Accepted Manuscript

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

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Please cite this article as: Barata A, Martino R, Gich I, García-Cadenas I, Abella E, Barba P, Briones J, Brunet S, Esquirol A, García-Pallarols F, Garrido A, Granell M, Martinez J, Mensa I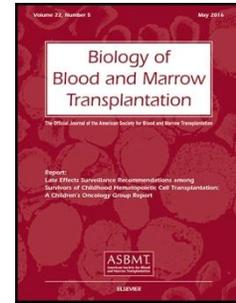, Novelli S, Sanchez-Blanco B, Valcárcel D, Sierra J, Do Patients and Physicians Agree When They Assess Quality of Life?, *Biology of Blood and Marrow Transplantation* (2017), http://dx.doi.org/doi: 10.1016/j.bbmt.2017.03.015.

Do patients and physicians agree when they assess quality of life?

Short title: Patients and Physicians Agreement on QoL

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Highlights:

- Patients and physicians agreement on patient-reported quality of life is moderate
- Exploratory analyses revealed poor agreement in social and emotional wellbeing
- Moderate agreement was found on physical and functional wellbeing and BMT Concerns.
- Physicians underestimated patients' wellbeing
- Patient-related variables poorly explained the variance within disagreement

Abstract

INTRODUCTION: Patients and physicians agreement on the most significant symptoms is associated with treatment outcomes and satisfaction with care. Thus, we seek to assess patient and physician agreement on patient-reported quality of life (QoL), and whether patient-related variables predicted disagreement. METHODS: This is a cross-sectional, multisite study; where patients and physicians completed the FACT-BMT at day 90. Agreement was analyzed with the Intraclass Coefficient Correlation (ICC). Rates of under- and over-estimation were calculated. Logistic regression models identified predictors of disagreement. RESULTS: We analyzed 96 pairs of questionnaires, filled in by 96 patients and 11 physicians. Patients' median age was 54, 52% were men, 52% received an allogeneic HCT. Physicians' median age was 42, 7 were men, and had worked on the HCT field an average of 12 years. Agreement on QoL was moderate (ICC=.436). Exploratory analyses revealed that agreement for emotional (ICC=.092) and social (ICC=.270) wellbeing was poor, whereas it was moderate for physical (ICC=.457), functional (ICC=.451) and BMT Concerns (ICC=.445). Patients' wellbeing was underestimated by physicians in 41-59% of the categories of wellbeing parameters, and overestimated in 10-24%. Patient's anxiety predicted less disagreement in all scales, except in social wellbeing, where non-significant associations were observed. Patient related variables explained 12-19% of the variance on disagreement across wellbeing scales. CONCLUSIONS: Patients and physicians agreement on QoL is suboptimal, particularly in emotional and social wellbeing. The implementation of patient-reported outcomes in the daily care of HCT recipients may thus contribute to improve patient-centered care.

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1.   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: early and long-term HCT-side effects, acute and chronic graft-versus-host disease (GVHD) and the side effects of immunosuppressants[2-4]. HCT-related morbidity impairs survivors' quality of life (QoL) [5] with significant rates of fatigue, pain, psychological distress, sleep and sexual dysfunction [6-8].

QoL is one of the patients' main concerns after HCT [9]. In addition, QoL information is critical for the clinical care of HCT-recipients as it helps to monitor symptoms, predicts wellbeing 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' wellbeing. Previous reports have identified several risk factors for physician-patient disagreement in QoL and symptom experience, including advanced age, female gender, anxiety, depression, low education and low performance status[13, 14]. Thus, we seek to assess 1) physicians' agreement on patient-reported QoL, 2) potential direction of disagreement (under- versus over-estimation), and 3) patient-related variables associated with disagreement. We hypothesized that 1) agreement would be moderate to low, with physicians overestimating patients' QoL, and 2) patient-related variables would be poorly associated with disagreement.

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2. MATERIALS AND METHODS

Design

This is a cross-sectional analysis of a larger, prospective and multicenter study. The study included consecutive adult patients scheduled to receive a HCT at Hospital Sant Pau and Hospital Vall d'Hebrón (Barcelona; Spain). Patients with insufficient knowledge of the Spanish language, presenting any physical condition that could preclude the self-administration of the questionnaires (for example, severe vision difficulties) and patients 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 one month before HCT and up to three months post-HCT. Afterwards some autologous patients returned to their center of origin. For descriptive purposes, physicians reported their age, gender and years of experience but no other variables in order to protect anonymity.

Methods

Patients' socio-demographic data was collected before HCT by means of a standardized form assessing age, gender, ethnicity, co-habiting status (living with a partner or not),

education, and subjective socioeconomic status. Clinical variables were extracted from the medical records: diagnosis, number of previous lines of chemotherapy, type of HCT (allogeneic versus autologous), donor sources, performance status (ECOG) and GVHD.

Quality of life was assessed by the Functional Assessment of Cancer Therapy-Bone Marrow Transplant (FACT-BMT) [15]. It consists of 47 items grouped in the following 5 dimensions: Physical Wellbeing, Social Wellbeing, Emotional Wellbeing, Functional Wellbeing, and the BMT Concerns Subscale. The FACT-BMT score is computed with the scores obtained in all dimensions of the questionnaire, and the FACT-G score by means of the first fourth dimensions. The FACT-G enables the comparison of the results obtained with normative data [16]. Higher scores on the FACT-BMT and the FACT-G indicate better QoL.

Anxiety and Depression were assessed by means of the Hospital Anxiety and Depression Scale [17], which consists of 14 items, 7 of each to assess anxiety and depression separately. Scores equal or higher than 8 indicate 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 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 fill in the FACT-BMT questionnaire. Physicians were blinded to patients' responses and had three days to return the questionnaire.

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Statistical Analysis

Descriptive analyses were performed to provide clinical and socio-demographic characteristics of the sample. The Intraclass Correlation Coefficient (ICC) was used to examine agreement between patients and physicians [18]. Bland and Almand plots were performed. We subtracted the physicians' from the patients' scores, and calculated the mean of the resulting values; this mean ± half of its standard deviation (SD) was used to determine the percentages of agreement, as well as the over- and under-estimations. Half the SD indicates clinically meaningful differences in QoL studies [16, 19]. Univariate analyses – χ^2 and t tests- were calculated to compare the level of disagreement with socio-demographic, 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 variable). Independent variables were derived from significant results ($p<.05$, two-tailed) in the univariate analyses. Multivariate analyses were adjusted for patient-related variables predictive of patient and physician disagreement on QoL (age, gender, education and performance status) [13]. Educational level was treated as a dummy variable, using high-school as the reference category. Analyses were performed with IBM-SPSS version 22.0.

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3. RESULTS

Physicians' sample

Eleven of the fifteen hematologists invited agreed to participate: median age was 42 years (range: 31-52 years), 7 were male and had been working as attending physicians on the HCT field for an average of 12 years (range: 3-23). Four hematologists declined to participate, and reported the study as time-consuming.

Patients' characteristics

At three months post-HCT, 132 patients were approached. Twelve patients were receiving a second HCT, and their outcomes were excluded from the present analyses. Fifteen patients refused to complete the questionnaires at this time -point, mainly due to being too ill or overwhelmed. The corresponding physicians' questionnaires were therefore not completed. Nine questionnaires were incomplete and excluded from the analyses. We finally analyzed 96 pairs of questionnaires filled in by 96 patients (response rate: 89%) and 11 physicians (response rate: 87%).

Socio-demographic and clinical characteristics of the sample are described in Table 1. Fifty patients (52%) were men; with a median age of 54 years (range 19-71). Fifty patients (52%) received an allogeneic HCT and 46 (48%) an autologous HCT. Among the former, 21 (42%) were from matched-related donors, 19 (38%) from unrelated

donors, 7 (14%) from single umbilical cord blood units, and 3 (6%) from related

haploidentical donors.

QoL and Agreement

The patient-reported mean score on QoL was 104.06 (Standard Deviation [SD]= 18.97),

whereas physician's mean score was 93.39 (SD=19.47) (Table 2). The ICC for QoL was

.436 (95% CI [Confidence Interval]: .189-.616, p<.001), indicating moderate

agreement. The Bland and Altman plot is shown in Figure 1A. The difference between

patients and physicians' estimation was 10.67, indicating that physicians estimated QoL

10.67 points lower than the patients' report (p=.040). Half the SD of this difference was

9.73. Accordingly, we observed that patients and physicians agreed in 41% (n=39) of

the cases, whereas physicians underestimated QoL in 49% of the cases (n=47) and

overestimated it in 10% (n=10) of the cases.

To explore the contribution of each subscale on the total agreement, we performed

exploratory analyses for each subscale. Descriptive results are displayed on Table 2.

Agreement was moderate to poor across subscales, with an ICC of .457 (95% CI:.284-

.601, p<.001) for physical wellbeing, ICC=.270 (95% CI : .050-.460, p<.001) for social

wellbeing, ICC= .092 (95% CI: -.087-.-.271, p=.159) for emotional wellbeing,

ICC=.451 (95% CI:.270-.600, p<.001) for functional wellbeing, and ICC= .445 (95%

CI: .264-.595, p<.001) for BMT Concerns. Bland and Altman plots for subscales are

displayed in Figure 1B to 1E. Rates of agreement across subscales ranged from 18% to

37%, with the lowest agreement found in social (28%) and emotional (18%) wellbeing.

Of note, patients' functioning on these subscales was underestimated in 59% and 58%

of cases, respectively. Figure 2 shows rates of agreement, over- and under-estimation of each subscale.

Univariate analyses revealed that anxiety was associated with patient and physician disagreement on QoL (p<.001), physical (p=.019), emotional (p<.001) and functional wellbeing (p<.001) and BMT Concerns (p<.001). Depression was associated with patient and physician disagreement on QoL (p=.019), functional wellbeing (p=.020) and BMT Concerns (p=.005). Other clinical and sociodemographic variables were not associated with patient and physician disagreement (p values >.05).

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 only included age, gender, education and performance status, and revealed non-significant results (p values >.05). Patient-related variables identified 17% of the variance within disagreement in QoL. The variance for the rest of subscales ranged from 12 to 19%. Anxiety diminished disagreement in all subscales. Performance status, type of HCT, number of previous lines of chemotherapy, ECOG and GVHD were not associated with disagreement. Results are displayed on Table 3.

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4.   DISCUSSION

QoL is increasingly recognized as an outcome of paramount importance in the daily care of HCT recipients, both by patients and physicians. Patients cite post-HCT QoL as one of their main concerns[9] and physicians extensively 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 explain 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 explain these disagreements. This is clinically relevant, since 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, regardless of its severity [21].

Exploratory analyses revealed the highest agreement on physical (ICC=.457) and functional (ICC=.451) wellbeing whereas, in contrast, agreement on emotional (ICC=.092) and social (ICC=.270) wellbeing was dramatically low. This discrepancy might be explained by physicians mainly focusing on the physical aspects of QoL, whereas patients refer primarily to the psychosocial aspects of QoL [22]. Nonetheless, attention should be paid to the low agreement found on the level of social and emotional wellbeing. Wener et al [23] observed very poor agreement (kappa values ranging from .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 observed in emotional wellbeing. We hypothesize that physicians might capture well worry and concerns, but not other symptoms assessed on the emotional wellbeing subscale, such as feeling sad, illness- adjustment, or feeling hopelessness.

The mean QoL score reported by patients in this study is in line with previous literature including mixed samples of autologous and allogeneic recipients at day 90 post-HCT[25, 26]. However, contrary to our hypothesis, physicians mean score was significantly lower than that reported by patients, this is, physicians underestimated patients' QoL. Studies assessing agreement between patients and physicians on QoL have yielded mixed results regarding the direction of disagreement (under- or over-estimation) [27-29]. As the introduction of patient-reported outcomes in the daily care of HCT-recipients has been associated with the earlier the detection of patients' symptoms [30], we expected that its absence would result in physicians underestimating patients' symptoms, and therefore, overestimating their QoL. However, physicians in this study underestimated patients' QoL (i.e., they assessed their patients' wellbeing as having lower levels of functioning than patients did). These results are in line with previous literature performed in patients with advanced [31] lung [32] cancer [27], and chronic diseases [33], which described that physicians underestimate patients' wellbeing, but slightly overestimate their symptoms[13]. We hypothesize that other patient-related variables, such us coping strategies to deal with HCT-symptomatology or resilience, might mediate between symptoms and its interference on patients' wellbeing.

Patient-related factors poorly contributed to explain the variance observed within disagreement (12 to 19%). Remarkably, anxiety predicted less disagreement in QoL as well as in all the subscales, except in social wellbeing, where non-significant variables emerged. Anxiety among HCT-recipients is associated with symptoms of depression and increased length of hospital stay [34, 35], whereas in non-cancer patients is associated with impaired physical and emotional health, and increased use of health care facilities and psychoactive drugs [36]. It is therefore hypothesized that the impact that anxiety has on patients' wellbeing might be more evident to physicians, and, therefore, explain the lower disagreement found. Depression was only associated with disagreement in QoL in the univariate analyses. Nonetheless, Zastrow et al. [14] indicated that depression was a risk factor for symptom underestimation among patients hospitalized in an internal medicine department. As the incidence of anxiety and depression among HCT recipients is high [10], attention should be paid to accurately detect both disorders.

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 recipients report significant QoL impairments [37].Remarkably, our results are based in patients and physicians filling in an identical questionnaire, which strengthens the results obtained . Moreover, we performed the study at 3 months post-HCT, since previous studies found that the number of encounters between patients and physicians is associated with longer talks about QoL [38]. However, some limitations should also be noted. The FACT-BMT was designed to be patient-reported, but not to be completed by physicians or other proxies [15], and therefore agreement is not expected in some items. In addition, our sample of physicians is relatively small, which precluded us from

examining physician-related variables that could influence agreement, although previous studies found that physician-related variables are not associated with disagreement on QoL [13]. Moreover, our sample of patients was predominantly Caucasian, well-educated and mainly from a single geographic area, which can limit the generalization of the findings. We tried to mitigate this limitation performing the study in two transplant-reference centers -Hospital de Sant Pau and Hospital Vall d'Hebrón- that receive patients from other areas. Future lines of research should assess patients and physicians agreement on QoL along 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 generalize these findings.

To conclude, the study described that patients and physicians' agreement on QoL is moderate, with rates 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 associated with a better detection and monitoring of unmet needs [40], specifically QoL, emotions and daily activities [41]. Moreover, the discussion of their results during clinical encounters is associated with patients' and physicians' satisfaction[41]. The implementation of patient-reported outcomes in the daily care of HCT recipients may thus contribute to improve patient-centered care.

Acknowledgements

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ISCIII PI14/00450, PIE15/00028, RD12/0036/0071, AGAUR 2014 SGR 1281, Cellex

Foundation, Barcelona, Obra Social "La Caixa", Barcelona.

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Figure 1. Displays Bland and Altman plots for all dimensions examined. X-axis displays the mean difference of physicians' and patients' scores. Y-axis describes degree of agreement. Zero value indicates perfect agreement, whereas positive and negatives values are indicative of over- and under- estimation respectively
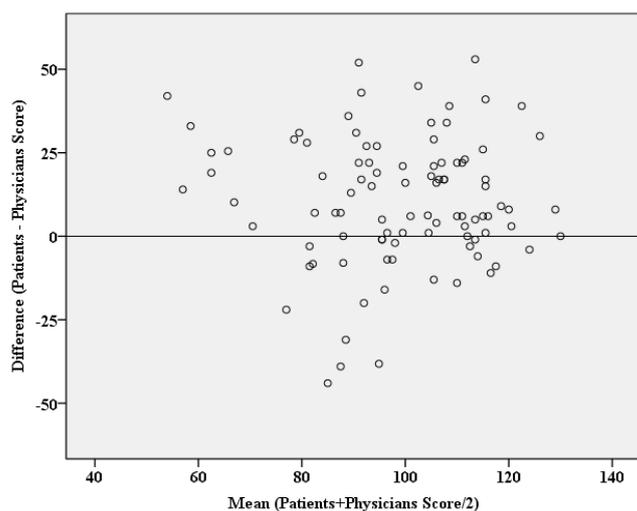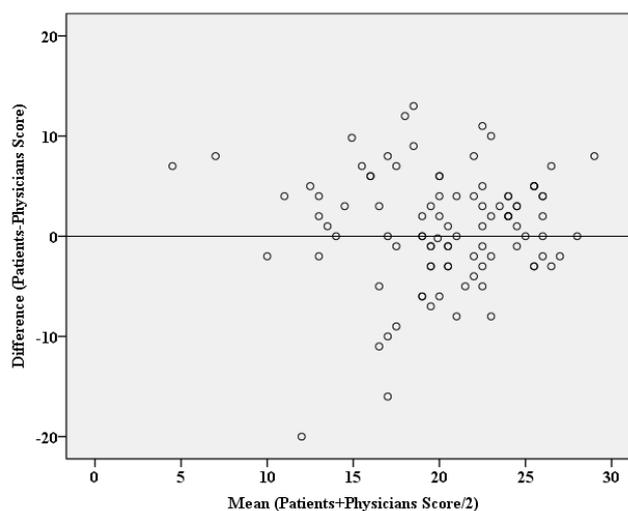
Figure 1A. QoL

Figure 1B. Physical wellbeing
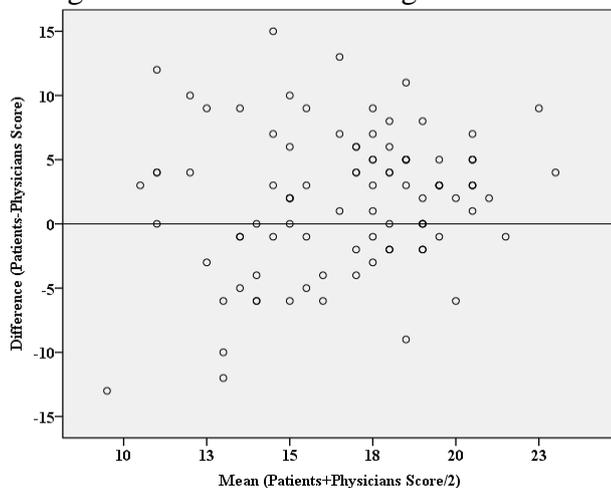

Figure 1C. Social Wellbeing

Figure 1D. Emotional wellbeing

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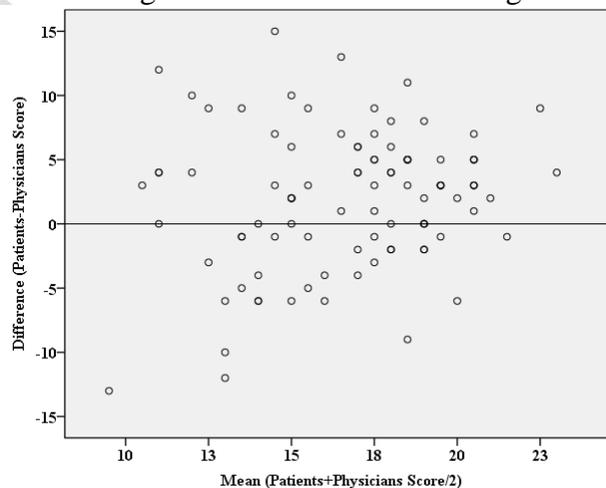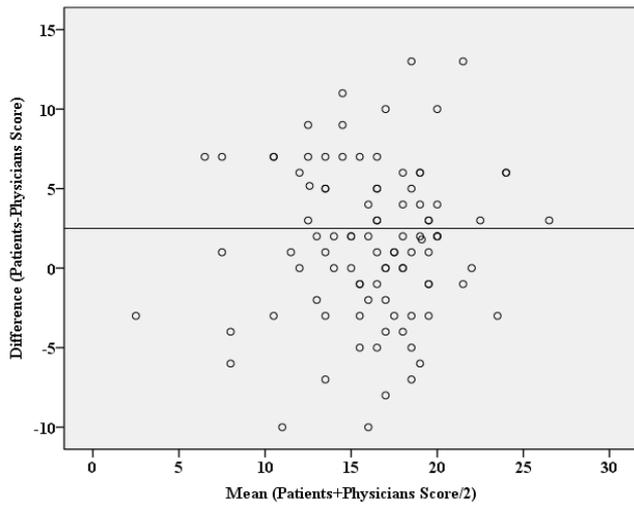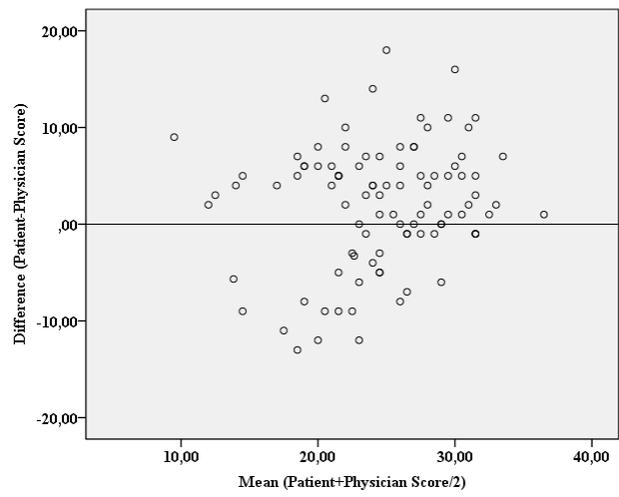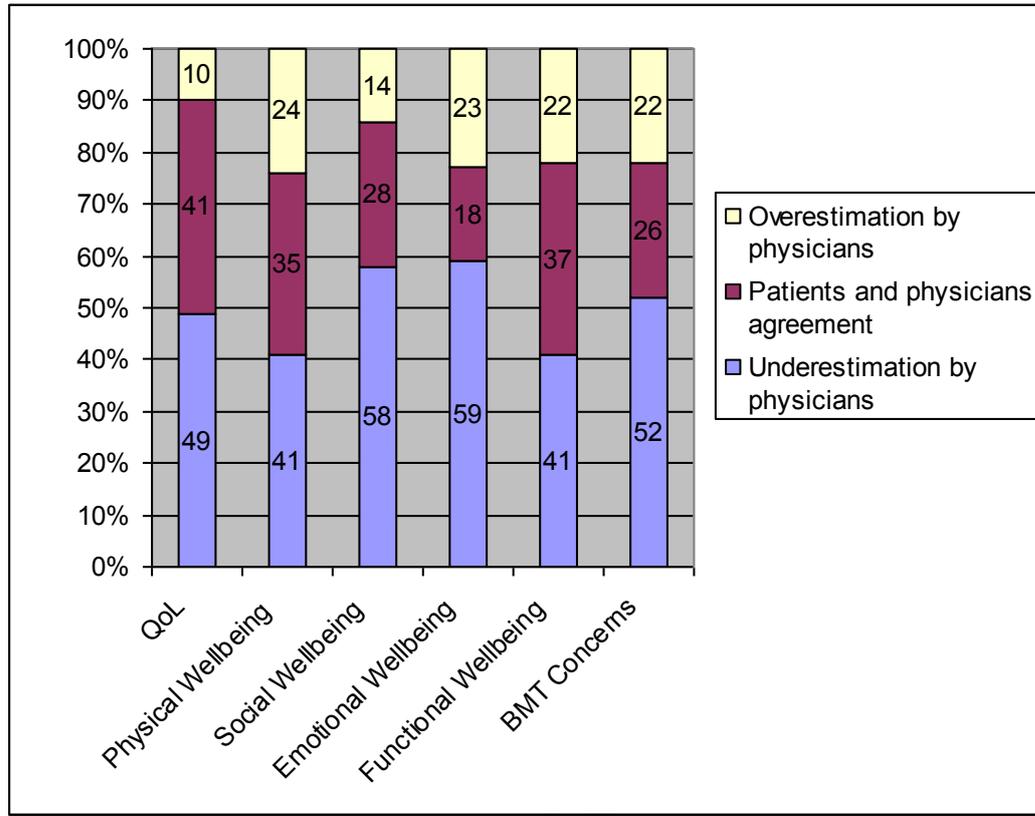## Figure 1D. Functional Wellbeing

Figure 1E. BMT Concerns

Figure 2. Percentages of agreement, underestimation and overestimation of QoL and physical, social, emotional, functional and BMT Concerns subscales

Table 1. Socio-demographic and clinical characteristics of the sample (N=96)

Age at HCT; Median (SD)	53.66 (13.01)
Gender, Men; 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; 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)

Note: AML: acute myelogeneous leukemia; MDS: myelodisplasic syndrome, ALL: acute

lymphoblastic leukemia, NHL: non-Hodgkin lymphoma, HL: Hodgkin lymphoma, MM: multiple

myeloma

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

Table 2. Descriptive scores on QoL and subscales of the FACT-BMT (N=96).

	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 Wellbeing	20.66 (5.51)	2-33	19.81 (5.38)	1-28	.004
Social Wellbeing	22.39 (3.31)	4-28	19.14 (5.10)	6-40	.081
Emotional Wellbeing	17.75 (4.31)	3-27	15.75 (3.63)	5-23	.684
Functional Wellbeing	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

Table 3. Stepwise regression analyses predicting disagreement on QoL, physical,

emotional, functional wellbeing and BMT Concerns

Outcome	Predictor	R^2	p value
Disagreement in QoL		.173	
	Anxiety		<.001
Disagreement in Physical Wellbeing		.158	
	Anxiety		.018
	Subjective Socioeconomic Status		.023
Disagreement in Emotional Wellbeing		.187	
	Anxiety		<.001
Disagreement in Functional Wellbeing		.121	
	Anxiety		.001
Disagreement in BMT Concerns		.122	
	Anxiety		.001

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