

Patient, family member, and clinician perspectives on advance care planning (ACP) in hematology and hematopoietic stem cell transplantation (HSCT).

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BACKGROUND

Background: ACP engagement and completion of advance directives (ADs) remain low in patients undergoing HSCT in spite of the high risks of treatment-related mortality and potential for intensive care unit (ICU) admission and/or life-sustaining measures. This study, as part of a larger program of research on ACP policy implementation, sought to understand readiness, barriers and facilitators to ACP in the setting of hematology and HSCT.

Objectives: To examine patient, family member and clinician perspectives on ACP in hematology and HSCT.

METHOD

This qualitative study used Thorne’s Interpretive Description methodology.

Participant accrual
* Purposive sampling
* Outpatient clinics at cancer center
* Informed consent

Semi-structured interview
* Audio-recorded
* Transcribed verbatim

Data Analysis
* Constant comparative method
* Repeated review of transcripts

Analysis of data occurred concurrently with data collection

RESULTS: SAMPLE

Patients (n=6)			
Age	Diagnosis	Treatment Status	AD
40	AML	Post-HSCT	Yes
49	MS	Post-HSCT	No
53	Leukemia NOS	Post-HSCT	No
56	MM	Pre-HSCT	No
59	MF	Post-HSCT	Yes
59	FL	Chemo	No
Family members: 4 spouses, 1 daughter			
Clinicians: 3 nurse practitioners, 3 physicians, 1 registered nurse, 1 social worker			
AML: acute myelogenous leukemia		MM: multiple myeloma	AD: advance directive
MS: multiple sclerosis		MF: myelofibrosis	
NOS: not otherwise specified		FL: follicular lymphoma	

RESULTS

- Participants thought ACP was both acceptable and important yet the majority had not engaged in ACP.
- Facilitators to ACP identified by participants included: integrating ACP as part of routine HSCT care, involving the multidisciplinary team in ACP and introducing ACP early and revisiting frequently.
- Barriers reported by participants are listed opposite.

RESULTS

System-related barriers

- Lack of process
- Lack of time

"You know...I've never met you before and here I am, I'm talking to you about goals of care. I barely know the diagnosis and now I'm supposed to put their level of care in the computer with my name on it saying that I've discussed it with the patient." (HSCT physician)

"I think it takes some more time and I think that's what ties most people down is time is short and so to open that discussion...you don't often close it in that same session." (HSCT physician)

Patient/family-related barriers

- Lack of understanding of:
-disease/prognosis
-ACP
- Need to keep positive

"...you see people who are genuinely surprised, shocked, angry...that things have come to this juncture and they will claim up and down that they had no idea it could be...it would be this way." (HSCT physician)

"I think that's [ACP] an acceptance that it is going to go bad." (patient)

"Because here, we're going off in our bubble and someone is poking a hole in the bubble, I mean, deflating the bubble just a tiny little bit." (Spouse of HSCT patient)

Disease & treatment-related barriers

- Aggressive treatment
- Prognostic uncertainty

"...that's the part where you need to recognize the shift that what started off as a curable disease is now complicated by incurable treatment. The disease isn't going to kill you...the treatment is." (HSCT physician)

"It is a bit of a unique situation from the point of view of the trajectory of their illness being so unpredictable. On the one hand, you could be cured and alive 10 years down the road, or you could be dead in the next 3 weeks." (HSCT physician)

RECOMMENDATIONS & CONCLUSION

- This study found that:
- engagement in ACP was poor in patients undergoing HSCT
 - clinicians described prognostic uncertainty as one of the biggest perceived barriers to ACP discussions
 - patients and family members expressed a desire to adopt a positive outlook at the expense of participating in ACP
- Future research should explore:
- The relationships between prognostic uncertainty faced by clinicians and patients' lack of understanding of disease, prognosis and expectations of treatment
 - The 'need to stay positive' reported by patients and family members → is this a reflection of lack of awareness of prognosis, a coping mechanism or perhaps a combination of both?
- Given the inherent challenges in engaging hematology and HSCT patients in ACP, we advocate the 'SETT' approach:

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- Standardize:** incorporate ACP into routine processes
- Educate:** on ACP, life-sustaining interventions, complications of treatment, prognostic awareness
- Timing:** introduce ACP early, revisit often
- Team:** multidisciplinary (including but not limited to: medicine, nursing, spiritual care, psychology, social work, palliative care)

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