

Iranian Nurses Perceptions of Cancer Patients Quality of Life

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Abstract

Background: Cancer is the third main cause of death in Iran only after cardiovascular diseases and accidents.

Objectives: The main aim of this research study was to identify nurses' understanding of cancer patients' Quality of Life (QoL) in an Iranian context.

Patients and Methods: This descriptive correlational study was conducted in an educative referral oncology center affiliated to Isfahan University of Medical Sciences, Isfahan, Iran in 2013. 50 pairs of cancer patients and their nurses were conveniently recruited. The sample of nurses were selected based on consensus sampling which included more than 70 percent of eligible nurses in the hospital. Patients and nurses were requested to complete the Farsi version of the world health organization quality of life (WHOQoL-BREF) questionnaire, separately. QoL was measured across four dimensions including physical, psychological, social relationship and environmental.

Results: The QoL mean domain scores of patients were 10.06, 11.88, 12.76 and 11.96, respectively. The corresponding scores of nurses were 11.6, 11.23, 12.65 and 12.07. Pearson correlations between patients and nurses scores were 0.42, 0.5, 0.25 and 0.58 which revealed a fair to moderate agreement between nurses' and patients' scores in different domains. Paired samples t-test values indicated that physical QoL mean domain scores of patients were significantly lower than the corresponding drawings of nurses [$t(49) = -3.41, P < 0.001$].

Conclusions: The main finding of this QoL study was that nurses generally have a moderate understanding of cancer patients' QoL. Therefore, in order to meet different physio-psycho-social needs of patients, nurses must enhance their understanding of patients' QoL particularly in more subjective and personal domains like social domain using a holistic approach.

Keywords: Cancer, Quality of Life, Perception, Nurses

1. Background

Cancer is the third main cause of death in Iran only after cardiovascular diseases and accidents (1). Local reports also indicate that cancers is on the rise in Iran (2). For example, a recent estimation indicated that lung, stomach, breast and prostate cancer increased between 2001 and 2015 in Isfahan Provenience in the centre of Iran (3). Due to increased number of cancer patients and limited resources, like many other developing countries, more attention has been paid to quantitative and physical criteria like increasing cancer patients' survival or decreasing patients' mortality rate (4). However, having cancer appears to be like a catastrophic experience that may have an impact on all aspects of individuals' lives and their quality of life (QoL) rather than only physical issues (5).

QoL is a concept used to emphasise that different aspects of individuals' lives such as physical, psychological, and emotional are important in determining the experience of living and its quality and need to be taken into consideration by health care professionals when caring for

those whose life is under threat (6). In addition, QoL information can be used for screening and prioritising potential problems, facilitating communication with patients and identification of their preferences. Patients can communicate their problems and priorities by filling out a QoL questionnaire or through an interview. Issues like sex life, personal relationships and financial issues, for example, are amongst those important matters patients usually do not express explicitly unless they are questioned. QoL assessment can prompt the process of revealing hidden problems more appropriately and lead to more holistic care (7).

Amongst health care providers, nurses are intimately involved with cancer patients and their perception of cancer patients' QoL may be vital in order to be more helpful in their caring roles and to increase patients' QoL (8). This is particularly important in Iranian oncology wards where nurses mainly have a Bachelor of Science qualification in nursing and significantly contribute in caring of cancer patients in a very busy oncology environment. Due to the lim-

ited number of oncologists and their time limitations, they may rely on nurses to convey to them information about patients' worries and concerns. In these situations nurses become a voice for their patients. So this voice needs to be accurate enough to convey to other health care professionals the broad spectrum of patients' problems, needs, and expectations (9).

A number of QoL studies conducted to identify nurses' understanding or nurses' perception about cancer patients' QoL outside Iran (10-13). However, the literature search for the research yielded no Iranian research comparing nurses' rating of patients' QoL with cancer patients' rating of their QoL. Moreover, many of these research studies used QoL tools developed in other countries including north America and U.K rather than the cross-culturally developed tools such as the world health organisation's quality of life brief questionnaire (WHOQoL-BREF). This questionnaire was established across a number of cultures (including Iran) and covers a broad spectrum of QoL issues.

The need for more research in this field in Iran was further reinforced with the researcher experiences. The researcher has worked with cancer patients in different clinical situations, particularly chemotherapy and radiotherapy departments, for more than 20 years in and outside Iran. Such experiences brought to his mind that for many people affected by cancer, life during and after therapy is not just concerned with how long they live, but how well they live. These experiences encouraged the researcher also to consider more deeply if health care professionals particularly nurses have a holistic understanding of needs, expectations, and desires of patients who are living with cancer.

Given this, assessing nurses' understanding or judgment about cancer patients' QoL is essential and worthy of exploration.

2. Objectives

The main purpose of this research study was therefore to identify nurses' understanding of cancer patients' QoL in an Iranian context. The secondary aim was to investigate the relationship between patients' and nurses' demographic and clinical variables and the level of agreement.

3. Patients and Methods

This descriptive correlational study was a portion of a bigger research entitled "Iranian nurses perception of cancer patients' QoL" with several specific aims. The procedure of the study was derived from the similar research

project that was completed by the researcher in Australia in 2008.

The study was conducted during a six month period in 2013 in Syeed-Al -Shohada hospital affiliated to Isfahan University of Medical Sciences, Isfahan, Iran. This hospital is an educative referral oncology centre that covers a varied number of patients from several provinces in Iran particularly Isfahan, Chaharmahal and Bakhtiari, Kohgiluyeh and Boyer-Ahmad and Lurestan. The research study was conducted in different medical-surgical oncology wards and an outpatient clinic. For purposes of measuring agreement between cancer patients and nurses, 50 pairs of cancer patients and their nurses were recruited to take part in the study using a convenient sampling (totally 100 patients and nurses). The sample of nurses selected based on consensus sampling which included more than 70 percent of eligible nurses in the hospital. Each nurse only took part once in the study as a patient proxy. So this prevented the bias of assessing many patients with a few nurses. Patients were heterogenous in term of their health condition, disease severity and their treatments in order to generalise QoL ratings to a broader sample of patients and nurses.

In order to measure QoL, the Farsi version of the WHOQoL-BREF questionnaire was implemented. This questionnaire consisted of 26 items which constituted four dimensions including physical (7 items), psychological (6 items), social relationship (3 items), and environmental (8 items). Global quality of life and general health were also measured with two items which did not contribute in structure of none of domains. All 26 items were evaluated using a Likert-type measure (e.g. ranging from very poor, to poor, neither poor nor good, good, and very good) (14).

As the WHO group (14) stated, associations exist between QoL domains of the WHOQoL-BREF questionnaire with the original lengthy tool WHOQoL-100, range from 0.89 in the social relationship domain up to 0.95 in the physical domain. The total score of test-retest reliability is 0.75 for all domains which is above the acceptable level of 0.7. A population based study in Iran also provided some preliminary evidences of reliability and validity of the Farsi version of the WHOQoL-BREF questionnaire (15). Moreover, in another study with the WHOQoL-BREF questionnaire in Iran, findings supported the four domain structure of the questionnaire and its appropriate reliability (16).

The questionnaire for nurses (Proxy version- Farsi) which was developed in the study was similar to that of patients' with only small modifications made to QoL items. For example, the item 'how satisfied are you with your health?' in the patient version the WHOQoL-BREF questionnaire was modified in the proxy version to 'how satisfied is the patient with his/her health?' Nurses were in-

structed to complete the survey specifically about the patient and the quality of life (QoL) they believe this patient has considering all QoL changes the patient might have.

Some other clinical and demographic information about patients (including age, gender, marital status, educational level, current cancer diagnosis, most common current treatment, treatment setting and patient performance status) and nurses (including age, gender, marital status, educational level, approximate contact time with patients, clinical experience, and how much nurses generally understand their patients' QoL) were also collected by the investigator. The researcher was interested to see how the daily living abilities of the patients might affect the patient-nurse agreement. Therefore, the patients' performance status were rated using the Eastern Cooperative Oncology Group (ECOG) performance status scale, ranging from 0 (fully active) to 4 (completely disabled).

Patients with any type of cancer, with the age of 18 years or above and the capability to read and write in Farsi (Persian) were invited to take part in the study. Qualified nurses were those providing nursing care for a selected patient and personally expressed that they understand that patient in a level to complete the questionnaire for him/her. The principal researcher or the assistant explained the aim and the process of the study to patients and nurses. If a patient presented a verbal agreement to take part in the study, the investigators gave the patient the WHOQoL-BREF questionnaire- Farsi to complete. The WHOQoL-BREF (Proxy version) was then completed separately by a nurse based on his/her perception of the patient's QoL. The investigators supervised the study in a way that nurses did not ask any question directly from patients or their family. However, to facilitate nurses' understanding about patients' QoL, they could review medical or nursing records. Nurses mainly completed questionnaires on the similar day when patients filled it during work hours and their rest time.

This research was approved by the nursing and midwifery care research centre of Isfahan University of Medical Sciences. Verbal information about the aim and the procedure of the study was provided for both patients and nurses and verbal consent was received. There was no need for patients or nurses to write their name on the questionnaires or forms. Instead, the same number was recorded on all questionnaires and forms related to each pair of patient-nurse (including the WHOQoL-BREF questionnaire completed by a patient, the WHOQoL-BREF questionnaire-proxy version completed by a nurse for a patient, and clinical and demographic information forms) and all of them put in an envelope. This allowed that information could be properly matched and participant anonymity was assured.

After coding, the data were inserted into SPSS 12 soft-

ware and QoL mean domain scores for both patients and nurses were calculated. They were then multiplied by four so that results can be compared with scores derived from WHOQOL-100, giving domain scores ranging from 4 to 20.

4. Results

4.1. Patients' and Nurses' Demographic and Clinical Variables

The mean patients' age was 41.86 (\pm 16.8 SD) years. Most patients were married (74.0%), male (56.0%), and under diploma was their highest level of education (59.6%). Patients had a range of cancer diagnoses, with Leukaemia (45.5%), colorectal cancer (18.2%), and non-Hodgkin lymphoma (11.4%) being the most prevalent. The highest percentage of patients completing the questionnaire were from inpatient departments (92.0%), with chemotherapy (67.3%) as their major treatment. The highest percentage of patients (32.0%) were classified as 'restricted but ambulatory' in their performance status.

Results also indicated that of 50 nurses who took part in the study, most were female (84.0%), and married (50.0%). Nurses had a range of qualifications with bachelor of science in nursing (90.0%), nurse's aid (8.0%), and associate degree (2.0%) being the most prevalent. The mean age of nurses was 29.88 (\pm 6.38 SD) with a range of 22 - 47 years. The mean time nurses spent providing care for a given patient (hour/shift) was 2.19 (\pm 1.98 SD) hours with a range of 0.3 - 8.00 hours. The mean of nurses' clinical experience was 5.91 years (\pm 5.74 SD) with a range of 0.5-23 years. The mean of nurses' clinical experience with cancer patients was 4.25 years (\pm 4.72 SD) with a range of 0.5 - 23 years. In response to this question "how much do you know the patient?" the majority of nurses (54%) stated that they knew their patients at a moderate level.

4.2. Outcomes of Measuring the Level of Agreement Between Patients and Nurses About Cancer Patients' QoL

The Pearson correlations between different mean domain scores of patients and nurses are shown in [Table 1](#). The following criteria were used to judge about the outcomes of correlations: less than or equal to 0.20, poor; 0.21-0.40, fair, 0.41 - 0.60, moderate; 0.61 - 0.80, substantial; 0.81 - 1, almost perfect (17).

Results indicated that there was a moderate significant correlation in the physical domain ($r = 0.42$, $P < 0.002$), a moderate significant correlation in the psychological domain ($r = 0.50$, $P < 0.000$), and a moderate significant correlation in the environmental domain ($r = 0.58$, $P < 0.000$). There was also a non-significant and fair correlation in the social relationship domain ($r = 0.25$, $P = 0.09$) between patients and nurses.

Table 1. Pearson Correlations Between Different Mean Domain Scores of Patients and Nurses

Domains	Patient-Nurse Correlation (r)	Significance
Physical	0.42 ^a	0.002
Psychological	0.50 ^a	0.000
Social relationship	0.25	0.090
Environmental	0.58 ^a	0.000

^aCorrelation is significant at the 0.01 level (2-tailed).

The results of paired t-tests between physical, psychological, social relationship, and environmental domains of patients and nurses are reported in Table 2.

Paired samples t-test values indicated that there were significant differences between physical QoL mean domain scores of patients and nurses [$t(49) = -3.41, P < 0.001$]. There was not significant differences between patients and nurses in the psychological aspect [$t(49) = 1.59$], social relationship [$t(49) = 0.18$] and environmental [$t(49) = -0.32$] QoL mean domains.

4.3. Outcomes of Assessing the Relationship of Demographic and Clinical Variables of Patients/Nurses and the Level of Agreement

In order to conduct multivariate analysis (standardised multiple regression), some demographic and clinical variables of patients and nurses that either significantly correlated with patient-nurse absolute differences at the bivariate level or were theoretically important, simultaneously entered into the equation. Adjusted R-square was used to determine the proportion of variance in patient-nurse differences which could be explained by the patient and nurse combined (Table 3).

At the Bivariate level only few variables were identified to be significantly associated with the absolute difference between patients' and nurses' QoL mean domain scores (being an indicator of agreement). However, using Multivariate analysis indicated that patients' performance status scale ($\beta = 0.345$) was the only statistically significant predictor of differences between patient and nurse scores obtained for the physical QoL domain scores.

5. Discussion

Cancer patients in developing countries like Iran are suffering from many QoL issues. QoL activities are very diverse and in the early stages of development. This research was an attempt to improve cancer patients' QoL in such a context. The main finding of this QoL study was that there was generally a moderate agreement between each

patient and nurse about a patient's QoL in physical, psychological and environmental domains. Similar to other research findings (10), correlation results indicated that nurses had lower agreement with their patients in QoL domains such as the social domain. Social relationship domain encompasses three items including having sex life, having friends, and having personal relationships. The general trend dominating these items is the private nature of them. This is not surprising to see that, for example, nurses had a very low understanding of how patients have received support from their friends. There might also be barriers for nurses to ask patients about their sex life. Unless a major issue exists in the patients' sex life, it is not acceptable for nurses to query patients about their sex lives in such a context.

Comparison of QoL mean domain scores of patients with nurses also showed that in contrast to other research studies (10), nurses in this study did not underestimate or overestimate patients' QoL, except for the physical domain. In this domain, which consisted of more objective items, nurses overestimated patients QoL and considered patients as having fewer problems as their patients actually did. This might imply that nurses that participated in the study may not have enough assessment skills to truly understand physical issues and concerns of cancer patients. So these issues impact on nurses' therapeutic relationships with patients and their role may not be as caring as it may be otherwise. This in turn may lead to unmet physical needs and decrease patients' QoL (18).

If we consider QoL as a gold standard to see if nurses have a holistic approach in their cares, results generally indicate that nurses need to improve their understanding of patient's QoL (19). However, this issue also needs to take into the consideration that having a moderate understanding of patients QoL may not be actually too bad as there might be reasonable justifications for differences in perceptions. Firstly, QoL has individualised meanings and nurses generally have difficulties understanding their patients' personal perspective or definition of QoL (18). Secondly, nurses' assessment of cancer patients' QoL in oncology wards is mainly made during their interaction with patients in providing care. In many occasions they might be uncertain if they actually assess QoL or not. Such an assessment may not facilitate nurses developing a more holistic picture of cancer patients' QoL. Time limitation, focus on care tasks, and discontinuity of care, might also work against nurses developing a more accurate understanding of cancer patients' QoL (7).

The third reason that might justify differences between patients and nurses about cancer patients' QoL might be related to psychometric properties of the WHOQoL-BREF questionnaire. While research findings indicated that the

Table 2. Paired Samples T-test Values Between QoL Mean Domain Scores of Patients and Nurses^a

QoL Domain	Patients	Nurses	Patient- Nurse Difference	Patient-Nurse (T-test)		
				t	df	Significance
Physical	10.06 ± 2.97	11.60 ± 2.99	-1.54 ± 3.20	-3.41	49	0.001
Psychological	11.88 ± 3.08	11.23 ± 2.71	0.65 ± 2.91	1.59	49	0.119
Social relationship	12.76 ± 3.55	12.65 ± 3.40	0.11 ± 4.25	0.18	49	0.856
Environmental	11.96 ± 2.66	12.07 ± 2.60	-0.11 ± 2.42	-0.32	49	0.749

^aValues are expressed as mean ± SD.

Table 3. Bivariate and Multivariate Correlations Between Patients' and Nurses' Clinical and Demographic Variables and Absolute Difference Between Patients and Nurses QoL Mean Domain Scores

Patients and Nurses Characteristics	Absolute Difference							
	Physical		Psychological		Social ^a		Environmental	
	r	Beta	r	Beta	r	Beta	r	Beta
Patient's age, y	0.253	0.180	-0.035	-0.102	0.183	0.074	0.174	0.138
Patient performance status (from fully active to completely disabled)	0.357 ^b	0.356 ^b	0.189	0.248	0.316 ^b	0.230	0.076	0.021
Time nurse spends with patients/shift, h	0.081	-0.086	0.034	-0.074	0.321	0.209	0.055	0.027
Nurse' clinical experience, y	0.068	0.165	0.092	0.072	-0.015	-0.132	-0.019	0.226
Nurse' clinical experience with cancer patients, y	-0.059	-0.263	0.040	-0.068	0.020	0.035	-0.094	-0.275
Nurse' understanding of patients' QoL (from very low to high)	0.072	0.070	-0.007	-0.046	-0.101	-0.057	-0.199	-0.204
Adjusted R square	0.08		-0.09		0.03		-0.05	

^aSocial relationship.

^bCorrelation is significant at the 0.05 level (2-tailed).

WHOQoL-BREF questionnaire generally is a useful tool to measure QoL, the reliability of the social relationship domain and the structure of domains of the questionnaire are challenged and recommended to investigated further in an Iranian context (15). Results of an exploratory factor analysis of the WHOQoL-BREF questionnaire also stated that some items of the questionnaire loaded on different domains as what originally was proposed for the questionnaire (16). This might indicate that some small modifications might be necessary to conduct in social items to improve this tool to a more acceptable level for a QoL assessment in an Iranian context. Therefore, it is suggested that the construct validity of the WHOQoL-BREF be explored further in the clinical area of cancer patients in Iran using factor analysis with a bigger sample size. This is currently being tested in another part of this research project.

The fourth reason that might justify the differences between patients and nurses perceptions is that the state of QoL might change as individuals' preferences, standards and goals are modified. So in order to measure QoL more accurately, QoL tools need to perform longitudinally and this is not always possible particularly in busy oncology

wards. Therefore, for a deeper understanding of patients QoL, whenever possible, nurses need to make deep relationship and rapport with their patients rather than using only QoL tools. Using QoL tools alone might marginalise some important issues and aspects which are important to individuals living with cancer (19).

Another important finding using Multivariate analysis was that only patients' performance status was identified to be a significant predictor of the level of agreement in the physical QoL domain. In other words, as patients had more limitations in their daily activities, nurses became less successful to judge correctly about patients physical QoL. The Multivariate analysis also showed that in the physical domain, patients' and nurses' clinical and demographic variables together explained around 8% of variance in differences between patient-nurse scores. In other words, clinical and demographic variables investigated in the current study may not be considered as significant predictors of the level of agreement. In a research study by Sneeuw et al. (20), several demographic and clinical variables of the patients and their significant others were found to be associated with the level of agreement using Multivariate anal-

ysis. But they explained less than 15% of the variance in patient-proxy differences which was considered as a trivial proportion. Given the fact that only 8% of variance in differences between patient-nurse scores was explained by clinical and demographic variables at the Multivariate level, it was necessary to investigate other clinical and demographic variables influencing the level of agreement.

There are several limitations that need to be taken into consideration. Firstly, the study was conducted in very busy oncology wards with nurses having several tasks and in some cases this may have affected the patients' and nurses' responses to the questionnaire. Secondly, although nurses' response was very good, it is suggested that a similar study with a bigger sample size of nurses and patients be conducted to provide more generalizable results. Thirdly, in this research study patients' scores were considered as the best possible information available and nurses' scores were compared with them. However, it can be argued that patients' scores themselves are prone to some bias. For example, patients may rate their QoL better to please health care professionals. Therefore, nurses might be closer in their rating of patients' QoL with that of patients' own rating in a real situation.

5.1. Conclusion

Differences exist between Iranian cancer patients and their nurses about cancer patients QoL that are far from the optimal level. This means that nurses may not have a holistic understanding of cancer patients' QoL. In order to minimize such discrepancies nurses need to enhance their relationship and rapport with cancer patients to underpin the assessment of cancer patients' QoL through various cues. As a result of such a well-developed relationship and rapport nurses might empathise with a number of issues, some of which are quite personal. While nurses develop their relationship skills, QoL tools like the WHOQoL-BREF questionnaire might also be useful in the clinical area to assess cancer patients' QoL more accurately.

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Footnotes

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