

What do patients think about palliative care? A national survey of hematopoietic stem cell transplant recipients

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Key Points

- Hematopoietic stem transplant recipients have positive perceptions of PC, although many have limited knowledge about its role.
- Patients who were more knowledgeable about PC were more likely to have positive perceptions of PC.

Palliative care (PC) benefits patients undergoing hematopoietic stem cell transplantation (HSCT), but it remains underutilized. Although transplant physicians report concerns regarding how patients perceive PC, HSCT recipients' perceptions about PC remain unaddressed. We conducted a multisite, cross-sectional survey of autologous and allogeneic HSCT recipients 3 to 12 months after transplant to assess their familiarity, knowledge, and perception of PC, as well as their unmet PC needs. We computed a composite score of patients' perceptions of PC and used a generalized linear regression model to examine factors associated with these perceptions. We enrolled 69.6% (250/359) of potential participants (median age = 58.1; 63.1% autologous HSCT). Overall, 44.3.8% (109/249) reported limited knowledge about PC and 52% (127/245) endorsed familiarity with PC. Most patients felt hopeful (54%) and reassured (50%) when they heard the term PC; 83% saw referral as a sign their doctor cared about what was happening to them. In multivariate analyses, patients who were more knowledgeable about PC were more likely to have positive perceptions of PC ($B = 7.54$, standard error = 1.61, $P < .001$). Patients' demographics, HSCT features, quality of life, and symptom burden were not significantly associated with perceptions of PC. HSCT recipients have positive perceptions of PC, though many have limited knowledge about its role. Patients who were more knowledgeable about PC were more likely to have positive perceptions of PC. These data do not support transplant physicians' negative concerns about how patients perceive PC and underscore the need to further educate patients and transplant physicians about PC.

Introduction

Patients undergoing hematopoietic stem cell transplantation (HSCT) endure substantial physical and psychological symptoms during and after their HSCT.¹⁻⁴ Physical and psychological symptoms result in a substantial quality of life impairment that is most notable during and immediately after the transplant

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period but sometimes persists years beyond HSCT.^{3,5-7} Integration of specialty palliative care (PC) clinicians in the care of patients undergoing HSCT has been shown to result in substantial improvements in patient-reported quality of life as well as physical and psychological symptoms during hospitalization for HSCT.⁸ Notably, these psychological benefits were sustained up to 6 months after HSCT, with a reduction in clinically significant depression and posttraumatic stress symptoms.⁹

Despite this encouraging evidence, the rate of PC referrals for patients undergoing HSCT remains low.¹⁰⁻¹³ Transplant physicians describe that 1 key factor limiting PC referral and consultation is the fear that patients would feel afraid, anxious, or deserted because of referral.¹⁴ Despite the fact that HSCT recipients' perceptions and needs are currently such critical barriers to PC referral, little research has assessed how HSCT recipients feel about PC and what they see as their own PC needs.¹⁵

To address these concerns and learn about HSCT recipients' perceptions of PC, we conducted a multisite, cross-sectional survey assessing familiarity, knowledge, and perception of PC, as well as unmet PC needs on this population. We also explored factors associated with positive perception of PC, hypothesizing that PC knowledge, quality of life, and other clinical features would be associated with positive PC perception. Results of this study will contribute to identify patients' perspectives regarding the potential benefits of PC and guide HSCT physicians caring for these patients.

Methods

Study design and population

The National Marrow Donor Program Institutional Review Board approved this multisite, cross-sectional, web-based survey study of HSCT recipients. The Center for International Blood and Marrow Transplant Research registry database was used to identify potential participants. Eligible participants were recruited from November 2020 to April 2021 and were adult (≥ 18 years), English-speaking, and 3 to 12 months from an autologous or allogeneic HSCT. We recruited participants from 11 transplant centers across the United States chosen for geographic and population diversity, who signed informed consent for the Center for International Blood and Marrow Transplant Research and agreed to be contacted for study participation. Participants who were within the first 3 months after transplant were excluded given concern that they may not have had sufficient time to be exposed to PC as well as a concern about their willingness to participate in this study early during the acute transplant phase.

Eligible participants were contacted by phone by members of the National Marrow Donor Program Survey Research Group, and, following the process of informed consent, those interested in participating were asked whether they preferred to complete the survey electronically or by paper format. The research team made 3 contact attempts on average to eligible patients. Participants who opted for the electronic format received a link to sign their consent. Once signed, they were directed for survey completion via the Qualtrics platform. Participants who opted for the paper format were mailed 2 copies of the informed consent form and 1 copy of the survey, along with a return envelope. Participants were instructed to return 1 signed copy of the consent form along with their completed survey and to retain the other copy for their

records. The research team attempted a maximum of 3 times to contact participants who did not return their survey and/or consent form. We offered participants a \$25 gift card.

Study measures

We used validated instruments previously used among patients with cancer and HSCT physicians and adapted them to build an appropriate survey for HSCT patients.^{14,16-19} The survey included the following domains: (1) demographics (10 items), (2) familiarity with palliative and hospice care (11 items),²⁰ (3) knowledge (13 items) and perceptions of PC (19 items),^{16,17} and (4) perceived unmet PC needs (15 items).^{17,18} Two items from the Patient Treatment and Perception of Prognosis Questionnaire were administered to assess the patient's understanding of their prognosis.^{21,22} The Edmonton Symptom Assessment Scale was administered to assess patient-reported symptom burden and well-being (9 items),²³ with higher scores indicating worse symptom burden. The Patient-Reported Outcomes Measurement Information System Scale-Global Health was used to examine patient-reported physical and mental health (10 items),^{19,24} with higher scores indicating greater quality of life.

The domains specific to PC were reviewed by the Palliative and Supportive Care Special Interest Group of the American Society for Transplantation and Cellular Therapy, which consists of a multidisciplinary team spanning the disciplines of transplant and PC including medical professions (ie, physicians, nurses, social workers, and clergy), as well as health services researchers, survey development experts, and former patients. This interdisciplinary team reviewed the content of the survey items to ensure their readability, interpretability, and applicability to the HSCT setting. Ten HSCT recipients tested the pilot survey and provided feedback on its face validity, instrument design, question format, and length of time to complete it. The time estimated for survey completion was 15 to 25 minutes.

Similar to prior studies, we generated composite scores for patients' perception of PC using the 19 items measuring this domain on the survey.^{14,16} Each of these 19 items was scored on a 0 to 4 scale. The composite score was created by summing all 19 items, with higher scores indicating more positive perceptions of PC. Because the focus of this study was to examine patients' perceptions of PC, this domain was identified a priori as an outcome of interest.

We used the same methodology to create composite scores for the other domains included in the survey that were defined a priori as potential factors associated with patients' perceptions of PC. Thus, we generated composite scores for the items included on the following domains: (1) familiarity with PC (higher scores indicate more familiarity with PC; range, 0-20), (2) knowledge of PC (higher scores indicate more knowledge; range, 0-13), and (3) perceived unmet PC needs (higher scores indicate higher unmet needs; range, 0-48).

Statistical analysis

We conducted descriptive and exploratory analyses of survey data in SAS Enterprise Guide version 6.1.

We used descriptive analysis to examine patients' demographics, clinical characteristics, and survey responses. Descriptive analysis included frequencies and percentages for categorical variables and means and standard deviations for continuous variables.

Demographic and clinical characteristics of participants were compared with those of nonparticipants χ^2 or Fisher exact tests.

We used univariate linear regression models to explore factors associated with patients' perceptions of PC (main outcome of interest). Predictors of interest were identified a priori by the research team^{20,25-27} and included demographic factors (age, sex, race, ethnicity, importance of spirituality, marital status, education), clinical factors (transplant type, Karnofsky performance status, hematopoietic cell transplant-comorbidity index, disease risk, and presence and severity of graft-versus-host disease), time since transplant, transplant center, region of transplant center, familiarity with PC, knowledge of PC, perceived knowledge of PC, perceptions of PC, unmet PC needs, patient's belief they will be cured with the transplant, symptom burden, and quality of life (physical and mental health). We assessed for collinearity between predictors using Pearson correlation coefficients and found positive collinearity between knowledge of PC (13-item survey) and perceived knowledge about PC (1 item in familiarity with PC domain) ($r = .67, P < .0001$). Perceived knowledge of PC was removed from the multivariate model. Variables that were associated with positive perception of PC at $P < .20$ were included in a multivariate linear regression model.

Results

Participant characteristics

Figure 1 depicts the study flow diagram. We enrolled 69.6% (250/359) of potentially eligible patients, and 249 were included for analysis. Participants and nonparticipants were similar with respect to demographic and clinical factors, except that participants were

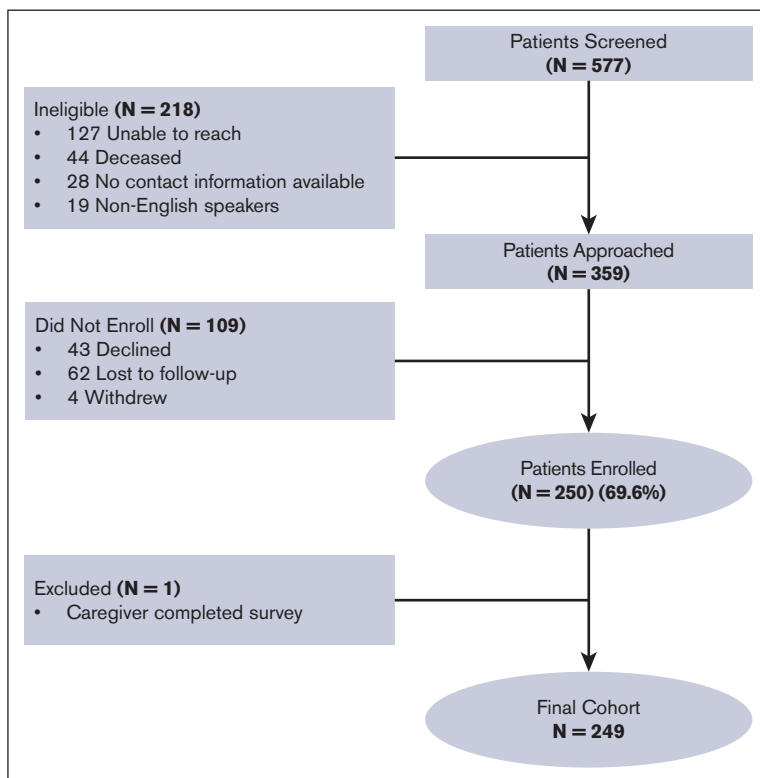


Figure 1. Consort diagram.

more likely to be female ($P = .03$). Participants' median age was 58.1 years old, and the majority were male (53%, 132/249), white (85.9%, 214/249), diagnosed with multiple myeloma (42.2%, 105/249), and received an autologous transplant (63.1%, 157/249). Among allogeneic HSCT recipients, 44 (47.8%) developed acute graft-versus-host disease. Participants were recruited from all the major regions of the United States. Table 1 depicts participants' characteristics.

Familiarity and knowledge about PC

Almost three-quarters of the sample (71.9%, 179/249) reported hearing about PC, mainly from a family member (33.5%, 60/179), the transplant social worker (25.1%, 45/179), and/or the transplant doctor (21.8%, 39/179). Fewer participants reported hearing about PC from the transplant nurse (16.8%, 30/179) or others, including friends (8.9%, 16/179), another member of the transplant team (1.1%, 2/179), or others such as other clinicians and via the Internet or social support groups (31.8%, 57/179). Overall, 10.6% (19/179) of participants reported not knowing where they heard about PC, and 5% (9/179) did not answer the question. Although almost 3-quarters of participants had heard about PC, only 52% (127/245) reported being familiar with it. Notably, most participants reported having no direct experience with PC (45%, 112/241), and less than a third reported experience with PC (33%, 79/241).

Regarding hospice care, almost all participants (96.48%, 240/248) reported hearing about it, mainly from a family member (62.25%, 150/240) or a friend (24.6%, 59/240), and to a lesser extent from the transplant social worker (5.8%, 14/240), the transplant doctor (2.9%, 7/240), the transplant nurse (2.1%, 5/240), another friend

Table 1. Participants' characteristics

Age, y, median (SE); IQR	58.1 (0.8786); 16.76
Sex, n (%)	
Male	132 (53)
Female	116 (46.6)
Not answered	1 (0.4)
Race, n (%)	
White	214 (85.9)
Black or African American	18 (7.2)
Asian	6 (2.4)
Native Hawaiian or other Pacific Islander	4 (1.6)
American Indian or Alaska Native	2 (0.8)
Other	9 (3.6)
Don't know	1 (0.4)
Not answered	1 (0.4)
Hispanic or Latin American, n (%)	
No	237 (95.2)
Yes	8 (3.2)
Not answered	4 (1.6)
Religion, n (%)	
Catholic Christian	69 (27.7)
Other Christian	98 (39.4)
Atheist	9 (3.6)
Other (Hindu, Jewish, Muslim, Sikh, Buddhist, something else)	24 (9.6)
Not religiously affiliated	44 (17.7)
Don't know	1 (0.4)
Not answered	5 (2.0)
Marital status, n (%)	
Married or domestic partnership	185 (74.30)
Never married	29 (11.65)
Divorced	23 (9.24)
Widowed	8 (3.21)
Separated	3 (1.2)
Not answered	1 (0.4)
What is the highest grade or level of education you have achieved, n (%)	
High school or lower	37 (14.9)
Some college or college graduate	133 (53.4)
Postgraduate	77 (30.9)
Not answered	2 (0.8)
Gross household income, n (%)	
<\$59 999	90 (36.2)
\$60 000- \$99 999	59 (23.7)
\$100 000 - \$149 999	44 (17.7)
\$>150 000	40 (16.1)
Don't know	8 (3.2)
Not answered	8 (3.2)
Employment status, n (%)	
Working full-time (≥30 h per wk)	69 (27.7)
Working part-time (<30 h per wk)	16 (6.4)
Caring for home or family (not seeking paid work)	7 (2.8)

Table 1 (continued)

Unemployed and looking for work (including laid off or furloughed)	7 (2.8)
Unable to work because of illness or disability	80 (32.1)
Retired	70 (28.1)
Student	6 (2.4)
Other, please specify	9 (3.6)
Diagnosis, n (%)	
Leukemias (AML, ALL, other leukemias)	42 (19.8)
MDS/MPN/CML	34 (13.7)
Lymphoma	55 (22.1)
Plasma cell disorder/multiple myeloma	105 (42.2)
Other	13 (5.2)
Karnofsky Performance Score	
<90	97 (39)
≥90	145 (58.2)
Missing	7 (2.8)
Patient regions, n (%)	
Midwest	107 (43.0)
Northeast	44 (17.7)
South	52 (20.9)
West	46 (18.5)
Transplant type	
Allogeneic HSCT	92 (36.9)
Autologous HSCT	157 (63.1)
HCT-CI	
0	45 (18.1)
1	45 (18.1)
2	36 (14.5)
3+	120 (48.2)
Unknown	3 (1.2)
Conditioning intensity	
Myeloablative conditioning	43 (17.3)
Reduced-intensive conditioning	28 (11.2)
Nonmyeloablative conditioning	12 (4.8)
N/A - autologous HSCT or nonmalignant	162 (65.1)
Unknown	4 (1.6)
Donor source, n (%)	
Unknown	4 (1.6)
Cord blood	6 (2.4)
Unrelated	44 (17.7)
Related	42 (16.9)
Donor type, n (%)	
Autologous, syngeneic	158 (63.5)
HLA identical sibling	20 (8.0)
Other related	21 (8.4)
Well-matched unrelated	39 (15.7)
Mismatched	5 (2.0)
Cord blood	6 (2.4)

AML, acute myeloid leukemia; ALL, acute lymphoblastic leukemia; CML, chronic myeloid leukemia; HCT-CI, hematopoietic cell transplant-comorbidity index; IQR, interquartile range; MDS, myelodysplastic syndrome; MPN, myeloproliferative neoplasms.

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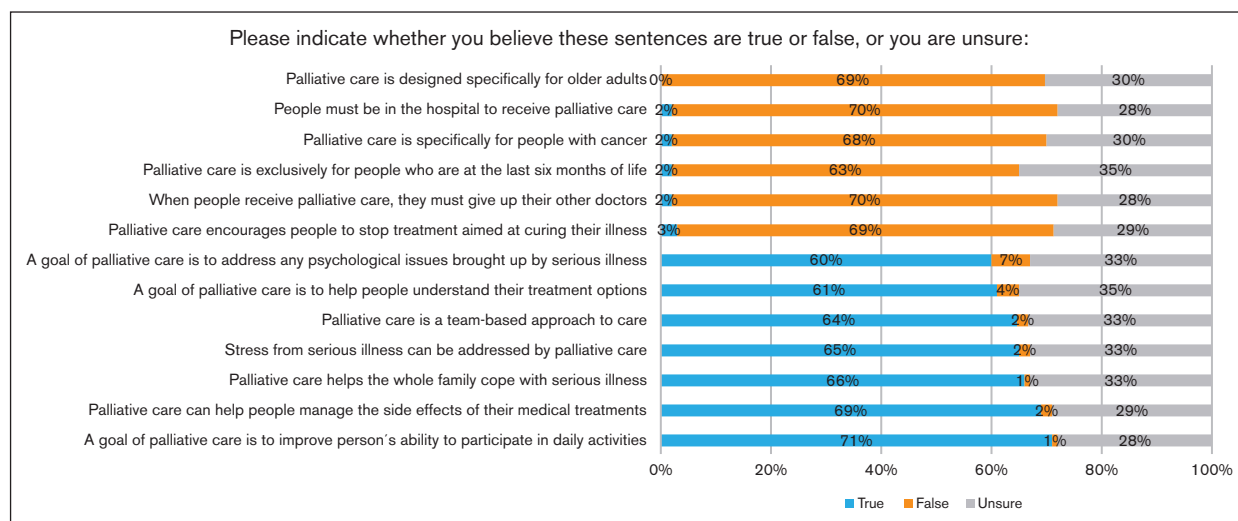


Figure 2. Responses to knowledge about PC.

of the transplant team (1.7%, 4/240), or others such as other clinicians or via the Internet or social support groups (24.6%, 59/240). A total of 8.3% (20/240) of participants reported not knowing where they heard about hospice care. Although 3-quarters of respondents reported being familiar (75%, 186/248) with hospice care, less than half of them reported having experience with it (45.5%, 111/244).

Overall, 43.8% (109/249) of participants reported limited knowledge about PC. Figure 2 describes participants' knowledge on PC. Notably, more than two-thirds of participants agreed that the goal of PC is to improve people's ability to participate in daily activities (71%, 173/245) and help people manage side effects of their medical treatment (69%, 169/245). In fact, 70% (172/246) of the participants disagreed that people receiving PC need to give up their other doctors, 70% (170/243) disagreed that patients have to be in the hospital to receive PC, and 69% (170/245) disagreed that PC is specifically designed for older adults. Interestingly, 35% (87/246) of participants reported being unsure about whether the goal of PC is to help people better understand their treatment options, and 35% (85/246) were unsure about whether PC is exclusively for people who are within the last 6 months of life. In fact, between 29% and 37% of participants reported being unsure about whether the statements they were asked about the goal of PC were true or false.

Perception of PC

Over half of participants reported that, if offered a PC referral, they would feel hopeful (54%, 131/243) and reassured (50%, 121/242), and few reported they would feel depressed (15%, 36/241), scared (21%, 51/243), stressed (22%, 54/242), or anxious (31%, 75/242) (Figure 3A). In fact, most participants reported that they would think that their doctor really cares about what is happening to them (83%, 203/246) and that the more support they get, the better they feel (74%, 183/246). Very few participants stated that, if referred to PC, they would think that they would lose contact with current doctors or nurses (5%, 11/244) and that their doctor has given up on them (7%, 18/244). A substantial percentage of participants reported being neutral on whether a PC referral would

lead them to think about the future more positively (47%, 115/246), to worry that PC would talk to them about dying (38%, 93/244), or to make them feel more in control of the situation (38%, 93/245). Figure 3B describes participants' thoughts and feelings if they are referred to PC.

Unmet PC needs

Participants identified multiple domains of perceived PC needs (Figure 4). Specifically, 58% (143/247) of participants reported wanting to prepare now for what might happen in the future, 42% (104/248) reported unmet needs for emotional support, and 34% (83/247) unmet needs for spiritual support. In addition, 31% (76/247) of participants reported wanting to talk with someone who understands what they are going through and that their family and friends need emotional support (26%, 64/246).

Factors associated with positive perception of PC

The univariate analysis revealed that the following variables were associated with positive perceptions of PC: age ($\beta = 0.12$, standard error [SE] = 0.06, $P = .04$), familiarity with PC ($\beta = 1.07$, SE = 0.23, $P < .01$), knowledge about PC ($\beta = -7.83$, SE = 1.50, $P < .01$), and fair/poor global mental health ($\beta = -6.00$, SE = 1.92, $P = .01$). Patient demographics, time since transplant, clinical factors, the presence of graft-versus-host disease, and transplant center were not associated with perceptions of PC. In the multivariable analysis, only higher knowledge of PC was associated with a positive perception of PC ($\beta = 7.54$, SE = 1.61, $P \leq .01$) (Table 2). We also conducted sensitivity analysis, including the transplant center as a random effect, and obtained similar findings.

Discussion

Findings from this study underscore that more than 40% of HSCT recipients reported limited knowledge and familiarity with PC. Nevertheless, most patients perceived PC positively, and higher patient's knowledge of PC was associated with more positive perceptions of PC. Notably, most of the HSCT recipients reported unmet PC needs across numerous domains. Improving HSCT recipients' knowledge of PC has the potential to improve

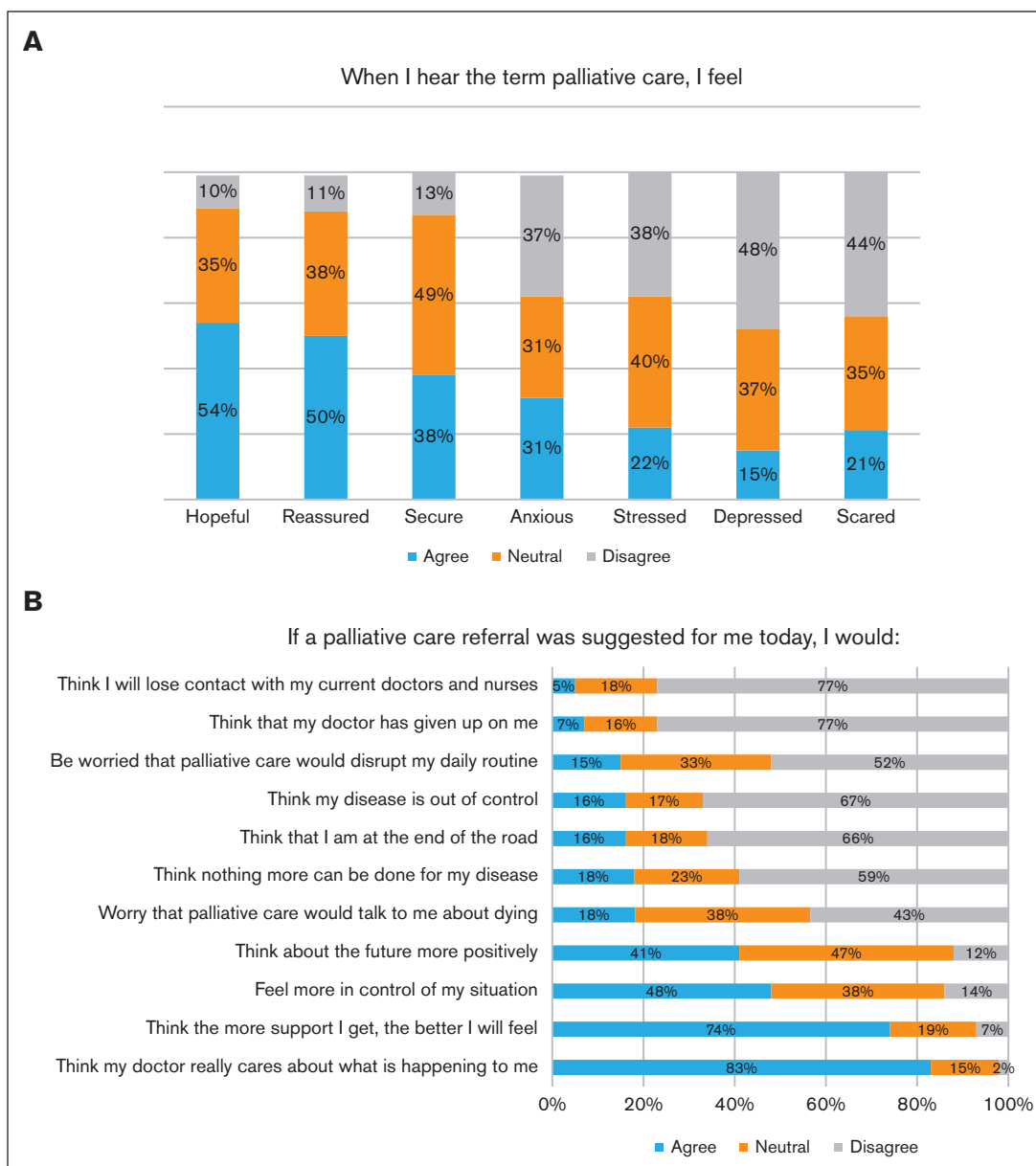


Figure 3. Patient perceptions about PC. (A) patients' emotional reactions toward PC; (B) patients' feelings and thoughts when referred to PC.

PC perception and would likely reduce barriers to accessing PC.²⁸

Over 70% of participants had heard about PC, mainly through family members, and a few reported hearing about PC through their transplant team. This may indeed explain why a significant proportion of HSCT recipients reported having limited knowledge of PC and being unsure about whether certain statements about PC were true or false. Interestingly, the proportion of participants reporting knowledge about PC was higher than that described in other populations. For example, 2 recent nationally representative studies in the United States reported that up to 66% of patients with cancer²⁹ and up to 71% of the general population³⁰ have never heard about PC. The limited knowledge and familiarity with

PC may lead to patients not inquiring about PC during their clinical encounters, despite the significant physical and psychological burden associated with HSCT.³⁻⁵ Therefore, increasing efforts should be made to improve PC knowledge among HSCT recipients. Data show that when patients are informed and educated about PC, they largely opt to receive it.³¹

Most participants had positive perceptions about PC and reported that when they hear the term PC, they feel hopeful and reassured, with only a few participants reporting feeling scared or stressed when hearing about PC. These results contrast with the recent results from a nationwide study we conducted in the United States, where most of the transplant physicians noted that patients feel scared, stressed, or anxious when they hear the term PC.¹⁴ Similar

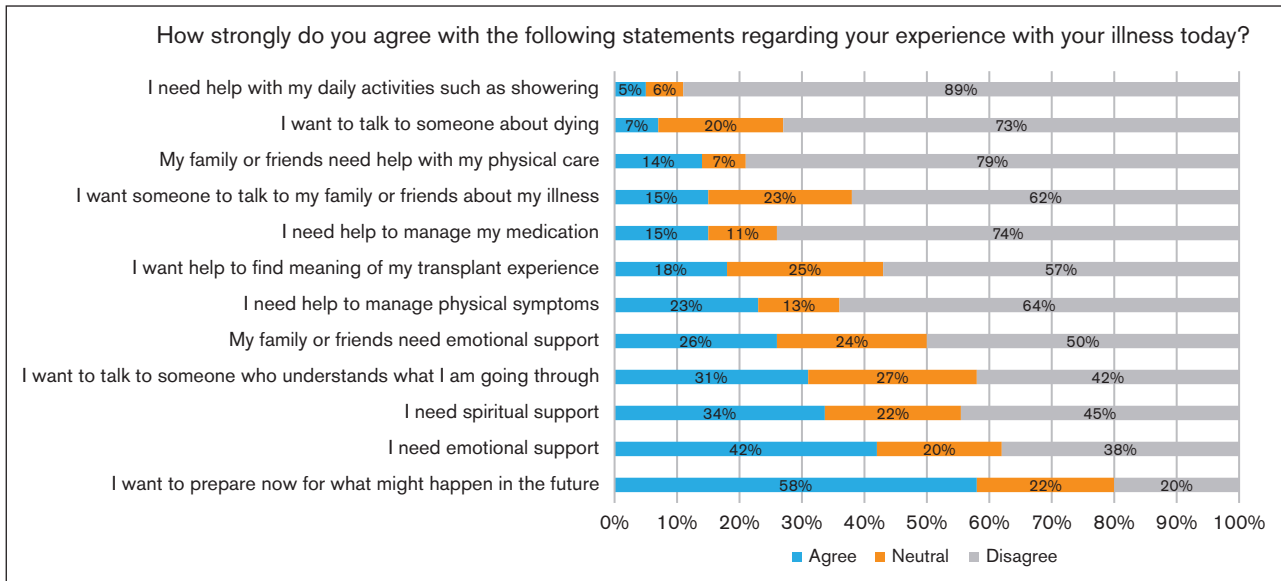


Figure 4. Participants-reported unmet PC needs.

discrepancies exist when patients and physicians are asked about how patients would feel if they were referred to PC. In fact, over 80% of patients reported that they would perceive a referral to PC as a sign that the doctor cares about what is happening to them. In

contrast, most transplant physicians reported that patients would perceive a PC referral as if nothing could be done for their disease or that they would feel deserted.¹⁴ Current results thus highlight that most transplant patients have positive perceptions of PC,

Table 2. Multivariable analysis of perception of PC (n = 228)

Parameter	Estimate	Standard error	T value	P value	Overall P value
Intercept	48.79	7.82	6.24	<.0001	
Age (continuous)	0.04	0.07	0.57	.5661	.5661
Education (ref = high school or lower)	0.00	–	–	–	.0983
Some college or college graduate	–4.47	2.44	–1.83	.0682	
Postgraduate	–5.55	2.60	–2.14	.0338	
Knowledge about PC (ref = 0-11)	0.00	–	–	–	<.0001
Knowledge scale 12-13	7.54	1.61	4.68	<.0001	
Global mental health (ref = excellent/very good)	0.00	–	–	–	.0620
Good	1.45	1.96	0.74	.4628	
Fair/poor	–3.05	2.05	–1.49	.1376	
Transplant type (ref = allogeneic)	0.00	–	–	–	.2647
Autologous	3.96	3.54	1.12	.2647	
Time from transplant to survey start (d) (continuous)	–0.01	0.01	–0.62	.5367	.5367
HCT-CI (ref: 3+)	0.00	–	–	–	.3068
1-2	0.30	1.83	0.17	.8679	
0	3.41	2.29	1.49	.1378	
Disease (ref: leukemias)	0.00	–	–	–	.5296
MDS/MPN/CML	2.29	2.95	0.78	.4392	
Lymphoma	–3.30	3.91	–0.84	.3997	
Myeloma	–0.10	4.23	–0.02	.9808	
Other (plasma cell disorder, solid tumor, severe aplastic anemia, sickle cell disease)	–1.55	4.37	–0.36	.7226	

This model also accounts for individual center effect (overall P value = .5863). Bold indicates statistical significance. CML, chronic myeloid leukemia; HCT-CI, hematopoietic cell transplant-comorbidity index; MDS, myelodysplastic syndrome; MPN, myeloproliferative.

which should indeed overcome transplant physicians-reported barriers to refer patients to PC.^{14,32} Results from a nationwide survey in the United States pointed out that most of the PC clinicians feel comfortable when managing symptoms in patients with hematological diseases, including HSCT, further supporting their potential role in this population.³³

Notably, a few HSCT recipients did have some misperceptions about PC, such as whether PC is aimed to address psychological issues brought by a serious illness, helps people understand their treatment options and encourages people to stop treatment aimed at curing their illness. Similarly, it is remarkable that approximately a third of participants reported being unsure about the goals of PC.

These findings underscore the need for educational interventions to enhance patients' knowledge about PC. Transplant and PC clinicians can indeed partner together to ensure that transplant recipients are fully informed about PC. Here, we found that greater patients' knowledge about PC was indeed associated with a more positive perception of PC. Interventions to improve knowledge about PC are not only acceptable and feasible,³⁴ but also result in increased PC knowledge,³⁴ reduced barriers, and more exposure to PC.^{28,35} When PC was clearly explained, up to 86% of HSCT recipients decided to enroll in a trial to test the efficacy of inpatient PC for improving outcomes in patients hospitalized for HSCT.⁸

Most of the transplant recipients reported unmet needs across numerous domains, and more prominently, on advance care planning and emotional and spiritual support. These unmet needs were also largely recognized by transplant physicians.¹⁴ Previous studies have demonstrated that PC is effective in addressing the physical, emotional, and quality-of-life needs of patients hospitalized for HSCT and is associated with more frequent and earlier goals of care conversations. In a randomized clinical trial, patients receiving PC during hospitalization for HSCT reported improvements in their quality of life, symptom burden, and psychological distress, including symptoms of depression and anxiety, compared with those receiving transplantation care alone.⁸ Interestingly, the effects of the intervention were sustained beyond the transplant hospitalization, as those receiving PC reported improvement in their depression and posttraumatic stress disorder symptoms up to 6 months after transplant.⁹ Given these benefits, patient and HSCT clinician education interventions should be paired with systematic strategies to routinely integrate PC in transplant care as needed.

The study does have notable limitations. First, most participants were white, non-Hispanic, English-speaking, with a college education. Thus, our findings may not be generalizable to other patients with different demographic characteristics. Second, we included participants who were 3 to 12 months after transplant,

and results should be interpreted within this context, as patients that were early during their hematopoietic cell transplant process and those at the end of life may have had different exposure to PC. Third, we do not have data on patients' direct exposure to PC clinician, which may influence their overall perception of PC. Fourth, we did not examine whether perceived knowledge of PC was associated with actual PC knowledge because it was out of the scope of the study. Fifth, we do not have data on the extent of PC integration at the transplant centers included in this study, which may affect the overall perception of PC. Future studies should examine this topic because the results will contribute to the design of interventions to improve PC knowledge among this population. In addition, future longitudinal studies are critical to help design and test the timing and impact of interventions to improve knowledge, perceptions, and familiarity with PC in this population.

In conclusion, most transplant recipients report a positive perception of PC despite their limited knowledge about its role. Those who were more knowledgeable about PC were more likely to report a positive perception of it. These findings indicate that when HSCT recipients are educated about PC, they are likely to view it favorably, an important step in promoting PC uptake. Furthermore, education for HSCT clinicians about how recipients actually view PC may overcome misperceptions and reduce unnecessary gatekeeping limiting recipient access to PC.

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Authorship

Contribution: All authors made substantial contributions to concept and design, acquisition of data, or analysis and interpretation of data; and all were involved in drafting the manuscript, revising it critically for important intellectual content, and providing final approval for publication.

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