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Hematopoietic Stem Cell Transplant Candidate and Designated Proxy Distress Levels Prior to Hematopoietic Stem Cell Transplantation

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Abstract

Hematopoietic stem cell transplantation (HCT) is associated with a high risk of morbidity, making advance care planning (ACP) essential. The purpose of this study was to assess and compare proxy and HCT candidate distress levels (Distress Thermometer) before (T1) and after (T2) ACP question completion. 79 participants (40 HCT candidates, 39 proxies) rated their distress. The T1, T2 mean distress scores (SD) for HCT candidates were 3.13(2.27), 2.96(2.10); 43% and 38% endorsed clinically significant distress (≥ 4). Proxies reported 4.21(2.48), 4.33 (2.46); 62% endorsed significant distress at T1, T2. The majority of proxies endorsed distress levels that were clinically significant and comparatively higher (T1 ($p = 0.047$) and T2 ($p = 0.009$)) than their paired HCT recipients. Responding to questions about ACP did not increase overall distress ratings.

Keywords

proxies; distress; advance care planning; hematopoietic cell transplant candidate; decision makers; end-of-life planning

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Introduction

Medical advances and complex treatments can increase the possibility of protracted illnesses, hospital deaths, and complex family decisions related to care.¹ Hematopoietic stem cell transplant (HCT) candidates may be at higher risk of encountering difficult medical decision making due to the intensity of treatment and potential side effects and complications. In this context, the advance care planning (ACP) process may be a source of additional distress for both HCT candidates and proxies. The proxies designated by health care recipients may be integral to future care yet remain under investigated. Given the heavy responsibility of the proxy role in potentially assuming decision making for patients undergoing HCT, their distress levels are of keen interest.

Distress is defined by the National Comprehensive Cancer Network² as a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, and emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatments. The International Psycho-Oncology Society recently updated screening guidelines that include distress screening for all new patients.³ It is estimated that approximately half of the HCT candidates experience significant distress levels (ie, 5 on the distress thermometer [DT]) at the time of the HCT workup.⁴ Further, recent findings suggest that caregivers may report distress levels that are equivalent to or even higher than those reported by the patients.⁵ Although the care giving literature has many implications for designated proxies, these proxies may or may not be patients' primary caregivers. That is, some patients choose their primary caregiver to be their designated medical decision maker, while others do not. Role differences may have implications for differences in distress levels and emotional well-being.

Our study objectives were (1) to assess proxy distress levels in comparison to HCT recipients and (2) to assess any changes in distress levels pre-and post-exposure to questionnaires about advance directive attitudes and family decision making. These data were part of a larger study designed to acquire a deeper understanding of how patients and loved ones prepare for significant health care decisions. Results here focus specifically on the distress levels reported by these groups.

Methods

All candidates and their proxies participated in a standard of care psychosocial assessment as part of the medical workup prior to HCT. This interview included specific questioning about ACP. Additionally, participants were asked to complete a battery of questionnaires in which ACP was the central topic, likely increasing the salience of the issues related to ACP. Every consecutive candidate scheduled for an HCT assessment at Wake Forest Baptist Health (WFBH) during the study time frame of December 15, 2011, to May 25, 2012, was a prospective candidate for the study. Inclusion criteria included (1) 18 years of age or older, (2) English literate, and (3) scheduled for HCT at WFBH or the designated proxy of someone scheduled. For participation in the designated proxy component of the study, the HCT candidates were asked to name their currently designated or, in the event that no one had been designated, the person most likely to make medical decisions on their behalf

should they be unable to speak for themselves. Most often, this designated person had accompanied the HCT candidate to the assessment. If not present, the HCT candidate was asked to provide contact information for this designated proxy as well as permission for a member of the research team to contact her or him. The HCT candidates could participate in the study even if their respective designated medical decision makers declined or vice versa. This study was reviewed and approved by the WFBH institutional review board.

The HCT candidates and proxies were introduced and consented to the study by a member of the research team immediately preceding or following the psychosocial assessment. Occasionally, the study was introduced over the phone, and materials were mailed. Participation was voluntary, and candidates were informed that their decision would not impact their care. Those who consented to the study agreed to (1) complete the brief survey packet (requiring approximately 15–20 minutes) and (2) allow a review of their electronic medical record at hospital discharge for the larger study (HCT candidates only). Participants completed the survey packet in the clinic or were provided return postage. Participants were given a US\$10 incentive upon return of the study packet and the consent form.

Instruments in the larger study packet included the Advance Directive Attitudes Survey,⁶ Family Decision Making Self-Efficacy Scale,⁷ Multidimensional Health Locus of Control, Form C,⁸ State-Trait Anxiety Inventory, Form Y,⁹ a Sociodemographic form, and the DT.^{2,10}

The DT

The DT is a screening tool that consists of a 1-item, self-report question presented in the form of a thermometer. The DT scale ranges from 0 (*no distress*) to 10 (*extreme distress*) and prompts respondents to rate average distress level over the past week.^{2,10} Pooled results from numerous studies indicate the DT has a specificity of 66.1% and a sensitivity of 77.1% relative to the detection of general distress.¹¹ The suggested clinical threshold indicating significant distress varies between four^{12,13} and five.¹⁴ We elected to utilize the cutoff score of 4 to indicate clinically significant distress on account of the research evidence suggesting that a cutoff score of 4 best distinguishes those with clinically significant depressive symptoms from those without.^{12,13} Distress was rated immediately before the questionnaires were administered (T1) and immediately after completion (T2).

Data Analysis

Summary statistics, including means and standard deviations (SDs) for continuous measures and frequencies and proportions for categorical data, were calculated for each study measure. To assess changes within groups between T1 and T2 and within dyads, paired *t* tests were used. The expected difference in these tests would be no difference (a value of 0), so the observed difference between times and within dyads was tested against the expected value of 0. Linear regression was used to look at the differences between groups in T2 distress, with baseline distress modeled as a covariate. Independent *t* tests were used to investigate the differences in DT at T1, T2, and the change between T1 and T2. A *P* value < .05 indicated a significant difference in comparative groups.

Results

A total of 93 individuals consented to the study (49 HCT candidates and 44 designated proxies; Table 1). Of those, 89 had distress data available for at least 1 visit (87 pre [43 CG, 44 HCT] and 81 post [39 CG, 42 HCT]). Those who completed the DT at only 1 time point ($N = 8$) were excluded from the analyses looking at both T1 and T2 DT values (Table 2).

At T1, HCT candidates ($N = 40$) reported a mean distress level of 3.13 ($SD = 2.27$), with 43% endorsing clinically significant distress. Proxies ($N = 39$) reported a mean distress level of 4.21 (2.48), with 62% endorsing clinically significant distress (Table 2). At T2, HCT candidates reported a mean distress level of 2.96 (2.10), with 38% endorsing clinically significant distress. Proxies reported a mean distress level of 4.33 (2.46), with 62% endorsing clinically significant distress at T1 and T2. Differences in reported distress within the paired HCT candidate–proxy dyads were examined. Within the dyads, proxy mean reported distress was significantly higher, with a mean difference of 1.15 (2.48) at T1 ($P = .006$; $N = 39$ pairs) and 1.35 (2.41) at T2 ($P = .002$; $N = 37$ pairs).

Proxy mean distress scores were significantly higher than those of HCT candidates at T1 ($P = .047$) and T2 ($P = .009$). No significant movement was noted within the respective HCT and proxy groups. Although no significant movement was noted within the respective HCT and proxy groups, the decrease in HCT candidates' scores from T1 to T2 ($-0.16 \pm SD$ of 0.54) approached significance ($P = .06$). The relationship between HCT recipient and proxy group membership and post-study distress reports also was examined, adjusting for baseline. The estimated mean T2 distress score was 3.46 (standard error = 0.09) within the HCT group and 3.82 (0.09) in the proxy group. These estimated means differ significantly ($F_{1,76} = 7.97$, $P = .0061$). We also investigated the number of individuals who crossed the threshold of significance from T1 to T2 (ie, moved from clinically significant [≥ 4] to nonsignificant or vice versa). Within the HCT group, only 2 candidates moved from ≥ 4 T1 to <4 T2; none moved from below to above clinical significance. Within the proxies, only 1 proxy moved from <4 to ≥ 4 at T2 and 1 proxy moved from ≥ 4 to <4 . In summary, both HCT candidates and proxy scores remain relatively consistent over the two administrations of the DT.

Discussion

A significant percentage of HCT candidates and their proxies endorsed clinically significant distress (ie, ≥ 4) at the time of medical and psychosocial workup. The scores of patients and proxies are consistent with those reported by other researchers on patients and their caregivers.^{4,5} The comparatively higher distress reported by proxies coupled with the fact that approximately two-thirds of the proxies reported clinically significant distress suggests that proxies may face even more intense distress than patients (at least in this stage of the transplant process). Findings here resemble those reported by caregivers in other studies. Although there is considerable role overlap between many primary caregivers and proxies, it is important to remember that designated proxies have unique roles. The role of the proxy often is not addressed directly in the broader caregiver literature. Within HCT candidate–proxy dyads, proxies endorsed distress levels that were significantly higher than their patient

counterparts at T1 and T2. Since the patient is the central focus of the transplant process, proxies may have many psychosocial stressors that are not identified or treated appropriately. Further research is needed on their particular experiences and needs.

Additionally, distress levels did not rise significantly for HCT candidates or their designated proxies after participating in research that examined attitudes toward future health care decisions in the event of health decline. It is possible, however, that the general distress experienced by HCT candidates and proxies may have masked any measurable movement in distress during the brief 20-minute completion period. Few individuals in either group crossed the threshold of significance across administrations. Patients generally did not move toward becoming distressed if they did not experience significant distress initially. This stability in distress level group membership (ie, those reporting nonsignificant distress levels vs significant distress levels) points to factors other than study participation that are impacting reported distress. The estimated mean distress levels for HCT candidates and proxies at T2 were 3.46 and 3.82, respectively, both below the level of clinical significance.

This lack of significant change in distress reporting from T1 to T2 suggests that exposure to ACP information, both in the interview where candidates were specifically questioned about ACP and in the questionnaires that could presumably increase the salience of the risks and need for a surrogate decision maker, does not add to the burden of patients and caregivers preparing for HCT. Previous researchers have examined how exposure to information impacts emotional well-being or distress. For example, Lyon et al examined the emotional impact of participating in an ACP intervention.¹⁵ In a randomized 2-arm design involving 40 Human immunodeficiency virus/AIDS-infected teens and 40 adult surrogates, those randomized to participate in an ACP activity did not experience significant distress or other unwanted emotional effects and were not influenced to discontinue active treatment. These results suggest that participation in research related to difficult topics does not add significantly to distress levels of participants. To understand the high distress levels endorsed by proxies, other contributory variables (eg, situational, psychological, and decision making) warrant further research.

There are limitations to this study. First, participants were from one academic medical center in the southeastern United States. Second, the DT has a 10-point scale and may not capture fine shifts of mood or distress from pre- to post-assessment. Although the results of Gessler et al indicate that the DT can be used to monitor psychological distress changes over time, its sensitivity in measuring change over short periods of time is unclear.¹⁶ Third, the number of patients was small, limiting power and generalization. Recipients of all kinds of transplants, including autologous, allogeneic, myeloablative, and nonmyeloablative, were included. Although this may increase the applicability of findings, recipients of different types of transplants and their designated proxies also may have unique experiences and morbidity risk profiles that warrant individualized research. Finally, the DT was designed for use with medical populations.² Certain researchers have reported limitations relative to the diagnostic utility of the DT with caregivers.¹⁴

In summary, a high percentage of patients (43%) and caregivers (62%) reported clinically significant distress at the initial HCT workup. Proxies reported significantly higher distress

levels than their matched HCT candidates. The unique role demands and experience of proxies warrant further investigation. Further, exposure to ACP questioning and questionnaires was not measurably distressing for HCT candidates or their designated proxies. Considering issues related to ACP at the initial HCT medical workup does not necessarily result in negative emotional consequences. These findings highlight the need for careful attention to distress levels of both proxies and/or caregivers who will be engaged in the HCT process. The brave caregivers and proxies who act in the service of their loved ones may need every bit as much psychosocial care as the recipients themselves over the course of HCT treatment.

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References

1. Field, M.; Cassel, C. *Approaching Death*. Washington, DC: National Academies Press; 1997.
2. National comprehensive cancer network (NCCN) practice guidelines for the management of psychosocial distress. *Oncology*. 2003; 13(5A):113–147.
3. Holland J, Watson M, Dunn J. The IPOS new international standard of quality cancer care: integrating the psychosocial domain into routine care. *Psychooncology*. 2011; 20(7):677–680. [PubMed: 21710503]
4. Trask PC, Paterson A, Riba M, et al. Assessment of psychological distress in prospective bone marrow transplant patients. *Bone Marrow Transplant*. 2002; 29(11):917–925. [PubMed: 12080358]
5. Beattie S, Lebel S. The experience of caregivers of hematological cancer patients undergoing a hematopoietic stem cell transplant: a comprehensive literature review. *Psychooncology*. 2011; 20(11):1137–1150. [PubMed: 21425389]
6. Nolan MT, Bruder M. Patients' attitudes toward advance directives and end-of-life treatment decisions. *Nurs Outlook*. 1997; 45(5):204–208. [PubMed: 9364529]
7. Nolan MT, Hughes MT, Kub J, et al. Development and validation of the family decision-making self-efficacy scale. *Palliat Support Care*. 2009; 7(3):315–321. [PubMed: 19788773]
8. Wallston KA, Stein MJ, Smith CA. Form C of the MHLC scales: a condition-specific measure of locus of control. *J Pers Assess*. 1994; 63(3):534–553. [PubMed: 7844739]
9. Spielberger, CD.; Gorsuch, RL.; Lushene, RD. *STAI: Manual for the State-Trait Anxiety Inventory*. Palo Alto: Consulting Psychologists Press; 1970.
10. Roth AJ, Kornblith AB, Batel-Copel L, Peabody E, Scher HI, Holland JC. Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer*. 1998; 82(10):1904–1908. [PubMed: 9587123]
11. Mitchell AJ. Pooled results from 38 analyses of the accuracy of distress thermometer and other ultra-short methods of detecting cancer-related mood disorders. *J Clin Oncol*. 2007; 25(29):4670–4681. [PubMed: 17846453]
12. Jacobsen PB, Donovan KA, Trask PC, et al. Screening for psychologic distress in ambulatory cancer patients. *Cancer*. 2005; 103(7):1494–1502. [PubMed: 15726544]
13. Ransom S, Jacobsen PB, Booth-Jones M. Validation of the distress thermometer with bone marrow transplant patients. *Psychooncology*. 2006; 15(7):604–612. [PubMed: 16208733]

14. Bevens MF, Mitchell SA, Barrett AJ, et al. Function, adjustment, quality of life and symptoms (FAQS) in allogeneic hematopoietic stem cell transplantation (HSCT) survivors: a study protocol. *Health Qual Life Outcomes*. 2011; 9:24. [PubMed: 21496339]
15. Lyon ME, Garvie PA, Briggs L, et al. Is it safe? talking to teens with HIV/AIDS about death and dying: a 3-month evaluation of family centered advance care (FACE) planning—anxiety, depression, quality of life. *HIV AIDS (Auckl)*. 2010; 2:27–37. [PubMed: 22096382]
16. Gessler S, Low J, Daniells E, et al. Screening for distress in cancer patients: is the distress thermometer a valid measure in the UK and does it measure change over time? A prospective validation study. *Psychooncology*. 2008; 17(6):538–547. [PubMed: 17973237]

Table 1

Sociodemographic Characteristics of HCT Recipients and Proxies.

Participant characteristic	HCT, N (%)	Proxy, N (%)
Total	46	43
Sex		
Female	14 (30)	28 (65)
Male	32 (70)	15 (35)
Race		
Black	6 (13)	6 (14)
White	40 (87)	37 (86)
Marital status		
Single	5 (11)	4 (10)
Married	29 (63)	35 (85)
Separated	2 (4)	1 (2)
Divorced	8 (17)	1 (2)
Widowed	2 (4)	1 (2)
Children		
Yes	38 (83)	38 (88)
No	8 (17)	5 (12)
Educational level		
1–8 grades	1 (2)	1 (2)
9–11 grades	5 (11)	6 (14)
High school graduate	15 (33)	6 (14)
Some college	14 (30)	15 (36)
Junior college degree	1 (2)	4 (10)
College degree	4 (9)	4 (10)
Some post college work	2 (4)	–
Advanced degree	4 (9)	6 (14)
Annual family income		
0–4999	2 (5)	2 (5)
5000–9999	1 (2)	–
10 000–19 999	6 (14)	6 (14)
20 000–29 999	6 (14)	4 (9)
30 000–39 999	7 (17)	5 (12)
40 000–49 999	5 (12)	7 (16)
50000–59 999	4 (10)	6 (14)
60 000–69 999	2 (5)	2 (5)
70 000+	9 (21)	11 (26)
Religious affiliation		
Protestant	39 (85)	35 (81)
Catholic	3 (7)	4 (9)
Other	3 (7)	3 (7)

Participant characteristic	HCT, N (%)	Proxy, N (%)
Spiritual, not religious	1 (2)	1 (2)

Abbreviation: HCT, hematopoietic stem cell transplant.

Table 2

Distress Scores, T1, and T2 of HCT Recipients and Proxies.

	T1		T2	
	X̄(SD)	No. (%)	X̄(SD)	No. (%)
HCT, N = 40	3.13 (2.27)	17 (43)	2.96 (2.10)	15 (38)
Proxy, N = 39	4.21 (2.48)	24 (62)	4.33 (2.46)	24 (62)

Abbreviations: HCT, hematopoietic stem cell transplant; SD, standard deviation; T1, prior to administration of questionnaires; T2, postcompletion of questionnaires.