

Abstract: PB2673

Title: EXPERIENCES AND VIEWS OF LEUKEMIA CARERS: A GLOBAL SURVEY

Abstract Type: Publication Only

Session Title: Quality of life and palliative care

Background:

The physical, emotional and psychological demands of caring can be demanding and stressful and are often referred to by researchers as '*the burden of care*'.

A global survey conducted by the Acute Leukemia Advocates Network (ALAN), CLL Advocates Network (CLLAN) and CML Advocates Network (CMLAN) was designed to understand these issues and obtain information on carers providing care and support to adult leukemia patients' quality of life (QoL).

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

Aims:

This survey was explicitly designed to focus on 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.

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 symptoms and 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 11 languages. It was promoted by ALAN, CLLAN, and CMLAN and member organisations via websites, newsletters, emails and social media.

Results:

There were 571 respondents caring for patients with different types of leukemia: acute myeloid leukemia (n=110), acute lymphoblastic leukemia (n=100), chronic lymphocytic leukemia (n=150), chronic myeloid leukemia (n=183) and other types of leukemia (n=28).

72% (n=405) of the respondents were female. Age and socio-economic status were varied. Responses were collected across 48 countries, 61% (n=347) from WHO region Europe. 93% (n=532) were a patient relative, 71% (n=408) living with the patient and providing a wide range of care and support to the patient.

At diagnosis, majority of carers (61%, n=353) partially understood/did not understand the information provided by healthcare professionals relating to leukemia. Therefore, 81% (n=464) of respondents had used the internet to find further information.

59% (n=340) felt that the patient they are caring for was sufficiently involved in decisions about their treatment and care, while 47% (n=273) thought they, as carers were sufficiently involved in those decisions. While 81% (n=464) of the respondents wanted to know about the patient's prognosis, only 53% (n=306) were provided this information. Similarly, 63% (n=364) used the internet to find out about the different treatment options, 43% (n=250) not being provided with/directed to written information.

51% (n=299) reported feeling both relieved and frightened when the patient started treatment, 65% (n=372) feeling moderately to extremely anxious about relapse and 71% (n=409) being worried while waiting for the results from regular monitoring.

56% (n=322) rated that caring for someone with leukemia has negatively impacted on their wellbeing and life.

Summary/Conclusion

To the best of our knowledge, this is the first international study to examine the experiences, perceptions, and quality of life of leukemia carers. In line with findings from other disease studies, our data show that carers face several physical, emotional and psychological challenges.

It also highlights the need for greater involvement of carers in treatment decisions and the importance of including them throughout the patient's journey and considering their own needs. As an example, carer home-care guidance, psychological and social support can help reduce their physical and mental burden.

Keywords: Caregiver, Patient, Quality of life, Leukemia