

Introduction

A deeper understanding of patients' experiences with leukemia is necessary given the ongoing discussions about patient-centricity and how to return the patient to the center of care.

The Acute Leukemia Advocates Network (ALAN) in collaboration with CLL Advocates Network (CLLAN) and CML Advocates Network (CMLAN) developed a multi-country survey to understand the issues and gather information on the current and emerging treatment landscape, experiences and quality of life (QoL) of adult patients with leukemia.

This survey was designed to focus on the patient perspective. This includes but not limited to: experiences through patient journey how it varies depending on the form of leukemia, the QoL and impact of leukemia on daily life, and what information and support was provided. Analysis of the data identified areas within the patient journey where opportunities exist to improve patient care and experiences.

Methods

Developed by a panel of leukemia patient advocates, the questionnaire was tested twice and comprises sixteen sections with the aim to collect insight and understanding into the patient's experience, rather than the clinical perspective. It did not seek to replicate the formal collection of scientific data such as patient preferences.

The questionnaire consists of 200 questions (some with sub-questions) including HM-PRO, a validated QoL assessment tool in those with hematological malignancies.

Patients completed the sections relevant to their type of leukemia. Data on relevant patient characteristics, such as gender, age, and countries of residence, were collected in the demographic section.

The administration of the questionnaire was web-based, between 18 September 2021 and 07 January 2022 and was made available in 10 languages. It was promoted by ALAN, CLLAN, CMLAN and member organizations via websites, newsletters, emails, and social media channels. Participation was on a voluntary basis therefore may not reflect the perspectives of all leukemia patients.

Results

There were 2646 respondents to the survey:

Leukemia Type	Respondents	%
Acute myeloid leukemia (AML)	312	12
Acute lymphoblastic leukemia (ALL)	104	4
Chronic lymphocytic leukemia (CLL)	1202	45
Chronic myeloid leukemia (CML)	896	34
Other types of leukemia	132	5
Total	2646	100

Of the 2646 patients who responded to the survey, 56% were female (n=1426), 56% were within the age range 55-74 years old (range <16 to >85), and living situation, employment status and education levels varied.

Responses were collected across 76 countries. Respondents were grouped into the designated World Health Organization regions; 66% (n = 1749) were from countries assigned to the European region, 14.7% (n=389) from the Americas region, 7.4% (n=195) from the Western-Pacific region, 2.1% (n=56) from Africa region and 1.5% (n=39) from Southeast Asia region.

Experiences and Views of Leukemia Patients: A Global Survey

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1- Acute Leukemia Advocates Network; 2- CLL Advocates Network; 3- CML Advocates Network; 4- HM-PRO; 5- IQVIA

- At diagnosis, 57 % of patients reported that they partially / did not understand information provided by their doctor.
- 51% of patients reported that they were not offered or directed to any support.
- 62 % of patients reported that they were not offered a choice of treatment and/or offered a clinical trial with a majority who wanted to be more involved.

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Results

Overall, at diagnosis, 48% (n=1255, [49% ALL, 46% AML, 47% CLL, 49% CML] of patients were offered written information on their leukemia without needing to ask for it. Of the 52% (n=1360, [57% ALL, 49% AML, 51% CLL, 53% CML]) who received written information, 57% (n=763 [61% ALL, 51% AML, 59% CLL, 55% CML]) of respondents partially / did not understand the information provided by their healthcare professional. In addition, 51% (n=1337, [32% ALL, 44% AML, 55% CLL, 51% CML]) were not offered or directed to any support to help with concerns and worries at diagnosis. The majority of patients who were not provided with written information or directed to support for concerns and worries reported they would have liked to receive these. Similar numbers are reported while under treatment

Majority of acute leukemia and CML patients (93% ALL, 87% AML, 66% CML) started treatment within less than a week after diagnosis, while it took over 2 years for 41% of CLL respondents. Chemotherapy remains the standard treatment option for acute leukemias (48% ALL, 42% AML) while targeted therapy tablets are used for chronic leukemias (58% CLL, 79% CML).

62% (n=1271, [65% ALL, 59% AML, 52% CLL, 67% CML]) of respondents reported that they were not offered a choice of treatment options and half (n=1028, [55% ALL, 47% AML, 43% CLL, 55% CML]) were not involved as much in decisions about their treatment as they wanted to be. 60% (n=1225, [52% ALL, 41% AML, 54% CLL, 70% CML]) were not offered the option of participating in a clinical trial, and of these 43% (n=523, [32% ALL, 32% AML, 46% CLL, 44% CML]) reported they would have liked to have had this option.

Fatigue (n=1103, [57% ALL, 60% AML, 44% CLL, 55% CML]) is reported as the main side effects across all the leukemia types, but chronic leukemia patients (68% CLL, 65% CML) reported that their side effects were "barely noticeable" or had a "small impact" on their QoL, while acute leukemia patients (51% ALL, 44% AML) reported that their side effects had a large impact.

Acute leukemia patients also appeared to be more worried about relapse compared to chronic leukemia patients (more than 20% reported being "extremely worried").

Patients reported similar physical behavior, social wellbeing, and emotional behavior, however, more than 50% acute leukemia patients (57% ALL, 51% AML) reported feeling isolated (versus 35% CLL, 37% CML) and more than 70% had to stop working because of their acute leukemia (75% ALL, 78% AML versus 31% CLL, 37% CML) with a greater financial impact.

Of the patients with childbearing potential (age range considered 18-55 years), 34% (n=860, [19% ALL, 19% AML, 34% CLL, 40% CML]) reported that fertility preservation was not discussed with their healthcare teams.

Conclusion

We believe this survey is the largest ever conducted among leukemia patients to gather information about their experiences, QoL, and preferences.

Although the data reveals differing aspects of acute leukemia patients compared to chronic leukemia patients, to our surprise, in most areas investigated, they reported similar type of experiences. Where differences are observed, they can be explained by the nature of the disease, the urgency of treatment and the treatments currently available in acute leukemia.

Our data show that opportunities to provide patients with understandable information / emotional support are still being missed. Additionally, there is still a need to include patients in decision-making and to place them at the center of care (for example, to discuss treatment options and clinical trials, to preserve fertility, etc.), confirming the need to continue discussions on patient centricity.