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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

Jayita Pal[1], Avradip Santra[2]*

[1]Department of Environmental/Occupational Health, Institute of Public Health, Kalyani, West Bengal, India
[2]Department of Pulmonary Medicine, Medical College and Hospital, Kolkata, West Bengal, India

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***Correspondence:**
Dr. Avradip Santra,
E-mail: avradipsantra@gmail.com

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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 QOLLTI-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.[2,5-7]

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.[5,8-11] 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-QOLLTI-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.[12] QOLLTI-F has seven domains-carer's own state, environment, carer's outlook, quality of care, relationships, patient state and financial worries. The QOLLTI-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.[13-15] 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 $p\leq0.05$ considered statistically significant. Socio-economic status had been assessed through B.G. Prasad scale modified for the year 2017.[16]

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)	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
	Graduate and above	51	24.3
Socio-economic class*	Upper middle	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)			
Age of caregiver (in completed years)	≤40 (median) >40	63 42	45 60	X2 =6.167, df=1, p=0.013	2(1.155-3.464)	0.688 (0.242-1.951)
Age of patient (in completed years)	≤62 (median) >62	69 36	51 54	X2=6.300, df=1, p=0.012	2.029 (1.164-3.538)	1.918 (0.743-4.955)
Sex of caregiver	Female Male	57 48	24 81	X2=21.886, df=1, p=0.000	4.008 (2.209-7.272)	9.732 (3.281-28.869)
Religion of caregiver	Muslim Hindu	39 66	18 87	X2=10.619, df=1, p=0.001	2.856 (1.501-5.436)	4.465 (1.311-15.203)
Marital status of caregiver	Married Unmarried/separated/widow/widower	78 27	75 30	X2=0.217, df=1, p=0.642	1.156 (0.629-2.124)	-
Education of caregiver	Upto secondary Higher secondary upwards	87 18	60 45	X2=16.531, df=1, p=0.000	3.625 (1.915-6.861)	1.016 (0.301-3.422)
Residence of caregiver	Rural Urban	75 30	51 54	X2=11.429, df=1, p=0.001	2.647 (1.496-4.684)	2.907 (1.022-8.266)
Type of family of caregiver	Joint Nuclear	72 33	66 39	X2=0.761, df=1, p=0.383	1.289 (0.728-2.283)	-
Socio-economic status	Lower class Up to lower middle class	48 57	18 87	X2=19.886, df=1, p=0.000	4.070 (2.154-7.691)	2.579 (0.802-8.299)
Earning ability of patient at present (includes pension)	No Yes	90 15	63 42	X2=17.554, df=1, p=0.000	4 (2.043-7.830)	8.983 (1.220-66.160)
Financial dependence of patient on caregiver	Yes No	93 12	75 30	X2=9.643, df=1, p=0.002	3.1 (1.486-6.467)	1.056 (1.005-7.679)
Cell type of carcinoma	Small cell Non-small cell	27 78	8 97	X2=12.377, df=1, p=0.000	4.197 (1.806-9.755)	7.474 (2.071-26.978)
Time elapsed since diagnosis	≥1 month < 1 month(medi	33 72	27 78	X2=0.840, df=1, p=0.359	1.324 (0.726-2.415)	-
Stage of carcinoma**	Advanced Early	96 9	69 36	X2=20.618, df=1, p=0.000	5.565 (2.518-12.302)	5.179 (1.250-21.464)
Disability in patients	High(>median) Low	81 24	24 81	X2=61.886, df=1, p=0.000	11.391 (5.981-21.693)	10.937 (3.188-37.527)
Depression among patients	Yes No	72 33	24 81	X2=44.211, df=1, p=0.000	7.364 (3.984-13.609)	2.089 (0.621-7.027)
		Hosmer lemeshow test: p=0.086 Nagelkerke r^2 = 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(5-7.67) 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).

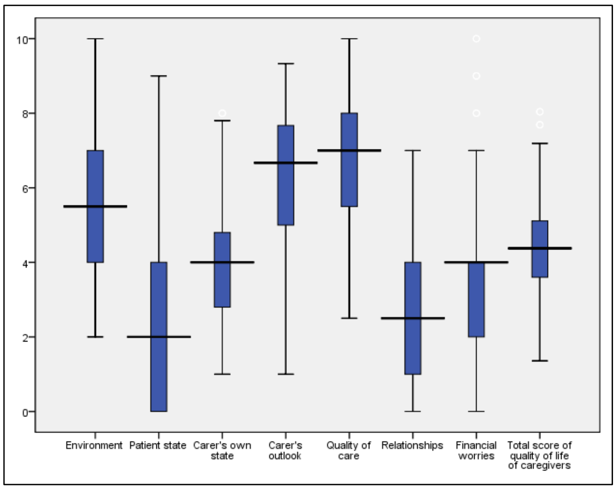

Figure 1: Box and whisker plot showing different subscale and overall scores of qualities of life of caregivers of the lung cancer patients (n=210).

DISCUSSION

The current study assessed the quality of life and its determinants among caregivers of lung cancer patients in a tertiary care center of Kolkata.

The study revealed that majority (48%) of the caregivers were in the age group of 35-45 years and male (61.4%); while a study by Nayak MG et al.[5] also found that most (53.6%) of the carers in their study belonged to age group of 20-40 years though majority were female (60.2%).

Half of the caregivers of current study had a quality of life score of less than the median value; whereas a study done among carers of breast cancer patients revealed that 17.5% had life quality lower than normal and 42.9% had moderate and only 39.7% had good quality of life though they had used a separate tool to measure quality of life of caregivers.[17] Hellstrom Y. et al, reported that quality of life was not found to be up to the mark among caregivers of cancer patients.[18] Other researches among caregivers of cancer patients also demonstrated an improper quality of life among the study population.[5,12]

The present study reported 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. Nayak MG et al, found that financial burden had negative impact on quality of life of the caregivers of cancer patients while Turkoglu N et al, reported that the factors like age of caregiver, income level, relationship with the patient and the patient having their own room were significant predictors of quality of life of caregivers.[5,19] Lim HA et al, demonstrated that caregivers who were male, belonging to Chinese ethnicity, having parental relationships with their care recipient, or caring for advanced-stage cancer patients were found to have impaired QOL.[20]

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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REFERENCES

1. Worldwide cancer data: Global cancer statistics for the most common cancers. Available at: https://www.wcrf.org/dietandcancer/cancer-trends/worldwide-cancer-data. Accessed 5 May 2019.
2. Fujinami R, Otis-Green S, Klein L, Sidhu R, Ferrell B. Quality of life of family caregivers: challenges faced in care of the lung cancer patient. Clin J Oncol Nurs. 2012 Dec;16(6):E210.
3. Vallerand AH, Collins-Bohler D, Templin T, Hasenau SM. Knowledge of and barriers to pain management in caregivers of cancer patients receiving homecare. Cancer Nursing. 2007 Jan 1;30(1):31-7.
4. Yun YH, Rhee YS, Kang IO, Lee JS, Bang SM, Lee WS, et al. Economic burdens and quality of life of family caregivers of cancer patients. Oncol. 2005;68(2-3):107-14.
5. Nayak MG, George A, Vidyasagar MS, Kamath A. Quality of life of family caregivers of patients with advanced cancer. IOSR J Nursing Health Sci. 2014;3 (2): 70-5.
6. Ryan PJ, Howell V, Jones J, Hardy EJ. Lung cancer, caring for the caregivers. A qualitative study of providing pro-active social support targeted to the carers of patients with lung cancer. Pall Med. 2008 Apr;22(3):233-8.
7. Hirdes JP, Freeman S, Smith TF, Stolee P. Predictors of caregiver distress among palliative home care clients in Ontario: evidence based on the interRAI Palliative Care. Pall Supp Care. 2012 Sep;10(3):155-63.
8. Palos GR, Mendoza TR, Liao KP, Anderson KO, Garcia-Gonzalez A, Hahn K, et al. Caregiver symptom burden: the risk of caring for an underserved patient with advanced cancer. Cancer. 2011 Mar 1;117(5):1070-9.
9. Glajchen M. Physical well-being of oncology caregivers: an important quality-of-life domain. Semi Onco Nurs. 2012 Nov 1;28(4):226-35.
10. O'Hara RE, Hull JG, Lyons KD, Bakitas M, Hegel MT, Li Z, et al. Impact on caregiver burden of a patient-focused palliative care intervention for patients with advanced cancer. Pall Supp Care. 2010 Dec;8(4):395-404.
11. Borges EL, Franceschini J, Costa LH, Fernandes AL, Jamnik S, Santoro IL. Family caregiver burden: the burden of caring for lung cancer patients according to the cancer stage and patient quality of life. J Brasil Pneumol. 2017 Feb;43(1):18-23.
12. Cohen R, Leis AM, Kuhl D, Charbonneau C, Ritvo P, Ashbury FD. QOLLTI-F: measuring family carer quality of life. Pall Medi. 2006 Dec;20(8):755-67.
13. World Health Organization Disability Assessment Schedule 2.0,2009: Available at: https://www.who.int/classifications/icf/WHODAS2.0_36itemsSELF.pdf. Accessed 8 December 2016.
14. Sheehan DV, Lecrubier Y, Sheehan KH, Amorim P, Janavs J, Weiller E, et al. The Mini-International Neuropsychiatric Interview (MINI): the development and validation of a structured diagnostic psychiatric interview for DSM-IV and ICD-10. J Clin Psych. 1998;59(20): 22-33.
15. Sheehan DV, Sheehan KH, Shytle RD, Janavs J, Bannon Y, Rogers JE, et al. Reliability and validity of the mini international neuropsychiatric interview for children and adolescents (MINI-KID). J Clin Psych. 2010 Mar;12:232-41.
16. Shaikh Z, Pathak R. Revised Kuppuswamy and BG Prasad socio-economic scales for 2016. Inter J Comm Med Pub Health. 2017 Mar 28;4(4):997-9.
17. Gorji MA, Bouzar Z, Haghshenas M, Kasaeeyan AA, Sadeghi MR, Ardebil MD. Quality of life and depression in caregivers of patients with breast cancer. BMC Res Notes. 2012 Dec;5(1):310.
18. Hellström Y, Persson G, Hallberg IR. Quality of life and symptoms among older people living at home. J Adv Nursing. 2004 Dec;48(6):584-93.
19. Turkoglu N, Kilic D. Effects of care burdens of caregivers of cancer patients on their quality of life. Asian Pacif J Cancer Prev. 2012;13(8):4141-5.
20. Lim HA, Tan JY, Chua J, Yoong RK, Lim SE, Kua EH, et al. Quality of life of family caregivers of cancer patients in Singapore and globally. Singapore Med J. 2017 May;58(5):258.

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