more negative results: greater illness uncertainty; more general symptoms, such as fatigue, nausea, and increased difficulty in sleeping; and higher risk of prostate cancer.

<sup>b</sup> Higher scores indicate more positive results: more support from others, more communication, and fewer prostate cancer-specific symptoms. comm—communication; EPIC—Expanded Prostate Cancer Index Composite; T1—baseline; T2—4-month follow-up; T3—8-month follow-up; T4—12-month follow-up; uncert—uncertainty

**Note.** Illness uncertainty was measured with the Mishel Uncertainty in Illness Scale (range = 28–140); general symptoms were measured with the Symptom Scale, a subscale of the Risk of Distress Scale (range = 0–32); partners' prostate cancer-specific symptoms were measured with the partner version of EPIC (range = 4–20); open dyadic communication was measured with the Mutuality and Interpersonal Sensitivity Scale (range = 32–160); social support was measured with the Personal Resource Questionnaire (range = 15–105).

than did patients. In addition, illness uncertainty for patients and partners was associated with their general symptoms, prostate cancer-specific symptoms, disease stage, social support from partners and from others, and the patient's PSA level. The effects of urinary symptoms on illness uncertainty differed by role. Findings from this study can inform the development of comprehensive interventions to manage illness uncertainty among patients and partners experiencing prostate cancer.

Findings show that illness uncertainty is a cognitive state that persists over time for patients with prostate cancer and their partners after controlling for the effects of demographic characteristics, as well as time-invariant and time-varying factors. Side effects, potential recurrence or appearance of a secondary cancer after curative treatment, and even environmental factors, such as media reminders for cancer screening, might provoke uncertainty for many patients, even years after treatment has ended (Yu Ko & Degner, 2008). Findings from the current study showed that patients' and partners' total scores on the illness uncertainty measure remained stable during the 12-month data collection period, suggesting that the patterns of change in couples' uncertainty over time are a function of survivorship context (e.g., the challenges and resources patients and partners have at different phases of survivorship), rather than the time variable itself. These findings fill the gap of describing the change in illness uncertainty over time in quantitative research.

This study has extended illness uncertainty research from patients with prostate cancer to their partners. Although findings showed that, overall, partners experienced significantly greater uncertainty than patients, non-White partners had the lowest levels of illness uncertainty, whereas non-White patients had the highest levels of illness uncertainty. Partners often face challenges when caring for patients with cancer, such as participating in treatment decision making, helping patients cope at home with treatment side effects, and providing other forms of support and care, potentially placing partners at greater risk of illness uncertainty because of unmet needs related to information and support from oncology care providers (Lehto et al., 2018). Partners frequently have reported worries and concerns about losing their partners and what the future holds (Lehto et al., 2018). That partners reported higher levels of uncertainty than patients in the current study may be related to their being unseen by healthcare providers, as well as the lack of sufficient information for

managing uncertainty (patients may receive information from care providers but do not share it with their partners) (Ervik et al., 2013).

A plausible explanation for racial differences in illness uncertainty levels among patients and their partners in this study may be that, compared with White patients, African American patients reported less medical trust (Kinlock et al., 2017), higher treatment-related regrets (Collingwood et al., 2014), more urinary symptoms and sexual functioning problems, and poorer access to psychosocial services (Skolarus et al., 2014). Given that African American men have the highest prostate cancer incidence and mortality rates in the United States (National Cancer Institute Surveillance, Epidemiology, and End Results Program, 2020), future research is needed to understand how African American patients experience illness uncertainty, to develop culturally appropriate interventions to help improve their trust in healthcare providers and in the healthcare system, and to promote access to medical and supportive care to reduce illness uncertainty in this population. At the same time, the current study found that non-White partners reported the lowest levels of illness uncertainty. Compared with White partners, African American partners or caregivers often have more diverse social support and more positive reappraisal as well as greater use of spiritual and religious coping strategies in dealing with the difficulties of taking care of their partners (Dilworth-Anderson et al., 2002). In addition, male patients may not have shared potentially upsetting information with their partners to protect them from additional worry (Friedman et al., 2012). However, this finding should be interpreted with caution, given the small number of non-White patients and partners in this study. Additional research with larger, more diverse samples is warranted.

This study also longitudinally examined relationships between uncertainty and its antecedents for patients with prostate cancer and their partners. Among the stimuli frame variables, the authors found that patients' and partners' uncertainty was related to their personal general symptoms (e.g., fatigue, pain, sleeping problems) and to their perceptions of patients' prostate cancer-specific symptoms (e.g., urinary incontinence, sexual dysfunction, hot flashes), phase of illness, and PSA level over time. Findings from this study were consistent with the antecedents identified in uncertainty in illness theory and expanded the findings of a previous cross-sectional study (Parker et al., 2016). Uncertainty in illness theory suggests that when patients have more types of symptoms, tracking and distinguishing between

**TABLE 4. Antecedents of Illness Uncertainty for Patients and Their Partners**

Variable	Full Model			Parsimonious Model		
	Estimate	SE	p	Estimate	SE	p
Intercept	71.79	11.16	0.0000	62.08	6.17	0.0000
Time since diagnosis	-0.02	0.09	0.8238	-0.05	0.03	0.0652
Role (ref: patient)	4.41	15.25	0.7726	4.82	1.53	0.0019
Age	0.19	0.14	0.1754	0.26	0.08	0.0017
Race (ref: White), non-White	6.93	3.16	0.0295	5.41	3.05	0.078
Length of relationship	0.1	0.08	0.2161	-	-	-
Family income (ref: \$50,000 or less), \$50,001 or greater	0.88	2.6	0.7367	-	-	-
General symptoms	0.46	0.22	0.0349	0.67	0.13	0.0000
EPIC bowel	-1.7	0.72	0.0184	-	-	-
EPIC sexual	-2.15	0.8	0.0072	-1.05	0.5	0.0364
EPIC urine	-2.62	0.79	0.001	-3.13	0.73	0.0000
EPIC hormonal	-1.42	0.82	0.0858	-1.38	0.51	0.0066
Phase of illness (ref: localized cancer), recurrent cancer	7.37	4.38	0.0934	12.44	3.02	0.0001
Phase of illness (ref: localized cancer), advanced cancer	5.74	3.14	0.0687	10.34	2.13	0.0000
PSA	0.01	0.01	0.4426	0.01	0.00	0.007
Open dyadic communication	-3.99	1.08	0.0002	-4.47	0.75	0.0000
Social support	-0.11	0.05	0.0423	-0.12	0.03	0.0004
Education	-0.61	0.3	0.0404	-	-	-
Time <sup>a</sup>	-0.00	0.00	0.9150	-	-	-
Time since diagnosis*partner (ref: patient)	-0.12	0.13	0.3612	-	-	-
Age*partner (ref: patient)	-0.06	0.22	0.7832	-	-	-
Race (ref: White), non-White*partner	-13.18	4.48	0.0036	-10.75	4.3	0.0132
Length of relationship*partner (ref: patient)	-0.06	0.14	0.6644	-	-	-
Family income*partner (ref: \$50,000 or less, patient), \$50,001 or greater*partner	-3.44	3.7	0.3534	-	-	-
General symptoms*partner	0.2	0.28	0.4611	-	-	-
EPIC bowel*partner (ref: patient)	1.43	0.97	0.1419	-	-	-
EPIC sexual*partner (ref: patient)	1.74	1.04	0.0953	-	-	-
EPIC urinary*partner (ref: patient)	1.9	1.05	0.0704	2.3	0.95	0.0161

*Continued on the next page*



**TABLE 4. Antecedents of Illness Uncertainty for Patients and Their Partners (Continued)**

Variable	Full Model			Parsimonious Model		
	Estimate	SE	p	Estimate	SE	p
EPIC hormonal*partner (ref: patient)	-0.08	1.06	0.9411	-	-	-
Phase of illness*role (ref: localized cancer, patient), recurrent cancer*partner	9.7	6.19	0.1187	-	-	-
Advanced cancer*partner	7.95	4.42	0.0732	-	-	-
PSA*partner (ref: patient)	0.01	0.01	0.4677	-	-	-
Open dyadic communication*partner (ref: patient)	-1.44	1.52	0.3447	-	-	-
Social support*partner (ref: patient)	-0.01	0.07	0.9129	-	-	-
Education*partner (ref: patient)	0.74	0.52	0.1544	-	-	-
Time <sup>a</sup> *partner (ref: patient)	0.00	0.00	0.5518	-	-	-

<sup>a</sup> Examination of the quadratic relationship between time and illness uncertainty revealed that the relationship was not linear but rather curvilinear. EPIC—Expanded Prostate Cancer Index Composite; PSA—prostate-specific antigen; ref—referent; SE—standard error

symptoms caused by disease or treatment is more difficult, which, in turn, prevents their recognition of a symptom pattern and contributes to their illness uncertainty (Mishel & Braden, 1988). In addition, compared with dyads managing localized prostate cancer, those managing recurrent or advanced cancer reported higher levels of illness uncertainty. Coupled with earlier evidence that patients with biochemically recurrent and advanced prostate cancer have less confidence in their ability to manage prostate cancer than patients with localized prostate cancer (Northouse, Mood, Montie, et al., 2007), these results indicate that patients with recurrent and advanced prostate cancer need assistance to enhance their uncertainty management. In addition, the current authors found that a rising PSA level was associated with greater uncertainty. PSA testing is widely used in prostate cancer surveillance after initial treatment (Carter et al., 2013). Rising PSA levels could understandably cause patients and partners to have difficulty interpreting and understanding how treatment might have affected the PSA level, resulting in greater uncertainty.

Among the antecedents that are structure providers, social support from external (e.g., assistance from friends and relatives) and internal (e.g., a couple's open communication about cancer) sources significantly reduced patients' and partners' uncertainty over time. These results provide support for hypothesized linkages between illness uncertainty

and variables in the antecedent portion of uncertainty in illness theory, as well as expand the findings of previous cross-sectional research (Hagen et al., 2015). As the seminal uncertainty in illness theory work has suggested, social support from members of one's social network can alleviate illness uncertainty by providing information, clarifying a situation, and sharing the meaning of an environment that supporters know from personal experience (Mishel, 1988). In addition, constructive and open communication between couples can promote their exchange of emotional and tangible support (Song et al., 2016), which functions as an internal source of social support, decreasing illness uncertainty for the couple. Contrary to a previous study by Kazer et al. (2013), the current study did not find a significant association between illness uncertainty and education after controlling for other demographic, time-invariant, and time-varying factors.

#### Limitations and Future Research

The limitations of this study should be considered when interpreting its results. These results from a relatively small and homogenous sample (mostly middle-income, White patients with at least some college education) might not be generalizable to more diverse samples. In addition, because illness uncertainty is affected by disease phase, the fact that patients with advanced cancer potentially dropped

out of the study because of death might have influenced the reported uncertainty level (Nanton et al., 2009). This study's dataset also did not include some of the important antecedents proposed by Mishel (1988), such as cognitive capacity and the structure providers referred to as credible authority (i.e., trust in providers with the expertise needed to address the problem at hand). Future research is needed to examine the effects of the aforementioned antecedents on illness uncertainty. Research is also needed to examine racial and possibly ethnic differences in theorized linkages between illness uncertainty and its antecedents using a larger and more diverse sample.

### Implications for Nursing

Knowing the antecedents of illness uncertainty and recognizing that it is persistent might produce better understanding of the survivorship experiences of patients with prostate cancer and their partners, which, in turn, could create better strategies for managing illness uncertainty and addressing its sources. The fact that patients and partners experienced comparable levels of illness uncertainty during different phases of prostate cancer may suggest that oncology nurses should monitor cancer-related uncertainty in all patients and their partners throughout the illness trajectory. The lack of change in illness uncertainty levels over time, after controlling for the contextual factors of cancer survivorship, suggests that future research should investigate whether uncertainty interventions implemented at an early phase of cancer survivorship would have long-term benefits for patients with prostate cancer and their partners, or whether the nature of uncertainty shifts over time, although the level may not, therefore requiring more precise interventions at specific points in the illness trajectory. The fact that partners generally experienced greater illness uncertainty than patients suggests that (assuming patients grant permission to share their health information) oncology nurses should include partners in their comprehensive person-centered care of patients with prostate cancer. Support for the theorized antecedents of illness uncertainty provides evidence that oncology nurses might address illness uncertainty in patients with prostate cancer and their partners through systematic symptom management and social support from others as well as between patients and partners, as indicated by previous interventions offering similar approaches (Mishel et al., 2002; Northouse, Mood, Schafenacker, et al., 2007). Finally, interventions for illness uncertainty management should be tailored

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### KNOWLEDGE TRANSLATION

- Illness uncertainty is a continual experience that influences patients in different phases of prostate cancer and their partners during cancer survivorship.
  - In the current study, partners experienced higher levels of illness uncertainty than did patients.
  - Interventions to reduce uncertainty for patients with prostate cancer and their partners may target symptom management and social support.
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based on cancer phase, role (patient versus partner), and race.

### Conclusion

Guided by Mishel's (1988) uncertainty in illness theory, the current authors' research used the longitudinal data from an RCT to examine patterns of change in illness uncertainty in patients with prostate cancer and their partners over time and verified its antecedents, as suggested by uncertainty in illness theory. Illness uncertainty is a continual experience that influences patients in different phases of prostate cancer and their partners during cancer survivorship. Interventions to facilitate symptom management and social support may reduce illness uncertainty and improve quality of life for patients with prostate cancer and their partners.

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