

Feasibility and Acceptability of Advance Care Planning in Adolescent and Young Adult Bone Marrow Transplant Patients

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Introduction

- Adolescent and young adults undergoing bone marrow transplant have significant morbidity and mortality
- Formal advance care planning/advance directives occur in a minority of patients

Needle J, Smith A The Impact of Advance Directives on End-of-Life Care for Adolescents and Young Adults undergoing Hematopoietic Stem Cell Transplant, J Pall Med 2016;19(3)

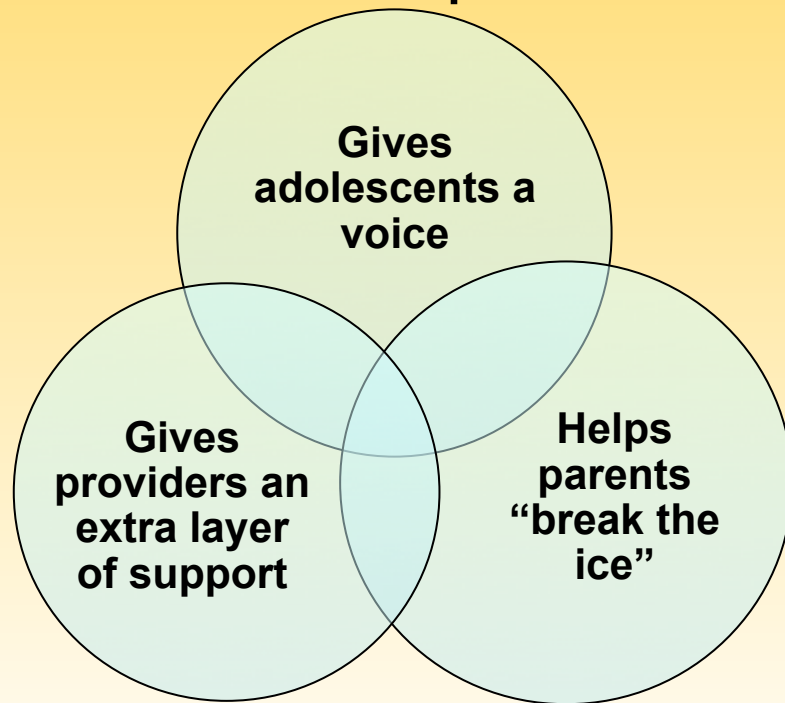


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Introduction

- FACE (**F**amily/**A**dolescent **A**dvance **C**are Planning) intervention is feasible, acceptable, safe and results in increased congruence between patients and surrogates



M.E. Lyon et al., "Family-Centered Advance Care Planning for Teens with Cancer," *JAMA Pediatr* 167, no. 5 (2013): 460-7.

M.E. Lyon et al., "Development, Feasibility and Acceptability of the Family-Centered (FACE) Advance Care Planning Intervention for Adolescents with HIV," *J Palliat Med* 12, no. 4 (2009): 363-72



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Specific Aims

- To determine the feasibility, acceptability, and safety of the FACE intervention for AYA BMT patients
- To determine the impact of the FACE intervention on congruence between AYA BMT patients and their surrogates regarding treatment preferences



Methods

Patients age 14-26

Undergoing BMT for any reason
Surrogate > 18 years, English speaking

Session 1 Lyon ACP Survey

Conclusion of workup week
*Pre-intervention SoTP

Session 2 Next Steps Interview

Within 48 hours of admission
*Satisfaction survey

Session 3 Follow up

Within 48 hours of Session 2
*Post-intervention SoTP

Day 100 or discharge

* In-person interview



Demographics (N=12)

Age (mean)	18
Race (% Caucasian)	83
Gender (% male)	75
Diagnosis (%)	
Acute lymphoblastic leukemia	34
Fanconi anemia	18
Acute myelogenous leukemia	8
Chronic myelogenous leukemia	8
Aplastic anemia	8
Sickle cell anemia	8
Metachromatic leukodystrophy	8
Chronic granulomatous disease	8



Feasibility, Acceptability, and Safety

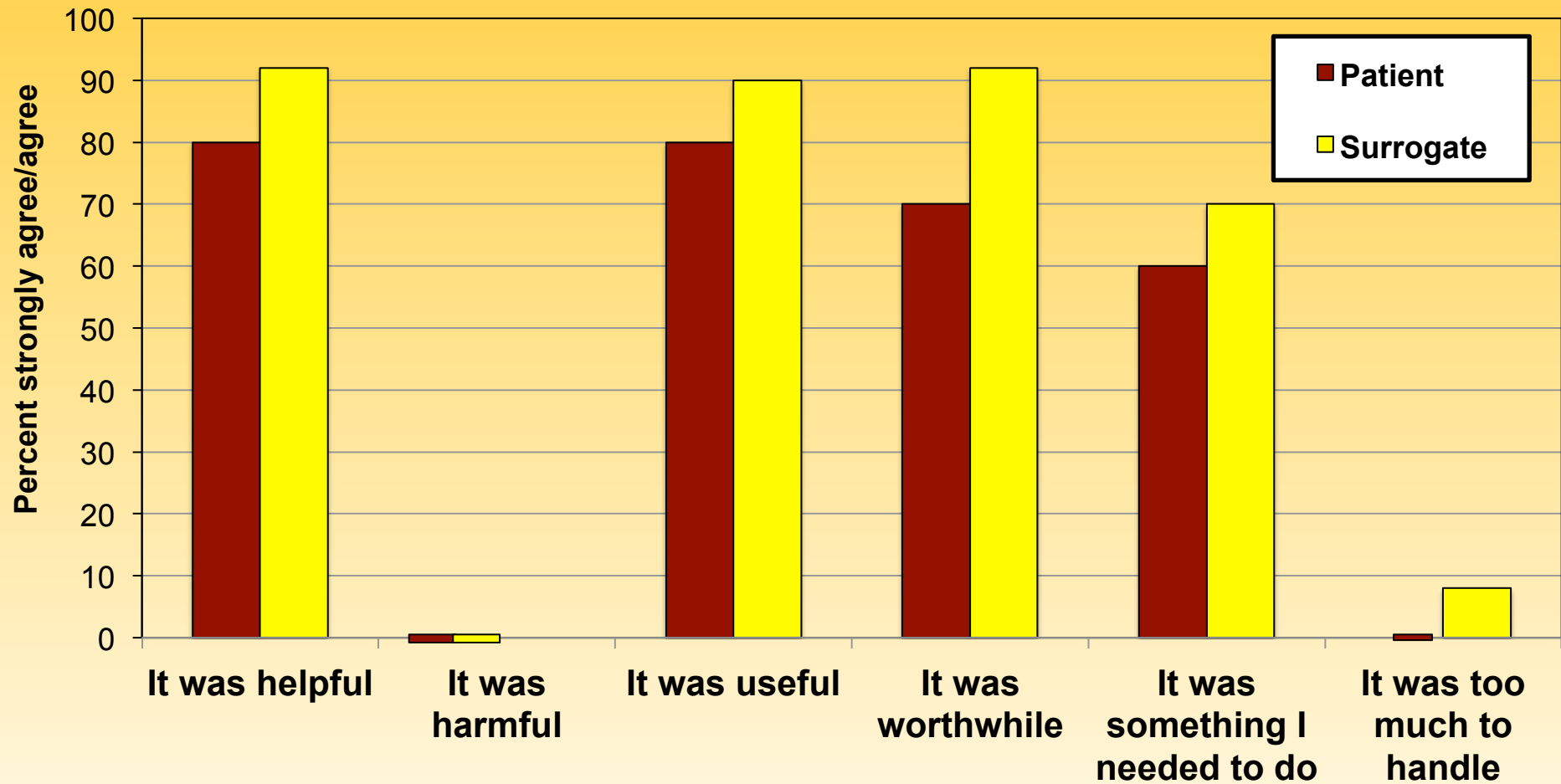
		Goal(%)	Actual
Feasibility	Enrollment	75	67
	Attendance	80	90*
	Retention	85	92**
Acceptability	Satisfaction ("It was helpful")	75	92
Safety	Adverse Events ("It was harmful")	0	0

*Five of 12 dyads completed all three sessions outside of protocol timeline

** One dyad withdrew



Satisfaction



Congruence

CONTINUE/DISCONTINUE TREATMENT IF...	Pre (κ)	Post (κ)	p-value
Serious complication(s) and low chance of living (5%)	0.61	NA	NA
Cancer has spread, treatment will extend life 2-3 months, serious side effects	0.06	0.74	0.01
Survival but inability to walk or talk and require 24 hour nursing care	0.36	1.0	<0.01
Survival but would not know who I was and require 24 hour nursing care	0.11	0.67	0.04



Conclusions

- Advance care planning is feasible, acceptable, and safe for adolescent and young adult BMT patients
- Satisfaction with the intervention was high for both patients and surrogates
- Given the tenuous clinical condition of patients prior to BMT, flexibility in protocol timing is necessary to complete all sessions
- Patient and surrogate congruence on treatment preferences improved following the FACE-BMT intervention



“I really appreciate you guys doing this study and I think it’s really important. It’s something that I feel like should’ve happened by now. It seems like there’s enough research done to show a lot of these things benefit families.”

22 year old patient



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Thank you!

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 - Maureen Lyon, PhD (mentor)
 - Gabe Gebremichael, MSW
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