



## Do Patients and Physicians Agree When They Assess Quality of Life?



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### A B S T R A C T

Patient and physician agreement on the most significant symptoms is associated with treatment outcomes and satisfaction with care. Thus, we sought to assess patient and physician agreement on patient-reported quality of life (QoL), and whether patient-related variables predict disagreement. In this cross-sectional, multisite study, patients and physicians completed the FACT-BMT at day 90. Agreement was analyzed with the intraclass coefficient correlation (ICC). Rates of underestimation and overestimation were calculated. Logistic regression models identified predictors of disagreement. We analyzed 96 pairs of questionnaires completed by 96 patients and 11 physicians. The patients' median age was 54 years, 52% were men, and 52% had undergone allogeneic hematopoietic cell transplantation (HCT). The physicians' median age was 42, 64% were men, and they had worked in the HCT field for an average of 12 years. Agreement on QoL was moderate (ICC = .436). Exploratory analyses revealed poor agreement for emotional (ICC = .092) and social (ICC = .270) well-being and moderate agreement for physical (ICC = .457), functional (ICC = .451), and BMT concerns (ICC = .445). Patients' well-being was underestimated by physicians in 41% to 59% of the categories of well-being parameters, and overestimated in 10% to 24%. Patient's anxiety predicted less disagreement in all scales except in social well-being, for which nonsignificant associations were observed. Patient-related variables explained 12% to 19% of the variance in disagreement across well-being scales. Patient and physician agreement on QoL was suboptimal, particularly in emotional and social well-being. The implementation of patient-reported outcomes in the daily care of HCT recipients may contribute to improving patient-centered care.

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### INTRODUCTION

Advances in the field of hematopoietic stem cell transplantation (HCT) are leading to an increasing population of survivors [1] who are challenged with significant post-HCT morbidity, including early and long-term HCT side effects, acute and chronic graft-versus-host disease (GVHD), and adverse effects of immunosuppressants [2–4]. HCT-related

morbidity impairs survivors' quality of life (QoL) [5] with significant rates of fatigue, pain, psychological distress, and sleep and sexual dysfunction [6–8].

QoL is one of patients' main concerns after HCT [9]. In addition, QoL information is critical for the clinical care of HCT recipients, because it helps to monitor symptoms, is predictive of well-being, and is an endpoint of treatment success [10–12]. Nevertheless, patient and physician agreement on patient-reported QoL has been overlooked in the HCT field, despite the fact that low rates of agreement could lead to a suboptimal estimation of our patients' well-being. Previous reports have identified various risk factors for patient-physician disagreement in QoL and symptom experience, including advanced age, female sex, anxiety, depression, poor education, and low Eastern Cooperative Oncology Group

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(ECOG) performance status [13,14]. Thus, we sought to assess (1) physicians' agreement on patient-reported QoL, (2) the potential direction of disagreement (underestimation versus overestimation), and (3) the patient-related variables associated with disagreement. We hypothesized that agreement would be moderate to low, with physicians overestimating patients' QoL, and that patient-related variables would be poorly associated with disagreement.

## MATERIALS AND METHODS

### Design

This was a cross-sectional analysis of a larger, prospective, multicenter study. The study included consecutive adult patients scheduled to undergo HCT at Hospital Sant Pau and Hospital Vall d'Hebrón, Barcelona. Patients with insufficient knowledge of the Spanish language, presenting with any physical condition that could preclude self-administration of the questionnaires (eg, severe vision difficulties), or refusing to sign the informed consent form were excluded. The study protocol was approved by the Institutional Review Board of the Hospital de Sant Pau.

Invited physicians were specialized hematologists working in adult HCT units. Physicians were in charge of the patients from at least 1 month pre-HCT to 3 months post-HCT. Afterward, some autologous HCT recipients returned to their center of origin. For descriptive purposes, physicians reported their age, sex, and years of experience, but no other variables, to protect their anonymity.

### Methods

Patients' sociodemographic data were collected before HCT via a standardized form eliciting age, sex, ethnicity, cohabiting status (living with a partner or not), education, and subjective socioeconomic status. Clinical variables were extracted from the medical records: diagnosis, previous lines of chemotherapy, type of HCT (allogeneic versus autologous), donor sources, ECOG performance status, and GVHD.

QoL was assessed with the Functional Assessment of Cancer Therapy-Bone Marrow Transplant (FACT-BMT) [15]. This assessment tool consists of 47 items grouped in the following 5 dimensions: physical well-being, social well-being, emotional well-being, functional well-being, and the BMT concerns. The FACT-BMT score is computed using the scores obtained in all 5 dimensions of the questionnaire, and the Functional Assessment of Cancer Therapy-General (FACT-G) score is calculated using the first 4 dimensions. The FACT-G enables a comparison of results obtained with normative data [16]. Higher scores on the FACT-BMT and the FACT-G indicate better QoL.

Anxiety and depression were assessed using the Hospital Anxiety and Depression Scale [17], which consists of 14 items, 7 of each to assess anxiety and depression separately. A score  $\geq 8$  indicates symptoms of anxiety and/or depression.

Patients completed the questionnaire before their scheduled visit with the HCT physician. Physicians in care of participating patients were unaware of the patients participating in the study and were able to address patients' QoL as part of their usual care. Once the visit ended, physicians were asked to complete the FACT-BMT questionnaire. Physicians were blinded to patients' responses and had 3 days to return the questionnaire.

### Statistical Analysis

Descriptive analyses were performed to identify clinical and sociodemographic characteristics of the sample. The intraclass correlation coefficient (ICC) was used to examine the agreement between patients and physicians [18]. Bland and Almand plots were performed. The physicians' scores were subtracted from the patients' scores, and the mean of the resulting values was calculated; this mean  $\pm$  one-half of its standard deviation (SD) was used to determine the percentages of agreement, as well as the overestimations and underestimations. One-half the SD indicates clinically meaningful differences in QoL studies [16,19]. Univariate analyses—using chi-square and *t* tests—were performed to compare the levels of disagreement in sociodemographic, clinical, anxiety, and depression scores. The paired-sample *t* test was used to assess the differences between the patients' and physicians' QoL scores. Multivariate linear regression analysis was used to identify predictors of disagreement (dependent variables). Independent variables were derived from significant results ( $P < .05$ , 2-tailed) in the univariate analyses. Multivariate analyses were adjusted for patient-related variables predictive of patient and physician disagreement on QoL (ie, age, sex, education, and ECOG performance status) [13]. Educational level was treated as a dummy variable, using high school as the reference category. Analyses were performed with SPSS version 22.0 (IBM, Armonk, NY).

## RESULTS

### Physician Sample

Eleven of the 15 hematologists invited agreed to participate. Their median age was 42 years (range, 31–52 years), 7 were male, and all had been working as an attending physician in the HCT field for an average of 12 years (range, 3–23 years). Four hematologists declined to participate, characterizing the study as too time-consuming.

### Patient Characteristics

At 3 months post-HCT, a total of 132 patients were approached. Twelve patients were undergoing a second HCT, and thus their outcomes were excluded from the present analysis. Fifteen patients declined to complete the questionnaires at this time point, owing mainly to being too ill or overwhelmed; thus, the corresponding physicians' questionnaires were not completed. Nine questionnaires were incomplete and were excluded from the analysis. We finally analyzed 96 pairs of questionnaires completed by 96 patients (response rate, 89%) and 11 physicians (response rate, 87%).

Sociodemographic and clinical characteristics of the sample are presented in Table 1. The median patient age was 54 years (range, 19–71 years), and 50 patients (52%) were men. Fifty pa-

**Table 1**  
Sociodemographic and Clinical Characteristics of the Sample (n = 96)

Characteristic	Value
Age at HCT, yr, median (SD)	53.66 (13.01)
Male sex, n (%)	50 (52.1)
Living with a partner, n (%)	60 (64.5)
Subjective socioeconomic status, n (%)	
High	7 (8)
Middle	59 (61.5)
Low	30 (31)
Ethnicity, n (%)	
Caucasian	74 (75)
Hispanic	17 (17)
Others	5 (4)
Education, n (%)	
Primary	23 (23.3)
High school	37 (38.9)
University	36 (37.8)
Type of HCT, n (%)	
Allogeneic	50 (52)
Autologous	46 (48)
ECOG status, n (%)	
0	51 (53)
1	37 (38.9)
$\geq 2$	6 (6)
Acute GVHD, n (%)	
Grade 0-I	29 (58)
Grade II-IV	21 (42)
Diagnosis, n (%)	
AML/MDS	34 (35.42)
ALL	7 (7.29)
NHL	18 (18.75)
HL	5 (5.2)
MM	27 (28.12)
Others	5 (5.22)
Lines of chemotherapy, n (%)	
0	4 (4.2)
1	62 (64.6)
$\geq 2$	30 (31.2)
Anxiety*, n (%)	31 (32.29)
Depression*, n (%)	15 (15.6)

AML indicates acute myelogenous leukemia; HADS, Hospital Anxiety and Depression Scale; MDS, myelodysplastic syndrome, ALL, acute lymphoblastic leukemia, NHL, non-Hodgkin lymphoma, HL, Hodgkin lymphoma, MM, multiple myeloma.

\* HADS  $\geq 8$  were considered indicative of symptoms of anxiety and depression.

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