Quality of Life, Uncertainty, and Perceived Involvement in Decision Making in Patients With Head and Neck Cancer

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Head and neck cancers only comprise about 3% of all cancers in the United States. The five-year survival rate is 61% for oral, pharyngeal, and laryngeal cancers, which is a better survival rate than that for stomach, esophagus, lung, liver, and pancreatic cancers (American Cancer Society, 2012). However, patients with head and neck cancer confront many functional problems with respect to speaking, breathing, eating, and swallowing, as well as difficulty maintaining a social life because of their altered facial appearance (Semple, Sullivan, Dunwoody, & Kernohan, 2004). Although all patients with cancer experience alterations in their quality of life (QOL), the challenges these particular patients face may result in a greater loss or change in their ability to take pleasure in life.

Uncertainty has been viewed as a common reaction to a cancer diagnosis (Molleman et al., 1984) and a major stressor to be addressed to maintain a person's well-being and QOL (Lazarus & Folkman, 1984). Mishel (1988) proposed the Uncertainty in Illness Theory to explain an adaptive process people use to maintain their QOL during unsettled time periods. Reduced uncertainty can facilitate patients' adapting to an illness experience. Mishel (1988) also postulated that when healthcare providers offer information regarding the course of a disease and address patient concerns, patients may feel more comfortable dealing with symptoms and making treatment decisions, thereby decreasing uncertainty and improving their daily lives.

Researchers have found that patients with cancer are more satisfied with health care when their perception of their involvement in decision making matches their desire to be involved in decision making (Keating, Guadagnoli, Landrum, Borbas, & Weeks, 2002) and when patients perceive that they share decision-making opportunities with their physician, regardless of their preference for involvement (Gattellari, Butow, & Tat-

Purpose/Objectives: To explore the relationship among perceived involvement in decision making, uncertainty, and quality of life (QOL) in patients with head and neck cancer in pre- and post-treatment periods using Mishel's Uncertainty in Illness Theory.

Design: A prospective, correlational design.

Setting: Six outpatient clinics at urban hospitals in New York, NY.

Sample: A convenience sample of 52 adults newly diagnosed with head and neck cancer.

Methods: Data were collected by a self-administered questionnaire containing a demographic datasheet, the Functional Assessment of Cancer Therapy–Head and Neck, Mishel Uncertainty in Illness Scale (Adult), and Perceived Involvement in Care Scale, at pretreatment (Time 1) and six weeks post-treatment (Time 2).

Main Research Variables: QOL, uncertainty, perceived involvement in decision making.

Findings: Post-treatment QOL was lower than pretreatment. QOL was associated with uncertainty and employment status at Time 1 and Time 2. Uncertainty and QOL at the time of pretreatment were predictors of post-treatment QOL after controlling for unemployment, chemoradiation, and physician. Perceived involvement in decision making was not associated with uncertainty or QOL.

Conclusions: The higher a patient's pretreatment QOL, the more likely QOL remains sound after treatment.

Implications for Nursing: Additional studies, including interventional evaluations to decrease uncertainty and to maintain employment and better income, are needed. Antecedents of Mishel's Uncertainty in Illness Theory may need to be refined for patients with head and neck cancer.

tersall, 2001). Those findings suggest that assessing patients' perception of their involvement in decision making in terms of evaluation of health outcomes is important. Despite a number of studies on QOL (Osoba, 2007) and patients' treatment decision making (Hubbard, Kidd, & Donaghy, 2008) separately, little research

exists on the association between patient involvement in decision making and QOL in patients with head and neck cancer. In addition, only a few studies pertaining to patients with head and neck cancer have addressed the concept of uncertainty (Detprapon, Sirapo-ngam, Mishel, Sitthimongkol, & Vorapongsathorn, 2009; Haisfield-Wolfe et al., 2011), although Mishel's Uncertainty in Illness Theory has been tested in other cancer populations (Sammarco & Konecny, 2008; Wallace, 2003).

The QOL of patients with cancer can change over time; it decreases during treatment and for the first few months after initiating treatment (Hammerlid, Silander, Hörnestam, & Sullivan, 2001; Schliephake & Jamil, 2002). That pattern suggests that QOL in this population should be studied longitudinally (Morton & Izzard, 2003). Similarly, Mishel (1990) describes the over time evolution of the uncertainty phenomena. For example, a person's negative appraisal of uncertainty may evolve into a positive experience over time.

The purpose of this study was to explore the relationships between uncertainty and QOL in patients with head and neck cancer prospectively in pre- and post-treatment periods. In addition, Mishel's Uncertainty in Illness Theory was tested to explore whether patients with head and neck cancer experience less uncertainty when they think they can express their concerns to their physician, receive adequate information about symptoms, and be involved in treatment decision making. Are patients who feel less uncertainty more likely to maintain their QOL?

Methods

Design

A prospective, correlational design was used. Data were collected using a self-administered questionnaire at two points of time: immediately after the consultation in which the treatment decision was made (Time 1, pretreatment) and six weeks after treatment was completed (Time 2, post-treatment).

Participants

The participants in this study consisted of adult patients who were newly diagnosed with head and neck cancer and had not yet been treated for the disease. Patients who had a history of other cancers or were unable to comprehend written English were excluded. A convenience sample was recruited at outpatient clinics through four physicians (physician A, B, C, and D) in six hospitals in the New York metropolitan area from November 2005 through November 2007. Sixty-five patients were recruited. Fifty-two of those patients (80%) agreed to be in the study and completed the Time 1 survey. Thirty-nine of the 52 participants (75%) com-

pleted both Time 1 and Time 2 surveys ("completers"). Thirteen participants withdrew from the study before the Time 2 survey ("noncompleters") for an unspecified reason (n = 8), being lost to follow-up (n = 3), being too sick (n = 1), and death (n = 1). The attrition rate was similar to previous longitudinal studies of patients with head and neck cancer, in which the attrition rates between pretreatment and three months post-treatment ranged from 27% (Bjordal et al., 2001) to 30% (Rogers, Humphris, Lowe, Brown, & Vaughan, 1998).

Approval to conduct this study was obtained from the institutional review board of each hospital (NYU Langone Medical Center, Bellevue Hospital Center, Long Island College Hospital, SUNY Downstate Medical Center, Kings County Hospital Center, and Montefiore Medical Center). Informed consent was obtained from each participant after the investigator discussed all elements of the informed consent.

Instruments

In addition to demographic and medical characteristics, which were collected by a self-reported demographic data sheet and medical chart review by the investigator, respectively, three scales were used. QOL was measured by the **Functional Assessment of Cancer Therapy–Head and Neck (FACT-H&N)** (Cella, 1997) scale. The FACT-H&N is a self-report instrument consisting of 27 items for general QOL and 10 items related to head and neck concerns. The total score of FACT-H&N ranges from 0–148, with higher scores indicating better QOL. The Cronbach alphas for the FACT-H&N in this study were 0.91 at Time 1 and 0.93 at Time 2. A study of 151 patients with head and neck cancer demonstrated the validity of FACT-H&N (List et al., 1996).

Uncertainty was measured by the 32-item **Mishel Uncertainty in Illness Scale (Adult) (MUIS-A)** (Mishel, 1997). Possible total scores ranged from 32–160, with higher scores indicating greater uncertainty. The Cronbach alphas for the MUIS-A in this study were 0.93 at Time 1 and 0.94 at Time 2. Validity has been supported by a correlational study (Mishel, 1981), indicating a moderate association between the original 28-item MUIS and Volicer's Hospital Stress Events (Volicer, Isenberg, & Burns, 1977) (n = 100, r = 0.35, p < 0.001) and a strong negative association between the original MUIS and the Comprehension Interview from the Recall Test (Cassileth, Zupkis, Sutton-Smith, & March, 1980) (n = 26, r = –0.56, p < 0.002).

The **Perceived Involvement in Care Scale (PICS)** (Lerman et al., 1990) was used to measure how patients perceived that they could express their concerns to their physician, receive adequate information about symptoms, and be involved in treatment decision making (perceived involvement in decision making). The PICS has 13 items and the possible score ranges from

13–52. Higher scores indicate that patients perceive more active involvement in decision making. The Cronbach alphas of the PICS in this study were 0.82 at both Time 1 and Time 2. After developing the PICS, Lerman et al. (1990) conducted another survey, which demonstrated validity.

Data Analysis

Data analyses were conducted using SPSS®, version 15.0. Data were entered once each by two people. Some data were missing in the scale variables; however, at least 84% of all items were answered and missing values were substituted by using participants' within-case mean (Tabachnick & Fidell, 2000). Level of statistical significance was set at an alpha of 0.05. Prior to analyzing relationships among study variables by using a regression analysis, descriptive statistics and bivariate correlational analyses were used to determine control variables. In addition, post-hoc power analyses were performed. With a sample of 52 at Time 1, the power for a bivariate correlation between the MUIS-A and FACT-H&N with an alpha of 0.05 and an observed r of 0.29 (indicating a medium effect size by Cohen [1988]) was 0.56, which indicates low power. However, for Time 2, with a sample of 39, the power for a bivariate correlation between the MUIS-A and FACT-H&N was 0.97 with an alpha of 0.05 and an observed r of 0.56, indicating a strong effect size (Cohen, 1988). The power of the regression analysis was 1.00, with an alpha of 0.05 and an observed R^2 of 0.69, corresponding to two theoretical independent variables of the PICS and MUIS-A and six covariates (unemployment; physician A, C, and D; chemoradiation; and FACT-H&N at Time 1) on the dependent variable of FACT-H&N at Time 2. Despite a small sample, the results of these power analyses indicated that the final sample of 39 was adequate to detect large effects, and close to sufficient to detect medium correlations with an alpha of 0.05.

Results

Sample Characteristics

The mean age of the participants was 58 years, and the majority was male. Most participants completed a high school education (see Table 1).

Table 2 presents participants' medical characteristics. In all 52 participants, the most common cancer site was the oropharynx. More than half of all participants had

Table 1. Demographic Characteristics at Time 1

Characteristic	Total (N = 52)		Completers (N = 39)		Noncompleters (N = 13)	
	X̄	SD	X̄	SD	X̄	SD
Age (years)	58.3	12.4	58.5	13	57.9	11
Characteristic	**n**		**n**		**n**	
Gender						
Male	37		29		8	
Female	15		10		5	
Race						
African American	20		13		7	
Asian	6		3		3	
Caucasian	22		20		2	
Hispanic	4		3		1	
Highest education						
Grade school	3		1		2	
High school	27		21		6	
College	17		14		3	
Graduate school	5		3		2	
Marital status						
Single	20		13		7	
Married	21		17		4	
Divorced or separated	7		6		1	
Widowed	4		3		1	
Annual family income ($)						
0–15,000	17		10		7	
15,001–50,000	16		12		4	
50,001 or more	19		17		2	
Employment status						
Employed	17		15		2	
Unemployed	10		4		6	
Retired	13		10		3	
Temporarily off	12		10		2	

stage IV cancer. The number of days between Time 1 and Time 2 surveys was 140.6 (SD = 38.6, n = 39), ranging from 75–244 days. Surgery alone had a shorter treatment period than radiation alone (p < 0.05) and combination modalities (p < 0.001). Four attending physicians cooperated in recruiting patients for the study. No association existed between physicians and treatment modalities by a crosstab (p = 0.2). No statistically significant difference existed in demographic and medical characteristics between completers and noncompleters, although racial minority, low income, and unemployed participants tended to withdraw from the study more frequently than others. They may have felt more vulnerable and, therefore, may have had difficulty maintaining participation in this study. Study results indicated that they had greater uncertainty and lower QOL than their study counterparts.

Scale Variables

As shown in Table 3, no statistically significant difference existed in perceived involvement in decision

Table 2. Medical Characteristics at Time 1

Characteristic	Total (N = 52) n	Completers (N = 39) n	Noncompleters (N = 13) n
Cancer site			
Oral cavity	7	5	2
Oropharynx	19	17	2
Nasopharynx	7	4	3
Hypopharynx	4	2	2
Larynx	7	5	2
Thyroid	2	2	–
Other	6	4	2
Stage			
I	7	6	1
II	8	6	2
III	9	7	2
IV	28	20	8
Treatment			
Radiation alone	9	8	1
Surgery alone	7	5	2
Chemotherapy alone	1	–	1
Chemoradiation	15	10	5
Surgery + radiation	10	7	3
Surgery + chemotherapy	2	1	1
Surgery + chemoradiation	8	8	–
Attending physician			
A (Hospitals 1, 2)	21	17	4
B (Hospitals 3, 4, 5)	18	11	7
C (Hospital 3)	7	5	2
D (Hospital 6)	6	6	–
Smoking status			
Currently smoking	8	5	3
Quit	27	22	5
Never	17	12	5
Alcohol consumption			
Very much or quite a bit	4	3	1
Somewhat or a little bit	11	9	2
Not at all	37	27	10

making (PICS) or uncertainty (MUIS-A) between Time 1 and Time 2. However, post-treatment QOL (FACT-H&N at Time 2) was significantly lower than that at pretreatment (FACT-H&N at Time 1) by paired t test (paired difference $\overline{X}$ = 10.5, paired difference SD = 17.78, p < 0.01). A strong correlation between Time 1 and Time 2 on uncertainty (r = 0.64, p < 0.001) and QOL (r = 0.73, p < 0.001) was observed. No statistically significant difference existed between completers and noncompleters in PICS, MUIS-A, or FACT-H&N.

Bivariate Analyses

Table 4 presents a correlation matrix of scale variables and ordinal demographic variables. A significant negative correlation existed between uncertainty and QOL at Time 1 (r = –0.29, p < 0.05) and Time 2 (r = –0.56, p < 0.001). However, perceived involvement in decision making was not statistically significantly correlated with uncertainty or QOL at Time 1 or Time 2.

Employment status was statistically significantly associated with QOL at Time 1 ($F_{[3, 48]}$ = 6.44, p < 0.01) and Time 2 ($F_{[3, 35]}$ = 5.61, p < 0.01). In a Tukey post-hoc test, unemployed participants had significantly lower QOL than those who were employed (p < 0.01) at Time 1 and Time 2, and those who were retired (p < 0.05) at Time 1. In other bivariate analyses, treatment modality ($F_{[3, 35]}$ = 4.41, p < 0.05) and physician ($F_{[3, 35]}$ = 2.93, p < 0.05) were statistically significantly associated with QOL. Those who underwent chemoradiation scored significantly lower than those who underwent surgery alone (p < 0.05) or surgery plus adjuvant therapy (p < 0.05). Age, gender, race, education, marital status, cancer site, cancer stage, smoking history, and alcohol consumption were not significantly associated with QOL at either time.

Multivariate Analysis

To control variables that were significantly associated with QOL in bivariate analyses, a multivariate hierarchical linear regression analysis was performed. Because a statistically significant association existed between employment status and annual family income at Time 1 (n = 39, uncertainty coefficient = 0.24, p < 0.01), only employment status was used in the regression analysis as dichotomously dummy-coded to "unemployment" and "other (reference category)."

As shown in Table 5, in the first step, unemployment explained about 16% of the variance in post-treatment QOL (p < 0.05). In the second step, physician (reference category was physician B) and chemoradiation (reference category was other treatment modalities) explained an additional 24% of the variance in post-treatment QOL (p < 0.05). The β coefficient for chemoradiation was statistically significant (β = –0.4, p < 0.05). None of the β coefficients for physicians was statistically significant. In the third step, pretreatment QOL was controlled for, which added about 24% of the variance in post-treatment QOL (p < 0.001). Finally, the pretreatment levels of perceived involvement in treatment decision making and uncertainty were entered. Adding those two variables did not make a statistically significant change in the model (R^2 change = 0.05, p = 0.11), whereas pretreatment uncertainty had a significant β coefficient (β = –0.27, p < 0.05).

Discussion

A major finding of this study was that uncertainty was significantly negatively correlated with QOL at

both pre- and post-treatment in patients with head and neck cancer, which supported Mishel's (1988) theory that patients who have reduced uncertainty have better QOL. In addition, pretreatment uncertainty and QOL were significant predictors of post-treatment QOL. Post-treatment QOL was significantly lower than pretreatment QOL. That finding is consistent with the previous literature, where a significant decrease in QOL was observed around two and three months after treatment for treatment-related toxicity, such as dry mouth, fatigue, and impaired swallowing, and decreased social and role functioning, such as inability to continue to work and eat socially (Bjordal et al., 2001; Schliephake & Jamil, 2002). Although QOL declined in the post-treatment period, patients who had relatively higher QOL at pretreatment maintained relatively higher QOL at post-treatment. That finding may be reflective of the subjective nature of QOL, but also suggests that eliminating as many factors lowering pretreatment QOL (e.g., uncertainty) as early as possible is important to maintaining better QOL in the post-treatment period.

Unfavorable economic status (unemployment and lower income) negatively affected QOL in this study. Mishel's (1988) theory does not postulate that socioeconomic status influences uncertainty, which may be

a limit of that model. Little research has been done on the relationship among uncertainty, QOL, and economic status. Mishel (1988) proposed social support as an antecedent of uncertainty. Her definition of social support included sharing information with people in a social network who care for the household and providing rides to a treatment facility. Socioeconomic status may be part of social support, but the current study suggested that patients with head and neck cancer may require better economic status rather than psychological or emotional social support to decrease uncertainty. The uncertainty may, for instance, be closely related to work-treatment conflict or available treatment depending on insurance. Researchers have paid more attention to socioeconomic

Table 3. Mean and Standard Deviation of Scale Variables for Time 1 and Time 2

Scale	Total (N = 52)		Time 1 Completers (N = 39)		Noncompleters (N = 13)		Time 2 (N = 39)	
	$\overline{X}$	SD	$\overline{X}$	SD	$\overline{X}$	SD	$\overline{X}$	SD
FACT-G	76.2	16.53	78.8	16.01	68.3	16.11[a]	72.7	18.09[b]
FACT-H&N	101.6	23.5	105	23.6	91.4	20.81	94.5	24.28[b]
Head and Neck	25.4	9.3	26.2	9.81	23.1	7.38	21.7	7.88[b]
MUIS-A	80.2	21.69	77.7	23.22	87.7	14.43	79.3	22.62
PICS	32.9	5.21	32.3	5.25	34.7	4.83	32.6	5.36

[a] p < 0.05; a difference existed between completers and noncompleters (t test).

[b] p < 0.01; differences existed between Time 1 and Time 2 for completers (paired t test).

FACT-G—Functional Assessment of Cancer Therapy–General (27 of the 37 items of FACT-H&N); FACT-H&N—Functional Assessment of Cancer Therapy–Head and Neck (37 items); MUIS-A— Mishel Uncertainty in Illness Scale (Adult) (32 items); PICS—Perceived Involvement in Care Scale (13 items)

Note. The Head and Neck scale is a 10-item subcomponent of the FACT-H&N.

Table 4. Correlation Coefficient Between Selected Demographic Characteristics and Scale Variables

Variable	Age	1	2	3	4	5	6	7	8
1. Highest education[a, c]	–0.04	–							
2. Annual family income at Time 1[a, c]	0.1	0.4**	–						
3. PICS at Time 1[a]	–0.07	–0.01	0.04	–					
4. MUIS-A at Time 1[a]	–0.06	–0.18	–0.41**	–0.00	–				
5. FACT-H&N at Time 1[a]	–0.04	0.13	0.3*	–0.09	–0.29*	–			
6. Annual family income at Time 2[b, c]	0.19	0.38*	0.96***	0.08	–0.41**	0.2	–		
7. PICS at Time 2[b]	–0.28	–0.2	–0.16	0.3	–0.03	–0.00	–0.18	–	
8. MUIS-A at Time 2[b]	0.02	–0.27	–0.49**	0.15	0.64***	–0.38*	–0.56***	–0.23	–
9. FACT-H&N at Time 2[b]	–0.03	–0.00	0.24	–0.04	–0.5**	0.73***	0.24	0.09	–0.56***

* p < 0.05; ** p < 0.01; *** p < 0.001

[a] N = 52 (total)

[b] N = 39 (completers)

[c] Spearman's correlation coefficient was computed for 1, 2, and 6. Otherwise, Pearson's correlation coefficient was computed.

FACT-H&N—Functional Assessment of Cancer Therapy–Head and Neck; MUIS-A— Mishel Uncertainty in Illness Scale (Adult); PICS—Perceived Involvement in Care Scale

Table 5. Hierarchical Regression Analysis for Variables Predicting Post-Treatment Quality of Life (Model 1)

Variable	B	SE B	β	ΔR²	R²
Step 1				0.16*	0.16*
Unemployment at Time 1	–31.16	11.93	–0.39*		
Step 2				0.24*	0.39**
Unemployment at Time 1	–10.11	12.24	–0.13		
Physician A	15.41	8.23	0.32		
Physician C	20.22	11.52	0.28		
Physician D	17.11	10.77	0.26		
Chemoradiation	–21.88	8.23	–0.4*		
Step 3				0.24***	0.64***
Unemployment at Time 1	3.36	10.04	0.04		
Physician A	11.33	6.52	0.23		
Physician C	15.62	9.1	0.22		
Physician D	15.93	8.46	0.24		
Chemoradiation	–13.07	6.73	–0.24		
FACT-H&N at Time 1	0.6	0.13	0.58***		
Step 4				0.05	0.69***
Unemployment at Time 1	9.35	10.04	0.12		
Physician A	7.93	6.43	0.16		
Physician C	14.4	8.75	0.2		
Physician D	10.71	8.47	0.16		
Chemoradiation	–12.71	6.45	–0.23		
FACT-H&N at Time 1	0.56	0.12	0.45***		
PICS at Time 1	–0.21	0.48	–0.05		
MUIS-A at Time 1	–0.28	0.13	–0.27*		

N = 39

* p < 0.05; ** p < 0.01; *** p < 0.001

Δ—change; B—unstandardized coefficient; FACT-H&N—Functional Assessment of Cancer Therapy–Head and Neck; MUIS-A—Mishel Uncertainty in Illness Scale (Adult); PICS—Perceived Involvement Care Scale; SE—standard error

In the current study, patients who underwent radiation with concomitant chemotherapy, or chemoradiation, had significantly reduced QOL compared to those who had the other treatment modalities. That finding was consistent with the literature, in which a concomitant chemotherapy particularly increases the risk and severity of the adverse effects of radiation because of oral mucositis (Elting, Cooksley, Chambers, & Garden, 2007). The current treatment paradigm of organ preservation leads more frequently to extensive chemoradiation (Zeller, 2006).

Although Mishel (1988) proposed the linkage that a patient's confidence in healthcare providers reduces the patient's uncertainty, the current study of patients with head and neck cancer did not support the linkage. In this study, PICS (Lerman et al., 1990) was used to measure patients' perception of how their physicians facilitated them in treatment decision making, how much information on their disease and its treatment they were provided, and how actively they were involved in treatment decision making. Mishel and Braden (1988) operationalized "credible authority" as a patient's perception on the quality of medical care, sufficiency of information from the physician, and trust in the confidence of the physician, and found a strong correlation (r = –0.59, p < 0.001) between uncertainty and credible authority in patients with gynecologic cancer. Existing literature has demonstrated mixed results about the relationships between patients' perception of involvement in treatment decision making and psychological or health outcomes. Gattellari et al. (2001) reported that the perceived role in decision making for patients with various cancers was associated with patient satisfaction with the amount of information and emotional support received from the physician. In contrast, no association has been found between perception of treatment choice with regard to chemotherapy and QOL in patients with breast cancer (Jansen, Otten, van de Velde, Nortier, & Stiggelbout, 2004) and facilitating patients' participation in medical decision making and psychological distress within one year after treatment in patients with prostate cancer (Davison & Goldenberg, 2003). Investigators have discussed that the various findings may depend on which domain of QOL is studied and the measurement tool used (Jansen et al., 2004). Establishing a strong relationship between the patient and physician and having well-informed patients are actually challenging goals in clinical practice, with only one or two contacts between

impact on patients with cancer since the early 2000s. A study of patients with head and neck cancer found that 52% (n = 201) of the patients who were working at the time of diagnosis were unable to return to work after treatment (Taylor et al., 2004). In a study conducted in the United Kingdom to explore the areas to be improved for the satisfaction of patients with head and neck cancer with information about their illness and treatment, the most frequent area picked by the participants as not provided was "who to ask/where to go for financial support," which represented 78% (n = 64) of the participants in pretreatment and 60% (n = 41) of those in post-treatment (Llewellyn, McGurk, & Weinman, 2006). The mean age of the sample of the current study was on the younger end of the traditional age range for patients with head and neck cancer (Piccirillo, Costas, & Reichman, 2007). That might have contributed to the significance of unemployment on QOL in this study, as being employed might be more critical for working- or younger-aged people than for retired or older people. However, age was not a significant factor on whether patients with head and neck cancer were able to return to work after treatment (Taylor et al., 2004), and was not significantly associated with QOL in this study.

patients and physicians before treatment decision making (Davison & Goldenberg, 2003). Theoretical clarification of the concepts pertaining to the patient-physician relationship and involvement and participation in decision making may be needed.

Limitations

A limitation of this study was the small sample size. Because of feasibility, the design was limited to pre-post comparison. If patients were followed up longer and more frequently, trends in the change in QOL over time could be observed more clearly, and the wide range of the number of days between pre- and post-treatment surveys because of treatment modality could be better controlled.

Implications for Nursing

One implication of this study is that economic or work-related impact should be taken into consideration when assessing for uncertainty and QOL in patients with head and neck cancer. Nurses can involve social workers and case managers early to discuss insurance issues, available financial entitlements, and coordination of schedules to maintain employment. Interventional studies can be conducted to examine whether early involvement of social workers is effective to improve QOL and what treatment schedule helps maintain employment.

The prospective design of this study was meaningful because the change in QOL was observed and factors affecting post-treatment QOL that could be modified in the pretreatment period or an earlier point of time were identified. Findings of this study provide knowledge about the experience of patients with head and neck cancer, as well as preliminary data that may help in the development of care plans to facilitate their adaptation in terms of QOL.

Conclusions

This was one of the few studies where Mishel's (1988) Uncertainty in Illness Theory was used for a theoretical formulation in patients with head and neck cancer. Study findings supported the conceptual link that when people experience less uncertainty, they experience better adaptation (operationally defined in this study as QOL), as proposed by Mishel (1988). Although the theory focuses on cognitive indices, such as information and knowledge about illness, the findings of this study suggest that economic factors, such as unemployment and low income, have a strong impact on uncertainty and QOL. The healthcare environment has been changing since Mishel (1988) developed the Uncertainty in Illness Theory. As technology has advanced, more information has become available and is more easily accessible. Given the current healthcare environment, Mishel's theory may need updating.

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References

American Cancer Society. (2012). *Cancer facts and figures, 2012*. Retrieved from http://www.cancer.org/acs/groups/content/@epidemiologysurveilance/documents/document/acspc-031941.pdf

Bjordal, K., Ahlner-Elmqvist, M., Hammerlid, E., Boysen, M., Evensen, J.F., Biörklund, A., . . . Kaasa, S. (2001). A prospective study of quality of life in head and neck cancer patients. Part II: Longitudinal data. *Laryngoscope, 111*, 1440–1452. doi:10.1097/00005537-200108000-00022

Cassileth, B.R., Zupkis, R.V., Sutton-Smith, K., & March, V. (1980). Information and participation preferences among cancer patients. *Annals of Internal Medicine, 92*, 832–836.

Cella, D.F. (1997). *FACIT manual, version 4.* Evanston, NY: Centre on Outcomes, Research and Education at Evanston Northwestern Healthcare and Northwestern University.

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum Associates.

Davison, B.J., & Goldenberg, S.L. (2003). Decisional regret and quality of life after participating in medical decision-making for early-stage prostate cancer. *BJU International, 91*(1), 14–17. doi:10.1046/j.1464-410X.2003.04005.x

Detprapon, M., Sirapo-ngam, Y., Mishel, M. H., Sitthimongkol, Y., & Vorapongsathorn, T. (2009). Testing of uncertainty in illness theory to predict quality of life among Thais with head and neck cancer. *Thai Journal of Nursing Research, 13*(1), 1–14.

Elting, L.S., Cooksley, C.D., Chambers, M.S., & Garden, A.S. (2007). Risk, outcomes, and costs of radiation-induced oral mucositis among patients with head-and-neck malignancies. *International Journal of Radiation Oncology, Biology, Physics, 68*, 1110–1120. doi:10.1016/j.ijrobp.2007.01.053

Gattellari, M., Butow, P.N., & Tattersall, M.H. (2001). Sharing decisions in cancer care. *Social Science and Medicine, 52*, 1865–1878. doi:10.1016/S0277-9536(00)00303-8

Haisfield-Wolfe, M.E., McGuire, D.B., Soeken, K., Geiger-Brown, J., De Forge, B.R., & Suntharalingam, M. (2011). Prevalence and correlates of symptoms and uncertainty in illness among head and neck cancer patients receiving definitive radiation with or without chemotherapy. *Supportive Care in Cancer.* Advance online publication. doi:10.10007/s00520-011-1291-9

Hammerlid, E., Silander, E., Hörnestam, L., & Sullivan, M. (2001). Health-related quality of life three years after diagnosis of head and neck cancer—A longitudinal study. *Head and Neck, 23*, 113–125. doi:10.1002/1097-0347(200102)23:2<113::AID-HED1006>3.0.CO;2-W

Hubbard, G., Kidd, L., & Donaghy, E. (2008). Preferences for involvement in treatment decision making of patients with cancer: A review of the literature. *European Journal of Oncology Nursing, 12,* 299–318. doi:10.1016/j.ejon.2008.03.004

Jansen, S.J., Otten, W., van de Velde, C.J., Nortier, J.W., & Stiggelbout, A.M. (2004). The impact of the perception of treatment choice on satisfaction with treatment, experienced chemotherapy burden and current quality of life. *British Journal of Cancer, 91*(1), 56–61.

Keating, N.L., Guadagnoli, E., Landrum, M.B., Borbas, C., & Weeks, J.C. (2002). Treatment decision making in early-stage breast cancer: Should surgeons match patients' desired level of involvement? *Journal of Clinical Oncology, 20,* 1473–1479. doi:10.1200/JCO.20.6.1473

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York, NY: Springer.

Lerman, C.E., Brody, D.S., Caputo, G.C., Smith, D.G., Lazaro, C.G., & Wolfson, H.G. (1990). Patients' Perceived Involvement in Care Scale: Relationship to attitudes about illness and medical care. *Journal of General Internal Medicine, 5,* 29–33. doi:10.1007/BF02602306

List, M.A., D'Antonio, L.L., Cella, D.F., Siston, A., Mumby, P., Haraf, D., & Vokes, E. (1996). The Performance Status Scale for head and neck cancer patients and the Functional Assessment of Cancer Therapy–Head and Neck scale. A study of utility and validity. *Cancer, 77,* 2294–2301.

Llewellyn, C.D., McGurk, M., & Weinman, J. (2006). How satisfied are head and neck cancer (HNC) patients with information they receive pre-treatment? Results from the satisfaction with cancer information profile (SCIP). *Oral Oncology, 42,* 726–734.

Mishel, M.H. (1981). The measurement of uncertainty in illness. *Nursing Research, 30,* 258–263. doi:10.1097/00006199-198109000-00002

Mishel, M.H. (1988). Uncertainty in illness. *Image, 20,* 225–232.

Mishel, M.H. (1990). Reconceptualization of the uncertainty in illness theory. *Image, 22,* 256–262. doi:10.1111/j.1547-5069.1990.tb00225.x

Mishel, M.H. (1997). *Uncertainty in illness scales manual.* Chapel Hill, NC: University of North Carolina.

Mishel, M.H., & Braden, C.J. (1988). Finding meaning: Antecedents of uncertainty in illness. *Nursing Research, 37*(2), 98–103, 127.

Molleman, E., Krabbendam, P.J., Annyas, A.A., Koops, H.S., Sleijfer, D.T., & Vermey, A. (1984). The significance of the doctor-patient relationship in coping with cancer. *Social Science and Medicine, 18,* 475–480. doi:10.1016/0277-9536(84)90003-0

Morton, R.P., & Izzard, M.E. (2003). Quality-of-life outcomes in head and neck cancer patients. *World Journal of Surgery, 27,* 884–889.

Osoba, D. (2007). Translating the science of patient-reported outcomes assessment into clinical practice. *Journal of the National Cancer Institute. Monographs, 37,* 5–11. doi:10.1093/jncimonographs/lgm002

Piccirillo, J.F., Costas, I., & Reichman, M.E. (2007). Cancers of the head and neck. In L.A.G Ries, J.L. Young, G.E. Keel, M.P. Eisner, Y.D. Lin, and M.J. Horner (Eds.), *SEER survival monograph: Cancer survival among adults: U.S. SEER program, 1988–2001, Patient and tumor characteristics.* Retrieved from http://seer.cancer.gov/publications/survival/surv_head_neck.pdf

Rogers, S.N., Humphris, G., Lowe, D., Brown, J.S., & Vaughan, E.D. (1998). The impact of surgery for oral cancer on quality of life as measured by the Medical Outcomes Short Form 36. *Oral Oncology, 34,* 171–179. doi:10.1016/S1368-8375(97)00069-9

Sammarco, A., & Konecny, L. M. (2008). Quality of life, social support, and uncertainty among Latina breast cancer survivors. *Oncology Nursing Forum, 35,* 844–849. doi: 10.1188/08.ONF.844-849

Schliephake, H., & Jamil, M.U. (2002). Prospective evaluation of quality of life after oncologic surgery for oral cancer. *International Journal of Oral and Maxillofacial Surgery, 31,* 427–433. doi:10.1054/ijom.2001.0194

Semple, C.J., Sullivan, K., Dunwoody, L., & Kernohan, W.G. (2004). Psychosocial interventions for patients with head and neck cancer: Past, present, and future. *Cancer Nursing, 27,* 434–441. doi:10.1097/00002820-200411000-00002

Tabachnick, B.G., & Fidell, L.S. (2000). *Using multivariate statistics* (4th ed.). Needham Heights, MA: Allyn and Bacon.

Taylor, J.C., Terrell, J.E., Ronis, D.L., Fowler, K.E., Bishop, C., Lambert, M.T., . . . Wolf, G.T. (2004). Disability in patients with head and neck cancer. *Archives of Otolaryngology—Head and Neck Surgery, 130,* 764–769. doi:10.1001/archotol.130.6.764

Volicer, B.J., Isenberg, M.A., & Burns, M.W. (1977). Medical-surgical differences in hospital stress factors. *Journal of Human Stress, 3*(2), 3–13. doi:10.1080/0097840X.1977.9936082

Wallace, M. (2003). Uncertainty and quality of life of older men who undergo watchful waiting for prostate cancer. *Oncology Nursing Forum, 30,* 303–309.

Zeller, J.L. (2006). High suicide risk found for patients with head and neck cancer. *JAMA, 296,* 1716–1717. doi:10.1001/jama.296.14.1716