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Quality of Life Among Community Dwelling Cancer Patients in a Hilly District of North India

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ABSTRACT

Quality of life among cancer patients is a serious concern. Future predictions point towards increasing number of cancer cases. Steps to improve quality of life of such cases will be required. This study was planned to assess the quality of life among cancer patients and to look into the aspects which affect their quality of life This study will facilitate to make recommendations to improve the quality of life of cases. Our study is a community-based cross-sectional descriptive study. Our study subjects are cancer patients registered with the state cancer registry and residents of Solan District in Himachal Pradesh. We used Karnofksy Performance Scale (KPS) and Functional Assessment of Cancer Therapy-General (FACT-) questionnaire to assess the activity level and quality of life domains in cancer patients. A total of 98 cancer patients were interviewed. Mean age of study subjects was 63.2 years and median 65 years. Most of the patients were in advanced stages and were on palliative care. Majority of participants were having a score between 50 and 70 on KPS, indicating dependence for daily activities. Participants had a mean FACT-G score of 59.3±15.8. Emotional and functional well being domains were most affected adversely. Our results show that the quality of life among cancer patients is low. Apart from the social domain of well being, all other domains were found to be low. These can be addressed by a focused approach to improve physical, functional and emotional dimensions in cancer patients under the National Programme for Palliative Care in India.

INTRODUCTION

Cancer is a one of the major public health problems and leading cause of death across the globe[1]. Globally nearly 10 million deaths and an estimated 19.3 million new cancer cases occurred in 2020.Incidence of cancer is expected to increase to 28.4 million cases by 2040[2]. The future disease load may be even higher due to increasing prevalence of risk factors, for instance smoking, physical inactivity and unhealthy diet[3]. Quality of life among cancer patients is adversely affected because of physical discomfort, mental stress, and financial burden by disease symptoms and treatment procedures or protocols of chemotherapy and radiotherapy[4,5]. An effective Palliative Care approach can provide apt support and control of symptoms for cancer patients[6]. The resolution number WHA 67.19 in the 67th World Health Assembly, called upon WHO and Member States for improving access to palliative care as a vital component of health systems emphasizing on primary health care and community/home-based care[7]. Palliative Care improves quality of life through prevention and relief of suffering by assessment, early identification and treatment of pain, helping with physical or psycho social problems and providing spiritual support[8]. The ‘Indian Association of Palliative Care’ was constituted in the year 1994. This organization acts as an umbrella organization for healthcare workers and for all people involved in palliative care in India. The Government of India launched the ‘National Program for Palliative Care’ in 2012, with the main objective of providing palliative care services at district level and integration of palliative care services horizontally into the general health care delivery system. Training of doctors, nurses, ASHA workers and other service providers in all the states has been carried out to provide Palliative Care services even in far-flung areas. Himachal Pradesh is predominately a hilly state in Northern part of India. District Solan is one of the twelve districts in Himachal Pradesh and is characterized by its hilly terrain and low population density. This study was designed to assess the quality of life and perceived palliative care needs of cancer patients residing in this part of the country.

MATERIALS AND METHODS

A cross sectional descriptive study was conducted among cancer patients receiving palliative care in health care facilities of Solan district in the state of Himachal Pradesh, India. The major health facilities in Solan district are one Medical College and Hospital, one Zonal Hospital, five Civil Hospitals, seven Community Health Centers, thirty-nine Primary Health Centers. All patients receiving palliative care services at these health facilities were included in the study.

Inclusion Criteria: All carcinoma, sarcoma and myeloma patients who were diagnosed, undergoing palliative chemotherapy or radiotherapy and seeking palliative care at health care facilities were included in the study. These study subjects were registered in the cancer registry in the state.

Exclusion Criteria: The exclusion criteria were: -

- Paediatric patients below 18 years.
- Cognitively impaired patients.
- Terminally ill patients who were admitted in a hospital.
- Patients not giving the consent for the study.

Study Tools: The study tool employed was a semi-structured interview schedule containing demographic details like age, gender, educational qualification, socio economic status, type of family, marital status, health insurance etc. The other details included in the questionnaire were cancer type, cancer stage, knowledge about their disease, acceptance of disease, extent of disease etc. The FACT-G (functional assessment of cancer therapy-general) questionnaire[9] for assessment of quality of life and the Karnofsky Performance Score (KPS)[10,11] for the assessment of patients’ performance in Activities of Daily Living were administered subsequently. The KPS is a widely employed tool for evaluating a patient's functional condition. David A. Karnofsky and Joseph H. Burchenal introduced it in the year 1949. The KPS delineates a patient's functional condition using an eleven-point scale that corresponds to percentage values spanning from 100% (indicating the absence of disease and symptoms) to 0% (representing mortality). The FACT-G questionnaire is a quality-of-life instrument for all types of cancer patients. In this, the patient is asked to rate his past seven days health with statement “not at all” (0 points) true to “very much” (4 points)true on a five-point Likert scale. FACT-G questionnaire includes domains of physical well being, social/family well being, emotional well being and functional well being, to appraise the quality of life during treatment and post treatment. It is a composite scale with 27 questions with a maximum score of 108. The emotional well being component had six questions while all other domains have seven questions each.

Data Collection: All patients from district Solan registered with state cancer registry and seeking palliative care at designated health care facilities were approached and invited to participate in the study. They were informed about the purpose of the study and a written informed consent was then obtained in presence the presence of two witnesses. The information was collected from patients who gave acceptance for the study, The investigator herself administered interview schedules and questionnaires. The data were collected over a period of one year from July 1st 2021 to June 30th 2022.

Statistical Analysis: Data was entered in MS excel and expressed as percentages and proportions. Analysis was done using Epi-Info version 7.2.

Ethical Considerations: The guidelines given by ICMR (1994) and Helsinki declaration (modified 2000), were adhered to in all the patients enrolled in the study. Study has been carried out after obtaining clearance from Institutional Ethics Committee of M. M. Medical College Solan. A written permission was also obtained from the Director Health Services., Himachal Pradesh. Every precaution was taken to respect the privacy and confidentiality of the patient's information. To minimize the impact of the study on his/her physical and mental integrity and his/her personality all due care and caution was taken. The participant was given the right to abstain from participation in the study or to withdraw consent to participate at any time of the study without reprisal. The study had not imposed any financial burden on the participants.

RESULTS AND DISCUSSIONS

In this study, a total of 98 cancer patients were interviewed. There were 52 females (53.1%) and 46 male (46.9%) participants in the study. (Fig. 1) shows the age distribution of study participants. Most of the participants were above the age of 60 years with 58% participants in the age group of 60-80 years and three participants above the age of 80 years. Mean age was 63.2 years and median age was65 years. Range of age of the study participants was 26 years through 90 years.

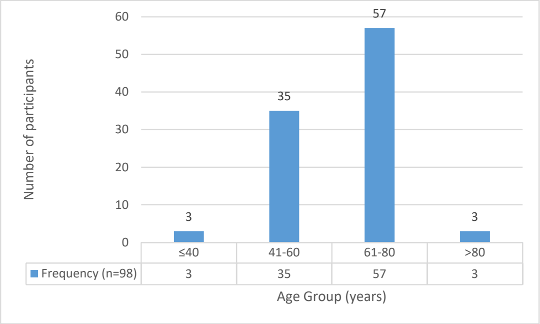

Fig. 1: Bar Diagram Showing the Distribution of Participants According to Age Group

(Table 1) shows the distribution of participants according to their educational qualifications. More than a third of participants were illiterate or had no formal education. Except for one participant, all the other participants were married. Around two- thirds of the participants were living in extended families and remaining one-third of study participants were living in nuclear families. Seventy-three participants (74.5%) were not having any occupation and were unemployed, the rest 25 participants (25.5%) reported to have been occupied mostly in agricultural pursuits.

Table 1: Educational Qualification of Participants

S. No.	Education Qualification	Frequency (n=98)	Percentage
1.	Illiterate	36	36.7%
2.	Primary	21	21.4%
3.	Secondary	28	28.6%
4.	Graduation	11	11.2%
5.	Above	2	2.0%
6.	Total	98	100%

According to the Modified Uday Pareek Scale, most of the patients (71.4%) were belonging to middle socio-economic status class. Around one-tenth of the participants belonged to upper class and the rest belonged to lower socio-economic status class. Sixty-six (67.3%) of the participants had health insurance and were enrolled under different insurance schemes like Him Care, State Insurance Scheme, Ayushman Bharat, ESIC. The rest did not have any insurance and were incurring out of pocket expenditure for availing health services. Localized or non-metastatic cancers were the diagnosis in 64 (65.3%) participants and metastatic cancers were diagnosed in 34 (34.7%) participants. (Table 2) shows the distribution of cancer diagnosis among study participants. Lung cancer and genito-urinary cancers were observed in higher frequency. Sixty-nine (70%) of the study participants were in the last stage of cancer i.e. Stage IV of cancer. This was followed by 18% of the participants in Stage III and 10% of participants in stage II. Only one participant was in stage I of cancer. The diagnosis of cancer was made within the last one year in 43 (43.9%) participants. The rest of participants had survived for more than one year since the diagnosis and 29.6% had been living with a cancer for over two years.

Table 2: Listing Distribution of Diagnosis of Participants

S. no.	Type of Cancer	Frequency	Percentage
1.	Gastro-intestinal cancers	17	17.3%
2.	Breast cancer	10	10.2%
3.	Lung cancer	22	22.4%
4.	Head and neck cancers	17	17.3%
5.	Genito urinary cancer (female)	17	17.3%
6.	Genito urinary (male) cancers	7	7.1%
7.	Multiple myeloma	4	4.1%
8.	Sarcoma	2	2.0%
9.	Malignancy of unknown origin	2	2.0%
10.	Total	98	100%

Around 62 percent of the participants had undergone more than six radiotherapy or chemotherapy sessions, while 25 percent had undergone three to five chemotherapy or radiotherapy sessions. The rest had not undergone radiotherapy or chemotherapy. Seventeen participants (17.3%) were not aware about their cancer diagnosis and eighteen participants (18.4%) did not know that their diagnosis could be fatal. As per the Karnofsky Performance Scores of participants(Table 3), 19(19.4%) were scoring in the group above 70 that corresponds to normal activity and work. These participants required no special care. Majority of the participants (75.5%) were having a score between 50 and 70 and they were unable to do any work and required assistance in some form. Five participants were not able to take care of self and were scoring below 40 on KPS.

Table 3: Distribution of Participants by Karnofsky Performance Scale Score (KPS)

S. No.	KPS	Frequency (n=98)	Percentage
1.	Score more than 70	19	19.4%
2.	Score 50-70	74	75.5%
3.	Less than 40	5	5.1%
4.	Total	98	100%

There are four domains of FACT-G (Table 4) questionnaire viz. physical well being, social well being, emotional well being and functional well being. Participants had a mean score of 14.04 (6.15) for physical well being and 20.96 (4.22) mean social well being score. Emotional and functional well being scores were even lower and were 12.69 (4.82) and 11.66 (5.20) respectively. The overall FACT-G score was 59.31(15.81).

Table 4: FACT- G Scores of Participants

S. No.	Sub Scale	Mean (SD)
1.	Physical well being	14.04 (6.15)
2.	Social well being	20.96 (4.22)
3.	Emotional well being	12.69 (4.82)
4.	Functional well being	11.66 (5.20)
5.	Total FACT-G Score	59.31 (15.81)

This study was done to get an insight on quality of life of cancer patients living in hilly areas of Shivalik ranges of Himachal Pradesh. The distribution of the disease was almost equal in both the sexes. Most common body parts involved were lungs, genito-urinary organs, gastro-intestinal tract and head and neck. Majority of the participants were having metastatic cancers. Cancers of all types adversely affect the quality of life. In this study, we used two scales Karnofsky's Performance Scale and the FACT-G questionnaire for assessment of well being and quality of life among cancer patients. Around three fourths of the participants had a KPS Score between 50 and 70 showing moderate limitation of activity and dependence for daily activities. The overall FACT-G score was 59.3±15.8) out of 108. Emotional well being and functional well-being scores were low among participants. Social well being was the only domain which had a mean score above 20 out of 27, indicating that the perceived social support is available in community dwellings. We have limited number of studies about quality of life of cancer patients in India. Nayak M.G. *et al.* reported a low quality of life in more than 80% of their study participants in a study done in hospitals in Karnataka[5]. They concluded that management of symptoms and pain are the major factors effecting the quality of life among cancer patients. Contrary to this the study done by Khanum R.S. *et al*. in Mysuru, Karnataka reports good quality of life among women diagnosed with cancer[12]. Most of their participants were having mild symptoms and likely disease was not in advanced stages. They also concluded that cancer poses a lot of financial burden on the families particularly those belonging to low socio-economic background. Ramasubbu[13] used FACT-G to assess the quality of life among patients receiving chemotherapy. They reported that chemotherapy adversely affects quality of life. The participants in their study had a mean FACT-G score of 61.9±5.8 which is similar to the results of our study[13]. They also concluded that there are limited number of tools available to assess of quality of life, particularly in Indian languages. A study done at All India Institute of Medical Sciences, New Delhi, among advanced cancer patients receiving palliative care reported that more than half of the participants had difficulty in daily living and around 80% had difficulty in doing heavy work[14]. They concluded that palliative care services at all levels of health care can improve quality of life in patients with advanced cancers. There is paucity of data regarding availability and quality of palliative care services. The findings of our study highlight that the physical and functional well being of cancer patients is below expected levels. Provision of quality palliative care services can improve these two domains, thus improving health and quality of life of patients living with cancers. In a developing country like India, public awareness and education of care-givers regarding palliative care are one of the first steps to improve quality of life of cancer patients. The National Palliative Care Programme was launched more than a decade ago. In present times, it is important to evaluate its outcomes, achievements and shortcomings. Surveys to assess palliative care needs and implementation of standard models of care to assess their feasibility and cost of services are required before implementation of the revised programme. Our study was done among the residents of a Hilly region of Himachal Pradesh. As such, the findings of the study cannot be generalized to the whole of country. Yet is must be kept in mind that the health infrastructure and indicators in this state are better than the National average and thus it can be cautiously presumed that quality of life among cancer patients in certain states can be worse. The major strength of our study was inclusion of all the cancer patients with advanced cancers in this area. It is among the few studies done in community settings and not in some tertiary care center, therefore, giving a better understanding into lives of patients. It can be concluded that patients with cancers (advanced) tend to have a low quality of life. Palliative care services can improve certain aspects of quality of life of these patients. With the rising number of cancer patients and time elapsed since the launch of the programme, a revision in the National Programme for Palliative Care has to be on the priority list of policy makers. An evidence-driven, cost-effective and comprehensive policy involving all aspects of cancer care, from prevention of specific cancers to end-of-life care, should be the back-bone for provision of care to cancer patients in the country. We don't have any such published study in northern India. The life of people in Himachal is tough, though the environmental pollution is less and also the reach of health services is better as compared to the other parts. It is a population-based study and thus the results have better generalizability than hospital-based studies.

CONCLUSIONS

The main limitation of the study is that, Himachal has a different topography, life-style, environmental scenario and health care setup which may not apply to other parts of the country, therefore the results may not be extrapolated to all parts of the country.

Recommendations: We need to include the contents of Palliative care in the curriculum of medical and nursing graduates with a focus on duties and responsibilities of Indian Medical Graduate in the field. Government of India needs to address the issue in its policy so that we can provide better health care to cancer cases and reduce out of pocket expenditure. We need to have more studies on the subject so that we have a better understanding and of the subject.

REFERENCES

1. IARC 2023. Global Cancer Observatory: World Health Organization. Cancer today [Internet]., Vol. 0.
2. Sung, H., J. Ferlay, R.L. Siegel, M. Laversanne, I. Soerjomataram, A. Jemal and F. Bray, 2021. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. CA: A Cancer J. Clinicians, 71: 209-249.
3. Bray, F., J. Ferlay, I. Soerjomataram, R.L. Siegel, L.A. Torre and A. Jemal, 2018. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA: A Cancer J. Clinicians, 68: 394-424.
4. Aboshaiqah, A., T.S.B. Al-Saedi, M.M.M. Abu-Al-Ruyhaylah, A.A. Aloufi and M.O. Alharbi *et al.*, 2016. Quality of life and satisfaction with care among palliative cancer patients in Saudi Arabia. Palliative Supportive Care, 14: 621-627.
5. Nayak, M., A. George, M. Vidyasagar, S. Mathew and S. Nayak *et al.,* 2017. Quality of life among cancer patients. Indian J. Palliative Care, 23: 445-450.
6. Lau, L.K.P., E. Mok, T. Lai and B. Chung, 2013. Quality-of-Life Concerns of Chinese Patients With Advanced Cancer. Social Work Health Care, 52: 59-77.
7. Resolution, W.H.A., 2014. Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course. The E-Book of Authorities [Internet]., Vol. 0 .10.3109/15360288.2014.911801.
8. Paiva, C.E., C.B. FARIA, M.S.D.A. Nascimento, R.D. Santos, H.H.L.R.C. Scapulatempo, E. COSTA and B.S.R. Paiva, 2012. Effectiveness of a palliative care outpatient programme in improving cancer-related symptoms among ambulatory Brazilian patients. Eur. J. Cancer Care, 21: 124-130.
9. Cella, D.F., D.S. Tulsky, G. Gray, B. Sarafian and E. Linn et al., 1993. The Functional Assessment of Cancer Therapy scale: Development and validation of the general measure.. J. Clin. Oncol., 11: 570-579.
10. ÇELTEK, N.Y., M. SÜREN, O. DEMIR and I. OKAN, 2019. Karnofsky Performance Scale validity and reliability of Turkish palliative cancer patients. TURKISH JOURNAL OF MEDICAL SCIENCES, 49: 894-898.
11. Wang, C.H., C.Y. Lin, J.S. Chen, C.L. Ho and K.M. Rau *et al.*, 2019. Karnofsky Performance Status as A Predictive Factor for Cancer-Related Fatigue Treatment with Astragalus Polysaccharides (PG2) Injection-A Double Blind, Multi-Center, Randomized Phase IV Study. Cancers, Vol. 11 .10.3390/cancers11020128.
12. Khanum, R.S., S.K.D. , S.K. Verma and N.M. R, 2021. Assessment of quality of life among cancer patients in a cancer care center of Mysuru. Int. J. Of Community Med. And Public Health, 8: 4470-4474.
13. Ramasubbu, S.K., R.K. Pasricha, U.K. Nath, V.S. Rawat and B. Das, 2021. Quality of life and factors affecting it in adult cancer patients undergoing cancer chemotherapy in a tertiary care hospital. Cancer Rep., Vol. 4 .10.1002/cnr2.1312.
14. Garg, R., S. Asthana, S. Bhatia, R. Dhoundiyal, S. Labani and S. Bhatnagar, 2019. Quality of life and needs of the Indian advanced cancer patients receiving palliative careAssessment of the quality of life, problems and needs of the advanced cancer patient receiving palliative care. Cancer Res., Stat., Treat., Vol. 2 .10.4103/crst.crst_61_19.