Perception and Quality of Life in Family Caregivers of Cancer Patients

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Abstract

Introduction: Cancer has been most feared among all the significantly increasing chronic diseases, and is widely assumed to be fatal. The quality of life (QOL) of the patient pertaining to physical, psychological, social, and spiritual well-being is altered, which ultimately affects the QOL of the family caregivers. The study was conducted to assess the QOL among family caregivers of cancer patients and how cancer changes and alters the vision about life for the patient as well as the family caregivers. **Objective:** The objective was to assess the QOL among family caregivers of the cancer patients. **Methodology:** A cross-sectional, questionnaire-based study was conducted after the protocol was approved by the institutional ethics committee and obtaining written informed consent from the participants. Two sets of validated questionnaire were used to assess the awareness and QOL of the family caregivers of the cancer patients. The filled questionnaires were received from the participants, and data were analyzed using descriptive statistics. **Results:** Nearly 74% (148/200) of the participants responded, with majority of the caregivers being females (71.62%). Majority (72.9%) expressed that cancer cannot spread from one person to another and were positive (70.9%) toward cancer cure. The caregivers (76.3%) opined that the diagnosis of cancer should be informed to the family members. Approximately 50% of the participants were aware that environmental toxins and tobacco would predispose to cancer. Although most of them (87.8%) believed that the cancer treatment cause ill effects, they (93.2%) were satisfied with the hospital facilities. Among the QOL parameters, most of the participants had complaint of decreased general physical health, difficulty to cope, reduced concentration, anguish over the first treatment, disease, and interference in household activities. Among the spiritual parameters, the participants expressed sufficient support from religious activities, prayer, and general spiritual well-being. **Conclusion:** Majority of the caregivers had awareness regarding the cancer and carcinogens from the environmental toxins. The QOL among caregivers of cancer patients is affected in all dimensions of life, with more emphasis on the social and psychological dimensions.

Keywords: Cancer caregivers, perception, quality of life

INTRODUCTION

Cancer has been one of the most feared among all the significantly increasing chronic diseases, and is widely comparable to death. In India, the annual burden for new cancers is approximately one million, and the mortality rate is 67.2/100,000, leading to significantly higher number of people dependent on the cancer-affected patients and wish for their recovery.[1,2] The concept of multimodal treatment for cancer, which has emerged few decades back, has increased survivals in India.[3] Lack of awareness fuels many myths and misconceptions related to cancer, which perpetuates the stigma associated with it.[4]

The quality of life (QOL) of the person suffering with cancer gets altered in physical, psychological, social, and spiritual dimensions, which ultimately affects the QOL of the caregivers in the family. Individuals with cancer have to be taken care at home, and the therapies take place in outpatient/inpatient or at home in more than 70% of the cases.[5] The private life of the family caregiver tends to get affected in all aspects and dimensions of life.

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Investigations regarding the contributory aspects affecting the individuals with chronic disease, including cancer, facilitate to recognize the impact of the role of caring and better understanding of the disease.[6] Multimedia campaigns were used under the National Cancer Control Program in India to educate the people about cancer and persuade them to undergo screening.[7] The World Health Organization defines QOL as "the perception individuals have of their existence, within the context of culture and the value system in which they live and in their relation to their objectives, expectations, norms and concerns."[2]

This study was designed to determine the awareness of cancer and quality of family caregivers of cancer patients. The study findings may lead to better understanding of the implications of family caregivers on the life and care of the cancer patients.

METHODOLOGY

A cross-sectional, questionnaire-based study was conducted by the Department of Pharmacology, Sri Devaraj Urs Medical College affiliated to Sri Devaraj Urs Academy of Higher Education and Research, Kolar, Karnataka, from February to November 2018. The study protocol was approved by the Institutional Ethics Committee with No. DMC/KLR/IEC/73/2019-20. The sample size was calculated using OpenEpi online software (Open Source Epidemiologic Statistics for Public Health, Emory University, Rollins School of Public Health, Atlanta, US, Version 3.01 Updated 2013/04/06). With the hypothesized percentage of frequency of outcome factor in the population to be 30% and confidence levels as 5%, design effect as 1, and confidence limit of 80%, the sample size required was 138. The family caregivers were approached randomly during a fixed time in the hospital visiting hours. The hospital caters to mainly rural populations. Among the 200 family caregivers approached, only 148 people agreed to participate in the study. They all were involved in the care of adult individuals (age >18 years) with cancer at R. L. Jalappa Hospital, Kolar, Karnataka. Two sets of validated questionnaire were used to assess the perception and QOL among them. The participation in the study was voluntary and those who agreed to participate were requested to sign the informed consent form. All the participants were explained about the objective of the study and were handed over the participant information sheet in their local language. The principal investigator administered the questionnaire and interviewed all the participants in their local understandable language during a fixed time in the hospital visiting hours from 4.30 p.m. to 6.30 p.m. This was the convenient time as it was beyond the working hours for the principal investigator and for the participants as they were relatively free after the chemotherapy and consultant rounds.

The first set of questionnaire was regarding demographic details and general awareness about cancer among the family caregivers. The questionnaire contained 12 questions. This questionnaire was self-designed and validated by the faculty in oncology and pharmacology department from the same institute. The questionnaire was administered to ten family caregivers for their understandability and validity. Following which, modification was done accordingly. The family caregivers were informed to read the questions or they were explained regarding the questions (if illiterate) in the language they understood and were asked whether they agree, disagree, or don't have any idea about the statement.

The second set of questionnaire was a validated QOL-Family version which was obtained with prior permission. The family version of the QOL tool is an adaptation of the patient version QOL tool. The instrument was revised and tested from 1994 to 1998 in a study of 219 family caregivers of cancer patients. The test–retest reliability was $r = 0.89$, and internal consistency was alpha $r = 0.69$. Factor analysis confirmed the four QOL domains as subscales for the instrument. Psychometric data were provided in the patient version QOL tool.[8] It has information on the physical, psychological, social, and spiritual well-being of the family caregivers of the cancer patients. The questionnaire contained 37 questions, in which the physical dimension contains 5 items, psychological contains 16 items, social 9 items, and spiritual 7 items. Each item has ten responses which were graded from 0 to 10, and then the responses were recorded. While analyzing, the response options were divided into four groups starting from "No Problem" to "Very much problem." The responses were recorded as 0–1 = no problem, 2–4 = somewhat problem, 5–7 = much problem, and 8–10 = very much problem. Data were analyzed using descriptive statistics.

RESULTS

The majority of caregivers were females (71.62%). The female caregivers were in their different roles as daughters (17.56%), daughter-in-laws (12.16%), wives (19.59%), sister-in-laws (7.43%), sisters (11.48%), mothers (4.05%), mother-in-laws (0.67%), and aunts (0.67%), whereas the male caregivers were in their different roles of brothers (6.76%), brother-in-laws (2.03%), husbands (10.81%), fathers (2.03%), sons (4.05%), son-in-laws (2.03%), and uncles (0.68%). Nearly 68.92% of the participants were between 36 and 59 years of age and 21.62% were between 19 and 35 years of age, and the remaining 9.46% were 60 years and above. The demographic data are represented in Table 1. The awareness among the family caregivers is noted in Table 2.

Majority of the participants (108%–73%) knew that cancer does not spread from one person to another and 105 of them knew that cancer is curable. Around 95% wanted the treating physician to reveal the condition to the patient relatives. There was a mixed response for cancer-related pain, as 74 expressed regarding presence of pain and 66 as no pain. More than 90% felt that it is wise to spend on cancer treatment and were satisfied with hospital care.

The QOL of the caregivers is depicted in Tables 3 and 4. All the dimensions of life are affected in caregivers.

Table 1: Demographic profile of the participants (n=148)

Characteristics	
Age (years), mean±SD	46.15±16.85
19-35	32 (21.62)
36-60	102 (68.92)
>60	14 (9.46)
Gender (%)	
Male	42 (28.38)
Female	106 (71.62)
Relationship to the patient (%)	
Males	
Husband	16 (10.81)
Brother	10 (6.76)
Son	6 (4.05)
In laws (son-in-law, brother-in-law)	6 (4.05)
Father	3 (2.03)
Uncle	1 (0.68)
Females	
In-laws (daughter-in-law, sister-in-law, mother-in-law)	30 (20.17)
Wife	29 (19.59)
Daughter	26 (17.56)
Sister	17 (11.48)
Mother	6 (4.05)
Aunt	1 (0.67)

SD: Standard deviation

The physical well-being was not affected to the great extent among most of the caregivers, but they expressed that most of the psychological components such as concentration, remembering, affliction, anguish over diagnosis, treatment, and general psychological health were affected. Socially, the impact was not much except for the financial burden. Spiritual well-being was good as most of them expressed that religious activity and prayers made them feel positive.

DISCUSSION

The care offered for a person who is sick, taking new responsibilities, and worrying about the future can be exhausting. A cancer diagnosis not only affects the patient, but equally affects the family, relatives, and close friends. Giving care and support to a cancer patient is dealt as a challenge as most of the caregivers have to put their own needs and feelings aside to focus on the person with cancer. This becomes more challenging because of the long duration of the treatment and fear associated with the disease.

We intended to assess the life of caregivers among the cancer patients of R. L. Jalappa Hospital, Tamaka, Kolar. Among the approached participants, nearly 75% showed interest to participate in the study. The study revealed that most of the caregivers were women of different age groups in their role as wives, daughters, sisters, daughter-in-laws, and mothers. A similar study done among the caregivers in Colombia also reflected that most of the caregivers were women.[2] The responsibilities expected from a women in the society are exhaustive, who continue having a priority role in all

Table 2: Knowledge and awareness among the cancer caregivers

Item	Male	Female	Total
Cancer can spread from one person to another			
Yes	7	12	19
No	33	75	108
Don't know	2	19	21
Cancer can be cured			
Yes	29	76	105
No	11	25	36
Don't know	2	5	7
Cancer is curse			
Yes	4	10	14
No	38	95	133
Don't know	0	1	1
Patients with cancer can lead a normal life after treatment			
Yes	34	79	113
No	8	25	33
Don't know	0	2	2
It is better to inform family and friends when diagnosed with cancer			
Yes	40	101	141
No	1	4	5
Don't know	1	1	2
Patient complains of pain at the tumor site			
Yes	24	50	74
No	15	51	66
Don't know	3	5	8
Environment contains carcinogenic elements			
Yes	32	72	104
No	9	22	31
Don't know	1	12	13
High-quality tobacco will not predispose to cancer			
Yes	10	18	28
No	21	54	75
Don't know	11	34	45
It is a wise decision to spend for the treatment of cancer			
Yes	42	101	143
No	0	5	5
Don't know	0	0	0
Cancer treatment will cause ill effects			
Yes	36	94	130
No	4	8	12
Don't know	2	4	6
Health-care facilities available in the hospital are satisfactory			
Agree	40	98	138
Disagree	2	8	10
Don't know	0	0	0
Falling of hair and weakness is due to incorrect dosage of drug			
Agree	2	4	6
Disagree	36	67	103
Don't know	4	35	39

Table 3: Quality of life for physical and psychological dimensions among cancer caregivers

Item	No (0-1) (%)	Somewhat (2-4) (%)	Much (5-7) (%)	Very much (8-10) (%)
Physical well-being				
Fatigue	94 (63.52)	22 (14.86)	22 (14.86)	10 (6.76)
Appetite changes	88 (59.46)	34 (22.97)	19 (12.84)	7 (4.73)
Pain or aches	56 (37.84)	32 (21.62)	32 (21.62)	28 (18.92)
Sleep changes	66 (44.59)	39 (26.35)	24 (16.22)	19 (12.84)
General physical health	4 (2.70)	30 (20.27)	42 (28.38)	72 (48.65)
Psychological				
Difficult to cope	0 (0.00)	1 (0.67)	37 (25.00)	110 (74.33)
Quality of life	11 (7.43)	104 (70.27)	29 (19.60)	4 (2.70)
Happiness	61 (41.22)	78 (52.70)	9 (6.08)	0 (0.00)
Control of things	6 (4.05)	49 (33.11)	84 (56.76)	9 (6.08)
Satisfaction of life	7 (4.73)	69 (46.62)	70 (47.30)	2 (1.35)
Concentrating, remembering	1 (0.67)	2 (1.35)	21 (14.20)	124 (83.78)
Feeling useful	0 (0.00)	10 (6.76)	85 (57.43)	53 (35.81)
Affliction, anguish regarding diagnosis	1 (0.67)	1 (0.67)	25 (16.90)	121 (81.76)
Affliction, anguish regarding treatment	0 (0.00)	1 (0.67)	45 (30.40)	102 (68.93)
Affliction, anguish over the first treatment	0 (0.00)	7 (4.73)	99 (66.89)	42 (28.38)
Anxiety, despair	0 (0.00)	6 (4.05)	99 (66.89)	43 (29.05)
Depression	2 (1.35)	7 (4.73)	101 (68.24)	38 (25.68)
Fear of second disease	27 (18.24)	46 (31.08)	42 (28.38)	33 (22.30)
Fear of recurrence	38 (25.67)	48 (32.43)	37 (25.00)	25 (16.90)
Fear of metastasis	39 (26.35)	39 (26.35)	46 (31.08)	24 (16.22)
General psychological health	3 (2.03)	42 (28.38)	94 (63.51)	9 (6.08)

Table 4: Quality of life for social and spiritual dimensions among cancer caregivers

Item	No (0-1)	Somewhat (2-4)	Much (5-7)	Very much (8-10)
Social				
Affliction, anguish over the disease	0 (0.00)	0 (0.00)	20 (13.51)	128 (86.49)
Level of support from others	7 (4.73)	12 (8.11)	46 (31.08)	83 (56.08)
Interference in relationships	46 (31.08)	61 (41.21)	29 (19.60)	12 (8.11)
Impact on sexuality				
Impact on employment	77 (52.03)	06 (4.05)	25 (16.90)	40 (27.02)
Interference on household activities	0 (0.00)	18 (12.16)	53 (35.81)	77 (52.03)
Isolation attributed to the disease	43 (29.05)	78 (52.70)	19 (12.84)	8 (5.41)
Financial burden	0 (0.00)	2 (1.35)	64 (43.24)	82 (55.41)
General social well-being	3 (2.03)	36 (24.32)	90 (60.81)	19 (12.84)
Spiritual				
Sufficient support from religious activity	5 (3.38)	4 (2.70)	39 (26.35)	100 (67.57)
Prayer support	6 (4.05)	4 (2.70)	42 (28.38)	96 (64.87)
Uncertainty of the future	31 (20.94)	75 (50.68)	19 (12.84)	23 (15.54)
Positive changes in life	23 (15.54)	88 (59.46)	35 (23.65)	02 (1.35)
Purpose or mission	14 (9.46)	86 (58.10)	40 (27.03)	08 (5.41)
Feels hope	3 (2.03)	15 (10.13)	35 (23.65)	95 (64.19)
General spiritual well being	1 (0.67)	01 (0.67)	46 (31.09)	100 (67.57)

tasks associated in offering care to the family. This situation worsens when the caregiver exhausts herself in multitasking roles more so when they are the breadwinning members in the family.

Regarding the awareness about the cancer among the caregivers, nearly 70% of the participants were aware that cancer cannot spread from one person to another and can be treated. This explains that the caregivers knew that being closely associated with the person does not transmit the condition so that the nursing can be continued. Majority of the participants believed that our environment contains carcinogenic elements, and falling of hair after the treatment was not because of incorrect dosage. Around 92% of the participants expressed that it was better to inform the family and friends when diagnosed with cancer and it was worth to spend money on the management of cancer. Most of the participants were aware of the fact that cancer treatment causes various ill effects and were satisfied with the health-care facility provided to them. The proportion of participants who believed that a cancer patient can lead a normal life after the treatment was around 76%. This belief in the treatment/cure of cancer could be increased by educating the caregivers so that they are more positive in their approach. As sedentary lifestyle, consumption of diet rich in fatty acid, and intake of alcohol are on rise and tobacco-related cancers have reached a new crest,[9-13] it was good to note that majority of the participants were aware that even high-quality tobacco can predispose to cancer. Here, education can play an important role in creating awareness among the caregivers.[14-16]

The QOL of the family caregivers of cancer patients was found to be affected in all dimensions of life including physical, psychological, social, and spiritual. The psychological and social dimensions as opined by the participants were found to be negatively affected. The findings were similar to that found in another study on the QOL of caregivers taking care of children suffering from chronic disease, where the caregivers were mostly affected by dealing with the disease and managing with stress, anguish, and anxiety.[10] According to another study on the QOL of family caregivers of persons with HIV-AIDS, there was a marked deterioration of the QOL in the psychological aspect, as they were exposed to multiple responsibilities and being exposed to stress, anxiety, and isolation.[17,18] The family is exposed to the reality of the chronic disease, and is subjected to contradictory opinions, which depends on the family members. As the individuals suffering from chronic conditions deteriorate, it will have an impact on both the patient and his/her family.[18]

The perception on physical well-being among the family caregivers was positive with minor concerns regarding fatigability and disturbed sleep patterns during their stay in the hospital. Few participants expressed change in appetite. As far as psychological dimension is concerned, most of the caregivers had a negative perception. The issues related to anguish and affliction regarding diagnosis, treatment, and depression were the most affected psychological components. The emotional tension and related health problems appear when there is high demand as perceived by the caregivers with limited facilities to manage the situation.[19] Most of the participants did believe that it is better to disclose the diagnosis to the close relative members and families, but few studies reveal that disclosing the disease diagnosis leads to increase in psychiatric morbidity among cancer patients.[18] According to the Code of Medical Ethics Regulations, 2002, notified by the Medical Council of India, it is mandatory to disclose the diagnosis and prognosis to the patient.[20] The fear of second disease, recurrence, and metastasis was also seen among a small proportion of participants. In spite of anxiety and depression among the caregivers, most of them found themselves useful.

The social dimension was the other area of concern as most of them perceived negatively. Around 90% of the participants had anguish and affliction over the disease. It is followed by economic burden incurred due to disease and treatments associated. The families belonging to lower socioeconomic are the most affected as the members will be the sole breadwinners for the families and in addition have the responsibility of household work and care for the diseased family member.[2] This finding is similar to a study which concludes that the anguish by the caregivers due to the family member's disease adds further to the existing economic burden, which finally has a greater impact on the social dimension. The positively perceived components among the caregivers are high in spiritual dimension. Almost 90% of the participants got sufficient support from religious activities. Religious activities gave them the strength to cope up the depression and brought in hope for their family member's well-being. The previous studies have shown a variable finding in the spiritual well-being among the caregivers as it depends on the personality and beliefs of the caregiver.[19] In few studies, the caregivers expressed that they were improving on spiritual and emotional parameters and having a wide view on life. They had a better picture of family values such as supporting each other, being compassionate, empathetic, and solidarity in spite of the hurdles in life.[18] Affection and understanding becomes the main focus of comprehending care for caregivers and thus influences positively on the patient's health.

CONCLUSION

Majority of the caregivers had awareness regarding the cancer and carcinogens from the environmental toxins. The QOL of caregivers of cancer patients is affected in all dimensions of life with more impact on the social and psychological dimensions. The health-care workers including the nursing staff should be able to intervene and provide adequate information and comprehensive support to diminish the feeling of uncertainty and give them hope for better life for both the patients and the family caregivers.

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Conflicts of interest

There are no conflicts of interest.

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