Patient Perceptions of Palliative Care in the Process of Allogenic Stem Cell Transplantation

Megan Melody MD, MS; Chimere Bruning PA-C; Rachel Mack APRN; Kimberley Parrott APRN; Richard Taylor MD; Judith Kaur MD; Ernesto Ayala MD; Mohammed Kharfan-Dabaja MD, MBA; Hemant Murthy MD; Molly Kilpatrick MD; Maisha Robinson MD

Introduction

- Allogeneic hematopoietic stem cell transplantation (allo-HSCT) is associated with significant sequalae that affect patients' overall quality of life (QoL). Although studies have shown improvement in patient QoL with the involvement of palliative care in the allo-HSCT process, perceptions regarding palliative care often impact referrals to palliative care. We conducted a study to examine patient perceptions of palliative care during evaluation for allo-HSCT.
- Primary endpoint was to assess the change in patient pre- and post-questionnaire responses.
- Secondary endpoint was to assess for completion of advance care planning documentation.

Study Design

- We conducted a prospective, single-center study, of adult patients who were referred for palliative care consultation as part of evaluation for allo-HSCT. Patients were administered a pre- and post-visit questionnaire to assess understanding and comfort level with palliative medicine.

Results

- We enrolled 32 patients undergoing evaluation for allo-HSCT (Table 2).
- Our study showed that the majority (56%) of patients reported a below-average (poor or fair) knowledge of palliative medicine and understanding of the reason for palliative medicine consultation.
- Following consultation with palliative care there was a statistically significant increase in patient understanding of reason for the appointment, p= 0.0006.
- There was also a significant increase in patients' knowledge of palliative care, with only 28% describing their knowledge as "good" or "excellent" prior to consultation and 79.3% after consultation, p <0.0001.
- There was an observed positive trend in patient comfort level with palliative medicine and likelihood to utilize palliative medicine during allo-HSCT following consultation, although not statistically significant.
- There was a higher rate of completion of advance care planning documentation following consultation with palliative medicine 56.3% vs 71.4%, p= 0.042.

Table 1. Survey Results

	Pre-Visit	Post-Visit	P-Value
My understanding of why I am at this appointment is…			
Poor	13	3	
Fair	6	0	
Average	7	1	0.0008
Good	8	11	
Excellent	0	16	
No response	0	3	
My understanding of my medical condition is…			
Poor	1	1	
Fair	0	0	
Average	3	1	0.40
Good	16	13	
Excellent	14	16	
No response	0	3	
My knowledge of palliative care is…			
Poor	12	3	
Fair	7	1	
Average	6	2	<0.0001
Good	8	13	
Excellent	1	12	
No response	0	3	
My level of comfort with palliative medicine is…			
Very low	1	3	
Low	3	0	
Average	20	5	0.51
High	5	6	
Very high	1	17	
No response	4	3	
The likelihood that I will continue to utilize palliative medicine during my bone marrow transplant following this appointment is…			
Very low	1	1	
Low	1	0	0.84
Average	17	8	
High	8	6	
Very high	1	15	
No response	6	4	
I have completed advance care planning such as advance directive, living will, or health care surrogate form…			
Yes	20	22	0.07
No	14	8	
No response	0	4	

Table 2. Descriptive Characteristics

Gender	
Male	16
Female	18
Intersex	-
Age (years)	
25 or Under	-
26-39	5
40-49	3
50-59	6
60-69	16
70-79	4
Ethnicity	
White	29
Hispanic or Latino	2
Black/African American	3
Native American/American Indian/First Nation	-
Asian/Pacific Islander	-
Other	-
Diagnosis	
ALL	2
AML	9
CML	-
HL	-
MDS	8
NHL	8
Other	7

Conclusions

- The majority of patients undergoing allo-HSCT report a poor understanding of palliative medicine.
- A palliative care consultation prior to allo-HSCT increases a patient's understanding of the role of palliative medicine in his/her allo-HSCT.
- A positive trend was observed in patients' comfort with and interest in continuing to utilize palliative medicine following initial consultation.