

Introduction

The Acute Leukemia Advocates Network (ALAN) ran a global survey to provide further evidence on acute leukemia (AL) patients' and their informal carers' lived experience and perceptions with a focus on quality of life (QoL).

ALAN is an independent global network of patient organizations, dedicated to improving the lives and survival of patients affected by AL and support patient organizations worldwide in providing help to patients and their relatives.

This survey was explicitly designed to focus on patients' and carers' perspectives. The aim was to gain insight and understanding into their lived experiences and perceptions via the administration of patient-reported outcomes (PROs) measures, rather than the clinical perspective.

Aim

The objectives were to: (1) get a broader picture of experiences and how it varies between patients and carers (2) understand impact of AL on wellbeing and QoL (3) identify issues which ALAN was partially or not aware of.

Methods

The survey questionnaire, designed and tested by an expert panel of patients advocates, consisted of 200 items, including those of the HM-PRO questionnaire, as well as additional questions about demographics. The HM-PRO is a validated questionnaire designed to measure PROs in patients with hematological malignancies which was incorporated into the study for assessing QoL and symptoms.

The survey questionnaire was made available online for three months, through a web-based platform and in 10 languages: English, Brazilian Portuguese, French, German, Hebrew, Italian, Korean, Simplified Chinese, Spanish and Russian.

The survey was promoted by ALAN and member organizations via websites, newsletters, emails, social media channels as well as member organizations' websites, newsletters, social media channels. Patients and carers completed different but linked surveys.

Results

There was a total of 626 respondents:

Acute Leukemia Type	Patients	Carers
Acute myeloid leukemia (AML)	312	110
Acute lymphoblastic leukemia (ALL)	104	100
Total	416	210

The majority of respondents were female (66%, n=418). Age, living situation, employment status and education levels were varied. Responses were collected across 79 countries, grouped geographically according to the designated World Health Organization regions; 74% (n=468) were from countries assigned to the European region.

Living with Acute Leukemia: A Global Survey of Patients and Carers Experience

Samantha Nier¹; Zack Pemberton-Whiteley¹; Jan Geissler¹;
Anne-Pierre Pickaert¹; Sophie Wintrich¹; Cheryl Petruk¹;
Esther Nathalie Oliva²; Tatyana Ionova²; Sam Salek²

1- Acute Leukemia Advocates Network; 2- HM-PRO

- **94% of patients and 87% of carers were not aware that the symptoms experienced by the patient could have been symptoms of leukemia.**
- **43% of patients and 42% of carers thought they were sufficiently involved in decisions about treatment and care.**
- **40% of patients and 60% of carers were not provided with or directed to written information on the different treatment options.**
- **Carers were more worried /anxious than the patients themselves and seemed to report a greater negative impact of acute leukemia on their own wellbeing compared to what patients reported for themselves.**

Results

Before diagnosis, 94% (n=377) of the patients and 87% (n=182) of the carers were not aware that the health problems experienced by the patient could have been symptoms of AL.

At diagnosis, majority of patients (56%, n=230) and carers (55%, n=115) partially understood/did not understand the information about the disease provided by their healthcare professional, leading to 81% (n=464) using internet to find information about AL.

Only 43% (n=182) of patients and 42% (n=88) of carers thought they were sufficiently involved in decisions about treatment and care. 81% (n=341) of patients and 68% (n=140) of carers used the internet to find out more about the different treatment options, 40% (n=165) of patients and 60% (n=124) of carers not being provided with or directed to written information.

Carers (76%, n=158) were more likely to report that side effects had a large impact on the patient or were "intolerable" compared to patients themselves (53%, n=197). Carers also reported to be more worried about relapse (49%) compared to patients themselves (23%). In addition, the proportion of carers who were extremely worried/anxious when waiting for the results of regular lab tests /monitoring were higher than that of patients (28% of carers vs. 15% of patients).

Mean score of the patients' disease impact on their wellbeing was 5.6 compared to 6.4 for that of the carers (scale 0-10; greater impairment with increasing scores).

Patients and their carers reported the negative financial impact of leukemia with 50% (n=212) of the patients having to stop working compared to 32% of the carers.

Conclusion

Although in some areas investigated patients and carers reported similar experiences and in line with findings from other disease studies, our data show that carers face several physical, emotional and psychological challenges. Carers were more worried /anxious than the patients themselves and seemed to report a greater negative impact of AL on their own wellbeing compared to what patients reported for themselves.

The survey highlights the need for greater involvement of patients and carers in treatment decisions, as well as the need for emotional support for carers and to consider their own needs. As an example, carer home-care guidance, psychological and social support can help reduce their physical and mental burden.

In addition, the data help to draw attention to areas where further policy and campaigning work should be undertaken (e.g., provision of information and holistic care package) or where efforts should continue to happen (e.g., awareness of AL and its impact of both physical and psychosocial functional behaviors).

EHA-1821 / P1688 - EHA2023 Hybrid Congress