



Quality of Life of Family Caregiver of Patients with Cancer

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Abstract

Background: Cancer diagnosis has a significant impact not only on patients with cancer, but also on their Primary caregivers. Understanding the effects of cancer diagnosis on various aspects of the family caregivers' QOL is significant because these variables are key components of their quality of life. This study intended to describe the impact of caring for patients with cancer on the quality of life among their primary caregivers.

Methods: Quantitative non - experimental descriptive design was used. Study was conducted in the oncology inpatients units of Tawam Hospital in Al Ain. The tools used were demographic proforma for the caregiver & patients and Caregiver Quality of life – Cancer (CQOLC- standardized tool: validated after translation with permission). Totally 120 samples were selected by systematic random sampling method; every second caregiver was included as per the criteria, followed by the informed consent from the patients and caregivers. The demographic profoma tools were also given to patients and caregivers to fill. When assistance was needed the researcher was available for them.

Results: Majority of caregivers (60%) belonged to 31-50 years of age and 60% of them were females. Most of the caregivers 74.2% were non-Emiratis, Muslims 82.5%, children of the patients 38%, Married 78.3%, studied high school 47%, employed 49.2% and 70 % had financial support for the treatment of the patient. 2. Caregiver QOL: Majority of the caregivers (62.5%) had moderate QOL, 35% had good QOL, 3.5% had poor QOL, and none of the participant had excellent QOL. All Caregivers' demographic variables showed significant difference with p value < .001. All Patients' demographic variables also showed significant difference with p value<0.5.

Conclusion: Majority of family caregivers of patients with cancer had moderate QOL and there is a strong association between the caregiver QOL with their demographic variables and with the demographic variables of the patients.

Keywords: Family Caregiver; Quality of life; Cancer

Abbreviations: CQOLC: Caregiver Quality of life – Cancer; QOL: Quality of Life; QOLA: Quality of Life Assessment; PC: Primary Caregivers.

Introduction

Cancer is a major health problem of the world, and the diagnosis of cancer has a great impact on both patients and their family caregiver [1]. In the year 2000, cancer was responsible for 56 million (12%) death worldwide. According to the World Cancer Report, by the year of 2020, cancer diagnosis rate could increase by 50% to reach 15 million new cases in that year [2]. Cancer diagnosis in most of the time is sudden and requires active involvement by both patients and their family members. Treatment of cancer would require family members to assume the responsibility for providing care and support needed by the patients. Complex cancer treatment regimen necessitates active involvement of family members in the plan of care. This type of care is complex in nature and family members are often lack the skill, knowledge, and uncertain about their new roles and what type of care to provide for their loved ones. Family caregivers are involved in the entire cancer journey, starting from the time of diagnosis, treatment phase, recurrence, progression, palliative care, and ends with end of life care [3]. Family caregivers of patients with cancer unconsciously tend to neglect their own quality of life by putting the patient's needs first. They report various problems from their care giving role that include physical health problems, psychological distress, conflict among their social roles, restriction of activities, and strain in marital and family relationship. These negative experiences would negatively impact on the general well-being and the quality of life of those caregivers [4].

Moreover, providing care to these patients may have a negative social impact, as social roles and relationships are enormously affected by cancer. Caregivers have less time to spend with friends, neglect their usual activities and relationships as they are engaged in the care giving role; consequently their quality of life is affected from social aspect [5]. The financial impact of cancer also contributes

to poor quality of life. Financial burden could be the result of having no insurance or inadequate coverage for the treatment, travelling to and from medical appointment, home-care, missing work, household adjustment, seeking alternative therapies such as herbal treatment and vitamins.

Purpose of the Study

The purpose of conducting this study is to assess the quality of life experienced by families of patients with Cancer, explore factors that influence family caregivers' quality of life, and determine which family caregivers are most at risk of having reduced quality of life.

Methodology

This chapter discusses the methodologies employed in the current study including characteristics of sample, population and setting. Also the instruments used in the study and the data collection procedure as well as human rights protection. The present study adopted a descriptive design and the purpose of conducting this study was to assess the quality of life experienced by families of patients with Cancer, associate family caregivers' quality of life with their selected demographic variables and with the demographic variables of the patients, and determine which family caregivers are most at risk of having reduced quality of life.

Research Design

This study required a quantitative non - experimental descriptive design. This design was chosen since it is the most appropriate design to the nature of the study as it helps in describing/obtaining information regarding variables of specific population. This design helped in observing, describing, and documenting aspects of phenomena (QOL of family caregiver of patient with cancer) as it occurs.

Setting of the Study

The study was conducted in Tawam Hospital in Al Ain, which is a 466 bed tertiary structured hospital located in the Eastern region of Abu Dhabi. The hospital serves as national and regional referral center for oncology services

neonatal care, and cardiac care. More precisely, the study took place in oncology unit (Inpatient settings).

Population

The target population of the study was all family caregiver of patients with cancer who were hospitalized at Tawam hospital. The accessible population was all family caregiver of patients with cancer treated in adult oncology unit in Tawam Hospital during the data collection period.

Sample

Inclusion Criteria: Being identified by the patient as the unpaid person (family member) most involved with their actual care. 18 years of age or older, able to understand and give consent for participation in the study. Family caregiver of a patient with either non metastatic (receiving curative treatment) or metastatic disease (receiving palliative treatment/palliative).

Exclusion Criteria: Person with chronic physical and psychological health problems. Family caregiver not staying with the patient for not less than 12 hours per day.

Sample Size and Sampling Technique

Probability sampling- systematic random sampling method was followed to select participants. In inpatient setting every second caregiver was recruited to the study. The sample size was estimated based on the hospital records for in patients during the period of January – December 2014. The number of patients admitted during the year 2014 was 660, with monthly admission rate of 55 – 80 per month. The total sample size was estimated as 120 samples.

Instrument

A. Caregiver Quality of life Index - Cancer

The CQOLC is a 35 item instrument that uses a 5-point Likert scale to assess the QOL of family care giver of Patients with cancer, developed by Dr. Weitzner [6]. The instrument is multidimensional with items measuring Physical functioning, emotional functioning, family functioning, and social functioning. It is ranged from 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit) and 4 very

much. It include ten items relate to burden, seven to disruptiveness, seven to positive adaptation, three to financial concerns and eight single items to additional factors (disruption of sleep, satisfaction with sexual functioning, day to day focus, mental strain, informed about illness, protection of patient, management of patient's pain and family interest in caregiving). The CQOLC scale is scored by adding up adding up the score on each item to yield a total score for the instrument. Score can range from 0-140. The highest score possible is 140; higher score means better quality of life. Reliability (internal consistency) of the instrument with alpha coefficient was 0.9. Correlation coefficient of test re test reliability (administrations 2 weeks apart) was 0.94. Convergent validity of physical component summary score was .10 and mental component summary score was 0.69. Dr. Michale Weitznere (author of the instrument) was contacted. Permission to use the instrument and translate it into Arabic language was given. Instrument was re tested for its reliability. The tool was translated into Arabic by Tawam Hospital Medical translation Department. The backward translation of the instrument was done by Dr. Faiza; Associate Professor in RAK Medicine and Health Science University, College of Nursing. The Arabic Tool was compared and checked against the English one by two oncologist, two psychologists, and two social worker. They were instructed to check the translation, look for any variation in the meaning between the two versions and to write their comments on a hard copy of the Arabic tool. Ethical approval was obtained from Tawam research committee prior start data collection.

B. Demographic Data Questionnaire (Family Caregiver)

Demographic Data Questionnaire was used to obtain data related to age, gender, marital status, nationality and religion, relation of the caregiver with the patient, level of education, occupation and financial support.

C. Demographic Data Questionnaire (Patients)

This questionnaire was used to obtain data related to age, gender, marital status, nationality and religion, level of education, occupation, diagnosis, reason for hospitalization, and length of hospitalization.

Data Analysis

Table 1: Demographic details of the family caregiver (n=120).

S. No	Details of the Family Caregivers	Frequency	Percentage
	Age in years		
	i. 20 or below	3	2.5
	ii. 21 - 30	28	23.3
	iii. 31 - 40	34	28.3
	iv. 41 – 50	38	31.7
	v. 51 - 60	14	11.7
	vi. Above 60	3	2.5
	Gender		
	i. Male	48	40.0
	ii. Female	72	60.0
	Nationality		
	i. Emarati	31	25.8
	ii. Non-Emarati	89	74.2
	Religion		
	i. Muslim	99	82.5
	ii. Christian	16	13.3
	iii. Other	5	4.2

Table 1 shows that 40% of the participants were males and 60% were females among the family caregivers. The religion wise distribution of family caregiver's was as **82.5%** of the respondents were Muslims, **13.3%** were Christians and **4.3%** were others (Hindus). It is also shows that the majority of the sample was non Emarati 74.2% and only 25.8% were Emarati.

Table 1.1A: Demographic details of the family caregiver --continued (n=120).

S. No	Details of the Family Caregivers	Frequency	Percentage
	Marital Status		
	i. Single	22	18.3
	ii. Married	94	78.3
	iii. Widow / Widower	3	2.5
	iv. Divorced	1	.8
	Education		
	i. Illiterate	1	.8
	ii. High School certificate	57	47.5
	iii. Diploma Degree	14	11.7
	iv. Baccalaureate Degree	39	32.5
	v. Master Degree	9	7.5

Table 1.1A represent the Demographic details of the family caregiver. **The marital status** of the family caregivers shows that the majority of the respondents were married 78.3 %, 25% were, 2.5% were widows/widowers and 0.8% were divorced. With regards to **educational Level**, the findings show that 0.8 % of the respondents were illiterate, 47.5% had high school certificate, 11.7% had a diploma degree, 32.5% had a baccalaureate degree and remainder 7.5 % had a master degree.

Table 1.1B: Demographic details of the family caregiver - continued (n120).

S. No	Details of the Family Caregivers	Frequency	Percentage
1.	Relationship with the patient		
	i. Daughter	24	20
	ii. Son	22	18
	iii. Wife	30	25
	iv. Husband	18	15
	v. Mother	5	4.2
	vi. Father	2	1.7
	vii. Sister	8	6.7
	viii. Brother	7	5.8
	ix. Other	4	3.3

Table 1.1B shows the Relationship of the caregiver with the Patient: results showed that 20% of the caregiver were daughters, 18.3% were sons, 25% were wives, 15% were husbands, 4.2% were mothers, 1.7% were fathers, 6.7% were sisters, 5.8% were brothers and 3.3 % of them were others (In laws).

Section II: Demographic Details of the Patients

Table 1.2: Demographic details of the patients (n = 120).

S. No	Details of the Family Caregivers	Frequency	Percentage
1.	Age in years		
	1. 20 or below	8	6.7
	2. 21 - 30	7	5.8
	3. 31 - 40	19	15.8
	4. 41 – 50	20	16.7
	5. 51 - 60	37	30.8
	6. Above 60	29	24.2
2.	Gender		
	7. Male	56	47.5
	8. Female	64	52.5

3.	Nationality		
	9. Emarati	20	30
	10. Non-Emarati	100	70
4.	Religion		
	11. Muslim	95	79.2
	12. Christian	20	16.7
	13. Other	5	4.2

Table 1.2 shows that 6.7% of the respondents were below 20, 5.8% were between 21-30; 15.8% were between 31-40; 16.7% were between 41-50; 30.8% were between 51-60 and 24.2% were above 60. It also shows that 47.5% of the respondents were males and 52.5 % were females. The majority of the respondent was Non -Emirati (70%) and the remainder 30% were Emirati. The Table also shows that 79.2 % of the respondents were Muslims, 16.7% were Christians and 4.2% were others.

Table 1.2A: Demographic details of the family caregiver --continued (n=120).

S. No	Details of the Family Caregivers	Frequency	Percentage
Marital Status			
1.	Single	15	12.5
2.	Married	73	60.8
3.	Widow / Widower	22	18.3
4.	Divorced	10	8.3
Education			
5.	Illiterate	9	7.5
6.	High School certificate	73	60.8
7.	Diploma Degree	6	5
8.	Baccalaureate Degree	28	23.3
9.	Master Degree	2	1.7
10.	PHD Degree	2	1.7

Table 1.2A represent the Demographic details of the patients **The marital status** of the patients' shows that the majority of the respondents 60.8% were married, 12.5% single, 18.3 % widows / widowers and the remainder 8.3% were divorced With regards to **educational Level**, the findings shows that the majority of the respondents 60.8% had high school certificate, 7.5% of the respondents were illiterate, 5.0% had a diploma degree, 23.2% had a baccalaureate

degree, 1.7% had master's degree and the remainder 1.7% had PHD.

Table 1.2B: Demographic details of the family caregiver - continued (n=120).

S. No	Details of the Family Caregivers	Frequency	Percentage
1.	Diagnosis		
2.	Head and Neck	12	10
	Lung Cancer	8	6.6
	Digestive tract and Digestive organ Cancers	36	30
	Breast Cancer	20	16.6
	Female Genital	11	9.1
	Male Genital	10	8.3
	Renal Cancer	7	5.8
	Bone/ Muscle / soft tissue Cancer	9	7.5
	Bone/ Muscle / soft tissue Cancer	1	0.8
	Skin Cancer	6	5
	Others		

Table 1.2B shows that 10% of the respondents had head and neck cancer, 6.6% had lung cancer, 30% had Digestive tract and Digestive organ Cancers, 16.6% had Breast cancer, 9.1% had Female Genital cancer and 8.3% had Male Genital cancer, 5.8% had renal cancer, 7.5% had Bone/ Muscle / Soft tissue Cancer, 0.8 has skin cancer and 5% had other type of cancer.

Table 1.2C: Demographic details of the family caregiver - continued (n=120).

S. No	Details of the Family Caregivers	Frequency	Percentage
1.	Presence of Metastasis		
	i. Yes	86	70
	ii. No	34	30

Table 1.2C shows that 30% of the respondents had no metastatic diseases were the majority 70% had metastatic disease.

Section III: Quality of Life (QOL) of the Family Caregiver

The details of the quality of life of the family caregivers are presented as follows:

Table 1.3: The overall QOL of the family caregivers of patients with cancer (n=120).

S. No	QOL	Frequency	Percentage
1	Excellent	-	-
2	Good	42	35
3	Moderate	75	62.5
4	Poor	3	3.5

In the QOL of family caregivers, majority of the caregiver 75 (62.5%) had moderate QOL, followed by good QOL 42 (35%) and poor QOL 3 (3.5%). None of the caregivers had excellent QOL.

Table 1.3A: Area wise QOL of the family caregivers of patients with cancer (n=120).

S. No	Area wise QOL	Maximum possible score	Range	Average
1	Burden	40	12 - 40	29.77
2	Disruptiveness	28	7 - 28	19.67
3	Positive Adaptation	28	0 - 21	10.74
4	Financial concerns	12	0 - 12	03.64
5	Total CQOLC (Includes the above four aspects and general components)	140	39 - 106	75.22

Table 1.3A shows area wise of QOL of the family caregivers of patients with cancer. The maximum possible score for CQOLC (Includes the four aspects and general components) was 140. In the current study, the highest obtained score was 106, and the lowest obtained score was 39.

Section IV: Association between the QOL and the Demographic Details of the Family Caregivers

The association between the QOL and the demographic details of the family caregivers are presented in this section for testing the following hypothesis.

Age: The chi-square was significant, 0.406, $p < .001$ for age and the QOL of family caregivers.

Gender: The chi-square was significant, 0.281, $p < .001$ for gender and QOL of family caregivers.

Nationality: The chi-square was significant, 0.3336, $p < .001$ for nationality and QOL of family caregivers.

Religion: The chi-square was significant, 0.586, $p < .001$ for religion and QOL of family caregivers.

Relationship with patient: The chi-square was significant, 0.167, $p < .001$ for relationship with patient and QOL of family caregivers.

Marital status: The chi-square was in significant, 0.077, $p < .001$ for marital status and QOL of family caregivers.

Education: The chi-square was significant, 0.289, $p < .001$ for education and QOL of family caregivers.

Occupation: The chi-square was very significant, 0.976, $p < .001$ for occupation and QOL of family caregivers.

Financial support for the treatment of patient: The chi-square was significant, 0.145, $p < .001$ for financial support and QOL of family caregivers.

Table 1.4: Association between the QOL and the demographic details of the family caregivers (n=120).

S. No	Variable	Frequency	Chi-Square	Df	P Value
1.	Age in year				
	20 or below	03	264.769 ^a	260	P < .001
	21 – 30	28			
	31 – 40	34			
	41 – 50	38			
	51 – 60	14			
Above 60	03				
2.	Gender				
	Male	48	57.440 ^a	52	P < .001
	Female	72			

		Relationship with the patient			
3.	Daughter	24	443.824 ^a	416	P< .001
	Son	22			
	Wife	30			
	Husband	18			
	Mother	05			
	Father	02			
	Sister	08			
	Brother	07			
	Others	04			

Discussion

In the present study, QOL of family caregivers, majority of them 75 (62.5%) had moderate QOL. In a study conducted by Grov and his colleagues to examine anxiety, depression, and QOL in primary caregivers of patients with cancer in the late palliative phase it was found that the physical QOL was significantly higher than norm in both genders, while mental QOL was significantly lower in male primary caregivers. The level of anxiety was significantly higher than norm in both genders. They have concluded that the primary caregivers (PC) of both genders had significantly more anxiety than norm samples [7]. Another study was conducted to examine the correlation between quality of life (QOL) in cancer patients and that of their spouse caregivers and to identify factors that influence this correlation [8]. The study revealed that the social/family and functional dimensions of patient QOL and total score for patient QOL were associated with each dimension of their caregivers' QOL and with the total score ($r=0.27-0.44$). Factors influencing the association between patients' and caregivers' overall QOL included cancer diagnosis, length of hospitalization, caregiving intensity and duration, marital satisfaction, and caregiving self-esteem.

Moreover, a study conducted by Heidari and his colleagues aimed to explore depression and quality of life and their relationship among caregivers of patients with breast cancer found that depression has strong negative correlation with QOL and participants with depression were more

likely to have a poorer overall QOL. Depression has some effects on QOL of breast cancer patients' care givers. Assistance and giving information through education and intervention from healthcare professionals is the key of improve the ability of caregivers to enhance their QOL [9]. On the other hand, the caregiver's age, gender and relationship with the patient were found to be significantly associated with their QOL, Similarly in another study conducted by Matthews [10] revealed that male family caregivers of cancer patients in Singapore had more impaired QOL than their female peers in the domains of physical/practical concerns and self-needs. This finding is in contrast to those of other studies that reported lower QOL among women due to their traditional gender role. In Singapore, as in many Asian societies, the responsibility of family caregiving traditionally falls on women, while men are expected to provide for the family. Thus, it seems that some men (i.e. sons or husbands) may experience additional role strain when they are forced to balance both the home and work spheres to care for a relative with cancer. Moreover, in present study the QOL of family caregiver and the patient's variables namely age, gender and type of cancer were found to be significantly associated. A study conducted by Malathi and his colleagues [11] to find the association between mean of QOL and study variables, used One-way ANOVA test to test the association between family caregivers QOL mean score and study variables such as age, gender, education, income, type & duration of illness. Result showed that there is association between means Family caregivers score and income of the family ($F=3.062$, $p=.017$), type of cancer ($F=2.781$, $p=.027$), duration of illness ($F=4.745$, $p=.003$). Thus research hypothesis was accepted for income, type of cancer and duration of illness. They revealed that social and functional aspects of patients' QOL play a significant role in determining the QOL of their spouse caregivers. The strength of association between patients' and spouse caregivers' overall QOL can be moderated by some factors.

Limitations

This study was limited to specific time period, conducted at a single clinical site, using primary caregiver sample that were collected only from inpatient setting. Data

from outpatients setting should also have been collected. However, this study represents the first attempt in UAE to assess QOL of cancer caregivers. Future studies should include larger samples from different emirates in UAE. In addition, pre-existing depression, anxiety, QOL, and burden may have had an influence on the findings. There are neither similar studies nor interventional studies in this area, but it is expected that these findings and recommendations provide an incentive to work on this area.

Conclusion and Recommendations

In summary, this study aimed to assess the quality of life of family caregiver of patients with cancer. According to the results of this study, majority of caregiver belonged to 41-50 years of age and 60% of them were females. Most of them were non-Emiratis, Muslims, children of the patients. Married, studied high school, employed and had financial support for the treatment of the patient. Caregiver QOL: Majority of them 75 (62.5%) had moderate QOL, 35% had good QOL, and none of the participant had excellent QOL. The study also showed that and there is a strong association between the caregiver QOL and their demographic variable and the demographic variables of the patients. This study added to the body of knowledge regarding this topic, since there are no study done in UAE and very few in Middle East region related to this aspect.

The result of this study encourages doing interventional study in order to enhance primary Caregiver's QOL. Future studies need to identify patients and caregivers who are at higher risk for poorer outcomes, so that interventions can be targeted to them. Although all caregivers should be provided with basic caregiving information as part of comprehensive cancer care program, every effort should be made to identify those families at greater risk who are likely to benefit from additional intervention. Future studies with larger samples would provide greater insights on the complexity of the interrelationships among factors affecting quality of life and health of family caregivers. In addition, longitudinal studies would also further our understanding of family caregivers' situations at different time points. The researchers could also compare family caregiver's burden in taking care of patients that had more ADL dependency

in order to further explore the relationship between patients' ADL dependency and the family caregiver's burden. Meanwhile, future research should take into consideration the length of care-giving experience. Also there is a need for well-funded, multi-sites studies to obtain large samples of patients and caregivers in a reasonable amount of time with a greater ability to generalize findings. Conducting intervention studies with Patients with cancer and their family caregivers is challenging and requires the support of clinicians, who can inform potential participants about available studies and encourage them to participate. These studies also need to be integrated into clinical care to determine how effectively they can be implemented in practice settings. Future research needs to further explore the concepts related to negative and positive outcomes of caregiving. Expanding the understanding of caregiving's impact and related factors in cancer caregiver populations would enable nurses to develop innovative interventions to decrease negative outcomes and improve positive outcomes of caregiving for patients with cancer.

The current study emphasized that quality of life evaluation is fundamental elements process of providing high quality of care. As a result, nursing education curriculum should therefore be enhanced to develop curriculum about the importance of performing quality of life assessment (QOLA) for caregiver of patients with cancer and implementing appropriate interventions accordingly. With regard to patient and family education, given the poor QOL of caregiver's experience, this study highlights the need for nurse-caregiver communication and education. There is a critical need to develop and implement interventions to support the caregiving role for caregivers of patients with cancer. Most importantly, healthcare professionals, including oncology nurses, need to ensure that caregivers receive the appropriate resources and support to care for their loved ones at home.

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