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

Jennifer Needle, MD, MPH
Assistant Professor of Pediatrics and Bioethics
University of Minnesota
Minneapolis, MN
• I have no conflicts of interest to disclose

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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)
Introduction

• FACE (Family/Adolescent Advance Care Planning) intervention is feasible, acceptable, safe and results in increased congruence between patients and surrogates.


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)

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean)</td>
<td>18</td>
</tr>
<tr>
<td>Race (% Caucasian)</td>
<td>83</td>
</tr>
<tr>
<td>Gender (% male)</td>
<td>75</td>
</tr>
</tbody>
</table>

#### 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

<table>
<thead>
<tr>
<th></th>
<th>Goal(%)</th>
<th>Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Feasibility</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enrollment</td>
<td>75</td>
<td>67</td>
</tr>
<tr>
<td>Attendance</td>
<td>80</td>
<td>90*</td>
</tr>
<tr>
<td>Retention</td>
<td>85</td>
<td>92**</td>
</tr>
<tr>
<td><strong>Acceptability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfaction</td>
<td>75</td>
<td>92</td>
</tr>
<tr>
<td>(“It was helpful”)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Safety</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adverse Events</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>(“It was harmful”)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Five of 12 dyads completed all three sessions outside of protocol timeline
**One dyad withdrew
Satisfaction

- It was helpful
- It was harmful
- It was useful
- It was worthwhile
- It was something I needed to do
- It was too much to handle

Percent strongly agree/agree

- Patient
- Surrogate
## Congruence

<table>
<thead>
<tr>
<th>Continuation/Discontinuation of Treatment If...</th>
<th>Pre (κ)</th>
<th>Post (κ)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Serious complication(s) and low chance of living (5%)</td>
<td>0.61</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Cancer has spread, treatment will extend life 2-3 months, serious side effects</td>
<td>0.06</td>
<td>0.74</td>
<td>0.01</td>
</tr>
<tr>
<td>Survival but inability to walk or talk and require 24 hour nursing care</td>
<td>0.36</td>
<td>1.0</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Survival but would not know who I was and require 24 hour nursing care</td>
<td>0.11</td>
<td>0.67</td>
<td>0.04</td>
</tr>
</tbody>
</table>
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
Thank you!

• Research team:
  • Angela Smith, MD (co-PI)
  • Maureen Lyon, PhD (mentor)
  • Gabe Gebremichael, MSW
  • Janet Ziegler, MSW
  • Marie Rodier, MSW
  • Andrea Martin
  • Respecting Choices©