RESEARCH ARTICLE

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Health-Related Quality of Life and Treatment Satisfaction of Patients with Blood Cancer in Kazakhstan: A Cross-Sectional Study

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Abstract

Blood cancer is the most prevalent health problem associated with poorer health-related quality of life (HRQoL). Associations between HRQoL and its determinants including physical, emotional, and functional domains are insufficiently investigated among blood cancer patients of Kazakhstan. We aimed to assess HRQoL and treatment satisfaction of blood cancer patients in Kazakhstan. **Methods:** This was a cross-sectional study, conducted from November 2022 to December 2022, which enrolled all adult blood cancer patients registered at the healthcare facilities of Semey. This study involved 87 respondents. A questionnaire of the authors' design and the SF-36 questionnaire were used to obtain the data, which was validated. **Results:** Out of 87 patients, 47 (54,0%) were males whose mean age was 35,72 ± 1,64 years and 40 (46,0%) were females with the mean age of 45,83 ± 1,57 years. None of the patients were very satisfied with their current clinical management and status monitoring and the overall rate of patient dissatisfied or somewhat dissatisfied was 48.9%. The two questions of "How long have you been seen by a hematologist?" (p=0,019) and "How do you evaluate the organization of medical care in the field of hematology?" (p=0,000) were predictors of patient satisfaction in multiple linear regression analysis. There was a significant difference in the individual SF-36 dimensions and overall QOL scored in different age group participants. **Conclusions:** Overall, the study found that the five determinates affect QOL revealed significant differences between individual age groups and identified key determinants of patient dissatisfaction. Also, it is the first attempt to understand the experience of blood cancer patients in the healthcare system in Kazakhstan, and the results may contribute to a discussion between healthcare professionals and patients on initiatives that need to be taken to improve the quality of healthcare services provided.

Keywords: SF-36- Kazakhstan- quality of life- blood cancer- treatment satisfaction

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Introduction

Cancer ranks as a leading cause of death and an important barrier to increasing life expectancy in every country of the world (Sung et al., 2020). It is the leading cause of disability and premature death globally and has significant health and economic burden on patients, families, and healthcare systems (Fisher et al., 2021). Compared to other countries as shown in OECD data published in 2019, the cancer death in most countries ranged from 164 per 100,000 persons in Japan, 167 per 100,000 persons in Switzerland, and 180 per 100,000 persons in Australia to the highest number of 264 per 100,000 persons in Hungary (OECD., 2022). Hematologic malignancies encompass a wide range of neoplasms, including leukemia, lymphoma, multiple myeloma, myelodysplastic syndrome, and myeloproliferative neoplasms, which all account for 10% of all malignancies (Jarden et al., 2016).

Health-related quality of life is a significant measure of hematological malignancies (Johnsen et al., 2009). At present, patient satisfaction is extensively used to evaluate the quality of healthcare services, as it is considered an important indicator of the healthcare system's functioning. Patient satisfaction has gradually developed as an outcome measurement for evaluating and improving health and care services (Manzoor et al., 2019). It is a special form of consumer attitude that is, a postexperience phenomenon reflecting how much a patient liked or disliked the service (Hwang et al., 2020). Patient satisfaction has multiple

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influences on patient compliance and retention, treatment outcomes, and medical malpractice claims (Tsigengagel et al., 2022). A study organized in the USA reported that most blood cancer patients had the worst health-related multiple symptoms encompassing fatigue, pain, psychological distress, and impairing treatment outcomes (Phillips et al., 2013). A more recent study reported that although survival has improved among patients with acute leukemia, there is still a considerable risk of severe complications throughout treatment. This contrast increases the interest in monitoring the health-related quality of life (HRQOL) in these patients (Moller et al., 2012). These measures provide a comprehensive assessment of the burden of preventable diseases, injuries, and disabilities (Yin S., et al 2016). Moreover, another study revealed that actually persisting fatigue limits the adherence of patients to cancer therapy (Tariman et al., 2016). It is important to develop successful interventions to address physical and psychosocial concerns across the course of cancer trajectory (Malik M et al., 2021).

Several systematic reviews have examined the impact of peer support in cancer populations (Driessen et al., 2022, Meyer et al., 2015, Walshe, C et al., 2018), and results indicated that patients improved over time in most psychosocial outcomes, which is consistent with other longitudinal studies exploring quality of life (QOL) and psychological health in patients with AL throughout the treatment trajectory (Korol et al., 2017, Jarden et al., 2016, Alibhai et al., 2015). In general, patients are likely to be satisfied with the quality of services if they are provided in a timely, efficient, and patient-oriented manner. The nature of the disease (Hwang et al., 2020) might also affect satisfaction with the quality of care as patients suffering from chronic progressive disorders tend to be less satisfied (Karaca et al., 2019). Extensive research has been conducted in the developed world in this regard but limited data from developing countries, including Kazakhstan, is available on this issue as most of the studies have focused on prevalence (Aitbekov et al., 2022). Therefore, the present study was designed to assess HRQoL and satisfaction among blood cancer patients in Semey, East Kazakhstan.

Materials and Methods

This was a cross-sectional study, conducted from November 2022 to December 2022, which enrolled all adult blood cancer patients registered at the healthcare facilities of Semey. The Regional Health Authority has established a Clinical Registry that collects compulsory information on all patients with confirmed blood cancer during routine clinical practice. From the electronic database, we extracted information on all blood cancer patients aged 18 years and older, contacted them by phone, and invited them to participate in the study. The only exclusion criteria were a psychiatric disease-causing cognitive impairment and the inability of taking part in the study (according to the investigator's opinion) as well as the patient's refusal to participate. All 87 invited patients accepted to participate. We calculated the response rate as 33.1 %, which is a good response.

Data Collection Tool

Two instruments were used for obtaining the data: (1) a questionnaire of the authors' design and (2) the SF-36 questionnaire. All patients were asked to complete a paper questionnaire consisting of a demographic part and a patient satisfaction part. A nonstandardized questionnaire of the authors' design was used to identify the sociodemographic profiles of patients, containing six items. The studied factors covered age, education, marital status, and employment status. To describe the degree of satisfaction with current clinical management and status monitoring, patients were asked to self-evaluate the extent of their satisfaction based on a six-point Likert scale (very satisfied, satisfied, somewhat satisfied, somewhat dissatisfied, and dissatisfied) (Pascoe et al., 2018).

We employed a short form 36 (SF-36) health survey questionnaire, i.e., an abbreviated version containing 36 questions. For this purpose, the Russian-language version of RAND SF-36 health survey questionnaire was used and underwent validation (Pascoe et al., 2018, McHorney et al., 1993, Pogosova et al., 2014). In order to ensure the accuracy of the translation, the questionnaire was translated from Russian into Kazakh and compared with the original version. Further, it was validated through a pilot run using a group of 10 randomly selected individuals who were interviewed to ensure the reliability and suitability of the survey. The results of the pilot testing confirmed minor changes, and, based on the results of the pilot run, the final corrected version of the questionnaire was utilized to carry out the current study. This standardized questionnaire can be used to discover all health problems of a physical character, as well as general mental health, in order to make a general evaluation of the quality of life. The questionnaire is composed of 36 items divided into 8 dimensions. The individual dimensions are as follows: PF, physical functioning; RP, restrictions due to physical problems; BP, body pain; GH, general health; VT, vitality/tiredness; SF, social functioning; RE, restrictions due to emotional problems; MH, mental health. The patients' physical and psychological spheres were also generally assessed. Each item (question) contains several suggested answers according to the scale principle.

Statistical Analysis

The data were analyzed using IBM SPSS version 23.0 statistical software and descriptive statistics and nonparametric tests were used to analyze the data. Tests of the distribution of variables (Tests of Normality) were exploited using the Kolmogorov-Smirnov and Shapiro-Wilk tests. The 95% confidence interval of proportion was calculated using the Wald method. In the first stage of data analysis, basic descriptive statistics were directed at the sociodemographic and clinical characteristics of blood cancer patients. In the second stage of data analysis, descriptive tests of various sociodemographic and clinical factors connected with patient satisfaction were carried out. We performed multiple linear regression analysis for dichotomous outcomes to analyze various risk factors interrelated with patient satisfaction. For this, we combined two grades of satisfaction (satisfied and somewhat satisfied) into one (satisfied). In the third

stage, we executed nonparametric tests (Chi-Square, Mann-Whitney, and Kruskal-Wallis tests) which were applied to the significance calculations. Based on this analysis, data was interpreted and relevant tables were processed.

Results

Overall, this study comprised 87 patients with blood cancer, of whom 47 (54.0 %) were males with the mean age of 35,72 ± 1,64 years and 40 (46,0%) were females whose mean age was 45,83 ± 1,57 years. More than half of all patients 49 (56.3 %) had attained secondary vocational education and over were either married. Most patients (55.2%) were employed, as depicted in Table 1.

None of the patients were very satisfied with their current clinical management and status monitoring. Only 13 patients (15.1 %) were satisfied and 31 patients (36,0%) were somewhat satisfied with the quality of care and the rest were dissatisfied to a certain extent. Furthermore, questions such as "How long have you been seen by a hematologist?" (p = 0,036), "Does the hematologist inform you about the features of your disease?" (p = 0,025), "How many times have you been treated in a hematology hospital during the last year?" (p = 0,056)

Table 1. Sociodemographic Characteristics of the Study Participants (n = 87)

Characteristic	N	%
Gender		
Male	47	54
Female	40	46
Education		
Unfinished secondary	5	5.7
Secondary vocational	49	56. 3
Higher	33	37. 9
Marital status		
Single	38	43.6
Married	49	56.3
Employment status		
Unemployed	39	44. 8
Employed	48	55. 2

*n, sample number/ frequency; %, percentage

Table 2. Patient Satisfaction in Relation to Clinical Characteristics (n = 87)

Characteristic	Overall satisfaction										Test of difference	
	Very satisfied		Satisfied		Somewhat satisfied		Dissatisfied		Somewhat dissatisfied		$\chi 2$	P-value
	n	%	n	%	n	%	n	%	n	%		
Are you registered with a hematologist?												
Yes	0	0	13	15.1	31	36	6	7	37	41.9	2.132	0.712
No	0	0	0	0	0	0	0	0	0	0		
Self-assessed health												
Very good	0	0	0	0	0	0	0	0	0	0	24.209	0.45
Good			0	0	0	0	0	0	1	11.1		
Fair	0	0	3	23.1	10	32.3	5	83.4	4	44.4		
Poor	0	0	6	69.3	15	48,4	0	0	2	22.2		
Very poor	0	0	4	30.8	6	19.4	1	16.6	2	22.2		
How long have you been seen by a hematologist?												
Up to 1 year	0	0	4	30.8	6	46.2	3	23.1	0	0	22.155	0.036
2-4 years	0	0	4	9.10	19	43.2	17	38.7	4	9.1		
5–7 years	0	0	4	14.8	5	18.5	9	59.2	2	7.4		
8–10 years	0	0	1	33.3	1	33.3	1	33.3	0	0		
Does the hematologist inform you about the features of your disease?												
Yes	0	0	10	25.6	15	38.5	2	5.1	12	30.8	17.504	0.025
No	0	0	3	6.8	16	36.4	4	9.1	21	47.7		
Not always	0	0	0	0	0	0	0	0	4	100		
How many times have you been treated in a hematology hospital during the last year?												
One time	0	0	3	27.3	6	54.5	0	0	2	18.2	20.655	0.056
Two-three times	0	0	7	15.2	15	32.6	5	10.9	19	41.3		
Four-six times	0	0	0	0	4	4.44	0	0	5	55.5		
More than 6 times	0	0	0	14.3	6	28.6	1	4.8	11	52.4		
How do you evaluate the organization of medical care in the field of hematology?												
Excellent	0	0	1	100	0	0	0	0	0	0	50.19	0
Good	0	0	6	54.5	5	45.5	0	0	0	0		
Satisfactory	0	0	6	12.2	23	46.9	1	2	19	38.8		
Dissatisfactory	0	0	0	0	3	11.5	5	19.2	18	69.2		

*, t-test.

Table 3. Multiple Linear Regression in Relation to Satisfied

Items (influence variables)	β	95% CI	P-value
Are you registered with a hematologist?	0.389	-1.74	0.68
Self-assessed health	-0.079	-0.200- 0.042	0.198
How long have you been seen by a hematologist?	0.306	0.051-0.561	*0.019
Does the hematologist inform you about the features of your disease?	0.111	-0.715	0.54
How many times have you been treated in a hematology hospital during the last year?	0.013	-0.668	0.939
How do you evaluate the organization of medical care in the field of hematology?	1.011	0.730- 1.292	*0.000

*β, regression coefficient; CI, confidence interval; p value < 0.05

were significantly related to patient satisfaction, and how medical care is organized in the field of hematology was associated with patient satisfaction (Table 2).

We implemented multiple linear regression in association with satisfied. The results expressed that there was a statistically significant relationship between the satisfied and the variable "How long have you been seen by a hematologist?" (p = 0.019) and "How do you evaluate the organization of medical care in the field of hematology?" (p = 0.000) (Table 3).

No significant differences (p≤0.05) were discovered considering gender-wise distribution of the QOL score in blood cancer patients. The tests did not observe any significant differences in the quality of life between male and female blood cancer patients (Table 4).

There was a significant difference in role functioning/physical, vitality, emotional well-being, social functioning, body pain and overall QOL scored in different age group participants. The rest of the QOL score did not differ significantly among different age groups shown in Table 5

Discussion

The main finding of our study is the low rate of patient satisfaction (15.1 %) and 31 patients (36,0%) were somewhat satisfied with the quality of care, whereas the rest were dissatisfied to a certain extent. Other studies have found null or inconsistent results related to satisfaction with care, survivorship knowledge or functioning, continuity of care, cost-effectiveness, and unmet needs (Kwak et al., 2013, Solberg et al., 2013, Schroecksnadel et al., 2007, Skoetz et al., 2014). Identification of determinants and correlates of life satisfaction can provide important insights into targets that can be potentially used to improve life satisfaction at a national and local level (Cavallo et al., 2015). According to the data obtained from our study, the variable "Satisfied" has a statistically significant relationship with variables such as "How long have you

Table 4. Mann-Whitney U test Comparison of QOL Scores with Respect to Gender

Subscale	Male (n=47)	Female (n=40)	SD	Mann-Whitney U test	P-value
Physical functioning	45.50	42.66	-0.501	886	0.616
Role functioning/physical	44.53	43.38	-0.279	915	0.78
Role functioning/emotional	46.88	40.61	-1.533	804.5	0.125
Vitality	43.56	44.51	-0.18	919.5	0.857
Emotional well-being	49.81	37.18	-0.695	863	0.487
Social functioning	43.95	44.06	-0.022	937.5	0.983
Body pain	42.50	45.76	-0.619	869	0.536
General health	42, 28	46,03	-1.542	768	0.123
Health change	41.91	46.45	-0.862	842	0.389

*, Standard deviation (SD); p value < 0.05

Table 5. Kruskal-Wallis Test Comparison of QoL Scores with Respect to Age

Subscale	Age (years)						Kruskal-Wallis test	P-value
	18-25 (n=23)	26-35(n=9)	36-45(n=10)	46-55 (n=22)	56-65 (n=16)	66-85 (n=7)		
Physical functioning	42.98	36.83	45.15	48.00	46.13	37.50	7.230	0.204
Role functioning/physical	41.85	36.89	51.95	48.73	46.66	27.93	14.608	0.012
Role functioning/emotional	45.17	53.00	47.15	37.73	37.53	58.57	7.519	0.185
Vitality	42.87	36.22	56.90	53.41	40.28	18.21	15.147	0.010
Emotional well-being	38.33	28.89	56.75	50.59	51.72	25.5	15.371	0.009
Social functioning	44.02	33.17	52.00	50.30	46.38	21.21	10.398	0.058
Body pain	42.09	36.11	52.95	52.93	44.88	17.57	13.196	0.022
General health	41.22	33.94	53.60	50.64	46.81	25.07	9.351	0.096
Health change	41.85	36.89	51.95	48.73	46.66	27.93	6.026	0.304

*, p value < 0.05

been seen by a hematologist?" (β = 0.306, p=0.019) and "How do you evaluate the organization of medical care in the field of hematology? (β = 1.011, P=0.000), which were found to be strong predictors of contentment. This finding helps to conclude that visiting a hematologist has a direct relationship with patient satisfaction. In addition, patients who evaluated the organization of medical care were satisfied with the management of hematological patients, which was consistent with the findings of previous studies (Kraska et al., 2017, Meng et al., 2018, Fiorio et al., 2018, Laureano et al., 2021). It is concerned with some factors such as the adequacy of facilities and equipment, the qualifications of medical staff and their organization, the administrative structure and operations of programs and institutions providing care, and fiscal organization (Han et al., 2019).

Survivors' self-assessed priority of and their satisfaction with various life domains often remain unclear (Deimling et al., 2019). As mentioned in Hitz's study (Hitz et al., 2013), performance status was a significant predictor of patients' satisfaction with treatment decisions in the Swiss oncology network for those with advanced cancer. Based on other study results, patients' global health was significantly correlated with their satisfaction with healthcare providers and other aspects of healthcare organizations and services (Semmar et al., 2020). In addition, a literature review suggests that greater treatment satisfaction is related to better treatment compliance and improved persistence (Barbosa et al., 2012). The authors stated that patients had required a change in their treatment because of disease progression or recurrence, which places some limits on the generalizability of the effects of treatment characteristics on treatment satisfaction (Bozic et al., 2021, Chim et al., 2018).

No significant differences in quality of life were discovered in blood cancer patients concerning their gender. The comparison of quality of life over age marked significant differences between the individual age groups, except for physical functioning, role functioning/emotional, general health, and health change. The quality of life of blood cancer patients in individual dimensions according to SF-36, except for physical functioning, role functioning/physical, general health, and health change, deteriorates with age. This deterioration can be also influenced by the increasing prevalence of depression, more fatigue, greater symptom burden, and worse physical QOL compared to people with no history of cancer matched on age (Kim et al., 2020). These results are well in line with earlier data exhibiting significant correlations between fatigue/decreased QOL in patients with different malignant diseases (Li et al., 2020). High-income countries tend to have higher average life satisfaction scores, and most countries that have experienced sustained economic growth and sociopolitical stability have seen increasing life satisfaction levels (Bérenger et al., 2022). However, the results of studies from the United States and Korea demonstrated that patients with blood cancer suffered from pain and fatigue affecting their overall life activities (Kwak et al., 2013, Solberg et al., 2013). A recent study displayed that comorbidities and age were factors associated with QOL improvement. Indeed, patients in this study with more comorbidities were more likely to complain of symptoms such as fatigue, pain, constipation, and diarrhea compared to patients without comorbidities and those who were under 60 years of age (Al-Shandudi et al., 2022). The abovementioned findings suggest that age closely relates to QOL improvement.

In conclusion, the results of this study describe the low satisfaction of blood cancer patients with medical services provided in Semey, East Kazakhstan and identify the key determinants of patient dissatisfaction. Life expectancy is increasing worldwide. There was a significant difference in the individual SF-36 dimensions and overall QOL scored in different age group participants. Physical functioning, vitality, emotional well-being, body pain, and social function were the most compromised health-related quality of life domains among blood cancer patients. The management of patients with blood cancer in Kazakhstan remains provider-centered and little emphasis is placed on the recognition of patients' perceptions and views. Consideration of patients' views and experiences is essential if a program aiming to improve the quality of care for blood cancer is envisaged. In addition, the results of our study can significantly help in the development of effective individualized treatment and preventive treatment of patients with blood cancer. Therefore, all stakeholders need to collaborate for designing appropriate interventions for addressing poor health-related quality of life and low satisfaction among blood cancer patients which in turn will enhance treatment outcomes and better survival rates.

Study Limitations

The current study has some limitations. It is challenging to determine the timing of the association between the patient group and the contributing factors because the study was originally cross-sectional. Second, because the study was carried out in a single city, the social desirability bias might have had an impact. Additionally, there is a risk that there will be other confounding factors that impact the study's findings. However, there are several strengths, the main among which is that this is the first Kazakhstani study to report on the experiences of blood cancer patients within the local healthcare system.

Author Contribution Statement

Aliya Atabayeva, Zaituna Khismetova, and Oxana Tsigengagel were responsible for conceptualization, software, methodology, curation of data, preparation of the draft, and reviewing, editing, and proofreading of the article. Gulzat Sarsenbayeva, Saule Maukayeva, and Maria Anartaeva contributed to data collection and curation, software, drafting, reviewing, and editing. All authors have approved the final manuscript.

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Scientific Approval

This research is carried out within the framework of the approved topic of the doctoral thesis of a 3-year doctoral student of the specialty "Public Health" of Semey Medical University

Ethical Declaration

The Ethics Committee of Semey Medical University (Semey, East Kazakhstan) approved our study before it started (Protocol No. 1, on 22 October, 2022). The survey's questions requested the participants' informed consent and a fully completed survey served as a confirmation of their consent to fill out the questionnaire. Respondents were assured of confidentiality and anonymity of personal data.

Conflict of Interest

The authors declare that there is no conflict of interest to be reported.

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