

Research Article

Uncertainty in Illness in Iranian Patients with Cancer and its Related Factors: A Cross-Sectional Study

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Received: April 21, 2016; **Accepted:** May 17, 2016;

Published: May 19, 2016

Abstract

Background: One of the most pervasive and major experiences of patients with cancer is uncertainty in illness, which can have significant effects on their psychological adjustment, quality of life and disease outcomes. Recognizing factors that impact illness uncertainty is important for nurses in that they can provide better services for patients.

Purpose: The present study was conducted to examine uncertainty in illness in patients with cancer and its relationship with certain demographic and clinical variables in them to determine its predictors.

Methods: A cross-sectional study was conducted on 420 patients with cancer admitted to two cancer referral centers in Tehran (Iran) in 2013 to investigate illness uncertainty and its related factors. Data were collected through a questionnaire on the demographic information and clinical details of the patients and also using the Persian version of the uncertainty in illness scale. Data were analyzed in SPSS-20 using descriptive statistics and statistical tests, including the Pearson r, chi-squared, independent t-tests and multiple linear regression.

Results: Participant's mean score of uncertainty in illness was 90.1 (SD = 16.8). Uncertainty of illness had a significant positive relationship with age ($r = .19, p < .001$) and metastasis ($r = .12, p = .026$). Uncertainty with illness had a significant negative relationship with the level of education ($r = -.47, p < .001$) and time since diagnosis ($r = -.15, p = .002$). The result showed that these variables can express 27% variance of uncertainty in illness in cancer patients.

Conclusion/Implications for Practice: Patients with cancer experience a significant level of uncertainty in illness. The assessment of uncertainty in illness and understanding factors affecting it can help perform appropriate nursing interventions for more effective coping or for reducing uncertainty in illness, which contributes to improving patient's quality of life and health.

Keywords: Cancer; Uncertainty in illness; Nursing; Iran

Introduction

Uncertainty is a normal part of the cancer experience that persists throughout the stages of the illness, from diagnosis to treatment and throughout follow-up. Uncertainty in illness is defined as the "inability to determine the meaning of events related to the disease and inability to assess events or predict the outcomes of the disease due to the lack of sufficient cues" [1]. Uncertainty is also considered a main psychological stressor [2,3], and most people seek to reduce it or find ways to cope with it [4].

Uncertainty is experienced in all acute or chronic diseases. Chronic diseases such as cancer in particular can lead to persistent uncertainty due to the long duration of the disease, the likelihood of disease recurrence or deterioration, and the patient's unknown prognosis. Contrary to the uncertainty in acute diseases, which involves only diagnosis, treatment and recovery difficulties, in chronic diseases, uncertainty affects a wider scope of the patient's life and daily activities and can compromise quality of life [3,5,6]. Several studies conducted in chronically ill patients with conditions such as

heart disease, dialysis, hepatitis, liver transplantation, Alzheimer's disease and specially in cancer have shown that uncertainty in illness is a challenging experience that can compromise quality of life and ability to cope with the disease [2,5,7-13]. Cancer is the second most common cause of death in Western societies [14] and the third in Iran after heart disease and motor vehicle accidents. The annual incidence rate of cancer in Iran is about 80,000 and is expected to rise in the coming decades and become a major health problem of the country [15]. The present-day technological advances for the diagnosis and treatment of cancer have increased patient's survival, thereby quality of life throughout the survivorship trajectory has become more pressing [16]. Due to the nature of their disease and the complexities of its symptoms and treatment, patients with cancer experience levels of uncertainty in illness that are caused by the problems associated with the inability to perform daily activities, inadequacy of treatments, and concerns about the recurrence of the disease [17,18]. Several studies have been conducted in Western countries on uncertainty in illness pertaining to different types of cancer [4,9,10]. The ultimate goal of these studies is to increase psychological adjustment to the disease

and to improve the patients' quality of life through the effective handling of uncertainty [16].

Uncertainty in illness is a multidimensional and dynamic phenomenon that is perceived differently by patients based on ethnic-racial differences and varying social environments. For example, several personal-related factors can affect perception of illness uncertainty, including age and education level; illness-related factors such as history of the disease, stage of cancer, and disease-related symptoms can influence uncertainty. The effects of these factors and their importance have been reported differently in different studies. Therefore, examination of uncertainty in diverse cultures and communities is essential in understanding its variability [19, 20]. Additionally, given that the response to uncertainty is shaped by social and cultural context and the background and experiences of the individual (despite a number of invariant responses), studies should be conducted in the context of different societies and cultures [3,21]. Understanding cultural, disease-related, and personal characteristics that predict uncertainty is essential so that nurses can recognize these differences as an essential nursing responsibility in order to provide optimal and holistic care to patients [11].

Despite the importance of the concept of uncertainty in illness for patients with cancer and its profound effects on patient quality of life, limited studies have been published on this subject in Iran. It is unknown which cultural, disease-related, and personal characteristics are associated with uncertainty in Iranian cancer patients and how these differ between Iranian and Western societies. Therefore, the purpose of this study was to determine predictors of uncertainty in illness in patients with cancer in Iran.

Methods

Study design and sample

The present descriptive correlational and cross-sectional study is part of a larger study conducted on uncertainty in illness through mixed methods. This study was approved by the Ethics Committee of Shahid Beheshti University of Medical Sciences, Tehran (code: 86-10837) [22].

The study population consists of patients with cancer admitted to the oncology clinics and wards of Imam Khomeini Hospital (the largest cancer referral center in Iran) and Taleghani Hospital in Tehran. Given that these centers admit patients from all over the country, the results of the study can be generalized to the entire population of Iran. A convenience sample of 420 patients with cancer were selected according to the inclusion criteria: 1) willingness to participate in the study, 2) being diagnosed with cancer by an oncologist, 3) being aware of one's own disease, 4) being of Iranian nationality, 5) having the ability to speak and understand Persian, 6) being at least 21 in age, 7) having no other serious diseases or known mental disorders (such as schizophrenia), and 8) undergoing cancer treatment. Patients with all types and stages of cancer and types of treatment were included in the study.

Instruments

Data collection instruments used in this study include a demographic and disease information questionnaire (with 10 items on age, gender, level of education, marital status, occupation, area of residence, type of cancer, time since diagnosis, presence or absence

of metastasis and the type of treatment) and the Mishel Uncertainty in Illness Scale Adult form (MUIS-A). MUIS-A has 32 items based on the Likert scale rated from 1 (completely disagree) to 5 (strongly agree). Higher scores signify a higher level of uncertainty. The instrument has four dimensions, including ambiguity, complexity, inconsistency and unpredictability [23]. Ambiguity has 13 items (unexplained disease symptoms or an overlap between the disease symptoms and other symptoms), complexity 7 items (pertaining to a diverse range of complex treatment and care systems), inconsistency 7 items (the inconsistency of the information the patient receives about his disease) and unpredictability 5 items (the inability to predict disease outcomes through its symptoms). Reliability was evaluated in several studies; Cronbach's alpha was calculated as $\alpha = .87$ for the complete scale. Dimension subscales ranged from $\alpha = .65$ to $\alpha = .86$, indicating the instrument's good internal consistency [23]. Results of a study conducted by Sajjadi et al. showed a good reliability and validity for the Persian version of this scale among a population of Iranian patients with cancer. Consistency of the instrument in that study with a three-week interval was $r = .91$. Cronbach's alpha was .89 for the whole scale of 32 MUIS-A items and $\alpha = .58$ to .86 for its four factors [24].

Data collection and analysis

Participants were informed of the study objectives and provided informed consent if they agreed to participate in the study. Questionnaires were then distributed to participants at the time of consent, completed on site, and collected after completion. The Principal Investigator (PI) was responsible for patient selection at the cancer clinics and wards, informed consent, distribution of questionnaires, and data collection. For illiterate patients or for those with vision or writing difficulties, the PI read the questionnaires aloud and marked patient responses. Completing the questionnaires took at most 20 minutes. Data were explored in SPSS-20 using descriptive statistics were used to examine and analyze the relationship between the patient's demographic and clinical factors and uncertainty in illness. Relationships between variables were tested using the Pearson r , chi-squared and independent t -tests as appropriate. Variables that had a significant relationship with illness uncertainty ($p < .05$) were entered into the model. Multiple linear regression was used to determine predictors on illness uncertainty. A total of four variables was entered into the regression model. They included age, level of education, time since diagnosis, and metastasis of cancer.

Results

The return rate for the questionnaires was 100% since all were returned at the time of enrollment and in the presence of the researcher. The participants' demographic information and clinical details are shown in Table 1. The majority of participants were female (51.7%), married (78.8%), nonmetastatic disease (63.7%), and most of them working in the home as a housewife (41.4%), were diagnosed less than 6 months (39.5%) and had a primary and guidance school education (36.0%). The most common type of cancer among participants was breast cancer (24.5%).

Findings revealed that patients experience a relatively high level of uncertainty in illness, mean 90.1 (SD=16.8) with a range of 42 to 133. Table 2 shows the total score of uncertainty in illness and its dimensions in patients included in this study. Mean scores

Table 1: Demographic and clinical characteristics of patients with cancer (N=420).

		Mean	SD (Range)
Age (year)		46.4	13.9 (21-79)
Time since diagnosis (months)		18.5	24.2 (3-168)
		N	%
Sex	Female	217	51.7
	Male	203	48.3
Marital status	Single	58	13.8
	Married	331	78.8
	Widowed or divorced	31	7.3
Education level	Illiterate	87	20.7
	Primary and Guidance school	151	36
	Diploma	107	25.5
	University degree	75	17.9
Area of residence	Tehran	191	45.5
	Other	229	54.5
Occupation	Self-employed	76	18.1
	Employee	34	8.1
	Housewife	174	41.4
	Unemployed	35	8.3
	Other	101	24.1
Time since diagnosis (months)	<6	166	39.5
	6-24	163	38.8
	>24	91	21.7
Type of cancer	Breast	103	24.5
	Colon and rectum	99	23.6
	Gastric/Esophagus	36	8.6
	Hematologic	72	17.1
	Uterus/ovarian	25	6
	Prostate	5	1.2
	Lung	21	5
	Skin	5	1.2
	Other	54	12.9
Metastasis	Yes	143	36.3
	No	251	63.7
Kind of Treatment	Chemotherapy	105	25
	Chemotherapy and Surgery	189	45
	Chemo and Radiotherapy	26	6.2
	All of them	90	21.4
	Other	10	2.4

SD: Standard Deviation.

for ambiguity, complexity, inconsistency and unpredictability subscales were 41.8, 15.1, 18.8 and 14.4 respectively. To conduct a better comparison between the conditions of uncertainty in illness in patients with cancer in Iran and in those in Western countries, the level of uncertainty in illness pertaining to the combined samples of patients with cancer provided in Mishel's database are also presented (Table 2) [23].

The present study also examined the relationship of demographic and clinical variables and uncertainty in illness. The results showed a positive, significant relationship between age and uncertainty in illness ($r = .19, p < .001$), indicating that older patients experience more uncertainty in illness. A significant negative relationship between the level of education ($r = -.47, p < .001$) and time since diagnosis ($r = -.15, p = .002$) also existed. Patients with higher levels of education and

Table 2: Comparison means of uncertainty in illness and its dimensions in Iranian patients with cancer with Mishel's data bank.

	Ambiguity Mean (SD)	Complexity Mean (SD)	Inconsistency Mean (SD)	Unpredictability Mean (SD)	Total Mean (SD)
Iranian patients with cancer (N=420)	41.8(9.4)	15.1(3.2)	18.8(4.2)	14.4(3.5)	90.1(16.8)
Mishel's combined data for cancer patients (N=761)	32.3(9.3)	16.5(5)	14.9(4.7)	15.8(3.7)	79.5(16.9)

Table 3: Correlation between uncertainty in illness and selected demographic and clinical variable in cancer patients (N=420).

Variables	Uncertainty in illness	Education	Age	Metastasis	History of diagnosis
Uncertainty in illness	r = 1	r = -.47**	r = .19** p < .001	r = -.12* p = .026	r = -.15** p = .002
Education		r = 1	r = -.33** p < .001	r = .04 p = .45	r = .04 p = .39
Age			r = 1	r = .05 p = .30	r = -.07 p = .14
Metastasis				r = 1	r = -.23** p < .001
History of diagnosis					r = 1

*p < .05, **P < .01

Table 4: Relationship between kind of treatment with inconsistency and complexity (N=420).

Treatment Variable	Chemotherapy (Mean±SD)	Surgery (Mean±SD)	All of them (Mean±SD)	Result of ANOVA analysis (p)
Inconsistency	19.6±4.1	23.8±6.8	18.4±4.2	.004
complexity	16.0±3.5	15.7±3.3	14.8±3.1	.004

longer histories of diagnosis experienced lower levels of uncertainty. Other variables in the model, associated with uncertainty in illness are presented in Table 3. A significant relationship between the type of treatment and the complexity and inconsistency dimensions was found. Those who had undergone surgery gave a higher score to the inconsistency dimension of uncertainty. Those who had experienced various types of treatments gave lower scores to the complexity dimension of uncertainty Table 4. The present study found no significant relationships between gender, marital status, occupation, type of cancer, and types of treatment and uncertainty in illness. Regression analysis revealed that education level, time since diagnosis and having metastatic disease accounted for 27% of the uncertainty variance in patients (Adj R² = .27, P < .002). Table 5. The equation for regression model is:

$$\text{Uncertainty} = 106 - 8 (\text{education level}) - 4.7 (\text{metastasis}) - .12 (\text{time since diagnosis}).$$

Discussion

This study was conducted to assess uncertainty in illness in Iranian patients with cancer and to examine uncertainty and its relationship with certain demographic and disease-related variables. The main findings of the study suggest that Iranian patients with cancer experience rather high levels of uncertainty in illness and a relationship exists between certain demographic and disease-related variables such as age, level of education, time since diagnosis, the presence or absence of metastasis, and the perception of uncertainty.

Since one of the objectives of this study was to determine the level of illness uncertainty and its dimensions in patients with cancer and social, cultural and underlying factors affecting it, the results of the present study were comparable with those of Mishel's study. When

Table 5: Multivariate Analysis of Demographic and Clinical Factors Predicting Uncertainty in illness in cancer patients (N=420).

Variables	Beta	t	P
Education	-.459	- 9.99	< .001
Age	.052	1.12	.26
Metastasis	-.137	- 3.09	.002
Time since diagnosis	-0.17	- 3.85	< .001

Adjusted R² = .27

comparing findings of the present study to other studies, which were primarily conducted in western countries, results indicate that the level of uncertainty in illness is higher in Iran compared to other societies [23]. Given that the participants of this study were a combination of patients with different types of cancer, it is most appropriate to compare this study's findings with a variety of other studies on patients with cancer. Findings are consistent with the results of a study conducted in patients with head and neck cancer [17], although uncertainty scores were higher in Iranian cancer patients. The higher degree of uncertainty found in this study may be due to the inherent differences in social-cultural contexts, the shortage of knowledge among patients in the Iranian society, the ineffective personnel-patient communication and the lack of adequate patient education in Iran [25] specially about cancer. These gaps are further emphasized through the significant differences found in the ambiguity and inconsistency subscales, since the ambiguity subscale reflects patients' knowledge and awareness of the cancer and inconsistency reflects the contradictory information received from care providers.

A significant relationship was found between age and uncertainty in illness with older patients experiencing more uncertainty. Other studies that have examined age in relation to uncertainty in illness have yielded contradictory findings. A study by Kazer et al. found that younger individuals experience less uncertainty in illness [11] whereas studies conducted by Bialy et al. and Haisfield-Wolf et al. found showed a direct relationship between age and uncertainty in illness [2,17], consistent with the findings of the present study. In contrast to these findings, one study by Lasker et al. found the lack of a

relationship between age and uncertainty [12]. Disparate results might be due to the small sample size and the close age range of participants in the latter study. The relationship between age and perception of uncertainty might be justified by noting that the cognitive capacity of individuals can increase with age and, in addition, the majority of older patients who participated in this study were diagnosed longer, which might have affected their perception of uncertainty.

The findings revealed a significant negative relationship between the level of education and uncertainty; that is, patients' uncertainty decreases as their level of education increases, which is consistent with the findings of other studies [10,11,17]. However, no relationship was found between these two variables in some studies [5,12]. Determining the role of education in the perception of uncertainty is difficult; however, the majority of studies conducted on the subject as well as the uncertainty in illness theory confirm the negative relationship between uncertainty and the level of education [3]. The lack of a relationship suggested by these studies is likely due to their limited sample sizes and participants' similar levels of education.

The findings of the present study revealed a relationship between the area of residence and uncertainty in illness; that is, individuals living in Tehran (the capital city of Iran) experienced lower levels of uncertainty compared to patients living in other cities. From a logical perspective, the area of residence is not likely to have a great effect on uncertainty; however, this finding might be partly due to the more proximity to health care in Tehran compared to other cities and the higher levels of awareness and education in the residents of Tehran.

A direct relationship between the presence of metastasis and uncertainty in illness was also found in this study; that is, cancer patients with metastasis experienced higher levels of uncertainty than patients without metastasis. Haisfield-Wolf et al. also showed that the level of uncertainty is higher in cancer patients with metastasis, consistent with the results of the present study [17]. However, this relationship is supported both logically and theoretically; as metastasis increases, the severity and complexity of symptoms increases, which may lead to increased uncertainty in illness.

A negative relationship was found between time since diagnosis and uncertainty in illness; that is, the longer since the disease was diagnosed, the lower is uncertainty. However, this finding is inconsistent with the results of studies conducted by Kang and Haisfield-Wolf et al., which indicated the lack of a relationship between the two variables [5,17]. Yet, strong theoretical bases support this finding. Based on the theory of uncertainty in illness, patients who are exposed to uncertainty for a long period of time reconceptualize their lives in a way that uncertainty becomes a natural part of it, and its intensity therefore reduces [3,26].

Finally, a relationship between uncertainty in illness and types of treatment was not found, but a relationship was found between the complexity and inconsistency subscales and types of treatment. Contrary to expectations, patients who had experienced various types of cancer treatment had a lower score for the complexity subscale than patients who had experienced only one type of treatment. In addition, the inconsistency subscale score was higher in patients who had only undergone surgery or chemotherapy compared to people who had received all types of treatment. This finding is partly explained by the

relationship between time since diagnosis and uncertainty. Patients who had experienced different types of treatment had a longer time since diagnosis and were more familiar with the disease, while those who had received only one type of treatment had a shorter time since diagnosis and a higher inconsistency score. Regression analysis revealed that demographic and clinical factors could explain 27% of the variance of illness uncertainty. This low value can be attributed to other important factors (except demographic and clinical factors) that affect illness uncertainty such as complexity of signs, level of complications and social support.

Implications/Conclusion

This study reveals that patients with cancer in Iran experience significant levels of uncertainty in illness and their perceptions are affected by various factors. Examining and understanding uncertainty in illness and its influential factors and considering these factors is effective for assisting patients in managing uncertainty in illness, which in turn leads to an improved quality of life for the patient. Nurses can use appropriate interventions to help reduce illness uncertainty in patients considering different factors affecting illness uncertainty. Due to the cultural and social differences between Iranian and Western societies, further qualitative studies should be conducted on the experiences of patients with uncertainty in order to gain a better understanding of the dimensions of this phenomenon in Iranian patients with cancer. Given the low variance, it is recommended that other important factors such as social support, disease signs and symptoms, and treatment side effects be investigated.

Limitations

This study acknowledges several limitations. First, the convenience sampling method may have caused sampling bias. Although data were gathered from two large and referral hospital in Tehran it may not be generalizable to all Iranian cancer patients. Second, the low variance of illness uncertainty occurred due to a lack of gathering data on important factors that affect illness uncertainty. Despite this limitation, this study had an adequate sample size, and results contribute to the existing literature on uncertainty in illness. This information can benefit Iranian nurses working in oncology centers around the country. This study may be a cornerstone for the future studies in the area of uncertainty in illness in other groups of patients in Iran.

Acknowledgement

The present study is a part of a nursing doctoral thesis adopted by Shahid Beheshti University of Medical Sciences (Tehran - Iran). Hereby, we express our appreciation to authorities and staff in wards and Iran Cancer Center of Imam Khomeini Hospital and Tehran Taleghani Hospital. Finally, we particularly thank all the participants.

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