

Physicians' attitudes about quality-of-life issues in hematopoietic stem cell transplantation

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Studies investigating quality of life (QOL) after hematopoietic stem cell transplantation demonstrate the spectrum of QOL outcomes awaiting survivors. Nevertheless, how transplantation physicians interpret and apply QOL information to clinical practice is poorly understood. We conducted a cross-sectional survey of transplantation physicians to address these issues and received 180 (24%) responses from physicians in 29 countries. Seventy-two percent reported that their patients are willing to accept poor QOL for a small

chance of cure. Only 28% said that QOL considerations "often" or "almost all the time" enter into patients' decisions about transplantation. This contrasted with physicians' reported attention to QOL in their discussions with patients. Although 53% of physicians reported using QOL results to modify practice, 55% would be more likely to use these data if they were more understandable. To ensure generalizability of the results, a validation sample was randomly selected, and these 85 physicians (response rate, 76%) confirmed the

findings of the original survey. Given the extensive data regarding posttransplantation QOL, resources should be devoted to exploring how patients and physicians use these data in clinical care and in devising methods to ensure that QOL results are interpretable and relevant to patients and physicians. (Blood. 2004; 104:2194-2200)

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Introduction

Quality of life (QOL) is determined by many factors, including the patient's physical abilities, symptoms, social well-being, psycho-emotional status, cognitive functioning, and spiritual/existential experiences. It reflects how well people feel, what they can accomplish, and how satisfied they are with their lives. Within this broad concept, health-related quality of life (HRQOL) refers to aspects of QOL that are attributable to health, disease, or medical treatment.

The number of 5-year survivors of hematopoietic stem cell transplantation (HSCT) is estimated to be 100 000 worldwide.¹ Many studies describe good health and good QOL after HSCT,² though up to 31% of survivors report serious functional limitations or poor QOL.³⁻⁵ Negative aspects of QOL after HSCT generally relate to slow or incomplete physical recovery, difficulty reassuming social roles, and problems related to chronic graft-versus-host disease (GVHD). Positive changes emphasize a greater appreciation for life and family.⁶⁻⁹

Global QOL is reportedly high after HSCT, despite many specific symptoms¹⁰⁻¹⁶ and limitations on daily activities.¹⁷ HSCT patients, especially those with chronic GVHD, report lower physical functioning and poorer overall health than the general population.^{16,18,19} Fatigue is bothersome.²⁰ Reported rates of psychiatric diagnoses are high, with a prevalence more than double those of population norms^{21,22} and a 5% prevalence of posttraumatic

stress disorder.^{23,24} Worries about relapse and fears about failing to return to levels of functioning that preceded transplantation are common.^{9,18,25} Dissatisfaction with appearance and sexual problems are also prevalent, with women reporting more difficulties than men.^{5,13,20,26-29} Approximately 60% to 90% of HSCT survivors eventually return to work.^{2,19,30-36} Concerns over finances²⁰ and difficulty obtaining health insurance are common after HSCT.³⁰ Sleep difficulties are also noted.³⁷

Thus, much is known about QOL after HSCT. Evidence shows that physicians value QOL differently when making recommendations about potentially curative rather than palliative treatments.³⁸ Yet, few studies have explored how physicians interpret and use QOL information in caring for patients and in advising them about the risks and benefits of procedures.³⁸⁻⁴¹ Taylor et al³⁹ performed a qualitative study of 60 Canadian and American oncologists. They reported different interpretations of QOL concepts but broad support for QOL data collection within randomized trials. However, only 34% felt that QOL instruments were reliable, and 7% reported they formally collected and used QOL information in patient care.³⁹ Bezjak et al⁴¹ developed a survey to assess physician attitude, current behavior, knowledge, and reported willingness to use QOL information. They surveyed 271 oncologists of the Eastern Cooperative Oncology Group (ECOG) (response rate, 76%) and reported that 84% felt their knowledge of QOL literature

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was limited; 62% admitted that they would be more likely to use QOL information if it were easier to understand; and 43% thought that most of their patients were willing to accept poor QOL for even a small chance of cure.

To address how HSCT physicians interpret and use QOL information, we conducted a cross-sectional study of transplantation physicians using a 5-page, self-administered survey addressing the following topics: perceived patient QOL after HSCT; attitudes about discussing QOL information with patients; attitudes and behaviors toward incorporation of QOL considerations into clinical decisions and care; exposure to the conduct and interpretation of QOL studies; and sociodemographics and practice information. Because of concerns about the low response rate and the generalizability of the first anonymous survey, we randomly selected 20% of the original population to be recontacted with an abbreviated survey with higher response rates.

Materials and methods

Survey development

All authors contributed to the design of the survey instrument. The survey asked physicians about their clinical experience with QOL issues, use of QOL information in decision-making, experience collecting QOL information from patients, and sociodemographics. Six items were taken from the MD-QOL survey validated by Bezjak et al.⁴¹

The first section presented 12 areas of QOL and asked physicians to indicate areas patients asked about before transplantation, areas discussed with patients before transplantation, and areas perceived as major deficits in QOL more than 1 year after HSCT, and to indicate where more research was needed. The categories provided were physical stamina and fatigue, chronic GVHD, medication adverse effects, depression/emotional adjustment, sleep disruption, sexual dysfunction, family stress, cognitive function, work- or school-related disruption, financial stress and worries, fear of relapse and spiritual issues. Physicians' comfort levels for discussing QOL issues with patients were assessed with response options of "very comfortable," "somewhat comfortable," "somewhat uncomfortable," and "very uncomfortable." Belief that interventions could improve QOL after transplantation was assessed with response options of "definitely yes," "probably yes," "probably no," and "definitely no."

A second section asked about use of QOL information, such as "How often do QOL considerations enter into your patients' decisions about whether to undergo transplantation?" and "Most of my patients are willing to accept a poor QOL for even a small chance of cure." Response options of "never," "once in awhile," "sometimes," "often," or "almost all the time" (collapsed into "never," "once in awhile," or "sometimes" vs "often" or "almost all the time") and "strongly agree," "agree," "disagree," "strongly disagree" (collapsed into "agree" vs "disagree") were offered.

The third section asked about experience collecting QOL information from patients, the role of the physician in QOL data collection, and the context for data collection and types of data collected. The final section collected characteristics regarding centers and physicians.

A 3-page abbreviated survey was administered to the validation sample. It included only those items of most interest based on analysis of the original sample.

Data collection

The Dana-Farber Cancer Institute Office for the Protection of Research Subjects deemed the original study exempt from requiring institutional review board approval because of the anonymity of the responses and the nature of the survey content. The survey was electronically mailed (e-mailed) to physicians participating in the International Bone Marrow Transplant Registry (IBMTR; $n = 755$) and the Pediatric Blood and Marrow Transplant Consortium (PBMTTC; $n = 75$) by those organizations. We estimate that 63 physicians received invitations to participate through

both mechanisms. A cover letter invited potential participants to complete the survey, skipping any questions they wanted. The letter noted that responses were confidential and that no identifying information would be retained or presented. A drawing for a cash prize was used as an incentive to encourage participation. Respondents were given the option of returning the survey by e-mail or fax. Any personal identifiers were removed from completed surveys on receipt. Two e-mailed reminders and another copy of the survey were sent, with a note that those who had already returned their surveys should ignore the e-mail. Because our survey procedures necessitated that the study sample be anonymous to us, sociodemographic characteristics of nonresponders were unavailable. Participants were surveyed from December 2002 through January 2003.

One hundred eighty surveys were returned out of 767 sent. Of the nonresponders, 16 were deemed ineligible based on undelivered e-mail ($n = 3$), no patient contact ($n = 2$), or no longer in practice ($n = 11$) and were excluded. One person declined on the basis of confidentiality concerns, and 12 specifically noted that they did not have time to complete the survey. The overall response rate for eligible physicians was 24% (180 of 751) in the original survey.

Because of this low response rate, a randomly selected sample of 150 (20%) physicians from the original IBMTR and PBMTTC mailing lists were reapproached to complete an abbreviated version of the survey to investigate the generalizability of the findings. Each potential participant received 2 e-mail notices, a fax, and a phone call from the study team until they either completed or opted out of the survey or indicated they were ineligible for study participation. Validation study content and procedures were approved by the institutional review board of the Dana-Farber Cancer Institute, and participants were surveyed from December 2003 to March 2004. All contact with potential participants included the elements of informed consent, but written informed consent was not required. Of this validation sample, 85 (57%) completed the survey, 5 (3%) declined, 22 (15%) were reached but did not return the survey, 15 (10%) were ineligible (eg, not practicing), and 23 (15%) could not be contacted. The response rate among eligible physicians who could be contacted was 76% (85 of 112), with 34 responding to the first e-mail, 18 responding to the second e-mail, and 33 responding to the fax or phone call.

Biostatistical analysis

Descriptive statistics are reported for sociodemographics, clinical experience with QOL issues, use of QOL information in decision-making, and experience collecting QOL information from patients. Various modeling approaches were used to examine associations between sociodemographic and practice physician characteristics and attitudes toward QOL information and research. We considered specialty (adult, pediatric, or combined practice), year training completed (dichotomized at the median: before 1988, 1988 or later), affiliation (academic, community, or both), sex, percentage of time devoted to patient care (less than 50%, 50% or more), and country (United States, other than United States) as potential predictors. Univariate analyses were performed first. If 2 or more explanatory variables were significant at $P < .1$, multivariate analyses were performed. Linear regression was used to model the number of topics discussed (summing the total number of items endorsed among the 12 presented). Proportional odds models were used to explore physician factors associated with answers to the questions, "How often do QOL considerations enter into your patients' decisions about whether to undergo transplantation?" and "How often do you discuss QOL issues with your patients when counseling them about whether or not to pursue transplantation?" because response options were ordinal. Explanatory variables were collapsed for presentation based on the modeling results. Logistic regression was used to model comfort in discussing QOL issues with patients ("very comfortable" vs all other categories), participation in the design or analysis of a QOL study ("yes" vs "no"), and responses to the questions "Most of my patients are willing to accept a poor QOL for even a small chance of cure" and "I use published QOL results to modify my practice pattern," dichotomized as "agree" versus "disagree." We tested for interactions between all significant variables. The McNemar test was used to compare physician discussion of short- and long-term QOL issues and patient interest in QOL issues before

and after transplantation with responses dichotomized as “often” or “almost all the time” compared with all other categories.

Information from the validation sample is presented separately and compared with data from the original sample using χ^2 , Fisher exact, Mantel-Haenszel χ^2 , or Wilcoxon rank sum tests as appropriate. Because our results were almost identical in the original and validation samples and potential participants were drawn from the same population, we emphasize the results from the original survey.

Results

Physician practice characteristics

Physician and center descriptions are presented in Table 1. Of note, the original sample was predominantly male (78%), practiced most often in academic centers (68%), and was heavily involved in patient care with a median of 50% clinical effort, 3 days per week in clinic, and 5 months per year of inpatient duties. Adult ($n = 68$) and pediatric ($n = 75$) specialists were well represented, with a relatively high percentage of pediatricians, and 35 respondents were in combined adult and pediatric practice. Fifty-one percent of respondents were from the United States. Median time since completion of training was 14 years for the original sample.

Table 1. Physician and center characteristics

Characteristics	Original sample, n = 180	Validation sample, n = 85
Specialty, n (%)		
Adult HSCT	68 (38)	44 (52)
Pediatrics	75 (42)	24 (28)
Combined adult and pediatrics	35 (19)	17 (20)
Missing	2 (1)	0 (0)
Sex, n (%)		
Men	140 (78)	74 (87)
Women	38 (21)	11 (13)
Unknown	2 (1)	0 (0)
Year completed training, n (%)		
Before 1980	24 (13)	16 (19)
1980-1989	67 (37)	39 (46)
1990-1999	70 (39)	30 (35)
2000 or later	5 (3)	0 (0)
Unknown	14 (8)	0 (0)
Practice setting, n (%)		
Academic center	122 (68)	53 (62)
Community setting	12 (7)	9 (11)
Both academic center and community setting	44 (23)	22 (26)
Unknown/other	4 (2)	1 (1)
Percentage of time, median		
Patient care	50	60
Administration/teaching	20	20
Basic research	0	0
Clinical research	15	20
Attending responsibilities, median		
Clinic	3 d	3 d
Inpatient service	5 mo	5 mo
Country, n (%)		
United States	92 (51)	34 (40)
United Kingdom	9 (5)	2 (2)
Canada	7 (4)	3 (4)
Germany	6 (3)	4 (5)
Italy	6 (3)	2 (2)
Brazil	6 (3)	4 (5)
Other	47 (26)	34 (42)
Missing	7 (4)	0 (0)

The institutions with which the original respondents were affiliated performed a median of 50 transplantations per year. Of these procedures, a median of 80% involved adults, 50% were allogeneic, and 85% were myeloablative. More than half reported access to staff to address QOL issues, including 141 (78%) with social workers, 135 (75%) with psychologists, 128 (71%) with clinical nurse specialists, 121 (67%) with physical therapists, 99 (55%) with occupational therapists, and 94 (52%) with psychiatrists. Only 25 (14%) reported ongoing studies testing an intervention to improve QOL.

Participation in QOL research

Two thirds ($n = 121$) of respondents in the original survey reported collecting QOL information from their patients. Of those collecting QOL information, 58% did so as part of clinical trials, 26% did so as part of QOL studies outside of clinical trials, and 66% did so as part of routine care (the sum equals more than 100% because multiple choices could be endorsed). There was no difference between the percentage of pediatric and adult HSCT physicians reporting collection of QOL data ($P = .8$). The most common QOL instrument used was the Functional Assessment of Cancer Therapy (FACT; $n = 50$, 41%), followed by the European Organization for Research and Treatment of Cancer (EORTC; $n = 21$, 17%) and the SF36 ($n = 18$, 15%) surveys. Ten (8%) used the National Comprehensive Cancer Network (NCCN) measures of symptoms and distress. Other instruments and approaches were also listed, including performance status measures and clinical observation. Fifty-seven (32%) respondents reported participating in the design or analysis of a QOL study, whereas 93 (52%) were investigators on studies that collected QOL from patients.

Clinical practice

Most ($n = 106$, 59%) original respondents reported they felt “very comfortable” discussing QOL issues with patients, whereas 64 (36%) felt “somewhat comfortable” and 9 (5%) felt “somewhat uncomfortable.” Respondents believed that QOL was modifiable, with 97 (54%) reporting that interventions “definitely” could improve QOL after transplantation, whereas 78 (43%) felt that interventions “probably” could improve QOL after transplantation.

Table 2 shows the percentages of respondents who endorsed QOL issues arising in clinical practice. Most notably, physicians reported their patients were likely to ask about relapse (84%), work or school-related disruption (72%), medication adverse effects (71%), and physical stamina and fatigue (50%) more than half the time. Patients were less likely to ask about chronic GVHD symptoms, depression, sleep disruption, sexual dysfunction, and financial strain and worry, all topics documented to affect substantial numbers of patients after HSCT.

Seventy-one percent to 91% of physicians reported they discussed the topics most frequently raised by patients more than half the time. In addition, physicians reported routine discussion of chronic GVHD (86%) and family stress (71%). Less than half reported discussion of depression/emotional adjustment, sexual dysfunction, cognitive function, and financial strain and worries more than half the time. Although self-reported behaviors may be influenced by a “social desirability” bias in which respondents give answers they believe reflect positively on themselves and are what researchers are expecting, the relatively low endorsement of sleep disruption (17%) and spiritual issues (10%) suggests that respondents were not indiscriminately reporting frequent discussions.

Table 2. Clinical experience with QOL issues

Issues	Discuss with patients at least half the time, %	At least half of patients ask, %	See major QOL deficits more than 1 year after HSCT, %	More research needed, %
Medication adverse effects	91	71	32	16
Chronic GVHD symptoms	86	31	73	62
Fear of relapse	84	84	50	25
Work- or school-related disruption	84	72	51	31
Physical stamina and fatigue	71	50	43	34
Family stress	71	28	45	36
Cognitive function problems (eg, memory lapses)	47	23	24	47
Depression/emotional adjustment	46	11	48	43
Financial strain and worry	44	38	36	18
Sexual dysfunction	42	10	36	36
Sleep disruption	17	4	15	22
Spiritual issues	10	4	4	20

Data from original sample only (n = 180).

Physicians perceived the major detractor from QOL more than 1 year after HSCT to be chronic GVHD (73%) and thought that more research was needed in this area (62%). More than one third thought that cognitive deficits, depression, sexual dysfunction, family stress, and fatigue required research. Other topics were judged to be less problematic and less in need of additional research.

Use of QOL information

Tables 3 and 4 summarize responses to questions about use of and attitudes toward QOL information. Physicians supported the importance of QOL information in patient discussions and clinical practice yet expressed doubts that patients used QOL information when deciding about transplantation. For example, 75% of physicians reported discussing QOL issues “often” or “almost all the time” when counseling patients about transplantation options, whereas only 28% said that patients consider QOL “often” or “almost all the time” when making transplantation decisions. Most (72%) agreed that “Most of my patients are willing to accept a poor QOL for even a small chance of cure.” Percentages were similar for adult and pediatric HSCT physicians (73% and 72%; *P* = .9). A substantial minority (36%) agreed with the statement, “Attention to QOL makes treatment decision-making difficult.”

Physicians were more likely to discuss QOL in the first year after HSCT than to discuss longer-term QOL (91% vs 70% “often” or “almost all the time”) (*P* < .001). They reported that patients were much more likely to ask about QOL issues after they underwent HSCT than before (62% vs 38% “often” or “almost all the time”) (*P* < .001).

Most (65%) said they often read studies reporting QOL results, and 53% say they use QOL results to modify their practice patterns. Fifty-five percent agreed with the statement, “If QOL results were easier to understand, I would be more likely to use them.”

Validation sample

Table 1 also presents the characteristics of the validation sample. The validation sample was similar to the original sample in sex, type of practice, year completed training, time spent in patient care and clinical research, days in clinic, and months on the ward, except that the validation sample contained a lower percentage of physicians from the United States (40% vs 51%; *P* = .05). Median age of physicians in the validation sample was 47 years.

The validation sample was also similar to the original sample regarding attitude. Specifically, 50 (60%) felt comfortable discussing QOL issues with patients, 62 (73%) collected QOL data from their patients, and 47 (56%) felt that interventions were likely to improve QOL. Although only 18 (21%) thought that QOL considerations entered into the decision about HSCT “often” or “almost all the time,” 59 (69%) discussed QOL issues with patients when counseling about HSCT “often” or “almost all the time.” Fifty-five (65%) agreed that most patients were willing to accept poor QOL for even a small chance of cure, whereas 41 (48%) use published QOL results to modify practice. These proportions were not statistically different than those in the original sample. Physicians in the validation sample were equally likely as in the original sample to routinely discuss the different aspects of QOL with patients before HSCT, except for a lower likelihood of discussing

Table 3. Use of QOL information

Question	Never, no. (%)	Once in a while or sometimes, no. (%)	Often or almost all the time, no. (%)
How often do QOL considerations enter into your patients' decisions about <i>whether</i> to undergo transplantation?	12 (7)	116 (65)	51 (28)
How often do you discuss QOL issues with your patients when counseling them about <i>whether</i> to pursue transplantation?	3 (2)	41 (23)	135 (75)
Before transplantation, how often do you discuss what QOL will be like during the <i>first year</i> after transplantation?	1 (1)	15 (8)	162 (91)
Before transplantation, how often do you discuss what QOL will be like <i>long term</i> (3-5 years) after transplantation?	4 (2)	49 (27)	126 (70)
Before transplantation, how often do your patients ask you about QOL issues?	0 (0)	110 (62)	67 (38)
After transplantation, how often do your patients ask you about QOL issues?	0 (0)	64 (36)	115 (64)

Data from original sample only (n = 180). For each question, 1 to 3 responses are missing.

Table 4. Attitudes toward QOL information (original sample only)

Statement	No. agreeing (%)	No. disagreeing (%)
Most of my patients are willing to accept poor QOL for even a small chance of cure	129 (73)	48 (27)
Attention to QOL makes treatment decision-making difficult	66 (38)	109 (62)
I often read studies reporting QOL results	117 (66)	59 (34)
I use published QOL results to modify my practice pattern	96 (55)	78 (45)
I often do not have the time required to discuss QOL with my patients	24 (13)	154 (87)
If QOL results were easier to understand, I would be more likely to use them	99 (57)	76 (43)

Data from original sample only (n = 180). For each question, 2 to 6 responses are missing.

cognitive function (29% vs 47%; $P = .008$). The only other difference noted between the validation sample and the original sample was a higher proportion of physicians in the validation sample agreeing with the statement, "If QOL results were easier to understand, I would be more likely to use them" (76% vs 57%; $P = .002$). Questions about participation in QOL research were not asked of physicians in the validation sample.

Physician factors associated with clinical practice and use of QOL information

Table 5 shows the physician factors associated with the use of QOL information in multivariate analyses. Physicians in the United States were more likely to report feeling "very comfortable" about discussing QOL information and reported discussing more topics than physicians from other countries ($P = .001$). Pediatricians ($P = .004$) and those spending some amount of time in academic practice ($P = .009$) were less likely to think that QOL considerations affected their patients' treatment choices. Physicians who completed training before 1988 ($P = .06$) and those spending less than 50% of their time in clinical work ($P = .001$) were more likely to participate in the design or analysis of QOL studies. There was no evidence of interaction between independent explanatory variables included in the regression models. No factors could be identified that were associated with collection of QOL data from patients, modification of practice based on QOL data, frequency of discussion of QOL topics when counseling patients about whether to undergo transplantation, or agreement with the statement "Most of my patients are willing to accept a poor QOL for even a small chance of cure."

Discussion

We report the results of a cross-sectional survey sent to adult and pediatric HSCT physicians participating in the IBMTR or the PBMTTC. Only 28% of respondents thought that QOL considerations "often" or "almost all the time" enter into patients' decisions about whether to undergo transplantation, and fully 72% of physicians agreed that most of their patients are willing to accept a poor QOL for even a small chance of cure. Nevertheless, 75% discuss QOL issues "often" or "all the time" with patients when counseling them about whether to pursue transplantation, and 53% reported they use published QOL results to modify their practice patterns. Physicians reported discussing many QOL topics, appar-

ently without prompting by patient questions. We interpret these findings to suggest that most HSCT physicians consider providing QOL data as part of their responsibility to inform patients about the process and risks of treatment but do not truly believe this information influences patients' decisions about undertaking HSCT. If this is true, we recommend that physicians confirm priorities with each patient or explicitly discuss their assumptions when making treatment recommendations. For example, "After reviewing your medical history and talking with you, I am recommending stem cell transplantation. I am assuming that your highest priority is to be cured of this disease and that you are willing to risk worse quality of life and an X% chance of death from transplantation to achieve a cure."

Although 97% of respondents believed that QOL was "definitely" or "probably" modifiable, a surprising minority (only 14%) indicated that clinical trials are under way at their institutions to establish the efficacy of interventions to improve QOL. Review of QOL intervention research indicates that few studies have been conducted to establish the efficacy of these treatments within the HSCT setting though efficacy in other settings is well established.⁴² For instance, psychoeducational methods and numerous other QOL-enhancing techniques have proven effective for cancer patients.^{43,44} Given the recognition of the relevance of QOL to long-term outcomes and the resources dedicated to providing for these needs, more clinical trials seem necessary.

Strikingly, 72% of transplantation physicians believe their patients are willing to accept poor QOL for even a small chance of cure. This figure is higher than a comparable study of 271 ECOG oncologists, of whom 49% agreed with an identical statement.⁴¹

Table 5. Physician factors associated with clinical practice and use of QOL information

Dependent variables and independent variables	Estimate or OR	95% CI	P
No. topics discussed with patients			
United States vs other	1.26*	0.51, 2.01	.001
More comfortable discussing QOL issues with patients			
United States vs other	3.4†	1.82, 6.52	< .001
Participation in the design or analysis of QOL study			
Trained before 1988 vs 1988 or later	1.90‡	0.96, 3.76	.06
Less than 50% vs 50% or more clinical time	3.20‡	1.61, 6.35	< .001
Belief that QOL considerations enter into patients' decisions about whether to undergo transplantation			
Pediatric vs adult/combination	0.48§	0.27, 0.83	.004
Academic/combined vs community	0.20§	0.07, 0.59	.009

Data from original sample only (n = 180).

For each model of independent variables, potential predictors included country (United States, other than US), year completed training dichotomized at the median (before 1988, 1988 or later), percentage of time devoted to patient care (less than 50%, 50% or more), specialty (adult, pediatrics, or combined), affiliation (academic, community, or both), and sex. If more than 1 variable was significant in univariate modeling ($P < .1$), multivariate modeling results are presented. Categories were collapsed based on modeling results.

*Coefficient estimate from a linear regression model (n = 173).

†Odds ratio (OR) from a logistic regression model (n = 172).

‡OR from a logistic regression model (n = 164).

§OR from a proportional odds model for ordinal response (n = 174). Community group is small (n = 12).

||Univariate analysis result: OR, 2.07; 95% confidence interval (CI), 1.08-3.99; $P = .03$.

This difference may reflect the composition of the samples (ECOG does not include pediatricians, who were more likely to endorse this statement in our sample) or the nature of HSCT, in which great risks and transient, poor QOL are accepted as necessary costs in pursuit of a cure. Furthermore, adult patients undergoing HSCT are on average significantly younger than patients undergoing nontransplantation oncology care and may be more interested in aggressive treatment.

We found that pediatricians and physicians in academic practices were less likely to think that QOL considerations entered into their patients' decisions about whether to pursue HSCT. It may be that pediatricians are reflecting their perceptions or experiences with surrogate decision-makers (parents and guardians), who may be more willing to accept the risk of poor QOL for a chance at improved survival when it comes to their children, or that pediatricians' attitudes reflect the fact that many pediatric transplantable diseases have worse outcomes without transplantation than adult transplantable diseases. The attitudes of academic physicians could reflect either the nature of the patient population seen at academic centers or a more aggressive therapeutic philosophy among academic physicians. It would be interesting to compare pediatric and adult patients and to compare academic and community patients to determine whether these inferred patient preferences are accurate and whether they emanate from the patients themselves or are instilled by their physicians.

The major limitations of our study were the data collection mechanism (e-mailed survey to IBMTR and PBMTIC physician members only) and the 24% response rate to the original survey. Because of our need to ensure the anonymity of the sample, demographic and clinical information was unavailable for nonresponders to the original survey. Concerns about generalizability are

mitigated by the validation study, which achieved a 76% response rate among eligible physicians contacted and confirmed the findings of the original sample. However, 24% of physicians still opted not to participate in the validation study despite several attempts to recruit them. Responding physicians were likely those with greater interest in QOL, potentially biasing results toward higher rates of response about the use of QOL data in patient discussion and in greater assignment of value to QOL results.⁴¹

Results clearly illustrate that improved efforts are needed to translate QOL findings into usable information for clinical practice. Forty-seven percent of physicians report not using QOL data, and this finding is a concern given the abundance of replicated QOL data that exist in HSCT. Fifty-five percent of respondents agreed that they would be more likely to use QOL information if it were more understandable. To facilitate this use, efforts are under way to define the clinical significance of QOL measures.⁴⁵⁻⁴⁸ Methods to help integrate QOL study results into clinical practice and clinical decision-making are necessary to justify the investment in research studies collecting these data. In future studies, we hope to focus more specifically on physician and patient interpretation and use of QOL information to better understand which types of QOL data are most valuable in actual clinical practice and to help guide researchers in providing this information in a manner useful to providers and patients.^{49,50}

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