Leukemia Research 39 (2015) 859–865

Contents lists available at ScienceDirect

Leukemia Research

journal homepage: www.elsevier.com/locate/leukres

Accuracy of physician assessment of treatment preferences and health status in elderly patients with higher-risk myelodysplastic syndromes

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ARTICLE INFO

Article history:
Received 21 January 2015
Received in revised form 27 April 2015
Accepted 5 May 2015
Available online 12 June 2015

Keywords:
Health status
Decision making
Myelodysplastic syndromes
Cancer
Oncology
Hematology

ABSTRACT

Higher-risk myelodysplastic syndromes (MDS) are rarely curable and have a poor prognosis. We investigated the accuracy of physicians' perception of patients' health status and the patients' preferences for involvement in treatment decisions.

We examined 280 newly diagnosed higher-risk elderly MDS patients paired with their physicians. Survey tools included the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30) and the Control Preference Scale.

Overall concordance was 49% for physician perception of patient preferences for involvement in treatment decisions. In 36.4% of comparisons there were minor differences and in 14.6% there were major differences. In 44.7% of the patients preferring a passive role, physicians perceived them as preferring an active or collaborative role. Absence of the patient's request for prognostic information ($P=0.001$) and judging the patient as having a poor health status ($P=0.036$) were factors independently associated with the physicians' attitude toward a lower degree of patient involvement in clinical decisions. Agreement on health status was found in 27.5% of cases. Physicians most frequently tended to overestimate health status of patients who reported low-level health status.

The value of decision aid-tools in the challenging setting of higher-risk MDS should be investigated to further promote patient-centered care.

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http://dx.doi.org/10.1016/j.leukres.2015.05.012
0145-2126/

1. Introduction

Patients suffering from myelodysplastic syndromes (MDS) with an intermediate-2 or high risk according to the International Prognostic Scoring System (IPSS) (i.e., higher risk) have poor prognosis. For untreated patients median survival is only about 12 months [1,2]. Although the availability of innovative treatment regimens, hypomethylating agents and/or allogeneic hematopoietic stem cell transplantation (HSCT) have made it possible to modify the natural history of the disease and to extend survival, clinical decision-making remains a challenge. This is due to the advanced age of most patients at diagnosis, the presence of comorbidities that can potentially limit efficacy of treatment and compound treatment side effects negatively impacting the patient's health related quality of life (HRQoL) [3–5].

In advanced-phase MDS with short life expectancy, it becomes essential to accurately evaluate the patients' wishes and preferences in light of the risks, benefits and appropriateness of treatment [6]. Previous data in a sample of 43 patients with acute myeloid leukemia (AML) or advanced MDS has shown that gaps might exist in communication with physicians, as patients tended to overestimate chances of cure [7].

Adding to the challenge of the assessment process is the lack of uniformity in preferences of patients faced with life-threatening conditions. We have previously examined patient's preferences for involvement in treatment decisions and found that decision-making preferences vary among newly diagnosed higher-risk MDS patients [8]. A personalized approach based on discussion and understanding patients' needs and preferences could lead to more satisfying outcomes as opposed to the "one-size fits all" approach. Therefore, in the current analysis, we examined the physicians' perception of their patients' health status and preferences for involvement in treatment decisions. A better understanding of the physicians' attitude toward patients' involvement in clinical decisions at the time of initial consultation could provide important information on how to improve communication effectiveness.

Some studies have shown that physicians often have a poor understanding of patients' views and preferences when considering their desire to be involved in treatment decisions and to receive prognostic information, as well as their perception of health status and general needs [9]. Many factors can potentially impact physicians' perception of patient preferences, such as differences in gender or education, number of encounters, patient age and performance status [10]. However, only a few studies have been conducted to address these issues in patients with hematological diseases [11,12].

The primary objective of this analysis was to investigate the accuracy of physicians' perception of patients' health status and the patients' preferences for involvement in treatment decisions. A secondary objective was to investigate physicians' attitude toward patient involvement in treatment decisions and to examine factors influencing physicians to be more patient inclusive or exclusive in the shared decision-making process.

2. Patients and methods

2.1. Study design and physician assessment

Higher risk MDS patients were consecutively enrolled into an international prospective cohort observational study whose primary objective was to investigate the prognostic value of baseline self-reported fatigue for overall survival. We herein report a secondary objective of this study that was registered on the US National Cancer Institute website (http://clinicaltrials.gov/); NCT00809575. Inclusion criteria have been previously reported [8]. Briefly, patients with MDS diagnosed according to the World Health Organization (WHO) classification [13] and with IPSS risk score of intermediate-2 or high risk, within 6 months before the date of registration were eligible. Patients with secondary MDS were not eligible. Data were centrally collected at Gruppo Italiano Malattie Ematologiche dell'Adulto (GIMEMA) Data Center. At the time of initial consultation, treating physicians were asked to complete a survey including a number of key socio-demographic characteristics and data regarding their clinical expertise. The following variables were ascertained: physician gender and age; the overall number of years in practice; the number of years of experience in treating MDS patients; primary field of clinical training (hematology vs. other fields).

We also assessed variables specific to each patient encounter: how often the physician discussed the various treatment options with the patient; the patient's explicit request for information about prognosis and expected survival; to what extent the physician considered it important to involve the patient in treatment decisions (not at all/a little bit/quite a bit/very much); the physician's opinion on the patient's role in the decision-making process and the physician's perception of the patient's health status. Methods and instruments used to assess these two aspects were the same for both physicians and patients and are described in the next paragraph.

The study was approved by the Ethics Committee of each participating Center, and all patients provided written informed consent.

2.2. Patient assessment, health status and preference for involvement in treatment decisions

Key patients sociodemographic and clinical characteristics were collected. In particular, as we expected to enrol basically elderly patients, we aimed at assessing living arrangements. Also, given the international setting of the study, we used a classification based on living arrangements determined by familial relationships of household members slightly adapted by the five mutually exclusive categories considered in the "Living arrangements of older persons around the world" report by the United Nations [14]. Patients and physicians were interviewed after having at least one encounter to discuss treatment options.

Patients were asked to express their opinion on the preferences for involvement in treatment decisions and to evaluate global health status at baseline (i.e., before starting treatment for higher-risk MDS). The Control Preferences Scale (CPS), for the measurement of preferred involvement in healthcare decisions, was used to assess patients' preferences [15,16]. The scale consists of five questions that can then be grouped into three broader categories, i.e., passive, collaborative and active role. For the purpose of this analysis, comparison was performed on the specific questions (these are summarized in Table 1). To assess health status, we used the global health status item of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 Items (EORTC QLQ-C30). This item is based on a Likert scale ranging from 1 (poor health status) to 7 (excellent health status) [17].

2.3. Statistical analysis

Descriptive statistics were used to characterize physicians' main characteristics. Responses to the control preferences scale were rated from one ("I prefer to make the decision about which treatment I will receive.") to five ("I prefer to leave all decisions regarding treatment to my doctor"). The responses to item 29 of the EORTC QLQ-C30 questionnaire ("How would you rate your overall health during the past week?") ranged from one ("Very poor") to seven ("Excellent"). Based on previous work [18] and for descriptive purposes, we defined complete agreement as an exact match between