ORIGINAL ARTICLE

The Quality of Life amongst Caregivers of Cancer Patients at Tertiary Care Centers in Lahore, Pakistan

Umbreen Navied[1], Sana Arshad[2], Uzair Ahmed[3], Aamir Hameed[4]

ABSTRACT

***Background and Objective*:** Cancer is a leading cause of death worldwide and is initiating an overburden in developing countries. A grave illness, such as cancer, not only affects lives of patients, but also the lives of their caregivers. A caregiver nurtures continuous support, responsibility, concern and care hence, undergoes immense psychological distress because of the fear of losing their loved one, thus affecting their own quality of life (QOL). The study aims to assess the QOL of caregivers of cancer patients by using the World Health Organization Quality of Life Instrument (WHOQOL BREF) Questionnaire.

Methods: This cross-sectional study of caregivers of cancer patient's was carried out at INMOL, Mayo Hospital, Jinnah Hospital and Children Hospital Lahore within 6 months in 2017. Interviews of 267 caregivers of diagnosed cancer patients were taken using WHOQOL BREF Questionnaire. Information was collected regarding QOL of caregivers and socio-demographic variables. Statistical Package for the Social Sciences (SPSS) software was used for data compilation and analysis hence taking P-value ≤0.05 as significant.

Results: The study results suggest that several conditions obtain an impact on the QOL of caregivers. For all measures the higher the score calculated the better the QOL. The caregivers of cancer patients reported the lowest mean score (6.89 ± 1.56) in general health and QOL. Caregiver's low educational status, married stature, along-with their own current illness and health problems described lowest mean scores in QOL.

Conclusion: The results of this study provided information that caregivers revealed a low QOL. Therefore understanding of several aspects affecting the QOL of caregivers may assist in improving their ability to care for patients and themselves. Initiation of patient care training programs for caregivers would be helpful.

KEYWORDS: Quality of life, Caregiver, Cancer patients, World Health Organization.

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INTRODUCTION

Cancer is a worldwide health problem and it is encumbering economically developing countries as a result of increased population aging and growth. The upsurges in adoption of cancer-associated lifestyle choices including smoking, physical inactivity, and "westernized" diets are considered the leading contributing factors.[1]

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1. Dr. Umbreen Navied
2. Dr. Sana Arshad
3. Dr. Uzair Ahmed
4. Dr. Aamir Hameed

1-4 Fatima Memorial College of Medicine and Dentistry, Lahore-Pakistan.

Correspondence to:
Dr. Umbreen Navied
Senior Demonstrator
Department of Community Medicine,
Fatima Memorial College of Medicine and Dentistry, Lahore-Pakistan.
Email ID: dr.umbreennavied@gmail.com

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Latest World Health Organization (WHO) figures released in February 2017 indicate that each year 8.8 million people die from cancer, mostly in low and middle-income countries. The dilemma that is faced in dealing with cancer is the difficulty in diagnosis. There is a need to reinforce and establish strategies in the health systems and services for early cancer diagnosis to save lives and reduce the financial burdens bared in the treatments of cancer cases.[2]

Since the establishment of Karachi Cancer Registry (KCR) and Aga Khan University Pathology based Cancer Registry (APCR), the cancer database in Pakistan has reported increase in the incidence of general cancers during the last decade.[3]

The statistics in Pakistan reveal that male cancers report for 48.1%, while female cancers 51.8% and 3.4% in children (0-15 years). In relation to the different types of cancers, it was noticed that in males, the five most frequent malignancies exist in head and neck (32.6%), lung (15%), gastrointestinal tract (GIT) (6.9%), lymphoma (6.1%), and in bone and soft tissue (4.9%). Whereas in females, breast cancer was the most common cancer accounting for 38.2% followed by head & neck (15.1%), cervical (5.5%), ovarian (4.9%) and GIT cancer (4.9%) respectively.[4]

Quality of life (QOL) is the condition of life resulting from the combination of the effects of the complete range of factors such as those determining health, happiness (including comfort in the physical environment and a satisfying occupation), education, social and intellectual attainments, freedom of action, justice and freedom of expression.[5]

A grave illness, such as cancer, not only affects lives of patients, but also the lives of their caregivers. They perceive psychological distress and low quality of life because of the fear of losing their loved one, and because of possible burdens, such as the provision of care and support, and restrictions regarding their social life.[6]

The distress that the family members experience from assuming the role of caregiver can be manifested as anxiety, depression, helplessness, burden, and fear and is mostly related to providing direct care, coping with disruptions in daily routine, and the need to provide emotional support to the patient. Specifically, they may experience distress from assuming the responsibility for communicating with healthcare professionals, administering medications, performing minor medical/nursing treatments, and handling the patient's behavioral and emotional reactions along with their own.[7]

Several aspects of life may change when dealing as a caregiver with cancer patients, creating distress and emotional disturbances affecting the well-being of the caregiver.[8]

The responsibility which a caregiver takes into account to provide physical care and emotional support to their patient needs commitment as well continuous effort; which affects their QOL. Therefore, this research was conducted to assess the QOL of caregivers of cancer patients in Lahore, Pakistan.

METHODS

This cross-sectional study was conducted within a period of 6 months at INMOL, Jinnah Hospital, Mayo Hospital and Children Hospital Lahore in the year 2017 after an ethical approval from Institutional Review Board vide Letter No. FMH-03-2017-IRB-235-M. A total of 267 male and female patients participated in this study. The patient's consent was taken, they were explained the purpose of the research prior to the interviews. The data was collected by self-interviewing method from the patients using a validated questionnaire World Health Organization Quality of Life Instrument (WHO QOL BREF). The minimum sample size needed to maintain a 5% margin of error and 95% confidence interval was calculated as 267. Convenient sampling was done. All the caregivers of diagnosed cancer patients were involved in the study.

The WHO QOL BREF questionnaire was used as it focuses on the study participants perceived QOL. It contains four domain scores and two individually scored items related to participant's overall perception of the quality of life (QOL) and general health. The four domain scores include physical health, psychological, social relationships and environment. Physical health is measured by seven items; pain, dependence on medical aids, energy, mobility, sleep and rest, activities of daily living and work capacity. The psychological domain is measured by six items; personal belief, positive feelings, body image, self-esteem, concentration and negative feelings. Social relationships are measured by three items; personal relationship, social support and sexual activity. Environment comprises eight items; financial resources, security, health and social care, home environment, access to information, physical environment, leisure activities and transportation. The domain score was computed by a simple algebraic sum of each item in each of the four domains, and then each domain score was converted to a transformed score (the domain scores were computed on the basis of WHO profiles) to allow comparison between domains. According to WHOQOL BREF; higher score in the domains refers to good QOL. QOL tables with domains were calculated. Means were compared using student's t test.

STATISTICAL ANALYSIS

Data was analyzed using Statistical Package for the Social Sciences (SPSS) software version 20. Frequencies, percentages, means and standard deviation were calculated respective to the variables hence taking P-value ≤ 0.05 as significant.

RESULTS

Among a total of 267 participants, 53.55% were males and 46.44% were females. As regard the age groups of participants; about 8.24% belonged to 15-25 years age, 34.84% belonged to age groups 26-35 years, 27.34% were from the age group 36-45 years, 20.97% were in 46-55-year age group and 8.61% were more than 56 years age. In regards to educational status 22.47% were illiterate, 26.60% had completed elementary school, 23.22% had completed high school and 27.71% had completed college. Majority of the participants were living as married88.4%, divorced were 0.37%, widowed were 1.87% and single were 9.36%. The majority of participants 25.85% were currently ill, whereas 74.15% were not ill. In relation to health problems (apart from cancer) 72.30% were not suffering and 27.70% had other health problems. (**Table-1** Demographic information of study participants).

The study derived the highest mean score for the QOL in the Environment domain 25.13 (± 6.01), Physical domain 24.65 (± 4.88), Psychological domain 20.06 (± 4.05), Social relationship domain 10.98 (± 2.32) and the least in the QOL and General health domain 6.89 (±1.56). (**Table-2** illustrates the QOL Transformed Domain Scores**).**

Table-1: Demographic information of study participants (N=267).

Demographic Information	N	%
Age (Years)		
15 to 25 years	22	8.24
26 to 35 years	93	34.84
36 to 45 years	73	27.34
46 to 55 years	56	20.97
More than 56 years	23	8.61
Gender		
Female	124	46.44
Male	143	53.55
Educational Level		
None at all	60	22.47
Elementary School	71	26.60
High School	62	23.22
College	74	27.71
Marital Status		
Single	25	9.36
Married	216	80.9
Living as married	20	7.5
Separated	00	00
Divorced	1	0.37
Widowed	5	1.87
Currently Ill		
Yes	69	25.85
No	198	74.15
Any Health Illness/Problem		
Yes	74	27.70
No	193	72.30

Table 2: QOL (Transformed) Domain Scores.

Domains of QOL (Transformed)	Mean	SD
QOL and General Health	6.89	± 1.56
Physical	24.65	± 4.88
Psychological	20.06	± 4.05
Social relationships	10.98	± 2.32
Environment	25.13	± 6.01

There was a significant difference in the QOL of respondents in the all four domains when compared in relation to their Educational level, which showed a standard deviation of (4.38) in those who have higher educational status compared to the standard deviation of (6.29) in the uneducated within the environment domain (P-value 0.000). The marital status of the respondents showed significant difference (P-value 0.000) in the Physical, Psychological and Environment domains of QOL, while there was no significant difference in Social relationships domain. (**Table-3** Educational level, Marital Status and QOL scores).

Table-3: Educational level, Marital Status of respondents and QOL scores.

Domains	Educational Level				
	None at all Mean (± SD)	Elementary School Mean (± SD)	High School Mean (± SD)	College Mean (± SD)	P –value
QOL and General Health	6.08 (± 1.70)	6.46 (± 1.51)	7.20 (± 1.28)	7.71 (± 1.22)	0.000
Physical	21.90 (± 4.93)	23.28 (± 4.81)	25.91 (± 4.39)	27.14 (± 3.63)	0.000
Psychological	17.58 (± 4.08)	19.04 (±3.76)	21.22 (± 3.59)	22.09 (± 3.26)	0.000
Social relationships	10.21 (± 2.30)	10.80 (±2.38)	11.22 (± 2.35)	11.56 (± 2.08)	0.006
Environment	21.00 (± 6.29)	23.26 (±5.69)	26.82 (±4.30)	28.87 (± 4.38)	0.000

Domains	Marital Status						
	Single Mean (± SD)	Married Mean (± SD)	Living as married Mean(± SD)	Separate Mean (± SD)	Divorced Mean (± SD)	Widowed Mean (± SD)	P –value
QOL and general health	7.92 (± 1.15)	6.83 (± 1.57)	6.50 (± 1.39)	0.00	8.00	5.80 (±1.64)	0.004
Physical	27.16 (±4.44)	24.65 (±4.75)	22.90 (±5.0)	0.00	15.00	21.20 (±6.37)	0.000
Psychological	22.48 (±3.21)	20.10 (±3.83)	17.35 (±4.90)	0.00	16.00	18.20 (±6.72)	0.000
Social relationships	10.72 (±1.74)	11.13 (±2.38)	9.55 (±1.84)	0.00	10.00	11.40 (±2.40)	0.006
Environment	28.28 (±4.25)	25.56 (±5.49)	16.80 (±6.66)	0.00	22.00	24.80 (±6.61)	.000

In regards to the perception of the current illness status of the respondents, when compared with the QOL score, showed no significant difference in Social relationships domain, whereas other three domains showed a significant difference P-value of 0.000. (**Table-4** Perception of respondents regarding current illness and QOL scores).

Table-4: Perception of respondents regarding Current illness and QOL scores.

Domains	Current Illness Yes Mean(± SD)	Current Illness No Mean(± SD)	P- value
Physical	21.39 (± 5.15)	25.79 (± 4.24)	0.000
Psychological	18.31 (± 4.66)	20.67 (± 3.64)	0.000
Social relationships	10.89 (± 2.22)	11.01 (± 2.36)	0.732
Environment	21.79 (± 6.89)	26.30 (± 5.21)	0.000

DISCUSSION

Cancer is one of the leading causes of death worldwide and a considerable health problem which is increasing in Pakistan. Cancer as a disease is of immense concern as it affects the physical health as well as influences the QOL of individuals. Considering the severity of this disease and its effects, the study focused on the QOL of caregivers taking care of cancer patients. QOL defined by the World Health Organization (WHO) "An individual's perception of his/her position in life in context of the culture and values systems in which he/she lives and in relation to his/her goals, expectations, standards, and concerns ". Thus provision of a good QOL needs to be addressed for the caregivers experiencing the sufferings and agony their dearest one's undergoes with cancer.

The WHO QOL BREF tool comprises of four domains which have already been mentioned in detail, that include Physical health, Psychological health, Social relationships and Environment. The QOL tables with respective domains were calculated in the study. According to the WHOQOL BREF; higher score in the domains refers to good QOL.

The study observed that among the study participants the least score 6.89 (± 1.56) prevailed in the QOL and general health in the environment domain. These results emphasize that the study participants showed an overall low QOL. Similarly a study conducted in Iran in 2013 also showed the lowest score in environment domain.[9]The study results in regards to education level of caregivers in the environment domain, demonstrated higher the education levels higher the score. Participants who were uneducated had a (21.00) score and participants with college education had a (28.87) score in environment domain. As realized in the study, education empowers one's mind to conceive positive thoughts and ideas creating a good influence on the QOL.

The study results revealed that in regards to the environment domain, the marital status of participants affected their QOL. Participants who were single showed the highest score (28.28) and participants who were living as married showed the lowest score (16.80). Caregivers living as married bear the responsibilities of their families therefore require extra effort, emotional and physical strength altering their QOL.

Caregivers who were not ill had a high score of

(26.30) as compared to those who were ill (21.79). Thus being healthy plays an important role in the care-giving of the patient. In contrary QOL score of environment domain on the basis of caregivers' age was not significant in the study, which was also documented in a study conducted by Kilic and Oz.[10]

In the study male caregivers had a better QOL score in physical domain as compared to females. Whereas a study showed that physical domain scored the lowest in QOL.[11] It was concurrent in the study results that being educated, single in marital status and healthy caregivers showed high scores in the physical domains in QOL. This was inconsistent with a research that took place in China in 2016.[12]

Whereas in the psychological domain of the study it was noticed that the mean score (20.06) was even less than the physical domain (24.65) but higher than the social domain (10.98). Psychological wellbeing of caregiver greatly depends upon the severity of the cancer patient's symptoms and the relationship of caregiver with the patient. Married caregivers showed a better QOL score in psychological domain as compared to single, observed in a study in China in 2016.[12] The QOL score in Psychological domain in terms of gender was better for males in the current study, showing that males had better ability to cope with the burden of care-giving, also observed in a study in Netherland in 2000.[13] The study results in the Psychological domain revealed that the highest QOL score was for the caregivers who were highly educated (22.09). Highly educated caregivers could handle stress in a better way and take less stress in the responsibility of care giving as reported in another study in China in 2017.[14]

In comparison to the other domains the social relationship domain (10.98) showed that study participants QOL were severely affected in this domain as compared to other domains, along-with the general health and QOL which showed the lowest score 6.89 (± 1.56). Social relationship domain includes the interactions of a caregiver with other people of society, his/her family and sexual relationship with spouse and social support. The relationship of marital status (11.13) in social relationship domain does not show any significant result in the study, which is inconsistent with a similar study performed in China in 2017.[14] Whereas the study results regarding educational level in social relationship domain (11.56) showed good social relationship scores. The gender in social relationship domain when compared showed that males have a higher QOL score as compared to the females, but this was not observed in a study in China in 2017.[14] This domain in terms of age showed no significant results in the study, but a study conducted in Unites States in 2014 showed that increased age was associated with negative social relationship score.[15]All the domains revealed different QOL scores, emphasizing that QOL is affected. According to current study QOL of caregivers needs to be prioritized and emphasized upon.

CONCLUSION

It is concluded that the caregiver demonstrates a roller coaster of emotions simulating the impact of the disease path with the cancer patients. Facing the uncertainties and fears associated with new diagnosis, decisions regarding treatment choices, symptoms and loss of functions. There should be training centers for care givers, to provide related knowledge about the disease, management as well as care of the patient and social support. Further research on the QOL of caregivers will be of assistance in treatment and care provision for their patients. A paramount responsibility is managed by a caregiver; this neglected domain is the requirement of today.

LIMITATIONS OF STUDY

This study has some limitations; it being self-funded only included few General Hospitals. There is a need to compare and understand whether other chronic diseases apart from cancer influence the QOL of caregivers. The study urges the need for further research regarding the QOL of caregivers; as QOL plays a pivotal role in an individual's life.

RECOMMENDATIONS

Health education and initiation of patient care training programs specific for caregivers will assist in improving their capabilities and boost their confidence in taking better care of their patients. The establishment of support groups for caregivers would be helpful to create solutions for problems faced by caregivers. In future, a study with a larger sample size should be conducted for results to be generalized.

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CONFLICT OF INTEREST

None to declare.

FINANCIAL DISCLOSURE

None to disclose.

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Author’s Contribution

UN: Conception of data, drafting article and critical revision for important intellectual content.

UA, SA, AH: Acquisition of data, Analysis and interpretation of data.

ALL AUTHORS: Approval of the final version to be published.