Assessment of health-related quality of life at diagnosis in an European Registry for low-risk and intermediate-1 risk MDS: report on the first 322 patients

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BACKGROUND and AIMS

To describe the demographics, the disease-management and the clinical outcome in Myelodysplastic Syndromes (MDS) a prospective, multicenter European Registry (EUMDS) for newly diagnosed IPSS low and intermediate-1 MDS has been initiated under the auspices of the European LeukemiaNet. As data on health-related quality of life (HR-QoL) in MDS patients are rare, the EQ-5D (European quality group 5 dimensions) descriptive system was introduced in the EUMDS evaluation.

METHODS

The EQ-5D represents a measure of HR-QoL in five dimensions: mobility, self-care, usual activities, pain/discomfort, anxiety/depression at level 1 (no problem), 2 (moderate problem) or 3 (severe problem, unable to do). In addition the patient rates her/his overall HR-QoL on a visual analog scale (VAS) ranging from 0-100 (Figure 1). The performance status was assessed by the Karnofsky score and comorbidities were assessed by the Sorror index. All analyses were conducted in Stata statistical software, using standard statistical methods.

RESULTS

In 330 out of 400 EUMDS patients (83%) analyzed so far the EQ-5D score has been applied at initial presentation. The median age was 74 yrs (female 75.2; male 73.5) with 203 (63%) male patients. Comorbidities were detected in a substantial proportion of patients (Sorror score mean 2.4, median 2.0, range 0 to 11). Whereas a reduced performance status as defined by a Karnofsky Index ≤ 70 was detected only in 20% of MDS patients, an impaired QoL was observed in a greater proportion. Using EQ-5D the dimensions mobility, self-care, usual activities and pain/discomfort were clearly age-dependent. No problem (Level 1) was detected in 80, 96, 50 and 50-59 years old persons, whereas the cohort of 70-79 years old revealed a lower percentage of 55, 80, 66 and 51% respectively (Table 1). Similarly the self-reported health as assessed by a VAS was lower in elderly patients; mean score of 74 (sd 19.0) in 50-59 yrs, 73 (21.3) in 60-69 yrs, 66 (22.2) in 70-79 yrs and 62 (20.3) in 80+ yrs (p<0.01) (table 2). Moreover, analyses revealed pronounced sex differences in distinct dimensions as no problem (Level 1) was detected in 58% male and 45% female patients in the dimensions mobility (p<0.05), in usual activities 70 vs 54% (p=0.004), in pain/discomfort 56 vs 41% (p<0.05) and in anxiety/depression 69 vs 45% (p<0.0001). In contrast this effect was less pronounced in the dimension self-care as Level 1 was detected in 86% of male and 80% of female patients (ns) (table 3). The EQ-5D status was reported in 10 different countries contributing to this registry. The mean EQ-5D VAS score was 68 (sd 21.9) and ranged from 52 (sd 16.4) in Austria (AU) to 84 (sd 13.1) in Greece (GR) (p=0.015) (table 4). This difference might be explained by inter-country, cross-cultural differences or differences in patient recruitment by country.

Figure 1. The EQ-5D score

Table 1. EQ-5D different dimensions in MDS

Table 2. EQ-5D VAS in different countries

CONCLUSIONS

This is the first prospective analysis of health-status and QoL in a large cohort of newly-diagnosed MDS patients. Relevant restrictions in self-reported health are shown. In the evaluation of QoL in MDS age- and gender effects as well as possible cross-cultural differences should be considered. EQ-5D value sets, representing the general population from European countries will allow comparisons to be made between the general population and patients with MDS and will contribute to understand the impact of MDS on QoL. EQ-5D will be prospectively re-assessed 6-monthly in all patients continuing follow up in the registry.