



Putting Patients First: Insights from the Specialized Working Group Session on Quality of Life in Haematology

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OVER the past decades, haematology has made great progress in understanding disease mechanisms, developing objective diagnostic criteria, and introducing new treatment options. However, during this period, the ‘subjective’ part of the patient’s follow-up, including personal experience such as symptoms, side effects, and perceptions about treatment, has often been overlooked. Clinicians have mainly focused on measurable medical outcomes, and there has been little time or space to address the subjective aspects of care. Today, this situation is beginning to change.

QUALITY OF LIFE AND PATIENT-REPORTED OUTCOMES

During the Specialized Working Group session, ‘Quality of Life and Symptoms: Promoting Connection Between Patients and Clinicians’, which took place at the European Hematology Association (EHA) 2025 Congress, Raul Cordoba, Instituto de Investigación Sanitaria de la Fundación Jiménez Díaz, Madrid, Spain, gave a presentation entitled ‘Assessment of Patients’ Quality of Life (QoL) and Symptoms in Routine Clinical Practice to Aid Treatment Decision Making’. Cordoba began by discussing the concept of value in healthcare, based on the model proposed by Michael E. Porter.^{1,2} In this model, value is defined as the health outcomes that matter to patients, divided by the cost of achieving those outcomes. Cordoba stressed that, in addition to objective results like survival, patients’ experiences and QoL must also be considered when evaluating healthcare value.

To support this shift, Cordoba emphasised the use of patient-reported outcome measures (PROM) and patient-reported experience measures (PREM) in routine practice. Tools such as the Patient-Reported Outcomes Version of the Common Terminology Criteria For Adverse Events (PRO-CTCAE[®]) system, developed by the National Cancer Institute (NCI), are already being used in diseases like chronic myeloid leukaemia and myelofibrosis.³ At Cordoba’s hospital, digital tools like the Casiopea patient portal and electronic medical record-integrated questionnaires help both patients and healthcare providers monitor care more closely. These tools also allow for analysis of large datasets to improve care processes.

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Although there are no universal PROM/ PREM standards in haematology yet, Cordoba's team has developed disease-specific datasets. These include not only traditional outcomes like treatment response and survival, but also QoL indicators such as treatment duration, nutrition, emotional well-being, and social relationships. One interesting innovation is a 'traffic light' system based on PROM data, which helps nurses make proactive interventions to prevent worsening of symptoms.

Cordoba also presented results from a 2023 EHA poster. In this study, patients with newly diagnosed aggressive lymphoma receiving intravenous therapy were monitored remotely using the E-Res Salud digital health system. Compared with a control group, these patients had significantly fewer emergency visits and unplanned hospitalisations, and also showed better overall survival.⁴

Including patient-centred outcomes in clinical decision-making can improve both individual care and system-wide efficiency. In a complex field like haematology, this shift toward value-based, patient-focused care may help raise awareness among clinicians and patients alike, and contribute to better outcomes for all.

In the session 'Quality of Life in Cardio-Hematology: Lessons from the Horizon 2020 Resilience Trial', Borja Ibañez, Centro Nacional de Investigaciones Cardiovasculares Carlos III, Madrid, Spain, presented updates from the ongoing RESILIENCE study.⁵ This trial focuses on one of the key challenges in real-world haematology practice: preventing anthracycline-related cardiotoxicity. It evaluates the potential protective effect of remote ischaemic conditioning in patients with high-risk lymphoma. The primary endpoint is the change in left ventricular ejection fraction, measured by cardiac MRI. The study also includes PROMs and QoL assessments to better understand how cardioprotective strategies affect patient experience.

Although the trial is still in progress, early observations shared at EHA 2025 suggest that combining imaging data with patient-reported outcomes is both feasible and valuable. This approach supports a more holistic model of cardio-haematology, one that considers not just survival, but also one of the most important factors affecting patients' physical and emotional well-being. It is promising to see large-scale studies like this being conducted, with the aim to reduce the cardiac side effects of chemotherapy.



The final presentation of the session, entitled 'Treatment Outcomes Preferences: What Matters to Patients with Acute Leukemia?', was delivered by Jan Geissler, Acute Leukemia Advocates Network (ALAN) and Patvocates. His talk focused on the disconnect between traditional clinical endpoints and what patients living with acute leukaemia actually value, particularly in the relapsed/refractory setting.⁶ As treatment options continue to grow, understanding patient perspectives has become more important than ever.

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Geissler presented the findings from a set of patient-driven studies, which explored treatment goals and priorities using methods such as discrete choice experiments, best-worst scaling, and structured interviews. In these studies, patients were asked to compare hypothetical treatment scenarios involving various trade-offs, such as likelihood of response, side effect burden, treatment duration, and impact on daily functioning. This approach helped quantify what patients are willing to prioritise or sacrifice in different clinical situations.

The results showed that chance of response remains the top priority for most patients. However, QoL during treatment ranked second, and in some cases, patients were willing to accept a lower response rate in exchange for fewer side effects, more convenience, or better overall well-being. Interestingly, two broad groups of patients were identified, one that focuses strongly

on maximising response, and another that values a more balanced approach between response and QoL. Patients with acute lymphoblastic leukaemia or acute promyelocytic leukaemia, and importantly, newly diagnosed patients, tended to place greater emphasis on response.

Another key aspect of the presentation was the evaluation of standard QoL tools like EuroQol 5-dimensional questionnaire. The studies included two additional dimensions, cognition and tiredness, which patients consistently rated as highly important. Notably, tiredness was given much more weight by patients than by the general public. These findings suggest that existing generic QoL instruments may not fully capture the lived experience of patients with acute leukaemia.

CLOSING REMARKS

In conclusion, these findings highlight the importance of a patient-centred approach that focuses not only on the disease, but on the person experiencing it. The author firmly believes that integrating patient-reported data and treatment preferences into routine care can significantly improve outcome, not just clinically, but also in terms of communication, satisfaction, and empowerment. Tools such as PROMs and preference studies not only help standardise the way patient symptoms and priorities are understood, but also strengthen the dialogue between physicians and patients. Most importantly, they give patients a greater voice in decisions about their own care, which is essential in building a healthcare system that truly reflects what matters to those it serves.

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