

HealthCare-Related Quality of Life and Lived Existential Experiences among Young Adults Diagnosed with Cancer: A Mixed-Method Study

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Abstract

Background: As cancer is a noncommunicable disease and it is a major global burden in terms of finances. It is also affecting quality of life of a person completely. **Aim:** The aim of the present study was to identify the effect of cancer on quality of life of an individual as a whole. **Methods:** The present study was triangulation study, and we examined 30 young adult cancer patients of age group 20–44 years who were admitted in different oncological units of our hospital in 2018. We included all their case datasheets for identifying clinical variables. Data collection tools used were the European organization for research and treatment for cancer quality of life questionnaire (version 3-Hindi). Qualitative data were collected using open-ended questionnaire regarding young adult cancer patient's experiences, feelings, and difficulties faced during cancer diagnosis and treatment. **Results:** Results concluded that young adult cancer patient's global health status score were average. Their physical function as well as social function score depicted that both were affected significantly, whereas cognitive functions were not affected anymore. Most commonly symptoms faced by young adult's cancer patients were pain, insomnia, fatigue, nausea, vomiting, and appetite loss. Financial burden was major burden faced by patient as well as caregiver during the diagnosis and treatment of cancer. From qualitative data of the study, it was concluded that when patient were first told about cancer diagnosis first, they feel sad. Their primary relatives were first informed about their diagnosis. Most of patient's cancer were diagnosed in first stage. Cancer had affected patient's personal as well as social life completely. Nobody helps them during the diagnosis and treatment of their disease. Majority of cancer treatment options were chemotherapy, radiation therapy, and surgery and majority of them were getting chemotherapy from AIIMS, Rishikesh. The most common difficulty the patient's faced during the diagnosis of cancer was financial. Patient's opinion for cancer and its treatment were that everybody who had any symptoms of cancer they should immediately come to hospital for treatment. When we asked them about effect of cancer as a whole their responses were disturbed family role, disturbed attachment with family and friends, disturbed social role, financial burden as well as disturbed education, respectively. **Conclusion:** From this study, we concluded that quality of life of young adult cancer patients were affected badly in terms of physical, social, symptomatically, and financially. It may also help to plan ahead by patients as well as health professionals to improve the patient's quality of life.

Keywords: Cancer, qualitative study, quality of life, young adult's cancer patients

INTRODUCTION

Noncommunicable diseases are major health problems globally and cancer is at top rank. It is a leading cause of death in developed as well as developing countries in the 21st century.^[1]

When we study cancer and its trend age wise, it was considered as disease of old age, for example, cancer breast, cancer prostate, and cancer colorectal. However, recent trend of different types of cancers showed that its incidence was now increasing in young age group (20–44 years) day by day.^[2] When we study the population-based cancer registry of

international versus Indian data (2006–2008), then comparison of age-adjusted rate of all sites of cancer, i.e., $C_{00}-C_{97}$ showed that in males highest incidence occurs in Brazil, i.e., in Goiania

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Submitted: 14-Dec-18 **Revised:** 30-Aug-19
Accepted: 02-Nov-19 **Published:** 28-Jan-20

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How to cite this article: Kalyani CV, Sharma SK, Kusum K, Lijumol KJ. Healthcare-related quality of life and lived existential experiences among young adults diagnosed with cancer: A mixed-method study. *Indian J Palliat Care* 2020;26:19-23.

Access this article online

Quick Response Code:



Website:
www.jpalliativecare.com

DOI:
10.4103/IJPC.IJPC_207_18

631.9/100,000, whereas in India, incidence was the highest in males in Kamrup Urban district, i.e., 206/100,000. Whereas in females again highest incidence was in Brazil, Goiania, i.e., 474.6/100,000 whereas in India, incidence were highest in Kamrup Urban district i.e., 174/100,000.^[3] When we study India's data (2006–2008) of Kamrup Urban district, the number of incidence of cancer in young age groups (20–44 years) in males were 273 out of 1952, i.e., 13.99%, whereas in females, it was 334 of 1304, i.e., 25.61%.^[3] Hence, in young adult population, cancer incidence were increasing day by day.

Quality of life meaning evaluation of the general well-being of individual and societies. According to the WHO, quality of life is defined as individual perception of life, values, objectives, standards, and interests in the framework of culture. Heydarnejad *et al.* studied on various factors affecting quality of life in cancer patients undergoing chemotherapy. It was a cross-sectional study with a total of 200 cancer patients participants who were taking chemotherapy. The study result showed a significant relationship between cancer type, pain intensity, and fatigue. There was significant difference between levels of quality of life in patients with <2 chemotherapy cycles and with 3–5 chemotherapy cycles.^[4] Thus, cancer is strongly affecting quality of life of cancer patients who were taking treatment in any form either chemotherapy. Thus, more and more researches should we require to explore areas which were affected from cancer diagnosis, treatment, and palliative care.

When we study cancer burden on Indian economy then in the year 2013 were 1086,783 rupees, whether, in the year 2015, it increases to 1148,692 rupees.^[5] Hence, cancer was leading cause of death in India, which majorly affecting young adult population of age group 20 years to 44 years and again creating a major financial burden on our country.

Bag *et al.* conducted a study cancer pattern in Nainital and adjoining districts of Uttarakhand (2012), an epidemiological survey study was conducted on 354 cases. Among these 354 cases, lung cancer cases (17.23%) were leading in males whereas in female breast cancer cases were the most prevalent (22.29%), followed by cervical (14.86%) and ovarian cancers (13.51%). They found that in man were mostly affecting from tobacco-related cancers, i.e., lungs (26.21%), larynx (11.16%), oropharynx (9.7%), etc., the finding of this study showed it was an attempt to make observation about pattern of cancer in Uttarakhand, larger studies required to assess different pattern of all sites cancer in this region.^[6]

Sharma and Singh conducted a study on spectrum of cancer in adolescents and young adult (2016). A retrospective observational study included cancer cases registered from 2011 to 2015 of age group 15–29 years of population of North India. The result showed that the incidence rate of malignancy in adolescent and young adult's age were 5.71%. Most common cancers in young age group, i.e., 15–19 years was ALL, Hodgkin lymphoma and bone tumors, whereas in older adult, i.e., 25–29 years common cancers were the head-and-neck cancers, central nervous system, breast, and gastrointestinal

cancers. Hence, spectrum of malignancies varies according to demographic distribution and age wise also.^[2]

Quality of life for cancer patients from diagnosis to treatment and beyond.... If we study how a female newly diagnosed with lymphoma at age 20 will ask the following questions. Will it hurt? Will my hair fall down? Can I still go out with my friends? How will my life going to be change? These questions will be commonly asked when as a health personnel you will be in contact with newly diagnosed patient's that why we need to have in-depth knowledge of cancer, information about treatment and effect of it on quality of life. Then only we can understand their problem and give them best possible solution for it.

Hence, the main focus of the study was to collect qualitative as well as quantitative data from cancer patients of young adult age group and to identify their quality of life.

METHODS

The study was conducted at the All India Institute of Medical Sciences (AIIMS) Rishikesh in 2018. This research study is a mixed method. The design used is a convergent parallel design entails that investigator concurrently conducted quantitative and qualitative data collection in same phase and weighs equally quantitative and qualitative data. Both data analyzed independently.

The written consent was taken from all the participants of the study. A total of 30 participants were included in the study. Ethical approval for the study was taken from Institute Ethical Committee of institute. Data collection tools for quality of life assessment were the European organization for research and treatment for cancer-quality of life questionnaire (QLQ version 3-Hindi) questionnaire.^[7] Qualitative data were collected using open-ended questionnaire, and data collection method was interview schedule. Qualitative data regarding lived existential experience has assessed using six open-ended questions. Through interview method samples allowed to express their experience without hindrance. Investigator listened and noted all conversation. After completion of data collection, all discussed points arranged from maximum number of view of experiences grouped under experiences vocalized by samples grouped under various categories. Each category according to frequency allotted rank. This rank order shows according to majority of experiences of samples.

RESULTS

The quality of life was assessed using QLQ questionnaire which includes their overall global health status, physical functioning, symptom scale scoring, and qualitative data were collected by open-ended questionnaire.

Tables 1 and 2 depicts that global health status scale score showed majority of the cancer patients had average (750) health status followed by poor (625) health status. Physical function was very much (540) affected, whereas role function

was disturbed a little (630). Emotional function were affected a little (490) followed by very much affected (480), whereas cognitive function of young adult cancer patients were not at all affected (500). Data also depicted social function of young adult cancer patients were very much (730) affected from the diagnosis and treatment of cancer.

Table 3 depicts commonly faced symptoms by young adult cancer patients were fatigue were quite a bit (860), nausea and vomiting were a little (530), pain was very much (830) common symptom, dyspnea was not at all (700), whereas insomnia was very much (633) common symptom faced by cancer patients. Table 4 depicts that young adult's cancer patients also faced symptoms such as appetite loss was a little (766), constipation (533), and diarrhea (866) were not at all symptom faced by them. Financial difficulties were very much (1700) problem faced by them during the diagnosis and treatment of cancer.

Table 5 shows qualitative data regarding patients experience when they first know about their diagnosis as cancer, they feel were sad (9). Most of young adult cancer patients (23) preferred to tell about their diagnosis to their primary relatives. Majority of patients (17) cancer were diagnosed in first stage and least patients (3) were diagnosed in the 2nd stage. Table 6 shows that most of patient's had said about effect of cancer on personal life were very much affected (12), whereas social life also affected were very much (15).

Table 7 depicts that helpful activity for cancer patients during diagnosis and treatment of cancer were nobody (11), i.e., no one help them when they were diagnosed and treated for cancer. Cancer treatment options after diagnosis were chemotherapy (22), and majority of cancer patients treatment were going with chemotherapy (19) only. Table 8 depicts that

young adult cancer patients most common difficulties faced during the diagnosis of cancer were financial difficulties (21) and during their treatment difficulties faced were physical (10) as well as financial (10) difficulties.

Table 9 depicts that young adult cancer patient's opinion for cancer and its treatment were that everyone should come immediate to the hospital for treatment at hospital (22). Table 10 depicts that effect of cancer on young adult life as a whole were disturbed family role (8), followed by disturbed attachment with family and friends (5), whereas no formal change (4) followed by least effect were on disturbed nutritional (1) as well as disturbed education (1) after having cancer diagnosis in young adult age groups.

DISCUSSION

The findings of the study were revealed that young adult cancer patients' global health status was average (750). The most common physical function (540) and social function (730) were very much (540) affected, whereas role function (630) and emotional function (490) were disturbed a little and cognitive function were not at all affected (500). Most common symptoms faced by young adults cancer patients were pain (830) and insomnia (633) were very much common symptom, fatigue were quite a bit (860) symptom, nausea and vomiting (530), and appetite loss (766) were a little symptom, dyspnea (700), constipation (533), and diarrhea (866) was not at all (700) symptom faced by them, whereas financial difficulties were very much (1700) problem faced by them during diagnosis and treatment of cancer in young adult cancer patients.

Qualitative data of the study also revealed that when patient were first diagnosed about cancer, they feel were sad (9) and most of the young adult cancer patients (23) preferred to told about their diagnosis to their primary relatives and many of patients (17) cancer were diagnosed in the first stage (17) and least patients (3) were diagnosed in the 2nd stage. When young adult cancer patients were asked about effect of cancer on your life then, on personal life affected very much (12) and on social life were very also much (15). Most commonly helpful activity during the diagnosis and treatment of cancer were nobody (11) help them when they were diagnosed and treated for cancer. Cancer treatment options after diagnosis were chemotherapy (22), and majority of cancer patients treatment were going with chemotherapy (19) only. Young adult cancer patients most common difficulties faced during

Table 1: Frequency and score of Global Health Status with quality of life questionnaire in cancer patients (n=30)

Global health status	Frequency	Score
1=very poor	6	33
2	3	33
3	9	208
4	23	750
5	3	180
6	5	230
7=excellent	11	625

Table 2: Frequency and score of physical function scale with quality of life questionnaire in cancer patients (n=30)

Item options	Physical function		Role function		Emotional function		Cognitive function		Social function	
	Frequency	Score	Frequency	Score	Frequency	Score	Frequency	Score	Frequency	Score
Not at all	60	266	21	216	27	47	38	500	29	350
A little	41	516	23	630	47	490	24	266	12	266
Quite a bit	25	366	5	116	23	327	12	66	6	166
Very much	24	540	11	600	23	480	24	266	13	730

Table 3: Frequency and score of symptoms scale with quality of life questionnaire in cancer patients (n=30)

Item options	Fatigue		Nausea and vomiting		Pain		Dyspnea		Insomnia	
	Frequency	Score	Frequency	Score	Frequency	Score	Frequency	Score	Frequency	Score
Not at all	17	150	29	450	15	216	22	700	17	533
A little	24	500	17	530	16	500	5	300	5	300
Quite a bit	27	860	7	316	16	733	2	166	3	266
Very much	18	766	7	433	13	830	1	100	5	633

Table 4: Frequency and score of symptoms scale with quality of life questionnaire in cancer patients (n=30)

Item options	Appetite loss		Constipation		Diarrhea		Financial difficulties	
	Frequency	Score	Frequency	Score	Frequency	Score	Frequency	Score
Not at all	8	230	17	533	27	866	7	200
A little	12	766	8	500	2	100	6	366
Quite a bit	5	466	4	366	0	0	4	366
Very much	5	633	1	100	1	100	13	1700

Table 5: Frequency and ranking of patients experience about cancer diagnosed first (n=30)

	Options	Frequency	Rank
Q. 1 When patient is first diagnosed as cancer, then experience about cancer	No effect	3	4
	Pain	3	4
	Sad	9	1
	Anxiety	1	5
	Fear	1	5
	Bit tension	8	2
Q. 1A. To whom they told first about their diagnosis of Cancer	Lot of tension	6	3
	Primary relative	23	1
	Secondary relative	5	2
Q. 1B. At what stage your cancer were diagnosed?	Friend	2	3
	Stage one level	17	1
	Stage two level	3	4
	Stage three level	-	-
	Stage four level	4	3
	Not explained	6	2

Table 6: Frequency and ranking on effect of cancer on your personal and social life

	Options	Frequency	Rank
Q. 2 Effect of cancer in your personal and social life?	No effect	8	2
	Affected	2	5
a. On personal life	Very much affected	12	1
	Work affected	7	3
	Work Role affected	4	4
b. On social life	No effect	12	2
	Affected	3	3
	Very much affected	15	1

the diagnosis of cancer were financial difficulties (21). Young adult cancer patient’s opinion for cancer and its treatment were that immediate treatment at hospital (22) is option only. Effect of cancer on young adult life as a whole was disturbed family role (8), disturbed attachment with family and friends (5),

disturbed social role (4), financial burden (4) as well as disturbed education (1) after having cancer diagnosis in young adult age groups.

CONCLUSION

Quality of life of each patient plays an important role in their life. According to this for improve quality of life of a person, the role what they possess to be preserve. As cancer is deadly disease, on the diagnosis of cancer itself every individual self-concept toward their goal has deviated. Self-concept about their individual role to preserved. For achieving a healthcare-related quality of life therapeutic communication is essential. This is to be started at the time of diagnosis of the disease. By explaining the disease and its related treatment an Individual will get hope. This should be followed throughout the disease process and side effects of treatment options should be told before patients and caregiver. The anxiety about disease, treatment, and role disturbance should be explained with proper communication. If young adults who are at the period of their education, their self-education goal, which is to be achieved, can be discussed. The reality hope about the disease, its treatment process should be explained. Family members also communicated and their role confusion goal to be achieved. A patient should be counseled properly with appropriate counselor, as per the role. Due to role deficit, the treatment process should not be disturbed.

The one more life experience every individual cancer patient come across was an economic stabilization. Economic condition which required for their treatment and family should be fulfilled. The prognosis of disease according to the stage which disease diagnosed should be explained well in advance. As a health-care professional never hesitate to discuss important concept of economic handling. Never focus only on treatment and prognosis part. By discussing various opportunity and options the anxiety of patient will be reduced and which helpful for effect of treatment also. In

Table 7: Frequency and ranking of helpful activity during diagnosis and treatment of cancer

	Options	Frequency	Rank
Q. 3. Activity helpful during diagnosis and treatment of cancer	No help	11	1
	Family	8	3
	Friends	2	4
	Doctor	10	2
	God	1	5
Q. 3 A. Cancer treatment options after diagnosis	Chemotherapy	22	1
	Surgery	11	2
	Radiotherapy	11	2
Q. 3 B How was the treatment of cancer	Chemotherapy	19	1
	Surgery	10	2
	Radiotherapy	4	3

Table 8: Frequency and ranking of difficulties faced during diagnosis and treatment

	Options	Frequency	Rank
Q. 4 Difficulties faced during diagnosis and treatment?	No effect	4	3
	Physical Difficulty	3	4
	Work role difficulty	6	2
	a. During diagnosis		
	Transport/convenience	2	5
	Financial difficulty	21	1
	b. During treatment		
	No effect	1	4
	Physical Difficulty	10	1
	Work role	6	2
Financial Difficulty	10	1	
Care difficulty	2	3	

discussing economic burden to patient alone can be stressful. The environment of family gives an enough understanding about treatment choice and economic role shifting of another person of a family. This communication helps effective treatment options. Every individual diagnosed and enroll for treatment to give importance in each discussion part of their treatment options and family commitments. This will improve their health-related quality of life of a patient. Every individual member of a health-care team equally participate in treatment options. To achieve quality of life, individual has to be acknowledged in each activity given to him.

Knowledge gained from this study could be useful for in-depth understanding of common problems faced by young adult cancer patients. It may also help to plan ahead by patients as well as health professionals to improve quality of life.

Financial support and sponsorship

Nil.

Table 9: Frequency and ranking of the opinion of other in cancer and its diagnosis

	Options	Frequency	Rank
Q. 5 In cancer and its diagnosis, what were other opinion	Immediate treatment at hospital	22	1
	No use of treatment	3	3
	Referral for another hospital/doctor	4	2
	Alternative treatment	1	4

Table 10: Frequency and ranking of the effect of cancer as a whole

	Options	F	Rank
Q. 6 Effect of cancer as a whole	No formal change	3	4
	Financial burden	3	4
	Family role disturbed	8	1
	Physical health disturbed	5	2
	Nutritional disturbed	1	5
	Social role disturbed	4	3
	Educational disturbed	1	5
	Attachment with family and friends	5	2

Conflicts of interest

There are no conflicts of interest.

REFERENCES

- Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* 2018;68:394-424.
- Sharma D, Singh G. Spectrum of cancer in adolescents and young adult: An epidemiological and clinicopathological evaluation. *Indian J Cancer* 2016;53:457-9.
- Sharma JD, Katak AC, Barman D, Sharma A, Kalita M. Cancer statistics in Kamrup urban district: Incidence and mortality in 2007-2011. *Indian J Cancer* 2016;53:600-6.
- Heydarnejad MS, Hassanpour DA, Solati DK. Factors affecting quality of life in cancer patients undergoing chemotherapy. *Afr Health Sci* 2011;11:266-70.
- National Cancer Registry Programme: Indian Council of Medical Research. Three Year Report of Population Based Cancer Registries: Incidence, Distribution, Trends in Incidence Rates and Projections of Burden of Cancer. Bengaluru, India: National Cancer Registry Programme: Indian Council of Medical Research; 2016.
- Bag A, Rawat S, Pant NK, Jyala NS, Singh A, Pandey KC. Cancer patterns in nainital and adjoining districts of Uttarakhand: A one year survey. *J Nat Sci Biol Med* 2012;3:186-8.
- Choosing between the EORTC QLQ-C30 and FACT-G for measuring health-related quality of life in cancer clinical research: issues, evidence and recommendations | *Annals of Oncology* | Oxford Academic [Internet]. Available from: <https://academic.oup.com/annonc/article/22/10/2179/236541>. [Last cited 2019 Mar 19].