

**An advanced care planning  
intervention for adolescents and  
young adults undergoing bone  
marrow transplant**

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**Objectives**

- Describe the history and current state of advance care planning
- Recognize misconceptions and myths about adolescent advance care planning
- Describe preliminary results from FACE-BMT study



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### Abbreviations

- Advance Care Planning (ACP)
- Adolescent and young adult (AYA)
- End of Life (EOL)
- Family Centered Advanced Care Planning(FACE)
- Statement of Treatment Preferences (SOTP)
- Blood and Marrow Transplant (BMT)



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### Key Definitions

- Dyad
- Congruence
- Surrogate
- ACP



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### Health Care Directive

**“...a tool to communicate formally one’s health care wishes regarding end-of-life care and, presumably, to enhance the likelihood that one’s wishes are followed by health care professionals.”**

C. Sabatino, 2010



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### History of ACP

- Evolution of ACP
- Influential cases
- Legal-transactional model
- Communication model



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### Why ACP is Important



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### SW Practice & Core Values

- Dignity and worth of a person
- Self-determination
- Social justice and advocacy



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**ACP Addresses**

- Concerns/Gaps in Knowledge
- Patients' Past Experiences
- Values, Beliefs and Goals
- Identification of Questions
- Formulation & Articulation of Plans



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**ACP addresses:**

**Concerns/gaps in knowledge:**



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**ACP addresses:**

**Patients' past experiences:**



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**ACP addresses:**

- **Values, Beliefs, and Goals:**



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**ACP addresses:**

- **Identification of questions:**



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**ACP addresses:**

**Formulation and articulation of plans:**

- **Decision maker**
- **Wishes**
- **Preferences in care**



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**Benefits and implications of ACP with AYA**

Involving AYA in ACP can help parents and health care agents make informed decisions, alleviate distress, avoid decisional conflict, and improve patient quality of life by respecting their religious, cultural, and familial values and beliefs.

(Wiener et al., 2012)



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**Professional examples**

- When ACP discussions have happened
- When you wished ACP discussions had happened



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**Misconceptions and Misunderstandings about ACP among AYA**



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**Legal issues unique to  
ACP with AYA**

- **Custody/guardianship**
- **Minor status**
- **Maturity/capacity**



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**Recent studies re: AYA ACP**



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**FACE-BMT Study**



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### FACE-BMT Study

**Overview:**

- Why
- Who/population
- Where
- Funding
- Timeframe
- Initial Findings



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### Training & Certification

- Next steps
- Honoring Choices
- Role playing
- Periodic check-ins



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### Aims of study



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### Feasibility/Acceptability



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### Operating procedures

- Determine eligibility
- Introduction to study
- Participation/incentive
- Informed consent process
- Four sessions
- Additional sessions, critical decision-making events; decisional conflict scale, medical record review



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### Eligibility

- 14-26 years old
- Diagnosis (updated)
- Preparing for BMT
- English speaking
- Capacity/IQ



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**Session One**

- **Lyon Advance Care Planning Survey**  
(adolescent and surrogate versions)  
Used as ice breaker
- **Initial SoTP**  
Administered pre-intervention to assess dyad's congruence



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**Session One**

- **Set-up/outpatient/after SW psychosocial assessment**
- **Examples**
- **Sample questions**
- **Quotes**
- **SoTP responses: yes, no, unsure**



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**Session One Examples:**

- **Experiences as facilitators**
- **Protection of child (cite article)**
- **Barriers/challenges**



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**Session Two**

**Respecting Choices Next Steps ACP:**

- The Intervention
- Structured interview to explore...
- Who, When, Where,
- Recorded session (optional)

**Post-intervention SoTP**

**Satisfaction Survey**



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**Session Two examples:**

- Quotes
- Experiences as facilitators
- Barriers/challenges



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**Session Three**

- Completion/review of SoTP & follow-up from Session Two
- Advanced directive, if eligible and not already completed
- Summary of SoTP entered into patient chart (not legal document if minor)



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**Session Three Examples:**

- **Quotes**
- **Experiences as facilitators**
- **Incentive**
- **Barriers/challenges**



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**Session Four**

**Qualitative interview**

- **Who**
- **When**
- **Where**
- **Why**



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**Additional sessions:**

- **Critical decision making events**
- **Focus groups with medical staff**
- **Tools:**
  - **Decisional Conflict Scale**  
Ottawa Hospital Research Institute
  - **Dyadic Option Scale**  
Melbourne, E, 2008



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## Results/Findings

Study status: Infant stage with goal of enrolling 20 over 2 years (possible extension)

Enrollment:

N=

Eligibility

Reasons patients/surrogates decline

Study completion versus withdrawal

Initial Survey results:

- Most likely to talk to about ACP/EOL with social worker or doctor
- Congruence about readiness for conversation child-parent
- Statistics...
- Pre/post intervention patient surrogate congruence
- ...
- ...

Qualitative interview results:

Study Design:



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## Patient/Surrogate Experiences:

- *Examples...*
- *Demographics*
  
- *18, AML, 4<sup>th</sup> bmt, etc...*



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## Quotes

- *Examples...*



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### Patient/Surrogate experiences:

- *Examples...*



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### Quotes:

- *Examples...*



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### Conclusions

- **Study is ongoing**
- **Current participants**
- **Feasibility Pilot Study**
- **Next steps**



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### Barriers/Challenges

- Clinical process patient is undergoing
- Illness/setting
- Fears/misconceptions
- Paradigm shift
- Capacity/functioning (*examples*)
- Custody/legal issues
- Family dynamics
- Surrogate challenges



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### Clinical practice and research implications

- Unexpected learnings
- Incorporation of skills into practice



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### Discussion/Questions?



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**Sources:**



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