



# Effects of discussing fertility preservation on quality of life of AYA oncology patients and their families

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## Aim

The aim of this study is to examine the effects of discussing fertility preservation (FP) on adolescent and young adult (AYA) oncology patients and their families.

## Clinical Question

How does discussing fertility preservation affect quality of life in adolescent and young adult (12-35 years old) oncology patients in comparison to patients with whom these measures are not discussed?

## Summary of Problem

- 80,000 AYAs are diagnosed with cancer yearly (Benedict et al., 2016a).
- There is a 79% survival rate of pediatric cancer, leaving these patients to deal with the long-term side effects of their treatment (Feig et al., 2009).
- Some long-term side effects of treatments include cardiovascular complications, secondary malignancies, and fertility issues due to gonadotoxic treatments (Ahmad et al., 2016).
- While recommended through clinical guidelines, FP is not a standardized discussion amongst AYA patients, and no state includes oncology-induced infertility as part of their FP insurance mandate (Otkay et al., 2018; Sisk et al., 2019).
- One FP procedure can cost anywhere from \$1,000 to \$3,000 (Sisk et al. 2019).

## Search Strategy

Database	CINAHL 2 articles retained	Medline 2 articles retained	Embase 2 articles retained
Key Words	"Fertility preservation" AND "Neoplasms OR cancer" AND "Coping" OR "Adaptation, psychological" OR "Stress, psychological" OR "Hope"	"Fertility preservation" AND "Cancer OR Neoplasms" AND "Adaptation, psychological" OR "Coping" OR "Stress, psychological" OR "Affective symptoms" OR "Hope"	"Fertility Preservation" AND "Cancer OR Neoplasms" AND "Coping" OR "Psychological Adaptation OR Mental Stress OR Hope"
Inclusion Criteria	Articles published since 2015, Adolescents (15-18 years old)	Articles published since 2015, Adolescents (13-18 years old), Young adult (19-29 years old)	Articles published since 2015, Adolescents (13-18 years old), Adult (18-64 years old)
Exclusion Criteria	Articles unrelated to PICO	Articles unrelated to PICO	Articles unrelated to PICO

## Table of Evidence

	Design	Results	Grade
Benedict et al., 2016b	Retrospective Qualitative Cohort Study	<ul style="list-style-type: none"> <li>All survivors had a level of concern about fertility</li> <li>Higher decision regret was seen in patients and families who didn't undergo FP</li> <li>Decision regret was especially high in those groups who had to bring up FP themselves</li> <li>Those who underwent FP expressed hope and acceptance when discussing their fertility</li> <li>Some had dissatisfaction with the discussion due to provider's lack of sensitivity</li> </ul>	2a
Benedict et al., 2018	Cross-Sectional Correlative Study	<ul style="list-style-type: none"> <li>Quality of life (QOL) did not vary based on fertility status, history of FP, or desire for future children</li> <li>Greater unmet fertility needs and decisional distress related to FP was related to lower QOL</li> <li>Greater decisional distress seen in patients with unmet information needs</li> <li>Factors of decisional distress included future child's cancer risk (62%), concern for future partner's disappointment about infertility (61%), stress of pregnancy (53%), and concerns of childbearing affecting cancer recurrence (47%)</li> </ul>	4a
Jayasuriya et al., 2019	Mixed-Methods Cross-Sectional Study	<ul style="list-style-type: none"> <li>18.6% of AYA cancer patients had high decision regret regarding their decision about FP</li> <li>80% of participants expressed hope related to their decision to undergo FP</li> <li>Parents expressed dissatisfaction with the process when they had to bring up discussion f FP themselves</li> <li>Low levels of regret are associated with FP in AYAs, and language of the discussion needs to be decided based on family's needs</li> </ul>	4a
Nahata et al., 2018	Cross-Sectional Correlative Study	<ul style="list-style-type: none"> <li>40% of patients had fertility-related discussions with their providers in survivorship; 49% did not have discussions with their providers</li> <li>80% reported desire to have a biological child</li> </ul>	4b
Taylor & Ott, 2016	Systematic Review	<ul style="list-style-type: none"> <li>Fertility grows in importance over time and there is high importance of trusted providers bringing up FP early and often</li> <li>Early discussion of FP allowed for patients and families to leave their options open</li> <li>Fertility is a long-term consideration when deciding on short-term treatments</li> <li>Self-determination plays a major role in patient's life after cancer and general satisfaction</li> </ul>	1a
Wyns et al., 2015	Cross-Sectional Correlative Study	<ul style="list-style-type: none"> <li>If the patient was hopeful to have future children, there was a higher rate of FP acceptance</li> <li>91.4% of adolescents considered their child as being capable in participating in the decision process</li> <li>52% of adolescents felt anxious at the time of FP discussion with greatest contributors being the concern for their future fertility</li> </ul>	4a

LEGEND Rating (Cincinnati Children's Hospital, 2020). Grade a= good quality study, b= lesser quality study.

## Recommendation

The clinical recommendations of this study are to: 1) further standardize the practice of discussing fertility-preserving among the AYA oncology population why planning treatment, and 2) the care team should undergo sensitivity training in order to address the patients with more sensitivity during this upsetting time.

## Implementing in Clinical Practice

### Components to Change

**Stakeholders:** Oncology care teams, fertility care teams, hospital administration, insurance providers, nursing staff, and patients and their family members  
**Barriers to Change:** Provider insensitivity with discussion, patient diagnosis and prognosis, patient and family emotions and beliefs, insurance coverage and cost, hospital policy and affiliation, types of FP available, and patient age  
**Facilitators to Change:** Clinical nurse leaders, nursing staff, families allowing patients to participate in decision regardless of age, and care providers

### Strategy for Change

- Meet with stakeholders to educate them on the emerging research regarding FP discussions amongst the AYA oncology population. Gather feelings about expanding this discussion.
- Educate teams on how to facilitate this discussion and motivate them to do so.
- Update progress through shift meetings and during team rounds. Communicate with administration on a monthly basis.
- Have stakeholder provide ongoing feedback about this change. Implement approaches to address actionable items.
- Disseminate results on a more macro level.

### Evaluation Criteria

**Formative:** Oncology and fertility care teams have 100% completion of FP discussion training module. Initial discussions are observed by change champions. Training of oncology nurses to support decision-making outside of initial discussion. Evaluation on a monthly basis by patients, their families, and team members via anonymous survey.  
**Summative:** Longitudinal data collection of decisions to undergo FP, family and patient satisfaction with FP, and frequency of FP discussion occurrence.

## Clinical Implications

- Greater standardization and facilitation of the discussion needs to be done at a systematic level in order to ensure access to FP for all AYA oncology patients regardless of insurance or care status.
- While return to health is the primary goal for AYA patients and their family members, the effects of gonadotoxic treatments permeate throughout survival and potentiate high levels of decision regret, supporting further research on long-term implications of FP with this population
- Nursing staff can provide emotional and knowledge-based support both during the discussion and during the decision-making process as an advocate for the patient and care team.

References available on handout upon request

## ACE Star Model of Knowledge Transformation

