Identifying Factors Associated With Variations in Quality of Life for Patients with Different Acute Leukemia Types: a global survey

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The results confirm there are differences in quality of life and symptoms (as measured by HM-PRO) in acute leukemia patients in remission following treatment, compared to undergoing treatment and relapse.

Patients with worse reported experience (Q13-18) have worse HM-PRO scores, suggesting that improving support in these areas may enhance overall quality of life.

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Introduction

The Acute Leukemia Advocates Network (ALAN) conducted a multi-country survey to gather information on the experiences, quality of life (QoL) and symptoms of adults (16+) with three different types of acute leukemia [acute myeloid leukemia (AML), acute lymphoblastic leukemia (ALL) and acute promyelocytic leukemia (APL)].

Aims

The aims were, for each acute leukemia type, to (1) examine if differences in QoL and symptom burden are observed according to disease stage and (2) whether there is a relationship between patients' experiences and QoL.

Methods

This survey comprised 99 items, designed from a literature review of QoL and acute leukemia followed by input from clinical and patient advocacy experts. The study material was translated (9 languages) and promoted via patient advocacy groups from March 1, 2019 to November 29, 2019.

The HM-PRO, an instrument designed to measure patient-reported outcomes in those with hematological malignancies, was incorporated into the study for assessing QoL and symptoms. This consists of Part A (impact/QoL) and Part B (signs and symptoms). A higher score in each part represents greater (negative) impact on QoL and symptom burden.

Question 9 of the survey provides a measure for disease stage: undergoing treatment, in remission following treatment or relapsed following treatment..

We hypothesised that patients with a worse experience in each of the following areas would report a worse overall quality of life:

Experience Category	Question
Physical symptoms and side effects	13
Emotional impact	14
Physical and mental health	15
Information from healthcare professionals	16
Ability to perform meaningful activities	17
Well-being of carers, friends and family	18

These are itemised on an interval scale ranging from 0-10, where 0 represents a bad experience and 10, a good experience.

Questions 19-99 investigated further each of the hypotheses, to identify patient issues and background demographic questions. Spearman rank correlation coefficient was used to determine the direction and strength of relationships between the measures. Wilcoxon rank-sum, Chi-squared and Kruskal-Wallis rank test were used to examine the differences between groups.

Results

There were 552 respondents to the survey:

Leukemia Type	Respondents	%
AML	332	60
ALL	139	25
APL	81	15
Total	522	100

The results suggests that there is no overall significant difference in either Part A (p=0.55) or and Part B (p=0.23) of the HM-PRO scores between different acute leukemia types, though there were differences in demographic factors (e.g. gender, geographical region, living situation, etc.)

Results

499 respondents provided information on their disease stage and there were significant differences for the 3 groups (p=0.01), with more patients in the ALL group undergoing treatment than the other two groups (Table 1).

Table 1: Number and percentage of respondents according to disease stage for the three types of leukemia

Stage	Type			
	ALL	AML	APL	Total
Treatment	29 (23.6)	40 (13.5)	12 (15.0)	81
Remission	86 (69.9)	236 (79.7)	68 (85.0)	390
Relapsed	8 (6.5)	20 (6.8)	0 (0)	28
Total	123	296	80	499

Despite this difference, the analysis confirmed that patients in remission had significantly different scores for both Part A and Part B of the HM-PRO than those relapsed or undergoing treatment ($p < 0.001$). There was no significant difference between relapsed and treatment group for Part A scores (p=0.195), whereas Part B scores were significantly higher in relapsed patients than treatment (p=0.046).

The different leukemia types showed similar distributions as above for part A and Part B of the HM-PRO according to disease stage (Figures 1 and 2).

Figure 1: Boxplots showing the distribution of HM-PRO Part A score according to the three disease stages

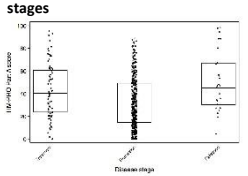
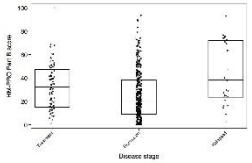


Figure 2: Boxplots showing the distribution of HM-PRO Part B score according to the three disease stages



The results confirmed our prediction that those with worse scores for Q13-Q18 reported a worse QoL (higher HM-PRO score). The correlations (negative) were all statistically significant ($p<0.05$), suggesting that low HM-PRO scores (improved) are associated with good experiences and vice versa.

For Part A scores, some correlations were weaker for the ALL group, whereas for Part B, some correlations for were stronger than for the other two types as shown in Table 2, 3 and 4.

Table 2: Pairwise correlations between HM-PRO Part A and Part B scores and Q13-Q18 for AML

	Part A score	Part B score	Q13	Q14	Q14	Q16	Q17	Q18
Part A score	1,00							
Part B score	0,64	1,00						
Q13	-0,42	-0,38	1,00					
Q14	-0,48	-0,41	0,80	1,00				
Q14	-0,54	-0,51	0,57	0,61	1,00			
Q16	-0,42	-0,37	0,66	0,66	0,55	1,00		
Q17	-0,71	-0,61	0,51	0,52	0,62	0,52	1,00	
Q18	-0,62	-0,52	0,43	0,52	0,56	0,45	0,73	1,00

Table 3: Pairwise correlations between HM-PRO Part A and Part B scores and Q13-Q18 for ALL

	Part A score	Part B score	Q13	Q14	Q14	Q16	Q17	Q18
Part A score	1,00							
Part B score	0,68	1,00						
Q13	-0,25	-0,18	1,00					
Q14	-0,30	-0,24	0,75	1,00				
Q14	-0,43	-0,42	0,53	0,47	1,00			
Q16	-0,37	-0,34	0,71	0,71	0,53	1,00		
Q17	-0,48	-0,47	0,28	0,21	0,44	0,37	1,00	
Q18	-0,44	-0,44	0,37	0,32	0,52	0,36	0,72	1,00

Table 4: Pairwise correlations between HM-PRO Part A and Part B scores and Q13-Q18 for APL

	Part A score	Part B score	Q13	Q14	Q14	Q16	Q17	Q18
Part A score	1,00							
Part B score	0,51	1,00						
Q13	-0,40	-0,29	1,00					
Q14	-0,43	-0,28	0,68	1,00				
Q14	-0,46	-0,42	0,56	0,48	1,00			
Q16	-0,39	-0,28	0,57	0,58	0,38	1,00		
Q17	-0,76	-0,48	0,37	0,35	0,56	0,42	1,00	
Q18	-0,53	-0,26	0,25	0,16	0,45	0,17	0,68	1,00

There were differences in responses to some of the questions about support from healthcare professionals. Answers to questions 13 (p=0.04) and 14 (p=0.01) differed significantly between the three groups, with more negative responses from APL.

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