

Introduction

Understanding patients' experiences at the time of diagnosis informs where efforts and policy, advocacy and campaigning work should be undertaken or should continue to happen to improve the experience and outcomes of those with leukemia.

The Acute Leukemia Advocates Network (ALAN), CLL Advocates Network (CLLAN) and CML Advocates Network (CMLAN) ran global study to understand the issues and gather information on the experiences, perceptions and quality of life (QoL) of adult patients with leukemia.

ALAN, CLLAN and CMLAN are independent global networks of patient organizations, dedicated to improving the lives and survival of patients affected by leukemia. They support patient organizations worldwide in providing help to patients and their family members/partners.

Aim

This study was designed to focus on patients' experiences. The aim was to gain insight and understanding into their lived experiences and perceptions of diagnosis via the administration of patient-reported experience measures, rather than the clinical perspective.

Here we report on the experiences reported by patients at the time of diagnosis.

Methods

The study questionnaire, designed and tested by an expert panel of patient advocates, consisted of 100 items, including participant demographics and HM-PRO. HM-PRO is a validated patient-reported outcome measure to assess the impact and symptoms of patients with hematological malignancies.

The study questionnaire was available online from 19 August 2023 to 05 January 2024 in 13 languages through a web-based platform and was promoted by ALAN, CLLAN, and CMLAN and member organizations via websites, newsletters, emails and social media.

Results

Leukemia Type	n	%
Acute myeloid leukemia (AML)	341	15,1
Acute lymphoblastic leukemia (ALL)	271	12
Chronic lymphocytic leukemia (CLL)	846	37,4
Chronic myeloid leukemia (CML)	660	29,2
Other leukemia	142	6,3
Total	2260	100

There were 55% (n=1251) females, median age was 60 years and varied socio-economic status. 43% (n=962) received their leukemia diagnosis between 2020 and 2023 and 31% (n=708) reported their leukemia was diagnosed following a routine blood test/health check.

Patient-Reported Experience of Being Diagnosed with Leukemia: A Global Study

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1- Acute Leukemia Advocates Network; 2- Novartis; 3- CLL Advocates Network; 4- CML Advocates Network; 5- Picker Institute; 6- Grande Ospedale Metropolitano Bianchi Melacriano Morelli; 7- Saint Petersburg State University Hospital; 8- University of Hertfordshire

- **90% of patients were not aware that the symptoms they were experiencing could be due to leukemia.**
- **Fatigue is the most common symptom reported prior to diagnosis (51%).**
- **62% consulted a healthcare professional (HCP) within 3 months of first experiencing symptoms.**
- **21% consulted their HCP four or more times before being diagnosed.**
- **50% were diagnosed within a month of first consulting their HCP.**
- **Only 15% were referred to patient organizations.**

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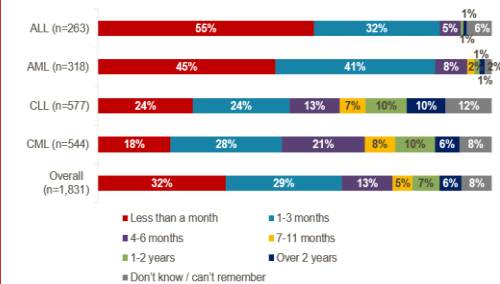


Results

Patients reported that fatigue (51%, n=1139) and fever/night sweats (31%, n=700) were the most common symptoms they experienced before their diagnosis. Patients with acute leukemia reported a higher instance of experiencing symptoms prior to diagnosis (ALL 98%, n=265; AML 94%, n=319) than respondents which chronic leukemia (CLL 69%, n=582; CML 84%, n=551). Concerningly, 90% (n=1648) of respondents did not know that the symptoms they were experiencing could be due to leukemia.

Overall, 32% (n=593) of patients waited less than one month from the time they first experienced symptoms to consulting a HCP (Figure 1). Patients with CLL (27%, n=155) and CML (24%, n=131) were far more likely to wait more than 6 months before speaking to a HCP, than patients with ALL (2%, n=4) or AML (4%, n=14).

Figure 1: Time from first symptoms to visiting a HCP



Only 33% (n=604) reported that they were diagnosed following their first consultation, while 21% (n=388) saw a HCP four or more times before they were diagnosed. 50% (n=1120) were diagnosed within a month of first consulting their HCP.

Overall, 52% (n=1133) partially understood or did not understand the explanation given by their HCP regarding their diagnosis, and 47% (n=1028) reported that the information they were given about their diagnosis was not clear. However, at the time of diagnosis, only 9% (n=173) were given or directed to information on psychological well-being, 11% (n=222) on side effects/risks of treatments and 2% (n=31) on finances. Only 15% (n=295) were referred to patient support groups or leukemia organisations.

Conclusion

This is the second global study conducted by ALAN, CLLAN and CMLAN and our data continues to show that opportunities to provide patients with tailored information, emotional support and/or referral to patient organizations are being missed.

The data demonstrates the crucial role of HCPs, especially primary care physicians in earlier diagnosis of leukemia.

The results draw attention to areas where further policy, advocacy and campaigning work should be considered (e.g., universal access to support, routine blood tests) and where awareness efforts should continue to focus (e.g., #BeLeukemiaAware awareness campaign, World Leukemia Day, etc.).