Quality of Life among Patients with Hematological Cancer in a Malaysian Hospital

D Priscilla, MSc*, A Hamidin, MBBS, M Z Azhar, MD**, K O N Noorjan, MBBS**, M S Salmiah, MD*, K Bahariah, MBBS*****

*Department of Community Health, **Department of Psychiatry, and ***Department of Medicine, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia, 43400 UPM Serdang, Selangor, Malaysia

SUMMARY

The aim of this study was to determine the prevalence of symptoms and problems in hospitalized hematological cancer patients. A cross-sectional design was carried out with 105 respondents in Ampang hospital in Kuala Lumpur. The European Organization for Research and Treatment of Cancer Quality Of Life questionnaire (EORTC QLQ-C30) was used. Patients with a minimum response of "a little" were defined as having a symptom/problem while patients with a response of "quite a bit" were classified as having a "severe symptom/problem". The four most prevalent symptoms/ problems identified were fatigue, financial difficulties, reduced role function and reduced social function. Multiple myeloma patients (MM) were identified as having the most symptoms/problems.

KEY WORDS:
Quality of life, symptomatology, hematological cancer

INTRODUCTION

Nearly 7.6 million cancer deaths have occurred worldwide in the year 2008[1]. In the year 2006, it was found that 21,773 patients in peninsular Malaysia were diagnosed with cancer[2]. There are various forms of hematological cancer which include leukemia, lymphoma and myeloma[3]. Statistics show that hematological cancer lymphoma is classified as one of the ten most frequent cancers. Lymphoma (4.2%) and leukemia (3.6%) fall into the rank of the ten most frequent cancers among male patients. In females, 2.4% are diagnosed with lymphoma, which is one of the ten most frequent cancers among them[2].

To the best of our knowledge, there are no published articles concerning the quality of life of Malaysian hematological cancer patients. A great deal of literature has been published from western data on hematological cancer patients [4,5]. However, important findings remain unknown about the Malaysian hematological cancer population. Studies have shown that hematological cancer patients suffer from reduced emotions[4,7], reduced physical activities[4,7], impaired level of functioning[8] and other clinical symptoms[8] that affect their quality of life[5,9]. In a recent study, Johnsen et al. found that patients with different hematological cancer diagnoses showed variation in 'symptoms/problems' affecting their quality of life. For instance, multiple myeloma (MM) patients were identified as having more symptoms and problems compared to other patients[4]. Thus it is becoming increasingly difficult to ignore the affected cancer patient with poor a quality of life who needs more attention and supportive cancer care[10]. Thus, the main focus of this study was to evaluate the quality of life in hematological cancer patients by diagnosis.

MATERIALS AND METHODS

The study location was at the Hematological ward of Ampang Hospital, Kuala Lumpur, Malaysia. The hospital is a tertiary referral center for cancer including hematological cancer. Cross-sectional study design was applied for a period of 8 months from May 2009 to December 2009. Eligibility criteria for patients to participate in the study were as follows: hematological cancer diagnosis; ability to communicate in English, Malay, Mandarin or Tamil; at least 15 years of age; conscious and fit to be interviewed. Mutual consent was obtained before the questionnaire was distributed to the patient. The socio-demographic profile and clinical status was assessed from patient and medical records. The Ethical Committees of the Ministry of Health and the Faculty of Medicine and Health Sciences, University Putra Malaysia, have given the approval for this study.

The validated European Organization for Research and Treatment of Cancer Quality Of Life (EORTC QLQ-C30) questionnaire, which comprised of four languages including English, Malay, Mandarin and Tamil, was used in the study[11,12]. The questionnaire measures the quality of life of cancer patients. The questionnaire comprised of a total of 30 questions with three different scales (functioning scales, symptoms scales and a global health status scale). It measures physical, role, cognitive, emotional and social function in the functioning scale. The symptoms scale includes fatigue, pain, nausea/vomiting, dyspnea, insomnia, appetite loss, constipation, diarrhea and financial difficulties. All scales are comprised of multi-item questions except the symptom scales of dyspnea, insomnia, appetite loss, constipation, diarrhea and financial difficulties, which are comprised of single-item questions[12].

The questions appear in likert scale format with answers as follows: "Not at all", "A little", "Quite a bit" and "Very much". The scales range from 1 to 4 except for the global health status scale, which has 7 points ranging from 1 ("very poor") to 7 ("excellent"). All scores ranged from a minimum of 0 to a maximum of 100 and were computed using linear transformation referring to the EORTC scoring manual.

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Corresponding Author: Priscilla Das, Department of Psychiatry, Faculty of Medicine and Health Sciences, University Putra Malaysia, 43400 Serdang, Selangor Darul Ehsan, Malaysia Email: daspriscilla@yahoo.com

Higher scores indicate better functioning and global health status, but higher scores for symptom scales indicate more symptoms. However, the questionnaire did not have any cut-off points or defined thresholds to interpret functioning and symptom score as a case. Thus, following the recent study procedures, the percentage of frequencies of “symptoms/problems” and the frequencies of “severe symptoms/problems” were computed. Patients with a “symptom/problem” responded with at least “a little” in the questionnaire and had function scale scores ≤ 67 and symptoms scale scores ≥33. Patients with a “severe symptom/problem” responded at least “quite a bit” and had function scale scores ≤34 and symptoms scale scores ≥ 66. The illustration of this method is shown in Figure 1[4].

The number of “symptom/problem” and “severe symptom/problem” answers were determined for each person with a range from 0 to 14. The global health status scale was excluded from this procedure, thus leaving 14 scales.

Descriptive statistics, such as frequencies, means and percentages, have been computed from Statistical Package for Social Sciences (SPSS) program version 17.0 to analyze the data in this study.

RESULTS

A total of 105 respondents (response rate: 83.3%) participated in the study. Twenty-one patients were excluded for different reasons (i.e., 6 patients refused to participate, another 2 patients were not able to understand the questionnaire and the remaining 13 patients were not hematological cancer patients).

The age of respondents ranged from 15.00 to 77.82 years old. The mean age was 40.43 (37.36 to 43.49; 95% confidence interval). The mean age of male patients was 43.61 and for female patients the mean age was 37.53. This difference was significant (t = 1.991, df = 103, p=0.049). Female patients represented 52.4 % of the respondents and 47.6 % were male. The majority of patients were diagnosed with non-Hodgkin lymphoma (23.8%) followed by acute myelogenous Leukemia (22.9%), acute lymphoblastic leukemia (14.3%), Hodgkin lymphoma 11 (10.5%), other lymphoma (12.4%), other leukemia (9.5%), multiple myeloma (5.7%) and other hematological cancer (i.e., histiocytosis; 1%). Of the participants in this study, 60% were Malay, 24.8% were Chinese, 13.3% were Indian and 1.9% were classified as ‘other’.

Table I shows the mean score of five multi-item function scales. The most severe impairment in functioning was with role functioning (mean score=47), followed by social functioning (mean score=56), emotional functioning (mean score=61), physical functioning (mean score=67) and cognitive functioning (mean score=70). The cut-off value, indicates that 68% of hematological cancer patients had impairment in role functioning (severity= 50%). Social functioning (severity=34) was also impaired in 68% of hematological cancer patients. Fifty percent of the patients had impaired functioning in physical functioning (severity=12). Cognitive functioning (severity=17%) was also impaired in 50% of hematological cancer patients. Emotional functioning was impaired in 56% of patients (severity= 28%).

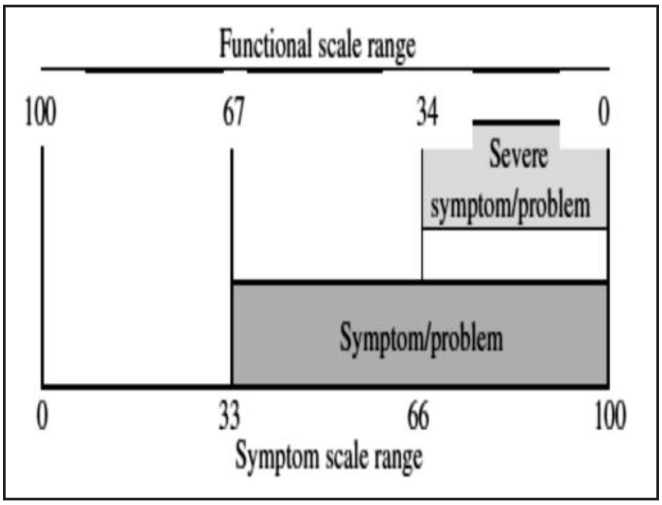

Fig. 1: Illustration of the definition of 'symptom/problem' and 'severe symptom/problem'[4].

In the symptoms counterparts, the most severe symptoms were financial difficulties (mean score=55), followed by fatigue (mean score =53), constipation (mean score=52), appetite loss (mean score=42), pain (mean score=30), insomnia (mean score=30), nausea and vomiting (mean score 23), dyspnea (mean score=18) and diarrhea (mean score=16). Using the cut-off values, 79% of the patients had fatigue (severity 38%), 38% had nausea and vomiting (severity=14), 54% had pain (severity=8%), 35% had dyspnea (severity=15%), 48% had insomnia (severity=28%), 62% had appetite loss (severity=42%), 64% had constipation (severity=54%), 32% had diarrhea (severity=10%) and 74% had financial difficulties (severity=57%).

In the study, the mean number of “symptoms/problems” was 7.8 while the mean number of “severe symptoms/problems” was 4.1. Interestingly, the study found 100% of the patients had at least one “symptom/problem” and all patients had at least one “severe symptom/problem”. Overall, the multiple myeloma (MM) patients had the most symptoms and problems with a mean number of 9. The mean number of “symptoms/problems” ranged from 6.3 (other lymphoma) to 9 (MM); the mean number of “severe symptoms/problems” ranged from 3.3 (other lymphoma) to 4.6 (Non-Hodgkin lymphoma). The mean score for other hematological cancer diagnoses, such as Histiocytosis, are shown in the table. However, the percentage of symptoms cannot be computed since the sample consists of only one patient.

DISCUSSION

The present study was aimed at determining the extent of symptoms and problems affecting the quality of life of hematological cancer patients. The data well represent the population of Malaysia as Malays comprised the highest proportion followed by Chinese, Indian and others who participated in the study[2]. The study confirmed that symptoms and problems were prevalent and frequent among the patients. The cut-off percentage on each of the 14 scales showed that the most prevalent symptoms/problems were fatigue (79%; severe: 38%), financial difficulties (74%; severe: 57%), reduced role functioning (68%, severe: 50%), reduced social functioning (68%, severe: 34%), constipation (64%;

Table I: Mean score and prevalence for the total sample and by diagnosis of hematological cancers

Diagnosis		PF	RF	EF	CF	SF	QOL	FA	NV	PA	DY	SL	AP	CO	DI	FI	Mean No symptom	Mean No severe symptom
Total	Mean score	67	47	61	70	56	55	53	23	30	18	30	42	52	16	55	7.8	4.1
N=105	%symptoms	50	68	56	50	68		79	38	54	35	48	62	64	32	74		
	%severe	12	50	28	17	34		38	14	8	15	28	42	54	10	57		
AML	Mean score	80	54	58	70	48	62	56	22	27	15	38	44	49	15	53	7.8	3.9
N=24	%symptoms	29	63	63	58	83		83	38	50	29	63	58	63	33	71		
	%severe	0	42	25	13	42		42	8	4	13	33	46	54	8	58		
ALL	Mean score	68	54	67	76	58	54	50	38	31	33	29	64	44	20	62	8.9	4.3
N=15	%symptoms	33	73	53	40	67		80	60	60	67	60	100	67	47	87		
	%severe	13	40	20	13	40		27	27	13	27	20	67	47	7	67		
HL	Mean score	69	53	58	74	56	60	39	21	33	42	39	30	45	15	58	8.2	3.8
N=11	%symptom	55	55	64	46	82		64	46	64	55	55	64	55	36	82		
	%severe	9	46	36	0	27		27	9	0	46	46	27	46	9	55		
NHL	Mean score	58	30	63	68	58	53	54	20	37	11	28	43	69	17	56	7.4	4.6
N=25	%symptom	52	80	48	48	56		72	24	60	24	44	60	76	28	72		
	%severity	24	68	24	24	32		36	16	16	8	24	44	72	12	56		
MM	Mean score	46	44	57	61	58	49	70	6	33	17	22	33	50	22	56	9.0	4.3
N=6	%symptom	100	67	67	83	67		100	17	83	33	33	50	67	50	83		
	%severe	33	50	33	17	33		67	0	17	17	17	33	50	17	50		
OTHER	Mean score	70	52	58	70	73	53	54	22	28	17	33	27	43	3	43	7.3	3.5
LEUKEMIA	%symptom	50	70	60	40	50		90	40	70	40	40	40	60	10	70		
N=10	%severe	0	50	30	30	10		40	20	0	10	40	30	50	0	40		
OTHER	Mean score	60	49	56	72	51	48	55	23	17	3	13	36	46	15	56	6.3	3.3
LYMPHOMA	%symptom	69	54	54	39	62		77	46	15	8	23	46	46	31	62		
N=13	%severe	15	46	39	23	39		46	15	0	0	15	31	46	15	62		
OTHER	Mean score	60	67	92	50	33	50	33	0	17	33	0	33	33	0	67		
N=1																		

AML, Acute Myelogenous Leukemia; **ALL,** Acute Lymphoblastic Leukemia; **HL**, Hodgkin Lymphoma; **NHL**, Non Hodgkin Lymphoma; **MM,** Multiple Myeloma;
OTHER LEUKEMIA: Chronic Lymphocytic Leukemia: 1, Chronic Myelogenous Leukemia: 2, Acute Promyelocytic Leukemia: 3 Hairy Cell Leukemia: 1, MDS-RAEB towards Leukemia: 1, MDS-CMMOL towards Chronic Leukemia: 1, Unclassified Leukemia: 1; **OTHER LYMPHOMA:** Peripheral-T-Cell Lymphoma: 1, NK-T-Cell Lymphoma: 3, CNS-Lymphoma: 2, Intravascular Lymphoma: 1 Follicular Transform Lymphoma: 1, Unclassified Lymphoma: 5 ; **OTHER:** Histiocytosis.
PF, Physical Functioning; **RF,** Role Functioning; **EF,** Emotional Functioning; **CF,** Cognitive Functioning; **SF,** Social Functioning; **FA,** Fatigue; **NV,** Nausea And Vomiting; **PA,** Pain; **DY,** Dyspnea; **SL,** Insomnia; **AP,** Appetite loss; **CO,** Constipation; **DI,** Diarrhea; **FI,** Financial difficulties.
% symptoms, proportion of patients scoring 67 at the most for function scales or at least 33 for symptoms.
% severe symptoms, proportion of patients scoring 34 at the most for function scales or at least 66 for symptoms.
No. of "symptoms", mean number of symptoms using the same cut-off point as in "% symptom" (quality of life excluded).
No. of "severe symptoms", mean number of symptoms using the same cut-off point as in "% severe symptom" (quality of life excluded).

severe 54%), appetite loss (62%; severe 42%), reduced emotional functioning (56%; severe 28%), pain (54%; severe 8%), reduced cognitive functioning (50%; severe 17%), reduced physical functioning (50%, severe 12%), insomnia (48%; severe 28%), nausea/vomiting (38%; severe 14%) and dyspnea (35%; severe 15%). These percentages are much higher than those found in a previous study in western hematological cancer patients which states that fatigue was 55%, reduced role functioning was 49%, insomnia was 46%, pain was 37% and dyspnea was 36%[4]. In addition, 82% patients met the criteria of at least one 'symptom/problem' in the previous study[4]. However, the patients in the present study met 100% of the criteria.

The present findings seem to be consistent with other research by Johnsen *et al*. that used a representative national sample of hematological cancer patients. In the study, patients with hematological cancers, such as lymphoma, leukemia and multiple myeloma, scored higher on the symptom scale for items such as fatigue, pain and insomnia[4]. The present study also proved that fatigue is the most prevalent problem that is being identified among the hematological cancer patients. In terms of functional scale, role functioning and physical functioning were found to be severely impaired[4]. This is in agreement with the present study as role functioning was the most impaired compared to other functioning scales.

MM patient's physical functioning mean score was 46% and was the lowest score out of all the hematological cancer patients. These findings are consistent with another study by Santos *et al.* in which it was found that MM patients had the lowest score of physical functioning when compared to other hematological cancer patients[13]. Physical functioning is defined as difficulties faced by the patients in carrying a bag, walking, eating, bathing, and dressing[12]. MM patients were found to have the most symptoms and problems[4]. This finding is in agreement with the present study which indicates that MM patients had the most symptoms and problems compared to other hematological cancer patients.

There are several possible explanations for this result and one of the most important factors was treatment. The patients under active treatment displayed reduced physical functioning, poor appetite and fatigue compared to patients in non-active treatment[4]. These symptoms often contributed to a poor quality of life. Studies have shown that the quality of life of hematological cancer patients worsens before and after seven days of treatment in the context of their physical status, energy level and systemic symptomatology. This is followed by fluctuations in their depression level. This marked increase of depression level also leads to poor physical health status after intensive treatment[7] as the present study included the patients under treatment.

LIMITATION

One of the limitations of this study that should be noted is that some of the self-rated questions were read to the patients to clarify their responses and to ensure patient understanding of the questions being asked. Therefore, the results solely depend on the patient's response and memory at the time the study was carried out.

CONCLUSION

The study proved that hematological cancer patients have impaired quality of life. The four leading symptoms and problems were fatigue, financial difficulties, reduced role function and social function. Even though there has been advancement in cancer management, overall curability remains poor. Physicians must be aware of the situation and help patients to overcome the situation by considering balanced pharmacotherapy and psychotherapy. Thus, there is a need for effective cancer management to improve the patient's quality of life.

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