Health Related Quality of Life among Blood Cancer Patients in Pakistan: A Cross Sectional Survey

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Abstract

The importance of health-related quality of life and its determinants including physical, emotional, and functional domains has long been recognized among blood cancer patients in the developed world but this concept is still in infancy in developing countries, including Pakistan. The objective of the study was to assess health related quality of life among blood cancer patients. A descriptive cross-sectional study design was used. A pre-validated questionnaire that is EORTC-QLQ-C30 was self-administered to a sample of 400 blood cancer patients selected using convenience sampling technique. After data collection, data was cleaned, coded, and entered in SPSS. Descriptive statistics comprising of frequency and percentages were calculated. Non-parametric tests Kruskal Wallis and Mann Whitney tests ($P \le .05$) were performed to find out the differences among different variables. The results highlighted that lowest scores for EORTC-QLQ-C30 were observed in the domain of emotional functioning (3.38, \pm 35.790), followed by cognitive function (4.56, \pm 30.368) whereas highest scores were observed in the domain of physical functioning (40.92, \pm 35.484). Significant difference ($P \le .05$) was observed among different domains of health-related quality of life of blood cancer patients treated in different sectors, provinces, setting, gender, and with different comorbidities. The present study concluded that blood cancer patients had poor health related quality of life in Pakistan. Emotional functioning and cognitive function were the most compromised health related quality of life domains among blood cancer patients. Females having blood cancer, those patients treated in private sector healthcare facilities, patients residing in tribal and rural setting had relatively better health related quality of life. No appropriate psychosocial care program for the blood cancer patients are available in Pakistan.

Keywords

blood cancer, health related quality of life, intervention, EORTC-QLQ-C30, psychosocial support, Pakistan

What do we already know about this topic?

The global cancer observatory reported nearly 8.2 million people died from cancer and it is predicted that this number will rise up to 13 million by 2030. Blood cancer is known as one of the most common malignancies around the world whose incidence is rising at an alarming rate.

How does your research contribute to the field?

The importance of health-related quality of life and its determinants including physical, emotional, and functional domains among blood cancer patients has been recognized in developed world but this concept is still in infancy in developing countries, including Pakistan. Limited evidence is available in this regard in Pakistan. The results of the study report poor health related quality of life among blood cancer patients in Pakistan. The study also highlights that female blood cancer patients and those patients treated in private sector healthcare facilities had comparatively better health related quality of life. Emotional functioning and cognitive function were the most compromised health related quality of life domains among blood cancer patients. This research can assist stakeholders to design and implement appropriate interventions for improving the health-related quality of life in blood cancer as well as help to initiate psychosocial care program for the blood cancer patients in the hospitals.

What are your research's implications toward theory, practice, or policy?

The stakeholders should design appropriate medical and psychosocial interventions which can be practiced in cancer care hospital wards by the healthcare team. Such interventions should include therapy changes, improved counseling practices, and enhanced palliative care. The factors affecting HRQoL should be assessed and interventions should be designed on the basis of the identified factors. The concept of quality of life must be incorporated while updating the national mental health policy for effective tackling of the issue.

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Introduction

Health related quality of life is a significant measure in hematological malignancies. It is a major concern while treating the cancer patients due to severity of symptoms as well as long duration of treatment.² Cancer patients often experience multiple concurrent symptoms and those symptoms are the predictors of changes in patient function, treatment failures, and therapeutic outcomes. A study conducted in USA reported that most of the blood cancer patients had worst health-related with multiple symptom including fatigue, pain, psychological distress, and impairing treatment outcomes.3 Similarly, studies from Canada and Germany revealed that patients of blood cancer had substantial symptom burden in disease trajectory affecting overall wellbeing. 4,5 Moreover, various symptoms like nausea, vomiting, anxiety, depression, dyspnea, fatigue, pain, and insomnia were reported to affect prognosis, quality of life, and work status of blood cancer patients in Spain.^{6,7} Another study from Iran reported that patients with cancer had lower quality of life during chemotherapy and off treatment. 8 Moreover, a study from Malaysia revealed that blood cancer patients had higher level of anxiety, depression, fatigue, pain, insomnia influencing their health outcomes.9 Another study conducted in Iran reported negative significant correlation between physical symptoms like fatigue, pain, and quality of life of cancer patients. Thus, it was suggested to design appropriate interventions such as counseling program which can help to improve symptoms, depression, and quality of life among cancer patients.¹⁰

Health-related quality of life is considered as an important endpoint in cancer. Assessing quality of life among blood cancer patients could contribute to improve treatment as well as survival of an individual.¹¹ According to WHO, in Pakistan 173 937 new cases were diagnosed with cancer in 2018 among them approximately 4.1% were of leukemia, 3.4% of non-Hodgkin's lymphoma, 0.92% Hodgkin's lymphoma, and 0.81% of multiple myeloma. 12 Limited access to health care facilities, less number of qualified oncologists, lack of technical equipment for diagnosis are the major factors effecting adequate control and prevention of blood cancer in Pakistan. Moreover, lower literacy rate, poor socio-economic status, socially stigmatized situation, and paucity of early detection programs for blood cancer add to burden of disease in Pakistan.¹³ Poor health related quality of life among blood cancer patients has been reported which highlights the need for appropriate counseling, social support, and financial support along with high quality medical treatment in collaboration with

radiologists, surgeons, pathologists, pharmacist, and other health care team which can improve survival rate among blood cancer patients in Pakistan. 14-16 As cancer is a chronic disease due to which patients feel difficulty to cope with it, which affect their health-related quality of life and they become depressed due to limited social support. Extensive research has been conducted in developed world in this regard but limited data from developing countries, including Pakistan is available on this issue as most of the studies have focused on prevalence. Therefore, the present study was designed to assess HRQoL among blood cancer patients.

Methodology

A descriptive cross-sectional study design was used to assess health related quality of life and impact of interventions applied among blood cancer patients in twin cities (Islamabad and Rawalpindi) of Pakistan. Study approval was taken from the Ethical Committee of Hamdard University (BASR-81-5.2). All health care facilities both from public and private sector treating blood cancer patients located in twin cities were included in study. Study respondents included patients diagnosed with blood cancer. Inclusion criteria for this study were blood cancer patients aged between 18 and 65 years, patients with co-morbidities such as hypertension and diabetes and patients receiving chemotherapy, radiotherapy, and Imatinib. All cancer patients other than blood cancer and those below or above the age range of 18 to 65 years were excluded. Approval was also taken from Medical superintendents of different healthcare facilities of Rawalpindi and Islamabad. Patients were briefed regarding nature and objectives of the study. Verbal and written consent were obtained prior to data collection. Respondents were ensured of the confidentiality of their responses along with full right to withdraw from the study at any time. The sample size was calculated by using Rao soft at 95% confidence interval and 5% margin of error which came to be 400. Convenience sampling technique was used for selection of respondents available and willing to participate at the time of data collection. Prospective data was collected from primary sources by selfadministering a pre-validated questionnaire that is European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) for assessment of HRQoL. The questionnaires were filled by the patients on spot and collected back to avoid biasness. EORTC QLQ-C30 is a disease-specific questionnaire administered to cancer patients to evaluate the quality of life. It consists of 30 questions, in the questionnaire comprises of 5 functional scales

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that measure physical, role, cognitive, emotional, and social functioning; 5 symptoms scale that measure fatigue, pain, and nausea or vomiting; 1 global health status scale; and a 6 single-item scale that measures dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial difficulties. ¹⁷ Pilot testing was performed on 10% of the sample size for assessing reliability of the tool. The value of Cronbach's alpha for EORTC QLQ-C30 was .78. Moreover, a structured observation form was designed to assess psychosocial care program for blood cancer patients at healthcare facilities and patients were also asked for feedback regarding provision of counseling about their disease. After data collection, data was cleaned, coded, and entered in SPSS. Descriptive statistics comprising of frequency and percentages were calculated. Non-parametric tests Kruskal Wallis and Mann Whitney tests ($P \le .05$) were performed to find out the differences among different variables.

Results

Patients Demographic Characteristics

Out of 400 respondents, 55.7% (n=223) were males and 44.2% (n=177) were females. Of the total respondents, 40% (n=160) were illiterate and 5.25% (n=21) were having master's degree. Moreover, 37.5% (n=150) were residents of urban settings whereas 62.5% (n=250) were from rural settings. Moreover, 12.7% (n=51) of the cancer patients were also suffering from diabetes, 19% (n=76) from hypertension whereas 68.5% (n=274) were free from any comorbid conditions. Patients receiving chemotherapy were 50.7% (n=203), radiotherapy 14.5% (n=58), and Imatinib treatment was 35% (n=140). A detailed description of demographic characteristics is given in (Table 1).

Health Related Quality of Life among Blood Cancer Patients

The results highlighted that lowest scores for EORTC-QLQ-C30 were observed in the domain of emotional functioning (3.38, \pm 35.790), followed by cognitive function (4.56, \pm 30.368) whereas highest scores were observed in the domain of physical functioning (40.92, \pm 35.484). A detailed description is given in (Table 2).

Comparison of HRQoL among Blood Cancer Patients by Demographic Characteristics

Significant difference ($P \le .05$) was observed in HRQoL of blood cancer patients treated in different sectors, provinces, setting, gender, and with different comorbidities. Female blood cancer patients and those patients treated in private sector healthcare facilities had comparatively better quality of life. Moreover, patients from rural settings had relatively

Table 1. Demographic Characteristics.

Indicator	n (%)
Age	
18-28 years	103 (25.7)
29-39 years	78 (19.5)
40-49 years	73 (18.2)
50-59 years	70 (17.5)
>60 years	78(19.5)
Hospital	, ,
Public	356 (95.5)
Private	44(4.5)
Province	(/
Federal	39 (9.7)
Punjab	248 (62)
Sindh	17 (4.2)
KPK	80 (20)
Baluchistan	16(4)
Gender	
Male	223 (55.7)
Female	177 (44.2)
Marital status	()
Married	287 (75.1)
Unmarried	113 (28.2)
Qualification	(20.2)
Illiterate	160 (40)
Primary	133 (33.2)
Secondary	54 (13.5)
Bachelor	34 (8.5)
Masters	21 (5.25)
No of children	2. (3.23)
None	51 (12.7)
One	60 (15)
Two	76 (19)
Three	84 (21)
More than three	130 (32.5)
Setting	130 (32.3)
Urban	150 (37.5)
Rural	250 (62.5)
Stage of blood cancer	230 (02.3)
Acute	218 (54.5)
Chronic	182 (45.5)
None	, ,
	274 (68.5)
Type of comorbidity	EI /I2 7\
Diabetes	51 (12.7)
Hypertension	76 (19)
Type of therapy	202 /527\
Chemotherapy	203 (50.7)
Radiotherapy	58 (14.5)
Imatinib	140 (35)

better quality of life. However, no significant difference $(P \le .05)$ was observed for HRQoL among different age groups, marital status, qualification level, number of children, stages of blood cancer, and type of therapy. A detailed description is given (Table 3).

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Table 2. Health Related Quality of Life among Blood Cancer Patients.

		Standard
Indicator	Mean	deviation (\pm SD)
Global health status	25.95	40.063
Physical functioning	40.92	35.484
Role physical	38.44	40.118
Emotional functioning	3.38	35.790
Cognitive functioning	4.56	30.368
Social functioning	15.14	34.783
Fatigue	10.21	69.672
Nausea and vomiting	4.89	31.866
Pain	8.93	44.992
Dyspnea	26.75	32.678
Insomnia	30.95	40.187
Appetite loss	20	40.599
Constipation	6.75	29.662
Diarrhoea	17.71	32.347
Financial difficulties	6.01	37.820

Psychosocial Care Program for Blood Cancer Patients during Treatment at Healthcare Facilities in Pakistan

No specialized psychosocial care program for blood cancer patients was present in healthcare facilities, however, counseling was been provided at only one of the tertiary healthcare facilities. It was observed that nurses were not much involved in counseling of blood cancer patients. However, few clinical pharmacists and doctors were providing counseling to the patients on chemotherapy and radiotherapy treatments. Pharmacists working at hospital pharmacy was also providing counseling to the patients during dispensing of the medication. The blood cancer patients were of the view that this counseling helped them to cope with their disease and reduce depression among them.

Discussion

Blood cancer has become one of the most prevailing cancer worldwide affecting overall standards of living of an individual. Due to prolonged therapy and recurrence of blood cancer, patients suffer from physical, emotional, social discomfort leading toward poor disease outcomes. Estimation of HRQoL is important in blood cancer, as it helps both patients and physicians in choosing better treatment option and improve health outcomes of patients. ¹⁸ The results of the present study reported a consequential impact on several domains of HRQoL among blood cancer patients in Pakistan. Most of the blood cancer patients enrolled in this study perceived their overall health and quality of life good which might be due to provision of social support and psychosocial intervention (counselling) among blood cancer patients. With regard to functional scale, the current study revealed that most of the blood cancer patients had

Table 3. Comparison of HRQOL Domains among Blood Cancer Patients by Demographic Characteristics.

Demographics	n	Mean rank	Test stats	P value
Age				
18-28	103	171.42	1.468	.831
29-39	78	177.84		
40-49	73	174.66		
50-59	70	167.17		
60-65	78	187.65		
Hospital				
Public	356	164.42	1294.5	.00 I a
Private	44	188.71		
Province				
Federal	39	186.12	18.817	.00 l ^b
Punjab	248	152.83		
Sindh	17	220.25		
KPK	80	204.43		
Baluchistan	16	279		
Gender				
Male	223	164.42	12887.5	.013a
Female	177	188.71		
Marital status				
Married	287	172.93	10106	.240
Unmarried	113	182.08		
Qualification				
Illiterate	160	184.8	4.858	.298
Primary	133	166.78		
Secondary	54	152.22		
Bachelors	34	187.5		
Masters	21	181.28		
No of children				
None	51	126.33	3.418	.488
1	60	111.97		
2	76	109.43		
3	84	109.03		
More than 3	130	126.18		
Setting				
Urban	150	159.2	12025	.018ª
Rural	250	183.08		
Stage of blood cand		105.00		
Acute	218	168.82	14109	.100
Chronic	182	182.49	11107	.100
None	274	117.17		
Type of comorbidit		117.17		
Diabetes	.y 51	145.37	10.897	.008ª
Hypertension	76	93	10.077	.000
Type of therapy	70	/3		
Chemotherapy	203	103.39	1.31	.544
. ,	203 58	57.5	1.31	.577
Radiotherapy Imatinib	38 140	37.3 105.99		
matinib	140	103.77		

^aMann-Whitney.

difficulty while performing various activities like carrying a heavy shopping bag, suitcase, taking a long walk except in emotional functioning (a little) while they were not having any difficulties at all in role, cognitive and social functioning. These findings are in line with the findings of a study conducted in

^bKrsukal Wallis Test.

 $P \leq .05$.

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Germany where most of the patients stated poor physical functioning.¹⁹ On symptom scale, the results of the present study revealed that blood cancer patients experienced pain, weakness and tiredness and few of them had vomiting, dyspnea, constipation, diarrhoea insomnia, appetite loss, and financial difficulties. These results are in line with findings of studies from USA and Korea where blood cancer patients suffered from pain and fatigue affecting their overall life activities.^{20,21}

The results of the current study highlighted relatively better health related quality of life among female cancer patients; those treated in private sector healthcare facilities, patients from tribal areas and rural settings which might be due to more intake of organic food, provision of social support, and performing daily activities by themselves depicted by higher physical functioning score. These findings are in line with studies from India, China, and Europe. 22-24 The current study revealed that cancer patients treated in private hospitals had comparatively better health related quality of life due to better facilities, advanced treatment modalities, and technologies. The findings are supported by a study from Australia in which treatment provided at private hospital was correlated with better quality of life.²⁵ Interventions are effective for improving health related quality of life.²⁶ It is important to develop successful interventions to address physical and psychosocial concerns across the course of cancer trajectory.²⁷ Psychosocial care is an essential part of the comprehensive care of the individuals suffering from cancer. These types of interventions are recommended in the management of emotional and physical distress to improve the outcomes of the cancer patients. Some of the psychosocial interventions include, cognitive-behavioral therapy, counseling, relaxation, exercise, support group, psychotherapy, communication skills training.²⁸ The results of the present highlighted that no patient counseling or social support program was available at healthcare facilities for cancer patients except in 1 healthcare facility. Physicians and hospital pharmacists were relatively involved in providing counselling to them which was well perceived by the patients in improving their coping skills and HRQoL. The findings are in line with the results of study from Australia which highlighted that support group is beneficial for improving quality of life of the people suffering from cancer.²⁹

Conclusion

The present study concluded that blood cancer patients had poor health related quality of life in Pakistan. Emotional functioning and cognitive function were the most compromised health related quality of life domains among blood cancer patients. Females having blood cancer, those patients treated in private sector healthcare facilities, patients residing in tribal and rural setting had relatively better health related quality of life. No specialized psychosocial care program for the blood cancer patients are available at healthcare facilities in Pakistan. Better quality of life among blood cancer patients can be achieved with increased level of optimism, lower level of psychological distress, and by social support.

Therefore, all stakeholders need to collaborate for designing appropriate interventions for addressing poor health related quality of life and depression among blood cancer patients which in turn will enhance treatment outcomes and better survival rates.

Declaration of Conflicting Interests

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