

## Quality of Life in hematology: European Hematology Association theme of the year ... and years to come

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For many years, through its dedicated scientific working group and sessions at its Annual Congress, the European Hematology Association (EHA) has underscored the commitment of hematologists to address the issue of Quality of Life of patients affected by hematologic diseases. Understandably, when the EHA Communication Committee initiated a “theme of the year” scheme as a thread to link all initiatives driven by hematologists on a specific item, the theme “Quality of Life” was unanimously selected as the first choice.

Quality of Life is no longer a pursuit of philosophers or a topic to be discussed by literary-prone aristocrats. Instead, it has finally been accepted as something completely inseparable from one’s existence and well-being. It still remains very much in the background of ones’ lives, like a second life, more often a dream or a treasure, far behind health or financial security in our list of priorities. Nevertheless, over recent years, Quality of Life has weighed more heavily than it used to, and it comes up as an issue very early in the decision-making process. The younger generation is more aware of its place in everyday life. Quality of Life will (should) very soon become completely integrated into patient care, treatment choices, assessment of therapy efficacy and cost. In times when some hematologic diseases are turning from acute, life-threatening diseases into life-long, chronic conditions, assessing and maintaining Quality of Life becomes even more important for patients. EHA takes a front-line position in the invaluable Quality of Life projects that relate to hematology.

Since June 2012, the starting point of EHA’s concept, “theme of the year”, initiatives in the field of Quality of Life in hematology have been highlighted. Through press releases and the press briefing at the 17<sup>th</sup> Congress in Amsterdam, Quality of Life as a theme was introduced publicly. Of the 2,075 abstracts submitted for the scientific program of the Congress, 27 were focused on the topic “Quality of Life”.

Awareness has been raised by one of the EHA scientific working groups (SWG): SWG “Quality of Life and Symptoms”. Recently, the SWG has been working with clinicians and researchers from 17 countries and 9 patient organizations on Guidelines of Patient-Reported Outcomes in Hematology,<sup>1</sup> with Quality of Life as one of its key components. The Guidelines provide recommendations to clinicians on patient-reported outcome assessments in clinical studies for patients with hematologic disorders. In an EHA Newsletter interview,<sup>2</sup> Professor Sam Salek, Chair of the SWG, explained the importance of “discussing Quality of Life issues ... with the involvement of patients. [...] It is planned to have a closer relationship with these organizations to improve understanding of the application of Quality of Life data to patient needs.” In line with this, from 2010,

the EHA and the patient community have been jointly conducting a patient advocacy session within the scientific program of its Annual Congress, attracting a large audience of hematologists and patient advocates. The third edition of the Patient Advocacy Session at the 17<sup>th</sup> Congress of EHA in Amsterdam focused on “Quality of Life - do patients perceive it the same way as doctors?”. The session was defined by the EHA Patient Working Group and chaired by Jan Geißler of the CML Advocates Network, as well as Androulla Eleftheriou of the International Thalassaemia Federation. In this session, the importance of Quality of Life for patients with hematologic diseases, as well as the growing importance of its appropriate measurement in therapy choice and reimbursement decisions, were addressed. In 2009, Myeloma Euronet (which recently changed its name to Myeloma Patients Europe) conducted a survey to look at the effects of treatment side-effects and the unmet needs of patients with multiple myeloma. The aim was to examine and compare the opinions of those affected by the disease, including family members and general caregivers, *versus* those in the medical profession. The results of this survey,<sup>3</sup> presented by Erik Low of Myeloma Patients Europe, show fundamental differences in perception between patients, nurses and doctors in assessing the impact on Quality of Life e.g. of hair loss, fatigue, reduced body function, neuropathy and thrombotic events. Physical and psychosocial effects of disease symptoms and side-effects of therapies are often prioritized differently, leading to challenges in communication and different priorities in making treatment choices. Erik Low also raised the issue of how patients’ representatives should become more involved in tailoring Quality of Life surveys, as well as introducing Quality of Life issues in trial designs and clinical care guidelines. The recently published Guidelines of Patient-Reported Outcomes in Hematology were also presented in this session by Tatyana Ionova, on behalf of the SWG Quality of Life and Symptoms. Denis Costello of the European rare disease patient organization EURORDIS presented the outline of a platform under development called RARECONNECT. This European patient self-reported outcome platform will enable patients and researchers to identify other patients with similar experiences, and compare their Quality of Life over time and against aggregated data from other patients with a similar disease journey.

Finally, parallel to this EHA initiative, we were pleased to report at the Congress the results of the Open Window Project.<sup>4,5</sup> Open Window (OW) is an innovative art intervention available at the National Stem Cell Transplant Unit at St. James’s Hospital, Dublin, where patients undergo bone marrow transplantations. The study showed that the use of an art intervention in adult hospitals is possible. The study

equally underscores the fact that rigorous evaluation of its impact can be carried out in the context of a randomized prospective trial. The study proved that art is beneficial for patients who have to deal with the daily challenge of being in protective isolation for the treatment of leukemia. The introduction of OW had a positive effect on Quality of Life as measured by levels of anxiety, depression and the experiences of patients having a stem cell transplant. Patients' expectations and hospitals' feedback are extremely valuable and any action, such as that of the OW, which can improve these, is welcome. In this issue of the Journal, Shaun McCann provides a perspective article on the OW project.<sup>6</sup>

During the course of the year, until June 2013, several EHA Committees and Units are contributing to the dissemination of the Quality of Life "theme of the year" using different tools such as the EHA website and articles, as well as meetings. The theme will naturally resonate strongly with groups such as patient organizations and EHA Scientific Working Groups.

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