Original Article

Assessment of Uncertainty in Illness and its Correlated Factors among Patients with Cancer at Tertiary Level Hospitals

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Abstract

Background: *Patients with cancer have great experiences of uncertainty in illness rather than the disease, which can have negative impacts on their psychological adjustment, quality of life and disease outcome.* ***Objective:*** *The aim of the study was to determine the relationship between illness uncertainty and its related factors among these patients.* ***Materials and method:*** *A cross-sectional study was conducted among 120 cancer patients from Bangabandhu Sheikh Mujib Medical University, Dhaka, Bangladesh. Data was collected by in depth interview through questionnaire. Data analysis was done using t-test, ANOVA, and correlation test.* ***Results:*** *The average score of uncertainty among cancer patients was 99.3 with a range of 63 to 136. Younger participants had significantly higher uncertainty in illness than elder ones (r = -25, p= 0.01). Male patients had higher uncertainty when compared to female (t= -3.35) and it was statistically significant (p=0.02). Uncertainty in illness was significantly higher (t=0.29, p=0.02) among participants who had metastasis than who had no metastasis.* ***Conclusion:*** *This study reveals that patients with cancer experience significant levels of uncertainty in illness and their perceptions are affected by various factors.*

Keywords: *Uncertainty in illness; Cancer; Cancer patients; Nurse.*

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Introduction

Uncertainty in illness can be both acute and chronic. Mishel defined uncertainty as "the inability to determine the meaning of illness related events" and further stated that "it is cognitive state when the person cannot adequately structure or categorize an event because of lack of sufficient cues".[1] Uncertainty occurs in a situation in which the decision maker or patient is unable to assign definite value to objects or events and/or is unable to predict outcomes accurately.[2]

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Patients suffering from chronic disease such as cancer experience illness uncertainty that different from patients with acute illness. In acute illness condition, patients experience uncertainty at diagnosis but are offered treatment to relieve symptoms and reduce uncertainty. In chronic illnesses like cancer where treatment might not be available or unnecessary, too expensive, or delayed, patients must learn to live with continued uncertainty.[3]

Cancer is the leading cause of death in economically developed countries and the second leading cause of death in developing countries.[4] Each year, 10 million people suffer from cancer and 6 million of them die in the world.[5] Currently, in Asia, the incidence of cancer cases and cancer death are 48% and 55% respectively in the world. The cancer incidence and mortality are expected to rise over the next two decades in Asia.[6] According to Bangladesh Bureau of Statistics, cancer is the sixth leading cause of death in Bangladesh though Bangladesh is still lacking a national cancer registry. International Agency for Research on Cancer (IARC) has projected that death from cancer in Bangladesh is 7.5% in 2005 and it will be increased up to 13% in 2030.[7] A study conducted on "Cancer Control in Bangladesh" found that there were 13 to 15 lakh cancer patients in Bangladesh, with about 2 lakh patients newly diagnosed with cancer each year. The rising number of cancer incidence and prevalence might have great negative impact on health care system and individual's quality of life all over Asia.[8]

In the journey of cancer, from the diagnosis to end of life, patients suffer from high level of illness related uncertainty.[9] The causes of uncertainty in illness are complexities of treatments and symptomsthat alter daily living activities, expensive and inadequate treatment and concern about the prognosis of disease.[10] Recognizing and measuring the impact of illness uncertainty during the cancer experience is critical to successful intervention development.

The Mishel Uncertainty in Illness Scale (MUIS) was developed in 1981 and has undergone repeated psychometric evaluation. The Mishel Uncertainty in Illness Scale-Adult form (MUIS-A) for adult patients, has four factors. These are ambiguity, complexity, inconsistency and unpredictability. Ambiguity is bodily warning about the condition of the illness that are unclear and most of the time they are confused and concern with other illness. Complexity is about treatment either it does work or not and health care system is difficult to understand. Inconsistency is about repeatedly changing information provided by health care provider and does not consistence with previous information. Physical symptoms have been changed continuously, that is why it is difficult to predict and compare present illness with previous illness experience.[11,12]

Personal characteristics of patients including, age, educational level and religious inclination are related to feelings of uncertainty in illness.[8,13] Illness-related factors such as history of the disease, stage of cancer, and disease-related symptoms such as pain, physical disability can also influence uncertainty.[3]

We do not know which disease-related, and personal characteristics are associated with illness uncertainty in Bangladeshi cancer patients. Therefore, the aim of the study was to determine the relationship between illness uncertainty and its related factors among these patients.

Materials and method

This descriptive cross sectional study was conducted from July 2019 to June 2020 at Bangabandhu Sheikh Mujib Medical University in Dhaka city.

Instruments information

The instrument in this study consisted two parts. These are Demographic questionnaire (DQ) and Bangla version of Mishel Uncertainty in Illness Scale-Adult form (MUIS-A).[13]

Part 1. Demographic questionnaire (DQ)

This questionnaire assessed the subjects' socio demographic and disease related characteristics including age, gender, religion, level of education, marital status, stage of cancer, time since diagnosis, monthly family income, type of cancer and presence or absence of metastasis.

Part 2. Mishel Uncertaintyin Illness Scale Adult form (MUIS-A) Bangla version

Bangla version of Mishel Uncertainty in Illness Scale, Adult form (MUIS-A) has total 32 items. Reverse score items are 6, 7, 10, 12, 21, 25, 27, 28, 30, 31, 32. For the four factor analysis, sum of 32 items for a total score is calculated and mean is determined. Higher scores indicate greater uncertainty. Individual factors are scored for Ambiguity (mean of items: 3, 4, 8, 9, 13, 14, 16, 17, 18, 20, 23, 24, 26), Complexity (mean of items: 6, 7, 10, 28, 31, 32, 33), Inconsistency (mean of items: 1, 2, 5, 11, 19, 22, 29) and Unpredictability (mean of items: 12, 21, 25, 27, 30).

Reliability of the instrument

Internal consistency reliability was tested for this scale. Chronbach Alpha was 0.734, which was accepted for the reliability of the instruments in this study.

Data collection method

Prior to data collection, the proposal was approved by the Institutional Review Board (IRB), BSMMU. The objectives of the study were explained to the nursing superintendents and ward-in-charges to provide help during data collection. The purpose of the study was explained by the researcher to the subjects. Data was collected through questionnaire. After explaining the purpose of the study, the researcher requested written informed consent from the subjects who agree to participate in this study.

Data Analysis

After completion of data collection, data was checked for consistency to minimize error. Data was analyzed using SPSS 20 version (Statistical Package for the Social Sciences) computer software. Categorical variable was presented in the form of percentages, mean and standard deviation. Data analysis was done using t-test, ANOVA, and correlation test.

Results

The mean age of the participants was 44.67 (SD14.08) years. Most of them were male (59.2%) and married (86.7%). According to educational degree, most of participants (58.3%) had primary education, while, 35.8% had obtained secondary education and only 5.8% participants had completed graduation. Most of the participants (68.8%) were unemployed and lived outside Dhaka (90.0%) (Table I).

Table I: Distribution of respondents by their general characteristics (N= 120)

Characteristics		(%)
Sex		
	Male	59.2
	Female	40.8
Marital Status		
	Married	86.7
	Unmarried	13.3
Education		
	Primary	58.3
	Secondary	15.0
	Higher Secondary	20.9
	Above	5.8
Occupation		
	Job	17.5
	Business	6.7
	Labour	15.0
	Unemployed	68.8
Area of residence		
	Inside Dhaka	10.0
	Outside Dhaka	90.0

Most of the respondents (75.0%) had been diagnosed within ≤1 year, while; only 25.0% of respondents had been diagnosed by ≥2 years.

More than seventy percent (77.5%) of them had no metastasis and more than fifty percent got chemotherapy (Table II).

Table II: Distribution of respondents by their disease and treatment (N=120)

Characteristics	Category(s)	(%)
Time Since Diagnosis		
	Less than and equal 1year	75.0
	More than and equal 2 years	25.0
Metastasis		
	Yes	22.5
	No	77.5
Type of cancer		
	Carcinoma	83.3
	Sarcoma	10.8
	Melanoma	.8
	Lymphoma	2.5
	Leukemia	2.5
Type of treatment		
	Chemotherapy	53.3
	Radiotherapy	3.3
	Oral Medicine	13.3
	Operation	10.0
	Combination therapy	20.0

Uncertainty in illness among cancer patients was high, average score was 99.3 (SD=13.8) with a range of 63 to 136. Average scores for ambiguity, complexity, inconsistency and unpredictability subscales were 33.7, 26.7, 21 and 18 respectively. (Table III)

Table III: Uncertainty in illness scores for ambiguity (N=120)

Sub-scales/Items	Strongly Agree n(%)	Agree n(%)	Undecided n(%)	Disagree n(%)	Strongly disagree n(%)	M(SD)
Ambiguity (13)						**33.7(8.78)**
illness is getting better or worse	7(5.8)	5(4.2)	18(15.0)	39(32.5)	51(42.5)	4.02(1.13)
my pain will be	6(5.0)	5(4.2)	19(15.8)	31(25.8)	59(49.2)	4.10(1.12)
to expect things will be done to me	64(53.3)	9(7.5)	12(10)	19(15.8)	16(13.3)	2.28(1.55)
continue to change unpredictably	58(48.3)	28(23.3)	3(2.5)	16(13.3)	15(12.5)	2.18(1.46)
My treatment is too complex to figure out	73(60.8)	8(6.7)	7(5.8)	16(13.3)	16(13.3)	2.12(1.55)
It is difficult to know if the treatment or getting are helping	35(29.2)	4(3.3)		37(30.8)	29(24.2)	
Because of the unpredictability of my illness, I cannot plan for the future	75(62.5)	24(10.0)	20(8.3)	8(6.7)	3(2.5)	1.63(1.04)
The course of my illness keeps changing. I have good days and bad days	78(65.0)	22(18.3)	1(.8)	11(9.2)	8(6.7)	1.74(1.25)
It's vague to me how at home	32(26.7)	16(13.3)	4(3.3)	30(25)	28(31.7)	
going to happen to me	61(50.5)	27(22.5)	8(6.7)	1210)	12(10)	
The effectiveness of the treatment is undetermined	26(21.7)	18(15)	15(12.5)	41(34.2)	20(16.7)	
It is difficult to determine how long it will be before I can care for myself	56(46.7)	26(21.7)	16(13.3)	15(12.5)	7(5.8)	
Because of the treatment, what I can do and cannot do keeps changing	40(33.3)	50(41.7)	20(16.7)	7(5.8)	3(2.5)	
Subtotal Mean						**2.59**

Table IV: Uncertainty in illness scores for complexity (N=120)

Sub-scales/Items	Strongly Agree n(%)	Agree n(%)	Undecided n(%)	Disagree n(%)	Strongly Disagree n(%)	M(SD)
						26.7(3.77)
The purpose of my treatment is clear to me*	23(19.2)	17(14.2)	2(1.7)	38(31.7)	40(33.3)	3.46(1.53)
When I have pain, I know what this means about my condition*	22(18.3)	8(6.7)	1(.8)	12(10)	77(64.2)	3.95(1.60)
I understand everything explained to me*	86.7()	24(20)	2(1.7)	50(41.7)	36(30)	3.68(1.27)
The treatment I am receiving has a known probability of success*	23(19.2)	11(9.2)	23(19.2)	33(27.5)	30(25)	3.30(1.43)
I can depend on the nurses to be there when I need them*	2(1.7)	6(5)	2(1.7)	77(53.5)	33(22.9)	4.11(.79)
The seriousness of my illness has been determined*	3(2.5)	5(4.2)	5(4.2)	19(15.8)	88(73.3)	4.53(.94)
The doctors and nurses use everyday language so I can understand what they are saying*	7(5.8)	17(14.2)	()	81(67.5)	15(12.5)	3.67(1.05)
Subtotal Mean						**3.81**

Table IV: Uncertainty in illness scores for inconsistency (N=120)

Sub-scales/Items	Strongly Agree n (%)	Agree n (%)	Undecided n(%)	Disagree n(%)	Strongly Disagree n(%)	M(SD)
Inconsistency (7)						**21(5.7)**
I don't know what is wrong with me	27(22.5)	5(4.2)	1(.8)	10(8.3)	77(64.2)	3.88(1.68)
I have a lot of questions without answers	43(35.8)	18(15)	11(9.2)	21(17.5)	27(22.5)	2.76(1.6)

The explanations they give about my condition seem hazy to me	38(31.7)	15(12.5)	2(1.7)	34(28.3)	31(25.8)	3.04(1.65)
The doctors say things to me that could have many meanings	30(25)	21(17.5)	1(5.8)	24(20)	38(31.7)	3.16(1.62)
I have been given many differing opinions about what is wrong with me	55(45.8)	14(11.7)	1(.8)	14(9.7)	36(25)	2.68(1.78)
The results of my tests are inconsistent	83(69.2)	6(5)	2(1.7)	7(5.8)	22(18.3)	1.99(1.61)
They have not given me a specific diagnosis	36(30)	12(10)	()	9(7.5)	63(52.5)	3.43(1.82)
Subtotal Mean						**3.0**

Table V: Uncertainty in illness scores for unpredictability (N=120)

Sub-scales/Items	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	M(SD)
	n(%)	n(%)	n(%)	n(%)	n(%)	
Unpredictability(5)						**18(3)**
I can predict how long my illness will last*	14(11.7)	5(4.2)	81(67.5)	10(8.3)	10(8.3)	2.98(.96)
I usually know if I am going to have a good day or bad day*	13(10.8)	13(10.8)	46(38.3)	15(12.5)	33(27.5)	3.35(1.28)
I can generally predict the course of my illness*	5(4.2)	6(5)	33(27.5)	33(27.5)	43(35.8)	3.86(1.09)
I'm certain they will not find anything else wrong with me*	31(25.8)	17(14.2)	3(2.5)	15(12.5)	54(45)	3.37(1.72)
My physical distress is predictable; I know when it is going to get better or worse*	3(2.5)	10(8.3)	2(1.7)	25(20.8)	80(66.7)	4.41(1.04)
Subtotal Mean						**3.6**

The result showed that younger participants had comparatively more uncertainty in illness than elder and it was statistically highly significant (r = -.25, p = 0.01). Male patients showed higher uncertainty in illness when compared to female patients (p = 0.001). Participants who were businessmen and laborers showed significantly lower level of uncertainty in illness (t = -3.35, p = 0.02). (Table VI)

Table VI: Relationship between general characteristics and uncertainty among participants (N = 120)

Variable (s)		M(SD)	t/F/r	p
Age			0.-25	0.01
Gender			0.20	0.001
	Male	102(13.1)		
	Female	94(13.7)		
Marital status			1.4	0.65
	Married	99.2(10.3)		
	Unmarried	101(.692)b		
Education			1.9	0.12
	Primary	97.5(14.5)		
	Secondary	99.6(13.1)		
	H.Secondary	105(12.8)		
	Above	96.8(6.5)		
Living area			0.07	0.67
	Inside Dhaka	97.7(15.0)		
	Outside Dhaka	99.5(13.8)		
Occupation			3.35	0.02 a,d>c,d
	Job (a)	106.3(14.2)		
	Business(b)	104.6(13.2)		
	Labor(c)	100(14.1)		
	Unemployed(d)	96(13.1)		

Uncertainty in illness was higher among participants who had metastasis than who had none and the result was statistically highly significant (t = 0.29, p = 0.02). Participants receiving chemotherapy had more uncertainty in illness than other groups and it was statistically significant (p = 0.05). (Table VII)

Table V: Relationship between disease related characteristics and uncertainty among participants (N=120)

Variable (s)	Category(s)	M(SD)	t/F/r	p
Time of Diagnosis			1.5	.72
	< 1 year	99.1(14.6)		
	> 2 years	100.1(11.4)		
Metastasis			.29	.03
	Yes	104.4(15.37)		
	No	97.8(13.0)		
Type of cancer			.89	.47
	Carcinoma	99.3(13.0)		
	Sarcoma	99.5(19.4)		
	Melanoma	97.0()		
	Lymphoma	88.6(19.8)		
	Leukemia	110(8.1)		
Treatment				
	CT (a)	101.6(12.8)	2.40	.05 a>b,c,d,e
	RT(b)	95.7(18.0)		
	Oral Medicine(c)	91.9(15.3)		
	Operation(d)	93.7(16.6)		
	Combination therapy(e)	101.5(11.6)		

Discussion

A state of uncertainty is a major component of all illness experiences and it affects psychosocial adaptation and outcome of disease. Though it is important to know which socio demographic and disease related factors are influencing factors to trigger the patients' psychiatric distress and physical as well, to my knowledge, there is no study in Bangladesh which tried to find out such factors before. Therefore, the study was conducted with the aim of determine the relationship between illness uncertainty and its related factors among cancer patients. We examined uncertainty in illness among patients with cancer and its relationship with certain demographic and disease related variables in them to determine its predictors.

In this study, the average mean score of uncertainty is 99.3. Similar result was found in other studies. In 2016, a study titled "Uncertainty in Illness in Iranian Patients with Cancer and its Related Factors" found that participants' mean score of uncertainty in illness was 90.1 (SD = 16.8).[3] In 2014, another study reported similar results.[14]

In this study, uncertainty had a significant negative relationship with age (r = 0.-25, p <0.01) with younger patients experiencing more uncertainty. Some studies were consistent with the result and some studies contradicted. A study found that younger individuals experience less uncertainty in illness whereas some other studies found a direct relationship between age and uncertainty in illness consistent with the findings of the present study.[10,11,15]

Conclusion

This study reveals that patients with cancer in Bangladesh experience significant levels of uncertainty in illness and their perceptions area 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 Bangladeshi 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 Bangladeshi 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 hospitals in Bangladesh it may not be generalizable to all Bangladeshi cancer patients.

Conflict of interest: None to be declared.

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