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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

(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 ≥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 ± 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 socioeconimic 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)
≥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)
≥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, myelodysplasic syndrome, ALL, acute lymphoblastic leukemia, NHL, non-Hodgkin lymphoma, HL, Hodgkin lymphoma, MM, multiple myeloma.

* HADS ≥8 were considered indicative of symptoms of anxiety and depression.

Table 2
Descriptive Scores on QoL and Subscales of the FACT-BMT (n = 96)

FACT-BMT, FACT-G, and Subscales	Patient Perception		Physician Perception		
	Mean (SD)	Range	Mean (SD)	Range	P Value
FACT-BMT	104.06 (18.97)	63-142	93.39 (19.47)	33-130	.041
FACT-G	78.09 (13.4)	48-105	70.35 (14.40)	28-98	.03
Physical well-being	20.66 (5.51)	2-33	19.81 (5.38)	1-28	.004
Social well-being	22.39 (3.31)	4-28	19.14 (5.10)	6-40	.081
Emotional well-being	17.75 (4.31)	3-27	15.75 (3.63)	5-23	.684
Functional well-being	17 (4.83)	1-28	15.40 (4.57)	3-25	.017
BMT concerns	25.6 (6.59)	10-38	23.52 (5.71)	5-36	.007

tients (52%) received an allogeneic HCT and 46 (48%) underwent autologous HCT. Among the former group, 21 (42%) transplants were from matched-related donors, 19 (38%) were from unrelated donors, 7 (14%) were from single umbilical cord blood units, and 3 (6%) were from related haploidentical donors.

QoL and Agreement

The patient-reported mean (SD) score on QoL was 104.06 (18.97), and the physician-reported mean score was 93.39 (19.47) (Table 2). The ICC for QoL was .436 (95% confidence interval [CI], .189-.616; $P < .001$), indicating moderate agreement. A Bland and Altman plot is shown in Figure 1A. The difference between patients' and physicians' estimation was 10.67, indicating that physicians' estimate of QoL was 10.67 points lower than the patients' report ($P = .040$). One-half the SD of this difference was 9.73. Accordingly, we observed that patients and physicians agreed in 41% of the cases (n = 39), whereas physicians underestimated QoL in 49% of the cases (n = 47) and overestimated it in 10% (n = 10).

To explore the contribution of each subscale on the total agreement, we performed exploratory analyses for each subscale. Descriptive results are displayed in Table 2. Agreement was moderate to poor across the subscales, with an ICC of .457 (95% CI, .284-.601; $P < .001$) for physical well-being, .270 (95% CI, .050-.460; $P < .001$) for social well-being, .092 (95% CI, −.087 to .−.271; $P = .159$) for emotional well-being, .451 (95% CI, .270-.600; $P < .001$) for functional well-being, and .445 (95% CI, .264-.595; $P < .001$) for BMT concerns. Bland and Altman plots for these subscales are displayed in Figure 1B-E. Rates of agreement across subscales ranged from 18% to 37%, with the lowest agreement found in social (28%) and emotional (18%) well-being. Of note, patients' functioning on these subscales was underestimated in 59% and 58% of cases, respectively. Figure 2 shows rates of agreement, overestimation, and underestimation for each subscale.

On univariate analyses, anxiety was associated with patient and physician disagreement on QoL ($P < .001$), physical well-being ($P = .019$), emotional well-being ($P < .001$), functional well-being ($P < .001$), and BMT concerns ($P < .001$). Depression was associated with patient and physician disagreement on QoL ($P = .019$), functional well-being ($P = .020$), and BMT concerns ($P = .005$). Other clinical and sociodemographic variables were not associated with patient and physician disagreement ($P > .05$ for all).

Stepwise regression models examined patient-related variables associated with disagreement. Independent variables were significant values on the univariate analyses, as well as patient-related variables associated with patient and physician disagreement [13]. No significant results were obtained in the univariate analyses for disagreement on social wellbeing; therefore, this stepwise regression model included only age, sex, education, and ECOG performance status, and results

were nonsignificant ($P > .05$ for all). Patient-related variables identified 17% of the variance within disagreement in QoL. The variance for the remaining subscales ranged from 12% to 19%. Anxiety diminished disagreement in all subscales. ECOG performance status, type of HCT, number of previous lines of chemotherapy, and GVHD were not associated with disagreement. Results are displayed in Table 3.

DISCUSSION

QoL is being increasingly recognized by both patients and physicians as an outcome of paramount importance in the daily care after HCT. Patients cite post-HCT QoL as a main concern [9], and physicians recognize it as a critical component of the daily care [20]. Despite this common interest, we found that agreement was moderate (ICC = .436), physicians considerably underestimated patients' QoL (49%), and patient-related variables poorly contributed to explaining this disagreement. These observations are novel in the HCT setting and suggest that patient-reported QoL might not be adequately perceived during the daily care of this population. In addition, the rates of agreement vary according to the dimensions assessed, with patient-related variables poorly contributing to explaining these disagreements. This is clinically relevant, given that the level of agreement between patients and physicians with respect to patients' concerns has been associated with better outcomes of care, as perceived both by patients and physicians [21].

Exploratory analyses revealed the highest agreement on the physical (ICC = .457) and functional (ICC = .451) well-being subscales, but dramatically low agreement on the

Table 3
Stepwise Regression Analyses Predicting Disagreement on QoL, Physical Well-Being, Emotional Well-Being, Functional Well-Being, and BMT Concerns

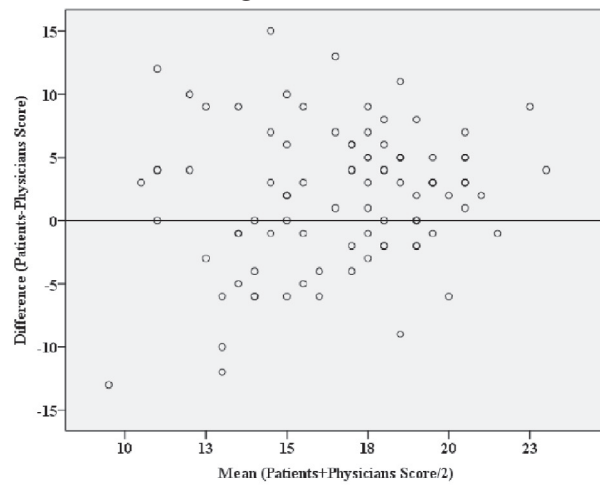| Outcome	Predictor	R^2	P Value
Disagreement on QoL		.173	
	Anxiety		<.001
Disagreement on physical well-being		.158	
	Anxiety		.018
	Subjective socioeconomic status		.023
Disagreement on emotional well-being		.187	
	Anxiety		<.001
Disagreement on functional well-being		.121	
	Anxiety		.001
Disagreement on BMT concerns		.122	
	Anxiety		.001

A. QoL
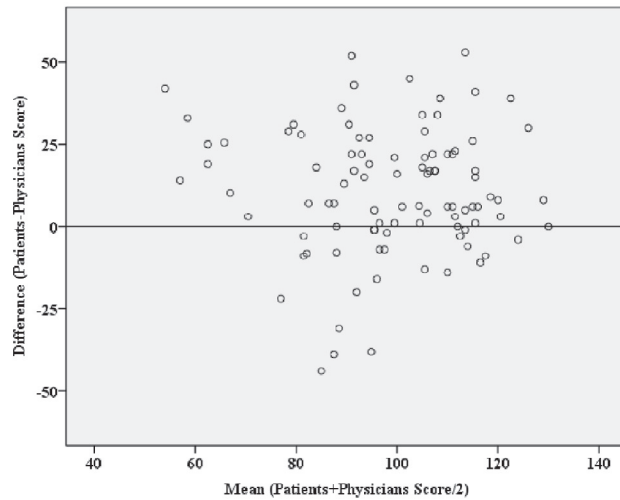
B. Physical wellbeing
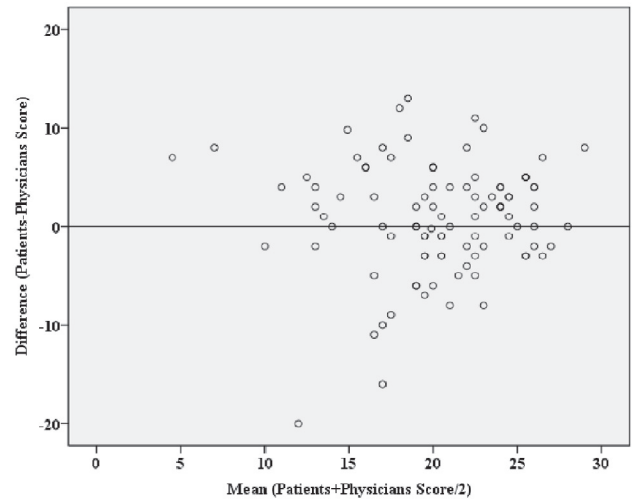
C. Social Wellbeing

D. Emotional wellbeing
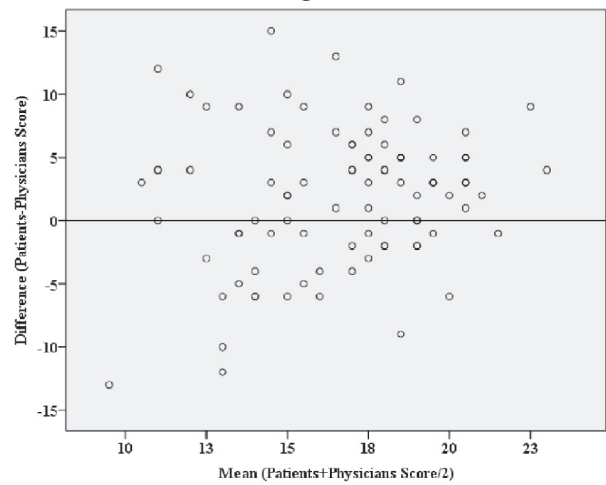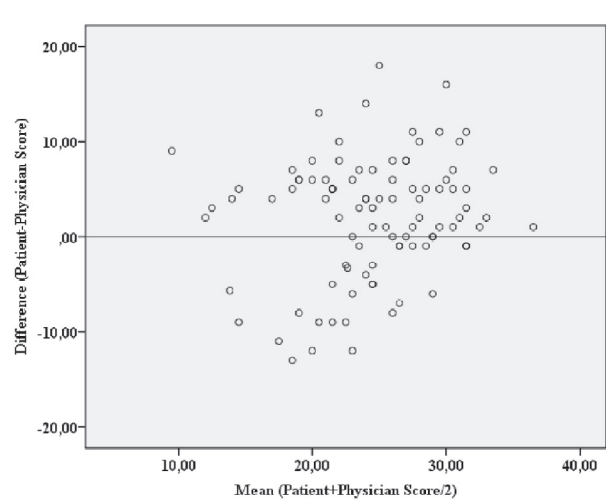
E. Functional Wellbeing
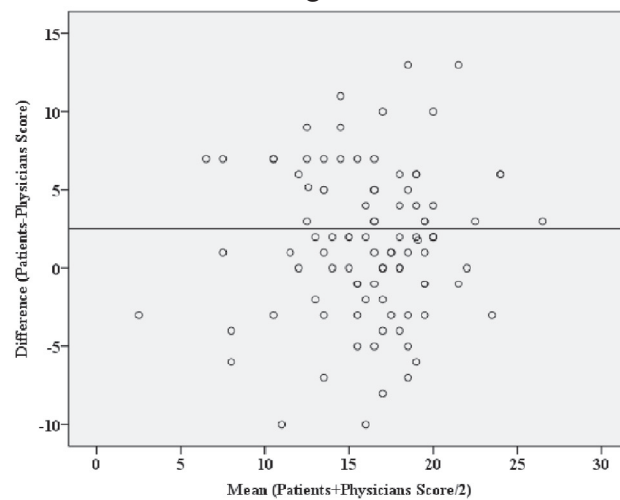
F. BMT Concerns

Figure 1. Bland and Altman plots for all dimensions examined. The mean difference between physician and patient scores is on the *x*-axis, and degree of agreement is on the *y*-axis. A value of 0 indicates perfect agreement, whereas positive and negative values indicate overestimation and underestimation, respectively. (A) QoL. (B) Physical well-being. (C) Social well-being. (D) Emotional well-being. (E) Functional well-being. (F) BMT concerns.
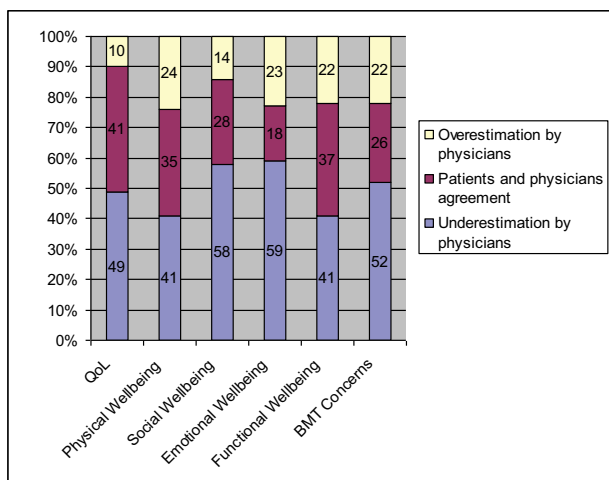
Figure 2. Percentages of agreement, underestimation, and overestimation of QoL and physical, social, emotional, and functional well-being and BMT concerns subscales.

emotional (ICC = .092) and social (ICC = .270) well-being subscales. This discrepancy might be explained by physicians focusing mainly on the physical aspects of QoL, and patients referring primarily to the psychosocial aspects of QoL [22]. Nonetheless, attention should be given to the low agreement in social and emotional well-being. Wener et al. [23] observed very poor agreement (κ values of .04-.09) between a mixed sample of patients with cancer and their clinicians on depression and anxiety, as well as in family and occupational functioning. Muffy et al. [24] reported an ICC = .06 for depression and an ICC = .15 for anxiety when assessing adolescents and young adults diagnosed with hematologic malignancies and a mixed sample of providers (attending clinicians, fellows, and nurses). Notwithstanding, we found that agreement in the BMT concerns subscale was moderate (ICC = .445), and higher than that for emotional well-being. We hypothesize that physicians might effectively capture worries and concerns, but not other symptoms assessed on the emotional well-being subscale, such as feelings of sadness and hoplessness and illness adjustment.

The mean QoL score reported by patients in this study is in line with previous literature including mixed samples of autologous and allogeneic HCT recipients at day 90 post-HCT [25,26]. However, contrary to our hypothesis, the physicians' mean score was significantly lower than the patients' mean score——that is, physicians underestimated patients' QoL. Studies assessing agreement on QoL between patients and physicians have yielded mixed results regarding the direction of disagreement (ie, underestimation or overestimation) [27-29]. Given that the introduction of patient-reported outcomes in the daily care of HCT recipients has been associated with earlier detection of symptoms [30], we expected to find that its absence would result in physicians underestimating patients' symptoms and thus overestimating their QoL. However, the physicians in this study underestimated the patients' QoL; that is, they assessed the patients' well-being at lower levels than the patients did. These results are in line with previous studies conducted in patients with advanced lung cancer [27,31,32] and chronic diseases [33] that reported that physicians underestimated patients' well-being, but slightly overestimated their

symptoms. We hypothesize that other patient-related variables, such us coping strategies to deal with HCT symptomatology or resilience, might mediate between symptoms and their interference with patients' well-being.

Patient-related factors poorly contributed to explaining the variance in disagreement observed (12%-19%). Remarkably, anxiety predicted less disagreement in QoL as well as in all of the subscales except social well-being, where nonsignificant variables emerged. In HCT recipients, anxiety is associated with symptoms of depression and increased length of hospital stay [34,35], whereas in patients without cancer, anxiety is associated with impaired physical and emotional health, and increased use of health care facilities and psychoactive drugs [36]. Thus, it is hypothesized that the impact of anxiety on patients' well-being might be more evident to physicians, explaining the lower disagreement. Depression was only associated with disagreement in QoL in the univariate analyses. Nonetheless, Zastrow et al. [14] identified depression as a risk factor for symptom underestimation in patients hospitalized in an internal medicine department. Considering the high incidence of anxiety and depression among HCT recipients [10], careful assessment of these disorders is important.

Our study is novel in assessing patient and physician agreement on patient-reported QoL. This is of remarkable importance in the field of HCT, where both autologous and allogeneic transplant recipients report significant QoL impairments [37]. Remarkably, our results are based on patients and physicians completing an identical questionnaire, which strengthens our data. Moreover, we performed the study at 3 months post-HCT, based on a previous study reporting an association between the number of encounters between patients and physicians and longer discussions about QoL [38]. However, some limitations should also be noted. The FACT-BMT was designed to be patient-reported and not to be completed by physicians or other proxies [15], and thus agreement is not expected for some items. In addition, our sample of physicians was relatively small, which precluded us from examining physician-related variables that could influence agreement; however, a previous study found no association between physician-related variables and disagreement on QoL [13]. Moreover, our patient sample was predominantly Caucasian and well-educated, and mainly from a single geographic area, which may limit the generalizability of our findings. We attempted to mitigate this limitation by performing the study in 2 transplantation referral centers (Hospital de Sant Pau and Hospital Vall d'Hebrón) that receive patients from other areas. Future lines of research should assess patient and physician agreement on QoL throughout the HCT process, when late effects and chronic GVHD worsen survivors' QoL. In addition, it remains to be elucidated how communication affects patient and physician agreement on QoL and treatment outcomes. A larger and more culturally diverse sample of HCT recipients and physicians could contribute to making our findings more generalizable.

In conclusion, in this study we found an overall moderate level of patient and physician agreement on QoL, with levels of agreement varying depending on the dimensions assessed. The introduction of patient-reported outcomes, such as QoL tools, in the clinical setting can overcome these deficiencies. Patient-reported outcomes are well accepted by patients [39] and are associated with better detection and monitoring of unmet needs [40], specifically QoL, emotions, and daily activities [41]. Moreover, the discussion of results during clinical encounters is associated with patient

and physician satisfaction [41]. Thus, the implementation of patient-reported outcomes in the daily care of HCT recipients may contribute to improved patient-centered care.

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