Original Research Article

Assessment of quality of life and its determinants among caregivers of lung cancer patients: a cross sectional study in a tertiary care centre of Kolkata, West Bengal, India

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ABSTRACT

Background: Lung cancer is the commonest cancer worldwide considering its incidence and mortality. It not only affects the life of the patient, but also has significant impact on the life of the primary caregivers too. The study aimed to assess the Quality of Life (QOL) among caregivers of lung cancer patients and to find out its determinants.

Methods: It was an institution based cross-sectional study conducted in a tertiary care center of Kolkata with the help of a predesigned, pretested, structured, standardized questionnaire where 210 patient-caregiver dyads were included by complete enumeration method to assess quality of life of the caregivers and its possible predictors.

Results: Half of the caregivers experienced poor quality of life (overall QOL score ≤ median score) as assessed by QOLITI-F (Quality of Life in Life-Threatening Illness-Family Carer Version). Multivariate analyses suggested that gender, religion, area of residence, financial burden, stage and type of lung carcinoma, disability and depression among the patients were important determinants of quality of life of the caregivers.

Conclusions: Comprehensive care covering different domains like financial risk protection, psycho-social assistance through governmental and also different non-governmental initiatives, self-help groups are the needs of the hour to address this important public health issue as caregiver’s life is equally important as that of the patient and they are highly interdependent.

Keywords: Caregivers, Determinants, Lung cancer, Quality of life

INTRODUCTION

Lung cancer is a major public health problem being the topmost cancer worldwide considering its incidence and mortality.¹ Different modalities of treatment like surgery, radiotherapy, chemotherapy alone or in combination are recommended for these patients. Despite of all sorts of therapeutic efforts, overall prognosis is poor. Long duration of treatment, variety and severity of symptom profile related to both disease and therapeutic side effects can affect not only the patients but also the principle caregivers of the patients deteriorating their Quality of Life (QOL).²

Diagnosis of cancer brings problems in different aspects for the patients and their caregivers too.³,⁴ The caregivers can be affected by economic problems arising out of costly and long duration of treatment, impairment of physical as well as mental health, and deterioration of social interactions. These in turn can have impact on patient’s physical health, mental health through lack of support to fight against the deadly disease, sustainability as well as compliance to treatment and thereby a low
quality of life. As the disease evolves over the time, a complex interaction between physical, mental, social and spiritual wellbeing of the patients can be seen with those of the caregivers.  

Several interrelated factors play to shape the quality of life of caregivers of lung cancer patients during the disease trajectory. There is utmost importance on giving attention to care of caregivers of cancer patients too. Although there are some studies enlightening this public health issue, researches are still scarce in eastern India. With this backdrop, the current study had been taken up to assess the quality of life of caregivers of lung cancer patients and its determinants.

**METHODS**

A cross-sectional study had been conducted in Medical College, Kolkata in the in-patient and out-patient department of Pulmonary Medicine from January 2017 to June 2017. The institution was purposively selected for the study. The study subjects i.e. patient-caregiver dyads were included by complete enumeration method after getting informed consent from each of them. Persons who were closely related to cancer patients (spouse, parents, children or siblings etc.), spending at least 2-3 hours per day in patient care and aged above 18 years were considered as primary caregiver. Ethical clearance was obtained from Institutional Ethics Committee. Caregivers who were not giving consent, physically or mentally ill or patients who were in moribund condition, not able to respond properly to the questionnaire, not willing to take part were excluded from the study. Thus, a total of 210 lung cancer patient-caregiver dyads were included for final analyses.

The study tool consisted of two separate questionnaires, one for the caregiver and the other one for the patient. The questionnaire of the caregiver contained two parts-the first one for collecting socio-demographic information and the second part was a standardized questionnaire to measure quality of life of the caregivers-QOLITI-F (Quality of Life in Life-Threatening Illness-Family Carer Version) was developed by Dr. Robin Cohen of the Division of Palliative Care, Departments of Oncology and Medicine, McGill University. QOLITI-F has seven domains-carer’s own state, environment, carer’s outlook, quality of care, relationships, patient state and financial worries. The QOLITI-F total score has a possible range from ‘0’ to ‘10’ where ‘0’ always indicates the worst situation and ‘10’ the best situation and the total score had been by calculating mean of 7 domain scores.

The questionnaire used for interviewing the patients consisted of three parts-the first part consisted of questions regarding different socio-demographic, economic profile, details of the present disease (stage of the disease, cell type of carcinoma, time elapsed since diagnosis etc.). The second and third parts were standardized questionnaires to assess disability- “WHO Disability Assessment Schedule 2.0” (WHODAS 2.0) and to diagnose major depressive episode (current i.e. in past 2 weeks)- MINI International Neuropsychiatric Interview English Version 5.0.0 DSM-IV. WHODAS 2.0 contained 36 items and six domains. Domain scores for each of the domain and an overall disability score were calculated with maximum and minimum attainable scores of 100 and 0 respectively where higher scores representing higher level or degree of disability.

The whole questionnaire was first prepared in English. Then it was translated into Bengali by a linguistic expert keeping semantic equivalence. To check the translation, it was retranslated into English by two independent researchers who were unaware of the first English version. Pretesting followed by pilot testing was done. Necessary corrections and modifications were made accordingly. Exit interview was conducted for every participant with this schedule.

Data thus collected had been entered and analyzed in SPSS 20.0 software. Categorical data were compared by chi-square with Yates correlation where applicable. Odds ratios (univariate regression) were calculated to predict the strength of association between the dependent and the independent variables. Multivariate logistic regression had been done to find out the strength of association between dependent variable and the independent variables after adjusting for all the independent variables. All the independent variables which were significantly associated with dependent variable in univariate regression or having biological plausibility to be associated with dependent variable, were entered in the multivariate logistic model (LINK FUNCTION=LOGISTIC) using enter method. Hosmer-Lemeshow test was applied to check model fitness (p>0.05 = good fit). Nagelkerke R2 (a pseudo R2) value had been mentioned in each model to demonstrate the proportion of variability of the dependent variable explained by the predictor variables. All analyses were two-tailed with p<0.05 considered statistically significant. Socio-economic status had been assessed through B.G. Prasad scale modified for the year 2017.

**RESULTS**

Majority (48.6%) of the lung cancer patients belonged to the age group of 60-69 years with the minimum, maximum and mean age of 23 years, 90 years and 60.27 (10.954) years respectively; while most of the caregivers (48%) were found in the age group of 35-45 years with the mean of 42.54(10.068) years, minimum age of 25 years and maximum of 65 years.

Most of the patients were currently married (84.3%), male (74.3%) and educated up to middle level (24.3%).

Majority of the patients were retired from their job (37.1%), currently not earning anything (72.9%), financially dependent on others (80%) with son (78.57%)
being the main financial supporter and belonged to upper-middle socio-economic class as per modified B.G Prasad scale 2016.

Table 1: Distribution of lung cancer patients according to socio-demographic, economic and disease related characteristics (n=210).

| Variables                        | Frequency | (%) |
|----------------------------------|-----------|-----|
| **Age (in completed years)**     |           |     |
| <40                              | 6         | 2.9 |
| 40-50                            | 27        | 12.9|
| 50-60                            | 39        | 18.5|
| 60-70                            | 102       | 48.6|
| ≥70                              | 36        | 17.1|
| **Sex**                          |           |     |
| Male                             | 156       | 74.3|
| Female                           | 54        | 25.7|
| **Marital status**               |           |     |
| Married                          | 177       | 84.3|
| Unmarried                        | 6         | 2.9 |
| Widow/widower/ separated         | 27        | 12.9|
| **Education**                    |           |     |
| Illiterate                       | 27        | 12.8|
| Below primary                    | 6         | 2.9 |
| Primary                          | 48        | 22.8|
| Middle                           | 51        | 24.3|
| Secondary                        | 39        | 18.6|
| Graduate and above               | 39        | 18.6|
| **Employment**                   |           |     |
| Employed                         | 63        | 30.0|
| Unemployed                       | 69        | 32.9|
| Retired                          | 78        | 37.1|
| **Socio-economic class***        |           |     |
| Upper                            | 36        | 17.1|
| Upper middle                     | 84        | 40.0|
| Middle                           | 63        | 30.0|
| Lower middle                     | 24        | 11.4|
| Lower                            | 3         | 1.4 |
| **Earning at present (includes pension)** | 57 | 27.1 |
| Yes                              | 57        | 27.1|
| No                               | 153       | 72.9|
| **Financial dependence**         |           |     |
| Yes                              | 168       | 80.0|
| No                               | 42        | 20.0|
| **Cell type of carcinoma**       |           |     |
| Small cell                       | 36        | 17.1|
| Non-small cell                   | 174       | 82.9|
| Adenocarcinoma                   | 39        | 22.4|
| squamous cell                    | 90        | 51.7|
| sarcomatoid                      | 3         | 1.7 |
| unclassified                     | 42        | 24.1|
| **Stage of carcinoma**           |           |     |
| Small cell extensive             | 27        | 75.0|
| limited                          | 9         | 25.0|
| Non-small cell                   |           |     |
| I                                | 6         | 3.4 |
| II                               | 30        | 17.2|
| III                              | 54        | 31.0|
| IV                               | 84        | 48.4|

*As per modified BG Prasad scale (2016)  

Most of these patients had non-small cell carcinoma (82.9%) of which 50% belonged to stage IV. Only 17.1% of study population were suffering from small cell type, while 75% of them were in extensive stage.

Table 2: Distribution of primary caregivers of lung cancer patients according to socio-demographic, economic and disease related characteristics (n=210).

| Variable                        | Frequency | (%) |
|----------------------------------|-----------|-----|
| **Relationship with the patient**|           |     |
| Son                              | 111       | 52.9|
| Daughter                         | 39        | 18.6|
| Wife                             | 36        | 17.1|
| Husband                          | 6         | 2.9 |
| Brother                          | 9         | 4.3 |
| Mother                           | 3         | 1.4 |
| Sister                           | 3         | 1.4 |
| Son-in-law                       | 3         | 1.4 |
| Age (in completed years)         |           |     |
| 25-35                            | 33        | 15.7|
| 35-45                            | 102       | 48.6|
| 45-55                            | 33        | 15.7|
| 55-65                            | 42        | 20.0|
| **Sex**                          |           |     |
| Male                             | 129       | 61.4|
| Female                           | 81        | 38.6|
| **Religion**                     |           |     |
| Hindu                            | 153       | 72.9|
| Muslim                           | 57        | 27.1|
| **Residence**                    |           |     |
| Rural                            | 126       | 60.0|
| Urban                            | 84        | 40.0|
| **Education**                    |           |     |
| Illiterate                       | 21        | 10.0|
| Primary                          | 27        | 12.9|
| Middle                           | 33        | 15.7|
| Secondary                        | 66        | 31.4|
| Higher secondary                 | 12        | 5.7 |
| **Earning at present (includes pension)** | 51 | 24.3 |
| Graduate and above               | 51        | 24.3|
| **Socio-economic class***        |           |     |
| Upper                            | 9         | 4.3 |
| Middle                           | 39        | 18.6|
| Lower middle                     | 96        | 45.7|
| Lower                            | 66        | 31.4|
| **Type of family**               |           |     |
| Nuclear                          | 72        | 34.3|
| Joint                            | 138       | 65.7|
| **Marital status**               |           |     |
| Married                          | 153       | 72.9|
| Unmarried                        | 33        | 15.7|
| Widow/widower/ separated/divorced| 24       | 11.4|

*As per modified BG Prasad scale (2016)  

More than half (71.4%) of the patient population were new cases showing no delay between diagnosis and start of treatment with a mean delay of 1.04 months (2.863) and a maximum delay of 20 months (1.4%).

Majority (52.9%) of the caregivers were son of the patient by relation, male (61.4%), Hindu (72.9%),
residing at rural area (60%), educated up to secondary level (31.4%), currently married (72.9%), belonged to joint family (65.7%) and lower middle socio-economic class (45.7%) (Table 1 and 2).

Table 3: Determinants of quality of life of caregivers of lung cancer patients (n=210).

| Variables                      | Quality of life | Test of significance | OR (95% CI) | AOR (95% CI) |
|--------------------------------|-----------------|-----------------------|-------------|--------------|
|                                | Poor (<median)  | Good (>median)        | X2 = df,    |              |
|                                |                 |                       | p            |              |
| Age of caregiver (in completed years) | ≤40 (median)    | >40                   | X2 = 6.167, df = 1, p = 0.013 | 2.155-3.464, 0.688 (0.242-1.951) |
|                                | 63              | 45                    |              |              |
|                                | 42              | 60                    |              |              |
| Age of patient (in completed years) | ≤62 (median)    | >62                   | X2 = 6.300, df = 1, p = 0.012 | 2.029 (1.164-3.538) |
|                                | 69              | 65                    |              |              |
|                                | 36              | 54                    |              |              |
| Sex of caregiver               | Female          | Male                  | X2 = 21.886, df = 1, p = 0.000 | 4.008 (2.209-7.272) |
|                                | 57              | 24                    |              |              |
|                                | 48              | 81                    |              |              |
| Religion of caregiver          | Muslim          | Hindu                 | X2 = 10.619, df = 1, p = 0.001 | 2.856 (1.501-5.436) |
|                                | 39              | 18                    |              |              |
|                                | 66              | 87                    |              |              |
| Marital status of caregiver    | Married         | Unmarried/separated/widowed | X2 = 0.217, df = 1, p = 0.642 | 1.156 (0.629-2.124) |
|                                | 78              | 75                    |              |              |
|                                | 27              | 30                    |              |              |
| Education of caregiver         | Upto secondary  | Higher secondary      | X2 = 16.531, df = 1, p = 0.000 | 3.625 (1.915-6.861) |
|                                | 87              | 60                    |              |              |
|                                | 18              | 45                    |              |              |
| Residence of caregiver         | Rural           | Urban                 | X2 = 11.429, df = 1, p = 0.001 | 2.647 (1.496-4.684) |
|                                | 75              | 51                    |              |              |
|                                | 30              | 54                    |              |              |
| Type of family of caregiver    | Joint           | Nuclear               | X2 = 0.761, df = 1, p = 0.383 | 1.289 (0.728-2.283) |
|                                | 72              | 66                    |              |              |
|                                | 33              | 39                    |              |              |
| Socio-economic status          | Lower class     | Up to lower middle    | X2 = 19.886, df = 1, p = 0.000 | 4.070 (2.154-7.691) |
|                                | 48              | 18                    |              |              |
|                                | 57              | 87                    |              |              |
| Earning ability of patient at present (includes pension) | No              | Yes                   | X2 = 17.554, df = 1, p = 0.000 | 4 (2.043-7.830) |
|                                | 90              | 63                    |              |              |
|                                | 15              | 42                    |              |              |
| Financial dependence of patient on caregiver | Yes             | No                    | X2 = 9.643, df = 1, p = 0.002 | 3.1 (1.486-6.467) |
|                                | 93              | 75                    |              |              |
|                                | 12              | 30                    |              |              |
| Cell type of carcinoma         | Small cell      | Non-small cell        | X2 = 12.377, df = 1, p = 0.000 | 4.197 (1.806-9.755) |
|                                | 27              | 8                     |              |              |
|                                | 78              | 97                    |              |              |
| Time elapsed since diagnosis   | ≥1 month        | < 1 month(median)     | X2 = 0.840, df = 1, p = 0.359 | 1.324 (0.726-2.415) |
|                                | 33              | 27                    |              |              |
|                                | 72              | 78                    |              |              |
| Stage of carcinoma**           | Advanced        | Early                 | X2 = 20.618, df = 1, p = 0.000 | 5.565 (2.518-12.302) |
|                                | 96              | 69                    |              |              |
|                                | 9               | 36                    |              |              |
| Disability in patients         | High(>median)   | Low                   | X2 = 61.886, df = 1, p = 0.000 | 11.391 (5.981-21.693) |
|                                | 81              | 24                    |              |              |
|                                | 24              | 81                    |              |              |
| Depression among patients      | Yes             | No                    | X2 = 44.211, df = 1, p = 0.000 | 7.364 (3.984-13.609) |
|                                | 72              | 24                    |              |              |
|                                | 33              | 81                    |              |              |

 Hosmer Lemeshow test: p=0.086
 Nagelkerke r² = 0.664

*As per modified BG Prasad scale (2016) **Stage III- IV of non-small cell type and extensive small cell carcinoma were considered as advanced stage of carcinoma

Regarding quality of life of caregivers, total seven domains had been assessed. The median score was 5.5(4-7) for environment subscale, 2(0-4) for patient state, 4 (2.8-4.8) for carer’s own state, 6.67(5.7-6.7) for carer’s outlook, 7(5.5-8) for quality of care, 2.5(1-4) for relationships, 4(2-4) for financial worries and 4.375(3.6-5.11) for overall quality of life (Figure 1).
Regarding the determinants of quality of life of the caregivers, multivariate logistic regression model suggested that quality of life was poor among female carers, if they were Muslim, residing at rural area, if the patient was not earning at present and financially dependent on caregiver, patient was suffering from small cell carcinoma of lungs and in advanced stage of the disease, patient was suffering from high disability or current attack of major depressive episode (Table 3).

Lung cancer patients have relatively poor prognosis due to lack of support of effective screening for early diagnosis and this leads to a situation of late detection and its consequences like costly and long duration of treatment, advanced stage of disease with related disability and depression among the patients which in turn create an immense impact on caregivers life.

To get a successful treatment, compliance and sustainability of therapy are the utmost needs which cannot be ensured without proper supportive care to the primary caregiver. The factors act bi-directionally influencing the life of patient and caregiver both. Therefore, a more holistic concept of care to be applied which will cover the care of not only the patients but also the caregivers, on whom the result of therapy on the patients depend a lot.

The current study was a quantitative one which had been done with a structured questionnaire. Qualitative studies like in-depth interviews are to be conducted further to bring out the hidden factors causing imperfect quality of life of the caregivers and thereby taking corrective measures.

CONCLUSION

The present study revealed that overall quality of life of caregivers of lung cancer patients was not up to the mark. Several socio-demographic factors play complex role in shaping their QOL. Holistic approach covering different domains like social security schemes to curtail financial risk burden, self-help groups for discussion to cope up mental stress, depression, spiritual upliftment to bring positive concepts for fighting against this deadly disease of near and dear ones are the needs of the hour to address this highly emerging yet neglected public health issue.

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