

Assessment of Quality of Life among Terminally Ill Cancer Patients Receiving Palliative Care at Hospice Centre, Ahmedabad City, India

Disha Geriya, Viral Dave¹

Department of Community Medicine, Dr. M. K. Shah Medical College and Research Centre, Ahmedabad, Gujarat, ¹Department of Community Medicine, GCS Medical College, Hospital and Research Centre, Ahmedabad, Gujarat, India

Abstract

Background: Cancer has been the leading cause of death worldwide, and palliative care is an approach that improves the quality of life (QoL) of patients and their families facing the problem associated with life-threatening illness. Hospice care helps patients and their family to cope with the change from treating the cancer to living life as fully as possible through their final days. This study aimed to (1) assess the sociodemographic and clinical profile of terminally ill cancer patients, (2) assess the QoL among terminally ill cancer patients receiving palliative care, and (3) study various determinants affecting their QoL. **Material and Methods:** A cross-sectional study was conducted among terminally ill cancer patients receiving palliative care at the Hospice Centre, Community Oncology Centre, Ahmedabad. Based on previous years' admission data, a sample size of 360 was taken. Patients who are seriously ill up to the extent that they were unable to respond and had a previous positive history of psychiatric illness before the diagnosis of cancer were excluded. Institutional ethical committee (IEC) permission was obtained before the study. Statistical analysis was performed using the Chi-square test in Statistical Package for the Social Sciences (SPSS) software. **Results:** The mean age of participants was 48.1 ± 13.0 years. The gender distribution of participants was males and females (226 (62.8%) and 134 (37.2%)), respectively. On studying, the involvement of various anatomical sites as "primary site of cancer" revealed that head and neck carcinoma had the highest (63.3%) involvement and hematological cancer had the lowest (0.6%) involvement. Of total, 62% of participants had "below-average QoL," followed by 34.9% of participants having "significantly poor QoL." There was a significant association between different age groups, time lag in cancer diagnosis, and treatment initiation and QoL. **Conclusion:** Spearman's rank correlations between the majority of factors fell in "low partially positive" category except for the physical well-being (factor 2) and psychosocial well-being (factor 3) with optimism and belief (factor 7), where they were in "low partially negative" category.

Keywords: Cancer, hospice, palliative care, quality of life, terminal ill

BACKGROUND

Cancer has been the leading cause of death worldwide, accounting for nearly 10 million deaths in 2020. In 2018, 8.2 million new cancer cases and 5.2 million cancer deaths were estimated in the Southeast Asia region.^[1] In India, a total number of 1324413 new cancer patients were registered and 851678 deaths occurred due to cancer in 2020. Cancers can be prevented, if screened for and/or detected early and treated at an early stage. This could significantly reduce the death rate from cancers.^[2] In Gujarat, a number of cancer cases and deaths registered were 29499 and 1823, respectively, in 2019.^[3]

Palliative care improves the quality of life (QoL) of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.^[4] Hospice care helps patients and

Address for correspondence: Dr. Disha Geriya, Department of Community Medicine, Dr. M. K. Shah Medical College and Research Centre, Ahmedabad, Gujarat - 382 424, India. E-mail: dishageriya@gmail.com

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: WKHLRPMedknow_reprints@wolterskluwer.com

How to cite this article: Geriya D, Dave V. Assessment of quality of life among terminally ill cancer patients receiving palliative care at Hospice Centre, Ahmedabad City, India. Indian J Community Med 2024;49:115-9.

Received: 14-02-23, **Accepted:** 06-11-23, **Published:** 12-01-24

Access this article online

Quick Response Code:



Website:
www.ijcm.org.in

DOI:
10.4103/ijcm.ijcm_88_23

their family to cope with the change from treating the cancer to living life as fully as possible through their final days. The availability of hospice center in India is minimal as compared to the total cancer cases in India, and there are only 144 hospice centers including only seven in Gujarat.^[5]

In India, the National Programme for Prevention and Control of Coronary Heart Disease, Diabetes, Cancer and Stroke (NPCDCS) is the mainstay for the management of cancer, including its terminal stage. Palliative care is also included, with the purpose to improve QoL of terminally ill cancer patients. Research on QoL among terminally ill cancer cases admitted in hospice centers is lacking all over India, especially in the state of Gujarat. Each national health program has obvious in-built component of evaluation within, but for cancer, the QoL at the terminally ill stage was found being handled inadequately. So, the present study was planned to assess sociodemographic and clinical profile of cancer patients and the QoL among terminally ill cancer patients receiving palliative care and study various determinants affecting the QoL of study participants.

MATERIALS AND METHODS

A cross-sectional prospective observational study was conducted among terminally ill cancer patients receiving palliative care at the Hospice Center, Community Oncology Center, Ahmedabad. A study was initiated after the approval of the Institutional Ethics Committee (DCGI Registration No. ECR/339/Inst/GJ/2013/RR16) with research proposal approval no. 2019/0056 and authorities of the study site. Various aspects of research, including data collection, data entry, and analysis, were conducted from February 2019 to September 2021.

Sampling technique and sample size

Data of patients admitted at selected Hospice center during last two years (2017 – 18 & 2018 – 19) number of patients were assessed which revealed number of patients registered were 326 and 383 respectively. Annually the average number of patients admitted in last two years were 354. Based on these, sample size of 360 was taken. Data collection was collected between Feb 2020 – May 2021. Due to COVID -19, in between duration, no patients were available at hospice center, so data collection duration was increased.

At each point of visits, the list of admitted participants was obtained and study participants were chosen by a simple random sampling method (lottery method) after applying exclusion criteria for avoidance of selection bias. During a single visit, four to six participants were interviewed, considering the details of questionnaire and feasibility.

Exclusion criteria

a) Patient who are seriously ill up to extent that they were unable to respond, b) had a previous positive history of psychiatric illness before the diagnosis of cancer, c) not giving consent to be a part of study, and d) undergoing only palliative outpatient department (OPD) care and not admitted at hospice center were excluded.

From all the patients, written informed consent was obtained before data collection. Data were collected using the prestructured questionnaire, which included various sociodemographic variables, including socioeconomic classification as per the modified Prasad classification,^[6] behavioral risk factors, comorbidities, details regarding cancer and its treatment taken so far, and information about palliative care received by the patient.

QoL was assessed using “Quality of life Questionnaire Version II-Indian Scenario.”^[7] A questionnaire regarding “QoL” of patients suffering from cancer was constructed and validated at Cancer Institute, Chennai, by Vidhubala *et al.* (2011).^[7] This questionnaire contained 11 factors with 42 items as follows: 1. general well-being (5 items), 2. physical well-being (11 items), 3. psychosocial well-being (8 items), 4. familial relationship (4 items), 5. sexual and personal well-being (2 items), 6. cognitive well-being (3 items), 7. optimism and belief (2 items), 8. economic well-being (3 items), 9. informational support (2 items), 10. patient–physician relationship (1 item), and 11. body image (1 item). The same questionnaire with added sociodemographic details was used for this study.

Scoring

Version II consists of a total of 42 items, of which 40 items had a 4-point Likert scale and the remaining two items (numbers 41 and 42) had a 10-point semantic scale. The maximum obtained score is 180, and the minimum score is 42. The interpretation of score for QoL was performed as follows: 1) below 99—significantly poor, 2) 99–117—below average, 3) 118–146—average, 4) 147–165—above average, and 5) above 165—significantly high.^[7]

Data entry was performed in Microsoft Office Excel, and analysis was performed using the Chi-square test using Statistical Package for the Social Sciences (SPSS) software. Qualitative data were described as frequency and percentages. A heat map was developed using Python Jupyter software for the Spearman rank correlation between various factors affecting QoL.^[8]

RESULTS

On assessing the age distribution, the mean age of study participants revealed was 48.1 ± 14.0 years. The majority of participants were in 41–60 years, and 12 (3.3%) participants were in <20 years of age group (including 2 just 4 years old). As per the gender distribution, there were more males (62.7%) than females (37.3%). Approximately one-third of study participants had family history of cancer diseases in first-degree relatives. Studying the involvement of various anatomical sites as “primary site of cancer” revealed that head and neck carcinoma had the highest (63.3%) involvement and hematological cancer had the lowest (0.6%) involvement. Tumor, node, and metastasis (TNM) classification for staging of cancer was obtained from medical records or case files. Most of them (96.7%) were in stages III and IV of carcinoma. Participants classified in stage II (12 or 3.3%) were admitted

in the hospice center due to certain social issues, mostly being nonavailability of caretaker at home. On analyzing, the time lag between cancer diagnosis and treatment initiation, in 134 (37.2%) cases, was between 2 and 3 months, of which 51 and 81 participants had significantly poor QoL and below-average QoL, respectively [Table 1].

Significantly poor QoL was seen among female genitourinary (66.6%) and breast cancer (46.6%). As long as there was a time lag between diagnosis and treatment of cancer, it affected the QoL among patients. A total of 66 (39.2%) participants of stage IV cancer had significantly poor QoL compared with other patients. Of total, 58.6% of cases who did not take any type of treatment suffered from significantly poor QoL. There was

a statistically significant association between type of cancer, time lag in diagnosis and treatment initiation, type of treatment taken, and QoL among study participants. No statistically significant association was revealed between various factors, such as education level, place of residence area, stage of cancer, behavioral risk factor, and presence of comorbidities with QoL [Table 2].

As described in the methodology, for assessing various factors of QoL, Python Jupyter software heat map was developed.^[8] On observing the same, it was revealed that Spearman's rank correlations between the majority of the factors fall in "low partially positive" category except for physical well-being (factor 2) and psychosocial

Table 1: Distribution of different variables pertinent to cancer among study participants (n=360)

Variables	Frequency (%)		
	Male	Female	Total
Age and gender-wise distribution			
Age (completed years)			
0–20	8	4	12 (3.34)
21–40	66	30	96 (26.66)
41–60	114	72	186 (51.67)
61–80	36	24	60 (16.66)
81–100	2	4	6 (1.67)
Total	226 (62.7)	134 (37.3)	360 (100.0)
Family history of cancer			
Yes		120 (33.3)	
No		240 (66.7)	
Site of primary carcinoma			
Head and neck		228 (63.3)	
Respiratory		14 (3.9)	
Gastrointestinal		48 (13.4)	
Hematological		2 (0.6)	
Male genitourinary		10 (2.8)	
Female genitourinary		18 (5)	
Bone and skeletal		10 (2.7)	
Breast		30 (8.3)	
Stage of cancer as per TNM classification			
II		12 (3.3)	
III		180 (50)	
IV		168 (46.7)	
Metastasis			
Yes		234 (65)	
No		126 (35)	
Type of treatment taken*			
Surgery		186 (51.6)	
Chemotherapy		134 (37.2)	
Radiotherapy		67 (17.7)	
Not any treatment taken		138 (38.3)	
Duration gap (in months) between diagnosis and treatment initiation			
<1		10 (2.78)	
1–2		110 (30.5)	
2–3		134 (37.2)	
3–4		26 (7.2)	
4–5		25 (6.9)	
5–6		52 (14.4)	
≥6		3 (0.83)	

*Multiple choices allowed

Table 2: Association of various variables with “quality of life” of cancer patients (n=360)

Variable	Quality of life			Total	Chi-square (P)
	Significantly poor	Below average	Average		
Type of cancer					$\chi^2=34.1$, df=7 (0.002)
Head and neck	86 (37.7)	136 (59.6)	6 (2.6)	228 (63.3)	
Respiratory	0 (0)	12 (85.7)	2 (14.3)	14 (3.8)	
Gastrointestinal	8 (16.6)	38 (79.2)	2 (4.2)	48 (13.3)	
Hematological	0 (0)	2 (100)	0 (0)	2 (0.5)	
Male genitourinary	4 (40)	6 (60)	0 (0)	10 (2.7)	
Female genitourinary	12 (66.6)	6 (33.4)	0 (0)	18 (5)	
Bone and skeletal	2 (20)	8 (80)	0 (0)	10 (2.7)	
Breast	14 (46.6)	16 (53.4)	0 (0)	30 (8.3)	
Time lag (months) between diagnosis and initiation of treatment					
<1	2 (20)	6 (60)	2 (20)	10 (2.7)	$\chi^2=26.833$ df=6 (0.008)
1–2	30 (27.2)	74 (67.2)	6 (5.6)	110 (30.5)	
2–3	51 (38.1)	81 (60.4)	2 (1.5)	134 (37.2)	
3–4	11 (42.3)	15 (57.7)	0 (0)	26 (7.2)	
4–5	9 (36)	16 (64)	0 (0)	25 (6.9)	
5–6	20 (38.5)	32 (61.5)	0 (0)	52 (14.4)	
≥6	3 (100)	0 (0)	0 (0)	3 (0.8)	
Stage of cancer					
II	2 (16.7)	10 (83.3)	0 (0)	12 (3.3)	$\chi^2=7.1$, df=2 (0.12)
III	58 (32.2)	114 (63.3)	8 (4.4)	180 (50)	
IV	66 (39.2)	100 (59.5)	2 (1.3)	168 (46.6)	
Type of treatment taken*					
Surgery	35 (18.9)	150 (80.6)	1 (0.5)	186 (51.6)	$\chi^2=132.27$, df=3 (0.00001)
Chemotherapy	7 (5.2)	126 (94.1)	1 (0.7)	134 (37.2)	
Radiotherapy	3 (4.6)	58 (90.8)	3 (4.6)	64 (17.7)	
Not taken any treatment	81 (58.6)	52 (37.6)	5 (3.6)	138 (38.3)	

*Multiple responses. **For calculation of Chi-square, average and below-average categories were merged

well-being (factor 3) with optimism and belief (factor 7), where the same was found to be in “low partially negative” category [Figure 1].

On observing, 212 (68.8%) participants had less than 25000 rupees spent for the out-of-pocket expenditure (OOPE) assimilated from the diagnosis of cancer till the time of interview, while 10 (3.2%) participants had the out-of-pocket expense of more than one lac rupees [Figure 2]. The median OOPE was Rs 15,000 with interquartile range of Rs 19800.

DISCUSSION

In this research, interview of a total of 360 study participants was conducted who were in the terminal stage of cancer and receiving palliative care at the time of interview. Of them, 226 (62.8%) participants were females and 134 (37.2%) were males. The mean age of participants was 48.1 ± 13.0 years, and almost equal results for mean age were found by Jacob *et al.*^[9] (49.1 ± 11.9 years) and Agarwal *et al.*^[10] (46.8 ± 13.8 year) in their similar research.

In the current study, it was found that, of total, 12 (3.3%) participants were below 20 years of age, and 96

participants (26.7%) were in the 21–40 years’ age group, while approximately half of the participants were educated up to primary and/or secondary level and 19.4% of people were illiterate. In a similar study by Sunderam *et al.*,^[11] 6.7% and 47.5% of patients were below 30 years of age and in 30–45 years of age, respectively, while 13.5% of participants were illiterate and the rest were classified as literate (30.5%) and intermediate (44.1%) literate, which could not reveal the actual educational status of patients in line with the present study. In the current study, the involvement of various anatomical sites as “primary site of cancer” revealed that head and neck carcinoma had the highest (63.3%) involvement and hematological cancer had the lowest (0.6%) involvement. Other comparable studies^[9,12] reported that 23.3% of participants had lung carcinoma and 28.3% of participants had non-Hodgkin’s lymphoma. In particular, in head and neck carcinoma, the majority of participants were suffering from oral cancer in the present research. The difference revealed in the results of the current study and others may be due to more tobacco consumption in various forms in Gujarat.

A significant association was revealed between type of cancer and QoL in the present study, while in other studies,^[12,13] no association was found between the same variables. On

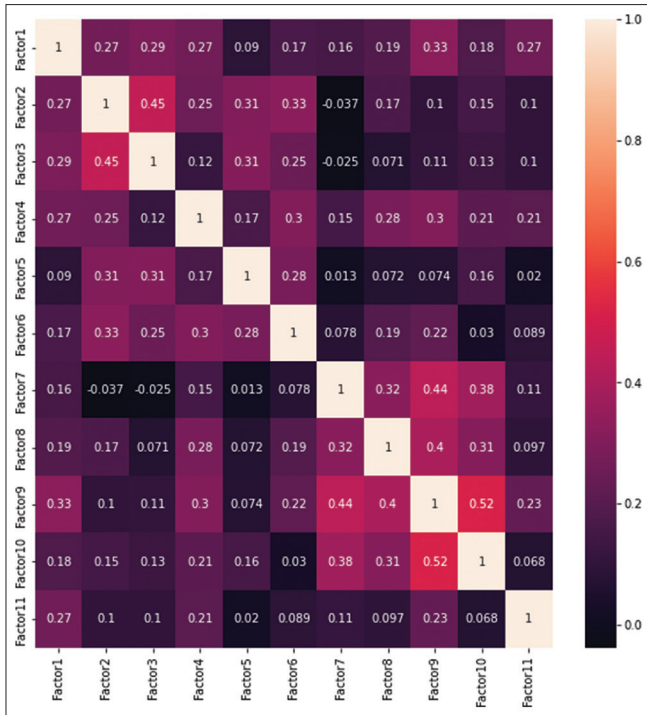


Figure 1: Correlation between different factor of quality of life among study participants (n = 360)

analyzing, there was no significant association reported between stage of cancer and QoL in this study and similar results were found by others.^[13] There was a statistically significant association noted between time lag in the initiation of treatment after cancer diagnosis and QoL in the present study.

CONCLUSION

In the present research, 62% of participants had “below-average QoL,” followed by 34.9% of participants with “significantly poor QoL.” A statistically significant association was found between various factors, such as gender, age group, occupation, socioeconomic class, type of cancer, and time lag in treatment initiation after cancer diagnosis with QoL. The mainstay of national health program is early diagnosis and treatment in terms of chemotherapy and/or radiotherapy at present. Country-wide concrete steps at the program level are lacking to provide palliative and/or hospice care, which finally results in increased physical, mental, and economic suffering on the part of not only patients but for their family members also. The matrix of sustainable services, community participation, strong political support, adopting recent advance and technologies in cancer diagnosis and treatment, high-quality research, and involvement of various media are needed at the time for better QoL for all patients diagnosed with cancer.

Limitations

Study participants were not followed up for the long term.

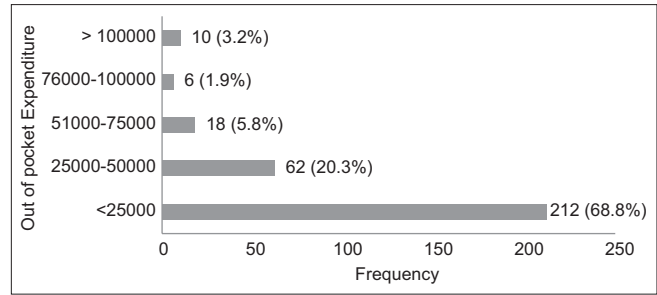


Figure 2: Distribution of “out-of-pocket expenditure” among study participants (n = 308)

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

REFERENCES

- WHO. Available from: <https://www.who.int/news-room/fact-sheets/detail/cancer>. [Online]. [Last accessed on 2023 Feb 11].
- Cancer India Organisation. Available from: <http://cancerindia.org.in/cancer-statistics/>. [Online]. [Last accessed on 2023 Feb 11].
- GCRI. Ahmedabad: s.n., 2018-2019. p. 14-5. Available from: <https://www.gcriindia.org/Download/Annual%20Report%202019-20.pdf>. [Last accessed on 2023 May 29].
- WHO. Available from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>. [Online]. [Last accessed on 2023 Feb 11].
- GLOBAL DIRECTORY OF PALLIATIVE CARE INSTITUTIONS AND ORGANIZATIONS. Available from: <https://hospicecare.com/global-directory-of-providers-organizations/search/?idcountry=39>. [Online]. [Last accessed on 2021 Aug 27].
- Majhi MM, Bhatnagar N. Updated B.G Prasad’s classification for the year 2021. *J Family Med Prim Care* 2021;10:4318-9.
- Vidhubala E, Latha, Ravikannan R, Mani CS, Muthuvel R, Surendren V, et al. Validation of cancer institute quality of life questionnaire version II for cancer patients in India. *Indian J Cancer* 2011;48:500-6.
- Python Software. Available from: <https://jupyter.org/try>. [Online]. [Last accessed on 2021 Oct 21].
- Jacob J, Palat G, Verghese N, Kumari P, Rapelli V, Kumari S, et al. Health-related quality of life and its socio-economic and cultural predictors among advanced cancer patients: Evidence from the APPROACH cross-sectional survey in Hyderabad-India. *BMC Palliat Care* 2019;18:94. Erratum in: *BMC Palliat Care* 2020;19:11.
- Agarwal S, Garg R, Minhas V, Bhatnagar S, Mishra S, Kumar V, et al. To assess the prevalence and predictors of cancer-related fatigue and its impact on quality of life in advanced cancer patients receiving palliative care in a tertiary care hospital: A cross-sectional descriptive study. *Indian J Palliat Care* 2020;26:523-7.
- Sunderam S, Haider S, Kumar M, Kashyap V, Singh SB, Jeseena S. Assessment of quality of life of cancer patients attending oncology clinic in a tertiary care hospital of Jharkhand, India. *Int J Community Med Public Health* 2016;3:281-6.
- Kannan G, Rani V, Ananthanarayanan RM, Palani T, Nigam N, Janardhan V, et al. Assessment of quality of life of cancer patients in a tertiary care hospital of South India. *J Can Res Ther* 2011;7:275-9.
- Nayak MG, George A, Vidyasagar MS, Mathew S, Nayak S, Nayak BS, et al. Quality of life among cancer patients. *Indian J Palliat Care* 2017;23:445-50.