

Original article

The Informational, Psychological and Social Needs of Patients Undergoing Chemotherapy, Visiting Imam Reza Teaching Hospital, Tabriz, in 2016

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SUMMARY

Understanding physical, psychological and social needs is the basis for disease management. The purpose of this study was to investigate the informational, psychological, and social needs of patients undergoing chemotherapy. The present study is a descriptive-correlational one conducted on 400 patients undergoing chemotherapy visiting a teaching hospital in Northwest Iran. The data collection instrument consisted of three sections, including the demographic information of patients, a researcher-made questionnaire to determine the informational needs of patients, and a Psychosocial Needs Index (PNI) provided to patients while receiving chemotherapy. Data were analyzed by descriptive and inferential statistics in SPSS 21 version.

The results showed that the mean score of patients' informational needs was high and the mean score of their psychosocial needs was moderate. Regarding the informational dimension, the highest level of need was reported for the item "I need to be aware of things to help me recover from my disease"; in the psychosocial dimension, the highest level of need belonged to the psychological dimension with the item "I need help to reduce my family's concerns about my illness"; in the physical and daily activity dimension, the highest level of need was related to item "I need help to reduce fatigue and gain energy"; in the care and support dimension, the highest level of need belonged to the item "I need the timely attendance of medical staff in case of physical needs and complications"; and finally, in the sexual dimension, the highest level of need was reported for the item "I need help to control changes in my sexual desire". The findings showed that patients with cancer have extensive needs after the diagnosis of the disease and during chemotherapy, and understanding these needs is important in planning care for these patients.

Key words: chemotherapy, informational needs, psychological and social needs

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INTRODUCTION

Cancer is the second cause of death in developed countries and accounts for one-third of the causes of adult death in developing countries (1). It is also the third most common cause of death in Iran (2). According to WHO, it is estimated that cancer rates will double by 2030 worldwide and the number of new cases, which was 12.3 million in 2007, will reach 16 million in 2020 (1).

Chemotherapy is now a major and systemic method of treating cancer, and one-third of patients with cancer receive chemotherapy as a part of treatment. Diagnosis and treatment can be financially and emotionally uncomfortable for patients. Studies show that 30-40% of people experience a significant level of emotional distress and psychiatric complications from the time of diagnosis to treatment, impairing their quality of life and constantly presenting the challenge of fighting and responding to it (3).

According to Benner and Wrubel, everyone needs information in order to plan and respond to challenges and change. Information is required throughout the course of the disease. However, the type of information patients need in order to make decisions during treatment differ from those they require when they receive chemotherapy (4).

Receiving information about diagnosis, treatment, and methods to reduce the complications of treatment is a tool with the help of which cancer patients can better contribute to the decision-making process, ultimately improving their quality of life (5).

On the other hand, psychosocial needs are a person's desire for support in the field of emotional-psychological health which, if not fulfilled, effect all the aspects of the individual's life (6). Lack of knowledge about the needs for disease management causes more pain and suffering, undermines the adherence to treatment, and is a threat to recovery.

A research conducted by Mossman (7) in the United Kingdom showed that providing information is an important part of care, and patients can receive this transparent information in a form through which they can have access to any of the options and results from the diagnosis to the treatment. Lack of this information may cause uncertainty, anxiety, distress, dissatisfaction, and limitations in patients' decision-making (7).

An accurate understanding of the needs and concerns of cancer patients, especially in the sensitive stage of diagnosis, is critical. Moreover, understanding the needs of patients in the face of cancer as well as their interests helps professional staff, especially nurses, provides

appropriate counseling services for patients and families. Since understanding the experiences, perceptions, and needs of cancer patients has a potential value in cancer care system and nursing care and is a very important issue for nurses, it is essential that nurses make an effort to evaluate and improve the quality of life of cancer patients in physical, emotional, mental, and social dimensions (8).

Patients need accurate information and emotional support to cope with the disease and treatments such as chemotherapy, and this would not be possible without knowing their informational (cognitive) and psychosocial needs.

Considering the importance of identifying these needs in the care plans for these patients as well as the increasing rate of cancer and lack of relevant studies, the researcher decided to study the informational and psychosocial needs of patients undergoing chemotherapy.

MATERIAL AND METHODS

This is a descriptive-coreational study in which the statistical population included the patients undergoing chemotherapy in the Oncology Ward of Imam Reza Teaching Hospital, Tabriz, Iran. Inclusion criteria were: age over 18 years; patient's informed consent to participate in the study; suffering from various types of cancer requiring chemotherapy diagnosed by an oncology physician; ability to read and write or interview in case of illiteracy; presence in the third session of chemotherapy; lack of cognitive impairment; and illness awareness. The exclusion criteria were the patient's unwillingness to participate in the study or refusal to continue the study for any reason, the presence of pain and nausea, and excessive fatigue before or during the completion of the questionnaire. Based on Mousavi's study, the sample size was estimated as follows (9): Considering $P = 62\%$, $d = 0.05$, $q = 38\%$, $Z_{1-\alpha} = 1.96$, and $\alpha = 0.05$, the sample size was initially determined as 362. Then, considering a 10% sample attrition, the sample size of 400 patients undergoing chemotherapy was determined and the information was gathered using a data collection tool. The first part of the questionnaire examined the demographic information of the patients (age, sex, marital status, income level, education, number of children, etc.), and the second part was the researcher-made questionnaire to determine their informational needs, comprising 25 questions. This questionnaire was designed using the American Cancer Society's texts and guidelines in line with the stated goal. Scoring was based on the Likert scale (1 = very important), (2 = important), (3 =

medium importance), (4 = low importance), and (5 = very low importance) with a range of 25-125. The third part of the Psychosocial Needs Inventory (PNI) contained 48 questions scored based on the Likert scale (1 = very important, 2 = important, 3 = medium importance, 4 = low importance, and 5 = very insignificant) with a score range of 48-240, provided to the patients during the third (moderately calculated) period of chemotherapy. The oncology wards of Imam Reza Hospital include hematology units, hematology clinics, and chemotherapy clinics. The researcher was present when examining the patients' files; identified the number, names, and bed numbers of eligible patients; and then visited them at their bedside and provided them with the questionnaire. The questionnaire was completed by the patients themselves in the presence of the examiner. For illiterate subjects, the questionnaire was completed by the interviewer through interviews.

In this study, in order to assess face and content validity, 10 faculty members of the Faculty of Nursing and Midwifery and the Faculty of Educational Sciences were asked to fill in the informational needs questionnaire. After applying their comments, the questionnaire was administered to patients. In order to test the reliability of the questionnaires, a test-retest method was employed through which the questionnaire was first given to 30 patients undergoing chemotherapy and then returned to them after 10 days. Next, reliability was calculated by Cronbach's alpha and 0.94 and 0.95 were obtained for the informational needs scale and the psychological needs questionnaire, respectively. In all the stages of the study, the required variables were collected and recorded. Finally, the collected data were analyzed using descriptive and analytical statistics at the significance level of ≤ 0.05 in SPSS.

The study was conducted after the approval of the Medical Research Ethics Committee of Tabriz University of Medical Sciences, receiving an ethical code (IR.TBZMED.REC.1395.1302).

RESULTS

Four hundred patients from the Oncology Wards of Imam Reza Teaching Hospital affiliated with Tabriz University of Medical Sciences participated in this study. The mean age of the participants was over 39.9 years and most patients were female (53.9%). Moreover, 29.7% of the participants had a high school diploma and 43.2% had a business of their own. In addition, 51.4% of patients were not suffering from other chronic diseases, and 82.6% were not smokers. Other demographic data are

presented in Table 1. The mean score of informational needs was 103.17 ± 16.09 with a range score of 25-125. Furthermore, the mean score of psychosocial needs was 33.99 ± 188.76 with the score range of 48-240 (Table 2).

There was a significant statistical relationship between age, educational level, marital status, smoking, level of satisfaction with the available information resources, primary information resources, patients' other chronic diseases, and the time the illness was diagnosed when informational needs were required (Table 3). There was a significant statistical relationship between marital status, economic level, smoking, occupation, patients' lifestyle, their primary information resource, and suffering from other chronic diseases on the one hand, and the psychosocial needs of patients on the other (Table 4).

DISCUSSION

The main purpose of this study was to determine the informational and psychological needs of patients undergoing chemotherapy visiting Imam Reza Teaching Hospital, Tabriz, in 2016. Results revealed that, considering the informational needs of patients undergoing chemotherapy, the highest means respectively belonged to the informational needs on how to reduce fatigue and gain energy (mean of 4.56 ± 0.76), control and pain relief (mean of 4.41 ± 0.92), insurance coverage of the cost of chemotherapy and the need for information on the number of sessions and duration of chemotherapy, and finally the concept of chemotherapy. Since these patients have informational needs from the time of admission and hospitalization, the initial assessment of these needs is the first and foremost step in identifying and influencing treatment (9). In a descriptive study by Lei CP et al. (10) to determine the informational needs of patients with breast cancer undergoing chemotherapy in the Malaya Medical Center in Malaysia, results showed that the informational needs of these patients were high, which is consistent with the results of the present study.

In a study by Lock KK et al. (11) to identify the awareness of educational needs in patients with cancer undergoing chemotherapy and radiotherapy, results indicated that the informational and educational needs of patients regarding radiotherapy care are high, in line with the results of this study. On the other hand, regarding the psychosocial needs, the need to receive accurate and honest information from the medical staff (mean of 4.50 ± 0.84) and the need for information required to control and relieve pain (mean of 4.41 ± 0.92) had the highest rate, indicating that obtaining accurate and honest infor-

Table 1. Absolute frequency distribution and the percentage in terms of demographic characteristics of the patients undergoing chemotherapy

Variable		No. / (%)	Variable		No. / (%)
Gender	Female	214 (53.9)	Marital status	Single	83 (21)
	Male	183 (46.1)		Married	283 (71.5)
Educational level	Illiterate	83 (20.9)		Widow(er)	17(4.3)
	Elementary	119 (30)		Divorced	13 (3.3)
	High school diploma	118 (29.7)	Residential place	City	229 (58.1)
	University	77 (19.4)		Village	165 (41.9)
Occupation	Business person	145 (43.2)	Family economic level	Income equals expenditure	119 (30.6)
	Homemaker	91 (27.1)		Income more than expenditure	38 (9.8)
	Government employee	78 (23.2)		Income less than expenditure	232 (59.6)
	University student	12 (3.6)	Do you smoke?	Yes	69(17.4)
	Unemployed	10 (3)		No	327(82.6)
Suffering from other chronic diseases	No	206 (51.4)	Patient's life style	Alone	55 (14.6)
	Blood sugar	36 (9)		With spouse	49(13)
	Hypertension	58(14.5)		With spouse and children	210 (55.6)
	Chronic respiratory diseases	25(6.3)		With children	33 (8.7)
	Other cases	75 (18.8)		With family	31 (8.2)
How information is received	Active	47 (12.7)		Patient's primary information resource	Internet
	Inactive (accidental)	322 (87.3)	Mass media (radio, TV, etc.)		21 (5.6)
Rate of satisfaction of the available information resources	Very low	20 (5.2)	Rellies, other patients		27 (7.2)
	Low	89 (22.9)	Colleagues		3 (0.8)
	Medium	145 (37.4)	Relatives and friends		17 (4.5)
	High	66 (17)	Health centers	283 (75.3)	
	Very high	68 (17.5)	Children	1	67 (23.9)
Having the family history of the present disease	Yes	154 (39.7)		2	102 (36.4)
	No	234 (61.3)		3	38 (13.6)
Age*	39.92 (14.07)	4		29 (10.4)	
Awareness*	4.26 (6.72)	5		26 (9.3)	
		6		7 (2.5)	
		7		2 (0.7)	
		8		8 (2.9)	
		9		1 (0.4)	

* mean (standard deviation)

Table 2. Mean score of informational-psychological needs of the patients undergoing chemotherapy

Dimensions	Mean (standard deviation)
Informational needs	103.17 (16.09)
Psychosocial needs	188.76 (33.99)

Table 3. Comparison of psychological needs in terms of demographic characteristics of patients undergoing chemotherapy

Variable		Standard deviation ± mean	Statistical indicators	Variable		Standard deviation ± mean	Statistical indicators
Gender	Female	109.34 ± 20.95	t= 0.96 df= 381 p= 0.33	Marital status	Single	180.34 ± 55.93	f= 3.66 df= 3 p = 0.01
	Male	186.33 ± 83.04			Married	192.32 ± 14.90	
Educational level	Illiterate	181.36 ± 90.60	f = 1.56 df = 3 p = 0.19		Widow(er)	173.37 ± 70.29	
	Elementary	192.3 ± 16.02			Divorced	191.36 ± 76.82	
	High school diploma	188.34 ± 66.10		Residential place	City	188.34 ± 31.03	t = 0.62 df = 378 p = 0.53
	University	190.33 ± 81.89			Village	190.33 ± 24.90	
Occupation	Business person	184.33 ± 51.03	f = 2.43 df = 4 p = 0.04	Family economic level	Income equals expenditure	188.31 ± 63.6	f = 2.42 df = 4 p = 0.04
	Homemaker	196.31 ± 62.46			Income more than expenditure	174.35 ± 78.16	
	Government employee	185.35 ± 20.07			Income less than expenditure	190.34 ± 85.64	
	University student	185.37 ± 16.27		Do you smoke?	Yes	179.33 ± 28.67	t = 2.40 df = 380 p = 0.01
	Unemployed	202.31 ± 70.98			No	190.33 ± 44.94	
Suffering from other chronic diseases	No	194.32 ± 32.35	f = 5.38 df = 4 p = 0.00	Patient's life style	Alone	186.33 ± 41.60	f = 2.80 df = 4 p = 0.02
	Blood sugar	187.31 ± 69.18			With spouse	197.33 ± 44.87	
	Hypertension	176.37 ± 47.01			With spouse and children	189.33 ± 69.76	
	Chronic respiratory diseases	199.29 ± 48.39			With children	185.34 ± 71.50	
	Other cases	173.34 ± 44.60			With family	172.33 ± 32.35	
How information is received	Active	207.20 ± 28.37	t = 0.79 df = 42 p = 0.43	Patient's primary information	Internet	207.20 ± 28.37	f = 3.11
	Inactive	199.43 ±			Mass media	199.43 ±	

	(accidental)	47.13		resource	(radio, TV, etc.)	47.13	df = 0 p = 0.00
Rate of satisfaction of the available information resources	Very low	177.31 ± 42.83	f = 0.87 df = 4 p = 0.48		Relatives, other patients	190.30 ± 13.10	
	Low	192.32 ± 45.07			Colleagues	184.60 ± 33.69	
	Medium	187.32 ± 57.23			Relatives and friends	33 ± 204.79	
	High	185.37 ± 92.84			Health centers	185.34 ± 10.01	
	Very high	190.37 ± 07.02				r	
Having the family history of the present disease	Yes	184.16 ± 02.12	t = - 1.98 df = 366 p = 0.04		age*	-0.04	0.43
	No	191.32 ± 22.09			Time after patient's awareness of diagnosis*	0.00	0.99

* Pierson statistical test

** T-test statistical test

*** Ano statistical test

Table 4. Comparison of informational needs in terms of demographic variables of patients undergoing chemotherapy

Variable		Standard deviation ± mean	Statistical indicators	Variable		Standard deviation ± mean	Statistical indicators
Gender	Female	103.16 ± 0.24	t = 0.20 df = 369 p = 0.83	Marital status	Single	102.15 ± 60.01	f = 4.64 df = 3 p = 0.00
	Male	103.15 ± 35.96			Married	104.15 ± 62.27	
Educational level	Illiterate	97.17 ± 67.61	f = 6.06 df = 3 p = 0.00		Widow(er)	88.12 ± 05.86	
	Elementary	15.1 ± 62.49			Divorced	97.27 ± 07.08	
	High school diploma	15.1 ± 49.49		Residential place	City	102.16 ± 98.72	t = 0.25 df = 366 p = 0.80
	University	14.1 ± 32.66			Village	15.1 ± 52.22	
Occupation	Businessperson	102.16 ± 13.43	f = 1.81 df = 4 p = 0.12	Family economic level	Income equals expenditure	103.16 ± 06.39	f = 0.65 df = 2 p = 0.58
	Homemaker	105.12 ± 40.43			Income more than expenditure	100.15 ± 02.49	

	Government employee	104.16 ± 50.43			Income less than expenditure	103.16 ± 45.15	
	University student	96.18± 41.91		Do you smoke?	Yes	96.17± 60.46	t = 3.45
	Unemployed	110.10 ± 88.02			No	104.15 ± 30.57	p = 0.00
Suffering from other chronic diseases	No	105.15 ± 43.19	f = 4.90 df = 4 p = 0.00	Patient's life style	Alone	101.16 ± 33.69	f = 0.78 df = 4 p = 0.53
	Blood sugar	101.12 ± 70.61			With spouse	105.18 ± 25.93	
	Hypertension	95.18 ± 29.0			With spouse and children	103.14 ± 40.57	
	Chronic respiratory diseases	107.12 ± 64.21			With children	99.18 ± 62.38	
	Other cases	101.17 ± 74.93			With family	104.17 ± 25.78	
How information is received	Active	113.17 ± 9.39	t = 1.01 df = 37 p = 0.31	Patient's primary information resource	Internet	113.9 ± 17.39	f = 3.15 df = 5 p = 0.00
	Inactive (accidental)	108.81 ± 17.40			Mass media (radio, TV, etc.)	108.17 ± 81.40	
Rate of satisfaction of the available information resources	Very low	90.22 ± 22.88	f = 3.94 df = 4 p = 0.00		Rellies, other patients	102.17± 50.86	
	Low	103.14 ± 33.96			Colleagues	112.12 ± 33.50	
	Medium	102.15 ± 30.59			Relatives and friends	107.15 ± 57.67	
	High	106.14 ± 68.58		Health centers	101.16 ± 65.09		
	Very high	104.16 ± 13.37			r	p	
Having the family history of present disease	Yes	101.16 ± 51.28	t = 1.44 df = 355 p = 0.15	age*	-0.14	0.00	
	No	104.16 ± 02.12		time after patient's awareness of diagnosis**	0.80	0.00	

mation and information on the disease is very effective in controlling and relieving pain in terms of patients' psychological dimension. These needs were followed by the need for family support (mean of 4.1 ± 15.15). Therefore, it seems that supportive care for patients should be broad and vital in order to let them have a purposeful and meaningful life. In a study conducted by Choi et al. (12) in South Korea with the aim of assessing the psychosocial needs of patients with cancer, the results showed that 52.22% of patients needed psychological support. Compared with the results of the present study, psychological needs were at a lower level than informational needs, which is not consistent with our results (12). This inconsistency may be due to differences in the culture and level of emotional and family relationships between the two research communities.

Another study revealed that family and friends are considered as the most important sources of support for patients suffering from breast cancer, and this support is a facilitating factor for the fast diagnosis of cancer (13). Although most cancer patients and their families have a normal psychological performance, uncomfortable psychological states are common in people with cancer (14). The prevalence of psychological problems varies according to the type of cancer, time of diagnosis, rate of physical and mental disorder, pain, prognosis, and other variables. In a comprehensive cancer research center in the United States studying 4,500 patients aging 19 years and above, significant psychological distress is found in 29% to 43% of patients with 14 most common cancers (15).

Informational and psychological issues can cause new social problems. While solving the underlying social problems is beyond the capabilities of healthcare providers, paying attention to these problems and how to address them within the limits of clinical practice is an integral part of high-quality healthcare.

Unofficial social support for patients (family members and friends) provides emotional, informational, and logistical support. When patients receive adequate support from family members or neighbors, friends, and others, they can use their help to perform their own duties. When they lack these supports, however, the effects of psychosocial problems will increase (16).

In order for patients to adapt to the course of the disease, it is necessary to provide information and familiarity with the normal course of the disease which results in more adaptation, reduction of fear caused by the relapse of the disease and its unknown nature, and increased bearing for the burden caused by the disease.

In a study conducted by Fu MR et al. (17) it was concluded that women suffering from breast cancer seek social support to help themselves, suggesting that having contact with support groups and receiving their support are some of the needs of these patients. Authors also consider nursing interventions for these women as a combination of receiving information, awareness, and social and emotional support. Regarding the significance of informational needs and psychosocial needs in the noted research, the results are consistent with those of the present study.

In Iran, as the systems for meeting the informational-social needs of patients with cancer are limited, families have a special support status. In order to achieve this, it is essential to guide the nurses and doctors to meet the needs of families (18).

It is necessary to pay attention to the informational needs of patients with cancer. These patients have a low social adjustment, causing extreme psychological problems for them. Awareness of the informational, psychological, and social needs of these individuals at different stages of treatment and providing them with appropriate information (by health professionals, health informers, nurses, and doctors) as well as removing the barriers and challenges in accessing information about their disease lead to the reduction or elimination of mental anxiety, creating serenity and psychological security in patients which can, in turn, impact the healing process.

Based on the results of this research, it is suggested that the authorities and managers of the health system of every country come up with strategies to understand and resolve the psychological, social, and informational needs of patients with cancer. Attention to this issue is increasingly needed since understanding the experiences and perceptions of these patients has a potential value in the healthcare system involving the important profession of nursing and is a major concern for healthcare providers.

The psychological condition of participants while completing the questionnaire is among the limitations of the present study which may have affected their response, a point which could not be controlled by the researcher. In addition, considering the sample size in this research, it is suggested that this study be replicated on a larger sample order to enhance the generalizability of results.

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Psihološke, društvene i potrebe za informisanošću bolesnika na hemoterapiji, lečenih u bolnici Imam Reza u Tabrizu tokom 2016. godine

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SAŽETAK

Razumevanje fizičkih, psiholoških i društvenih potreba bolesnika osnova je lečenja bolesti. Cilj ove studije bio je ispitivanje psiholoških, društvenih i potreba za informisanošću bolesnika na hemoterapiji. Ova studija deskriptivno-korelacionog tipa uključila je 400 bolesnika na hemoterapiji koji su posećivali bolnicu u severozapadnom Iranu. Instrument za prikupljanje podataka sastojao se od tri dela, što je uključivalo demografske informacije o bolesnicima, upitnik koji je odredio potrebe bolesnika za informisanošću, dok je indeks za određivanje psiholoških potreba podeljen bolesnicima u toku primanja hemoterapije. Podaci su analizirani primenom deskriptivne i inferencijalne statistike u okviru programa SPSS 21.

Rezultati su pokazali da je srednja vrednost potreba bolesnika za informisanošću bila visoka, dok je srednja vrednost psiholoških potreba bila umerena. Kada je u pitanju potreba za informisanošću, najviši nivo važnosti potrebe zabeležen je u vezi sa izjavom za koju se opredelio najveći broj bolesnika "Želim da budem svestan / svesna šta mi može pomoći da se oporavim"; što se tiče psihološke dimenzije, najviši nivo važnosti potrebe ogledao se u izjavi "Potrebna mi je pomoć kako bi moja porodica manje brinula zbog moje bolesti"; u domenu fizičkih i dnevnih aktivnosti, najviši nivo važnosti potrebe zabeležen je kod izjave "Potrebna mi je pomoć kako bih smanjio/smanjila umor i gubitak energije"; kada su u pitanju nega i podrška, najviši nivo važnosti potrebe primećen je kod izjave "Potrebna mi je blagovremena pomoć medicinskog osoblja u slučaju fizičkih potreba i komplikacija"; na kraju je procenjivan i seksualni aspekt i najviši nivo važnosti potrebe uočen je kod izjave "Potrebna mi je pomoć kako bih kontrolisao/kontrolisala promene u seksualnom nagonu". Rezultati su pokazali da oboleli od kancera imaju veliki broj potreba nakon donošenja ove dijagnoze i u toku hemoterapije. Razumevanje ovih potreba veoma je važno u planiranju nege ovih bolesnika.

Ključne reči: hemoterapija, potrebe za informisanošću, psihološke i društvene potrebe