

Abstract: P1688

Title: LIVING WITH ACUTE LEUKEMIA: A GLOBAL SURVEY OF PATIENTS AND CARERS EXPERIENCE

Abstract Type: Poster Presentation

Session Title: Quality of life and palliative care

Background:

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.

Aims:

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, a validated QoL assessment tool in those with hematological malignancies and demographics.

The survey questionnaire was made available online for three months, through a web-based platform and in 10 languages. It was promoted by ALAN and member organizations via websites, newsletters, emails and social media. Patients and carers completed different but linked surveys.

Results:

There was a total of 626 respondents: 416 were patients with acute myeloid leukemia ([AML], n=312) and acute lymphoblastic leukemia ([ALL], n=104) and 210 were caring for patients with ALL (n=100) and AML (n=110).

66% (n=418) of respondents were female. Age and socio-economic status were varied. Responses were collected across 79 countries, 74% (n = 468) were from countries assigned to the designated World Health Organization European region.

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 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/anxious about relapse (49%) and when waiting for results from lab tests (28%) compared to patients themselves (23% and

15%).

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).

Summary/Conclusion:

Although in some areas investigated patients and carers reported similar experiences, 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.

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).

Keywords: Quality of life, Patient, Acute leukemia, Caregiver