

INTRODUCTION

Preliminary results of a research conducted by AELCLÉS have shown that haematological patients often face difficulties balancing work with their illness, returning to their job, or finding new employment due to physical and emotional symptoms, medical appointments and treatments. Additionally, workplace adjustments are not always provided. We present the preliminary results of this study.

AIM

This study aimed to generate patient-based evidence on the occupational, economic, and social needs of individuals diagnosed with haematological diseases. The objective was to better understand the real-life impact of these conditions beyond the clinical setting, focusing on how the diagnosis affects patients' ability to work, their financial stability, and their social relationships. By collecting data directly from patients, the study seeks to highlight unmet needs, and identify areas where support services, policies and healthcare pathways can be improved to enhance quality of life and long-term outcomes. The study aims to provide a broad, patient-centered perspective to support future advocacy, and policy efforts.

METHOD

An ongoing multi-regional online survey was conducted, recruiting 207 questionnaires from haematological patients across 14 regions and 32 cities in Spain. The survey began on April 1, 2024, and is still recruiting participants.

It focuses on the occupational, economic and social needs of individuals with oncohaematological diseases.

Data presented as of February 26, 2025.

The sample includes a diverse representation of age groups, diagnoses and treatment stages:

The survey sample consists of 52.2% women and 47.8% men.

In terms of age distribution, 51.7% are between 35 and 54 years old, 31.4% between 55 and 69 years old, and 14.5% between 14 and 34 years old.

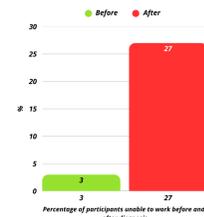
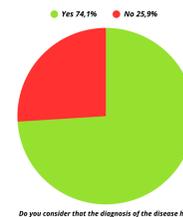
Regarding diagnosis, 40.1% (83 participants) had leukaemia, 31.4% (65) had lymphoma, 17.9% (37) had multiple myeloma, 3.9% (8) had myelodysplastic syndrome, 1.5% (3) had aplastic anaemia, 1.5% (3) had myelofibrosis, 1% (2) had polycythaemia vera, 1% (2) had AL amyloidosis, and 0.5% (1) had immune thrombocytopenic purpura.

Other diseases account for 1.2% of the sample.

RESULTS

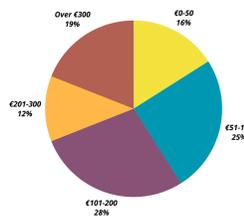
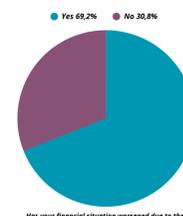
Work Impact:

At diagnosis, 35.3% were employed, but this drops to 12.4% afterward. While 10% were students before diagnosis, only 8% continued their studies. Additionally, 3% were classified as unable to work before diagnosis, increasing to 27.4% afterward. Overall, 74.1% reported that their diagnosis impacted their employment situation.



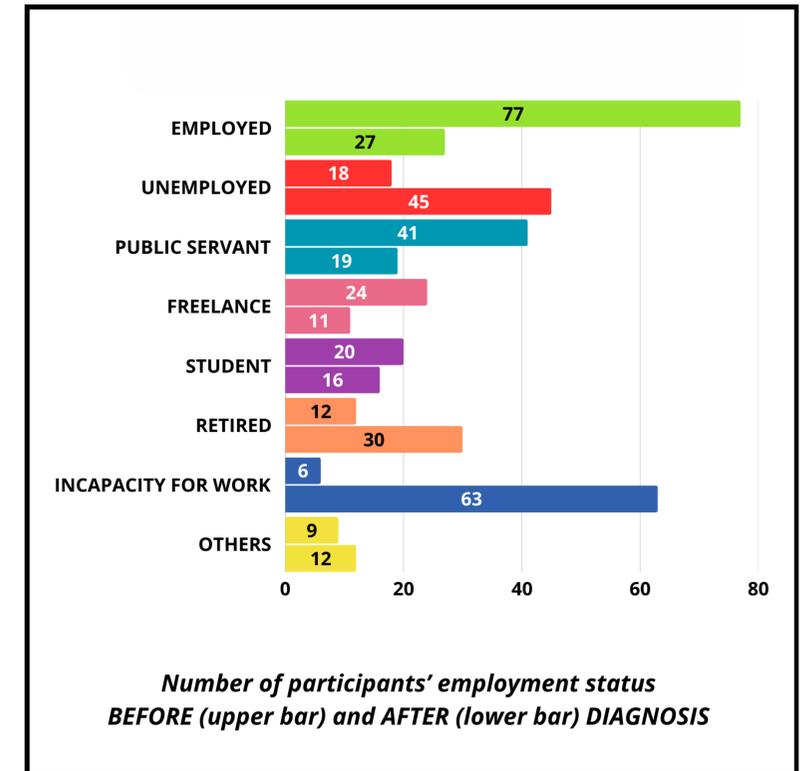
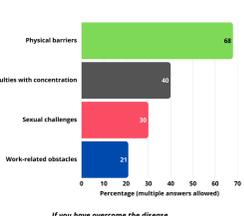
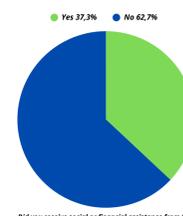
Economic Impact:

69.2% of patients reported that their illness worsened their financial situation. Regarding direct monthly expenses due to the disease, 25.4% reported costs between €51-100, 28.4% between €101-200, 11.6% between €201-300, and 19.4% over €300 per month. Additionally, 28.6% of respondents said their caregiver had to stop working to provide full-time care, while 31.3% reported that their caregiver had taken medical leave, an extended leave or work leave for this reason.



Social Impact:

62.7% did not receive social or financial assistance from the state due to their illness. 61.2% reported that they received emotional or financial support from family and friends. Respondents who overcame the disease identified the main challenges as follows: 67.6% reported physical barriers, 39.6% difficulties with concentration, 29.7% sexual challenges, and 20.7% work-related obstacles.



CONCLUSIONS

The study reveals that students and workers with oncohaematological diseases feel that the current educational and workplace systems do not adequately address their needs.

Additionally, they also face bureaucratic barriers such as issues with disability applications and access to financial support.

These challenges, combined with medical concerns, contribute to inequity, as patients and caregivers rely on personal resources for adequate quality of life, worsening their economic and professional difficulties.

Therefore, healthcare and public administrations must address the care of these individuals and their families beyond clinical assistance, also considering economic, social and occupational factors.

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