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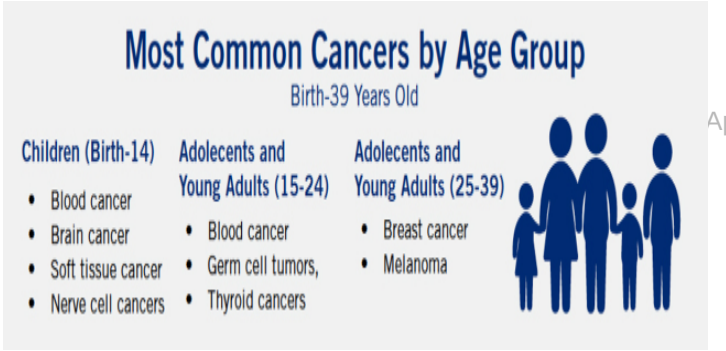
Reproductive Health Communication and Adolescent-Young Adults Patients with Cancer

Gwendolyn P. Quinn, PhD

Department of Obstetrics and Gynecology

Who are AYA?

- >70,000 people aged 15-39 diagnosed with cancer each year
- AYA age ranges vary by country – based on reproductive capacity
- Unique psychosocial and medical needs
- Adults survivors of pediatric cancer
- Social & Financial toxicity



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Defining Adolescents and Young Adults

- Adolescents and young adults (AYA) are between 15-45 years of age with unique quality of life concerns throughout the cancer care continuum, including reproductive health

ASCO American Society of Clinical Oncology

ACOG The American Congress of Obstetricians and Gynecologists

NCCN National Comprehensive Cancer Network®

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

AMERICAN SOCIETY FOR REPRODUCTIVE MEDICINE

AMA American Medical Association

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Reproductive Health

- WHO definition
- Reproductive health in the oncology setting extends beyond infertility and fertility preservation to include:
  - Romantic partnering
  - Friendships
  - Body image
  - Sexuality
  - Sexual identity and orientation
  - Contraception
  - Psychosexual adjustment
- Allied health professionals (AHPs) including: nurses, social workers, psychologists, and physician assistants often provide psychosocial care, health education, and information related to reproductive health

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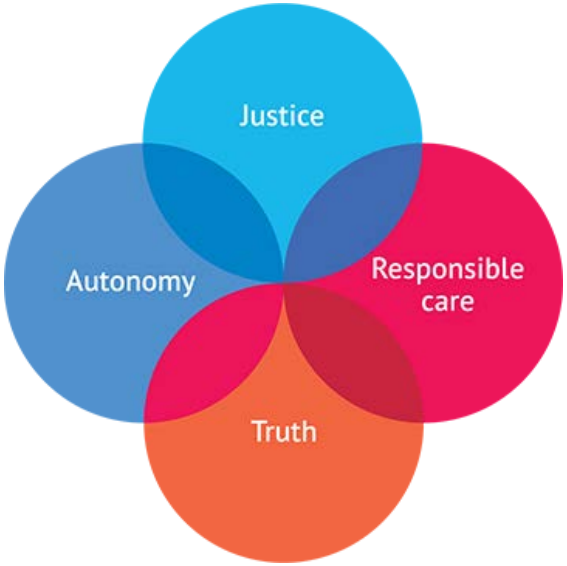
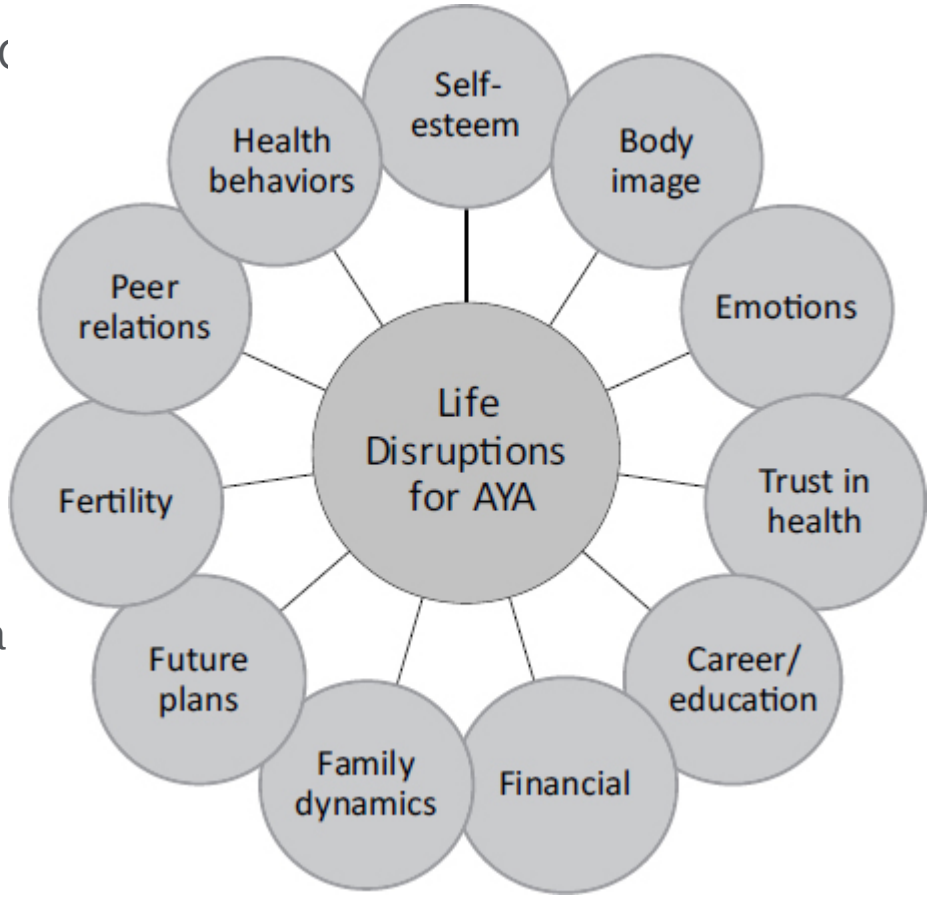
Communication Challenges

- Developmental stage
- Life stage
- Provider time
- Institution resources
- Role of parents/partner
- Overselling loss of fertility
- Impact of fertility



Health Literacy Issues

- Sterility/sterile
- CANCER,CANCER,CANCER,CANCER,(
- Future thinking (hope/false hope)
- Numeracy -
- Fertility is a marker for self-worth
- Risk taking
- FP before TX is best
- Family building after TX is still ok
- It's never too late to explore options
- Whatever road taken for FP or FB – it's a



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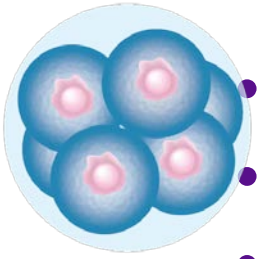
Reality Check

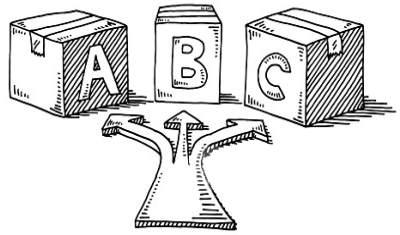
- Preserving sperm, oocytes or embryos does not guarantee a baby to take home
- Age matters
- Money matters
- How far are you willing to go?
- Issues of justice

Challenges



- A couple uses ART to create **12 embryos**
- Use of **1 embryo** creates healthy child
- The couple does not want any more children
- What happens to the remaining embryos?

- <u>Possible Choices:</u>
  - Donating to other infertile women/couples
  - Donating to medical research
  - Thawing without donating – *"compassionate transfer"*
  - Postponing the decision



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Adoption is an option?

- Extra obstacles for cancer survivors
- Was this your second choice?
- Timing

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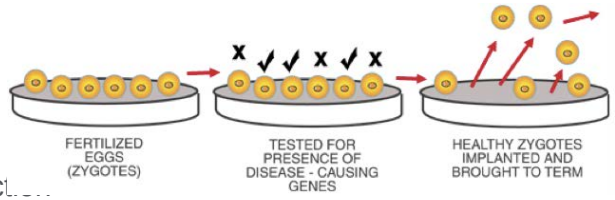
Health Literacy: Hereditary Cancer

- < 10% of cancer are hereditary
- 90% of AYA believe their cancer is hereditary
- Silent suffers
- Awareness of PGT
- If you don't personally agree with it, should you still have to discuss it?
  - PGT
  - Posthumous reproduction
- <u>Points to consider:</u>
  - Premeditated vs unplanned posthumous reproduction
  - Consent
  - Grief counseling
  - Psychological implications for the child



To push or not to push:
What is the question?

- **Josh = leukemia at 16**
  - *"I never want kids"*
- **Josh = survivor at 30**
  - *"Why didn't you make me do this?"*
- How can you know what you don't know, when you don't know it?
- Should we warn AYAs who say no that they may regret it later?

Child Free Living

- Is there life without children?
- Societal, family pressure

- Should we push to preserve now, and make a decision later?

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A transgender woman banking sperm

- Elisa - transgender woman taking hormones for several year
- Diagnosed with Sarcoma
- Has a long term partner who desires a biological child
- Questions need to stop taking hormones during TX
- Need to stop hormones for sperm banking
- <u>Points to consider:</u>
  - Prejudice/discrimination when visiting fertility clinics
  - Return of male features after stopping hormones
  - Hormonal damage to sperm
  - Need for prior discussion about fertility preservation

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Policy and Guidelines

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AMERICAN MEDICAL ASSOCIATION

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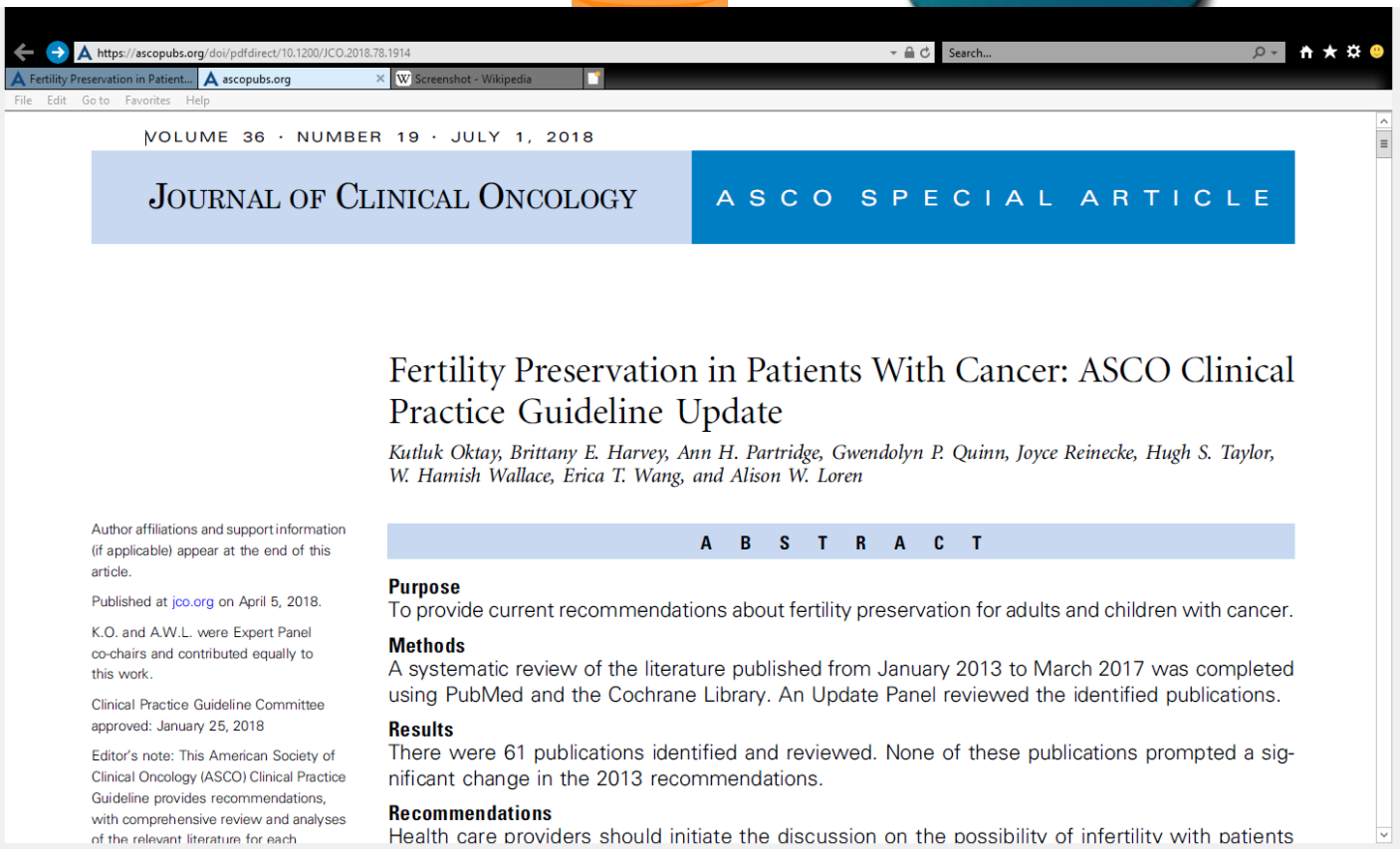
Policy Issues

- ASCO
- NCCN
- APA



https://ascopubs.org/doi/pdfdirect/10.1200/JCO.2018.78.1914

Fertility Preservation in Patient... | ascopubs.org | Screenshot - Wikipedia

File Edit Go to Favorites Help

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JOURNAL OF CLINICAL ONCOLOGY

ASCO SPECIAL ARTICLE

Fertility Preservation in Patients With Cancer: ASCO Clinical Practice Guideline Update

Kutluk Oktay, Brittany E. Harvey, Ann H. Partridge, Gwendolyn P. Quinn, Joyce Reinecke, Hugh S. Taylor, W. Hamish Wallace, Erica T. Wang, and Alison W. Loren

Author affiliations and support information (if applicable) appear at the end of this article.

Published at jco.org on April 5, 2018.

K.O. and A.W.L. were Expert Panel co-chairs and contributed equally to this work.

Clinical Practice Guideline Committee approved: January 25, 2018

Editor's note: This American Society of Clinical Oncology (ASCO) Clinical Practice Guideline provides recommendations, with comprehensive review and analyses of the relevant literature for each

A B S T R A C T

Purpose
To provide current recommendations about fertility preservation for adults and children with cancer.

Methods
A systematic review of the literature published from January 2013 to March 2017 was completed using PubMed and the Cochrane Library. An Update Panel reviewed the identified publications.

Results
There were 61 publications identified and reviewed. None of these publications prompted a significant change in the 2013 recommendations.

Recommendations
Health care providers should initiate the discussion on the possibility of infertility with patients

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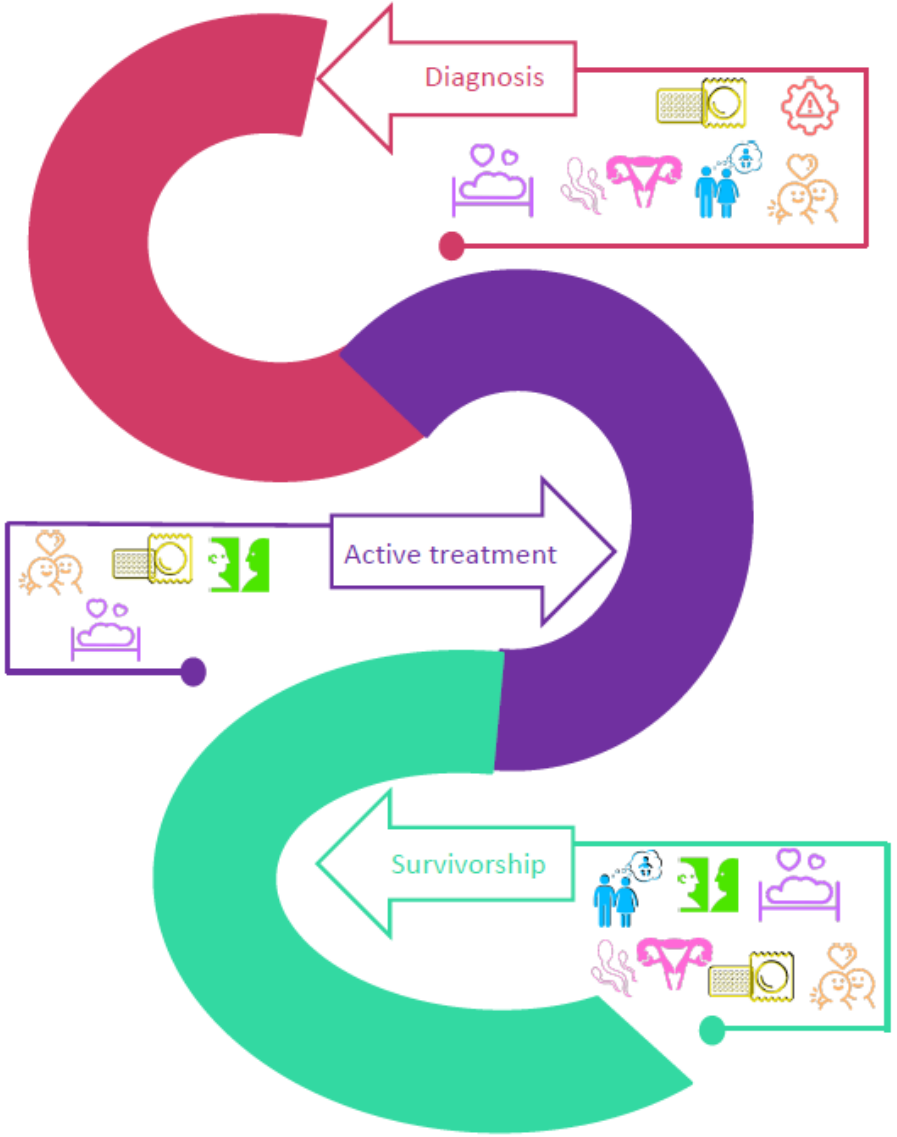
Reproductive Health Discussions Along the Cancer Care Continuum



Map Icon Key

** Please note that reproductive health conversations can/should occur across the cancer continuum. These are suggestions about key time points to discuss, but individual patient treatment plan should be considered.

Risk of infertility: Cancer treatment with chemotherapy, radiation, or surgery can affect the reproductive system in a variety of ways. It is important to communicate risk before cancer treatment begins.

Fertility preservation: Freezing of sperm, eggs, and embryos may preserve the ability of survivors to have a biologic child in the future. Additionally, there are options for minimizing reproductive damage (ovarian transposition, ovarian sugression, fertility sparing surgeries, testicular shielding, and nerve sparing surgeries). Refer interested patients to reproductive specialists. It is ideal to discuss these option before cancer treatment begins.

Sexual functioning: Stress, fatigue, and treatment side effects can affect on sexual functioning and desire. Providers should check-in with their patients on this topic at diagnosis and, throughout treatment, and into survivorship. Make appropriate referrals if a patient reports sexual dysfunction

Contraception: Promote safe sex by educating patients on the need to use contraception to prevent pregnancy and barriers (condoms) to prevent sexually transmitted infections. It is important to note the danger of an unplanned pregnancy and the effect that the cancer treatment could have on a developing fetus.

Romantic partnerships: Cancer can disrupt romantic partnerships through stress of diagnosis, change in roles, and treatment side effects. Consultations with mental health professionals can support both patient and partner during this challenging time.

Body image: Physical changes due to cancer treatment (hair loss, surgical scars, weight changes) can lead can lead to emotional distress and poor self esteem. Checking in with patients about their adjustment to these changes and referring to mental health professionals is important to address from diagnosis and into survivorship.

Alternative family building options: For those who are unable to have a biologic child or carry a pregnancy, other options for building a family are available, such as adoption; donor eggs, sperm, or embryos; and surrogacy. Bringing up these options at diagnosis and at survivorship is important to ensure family building goals are being met.

Institutional Readiness Checklist

- Referral pathways to reproductive specialists and mental health professionals
- Documentation system
- Communication training for providers
- Support during Reproductive Health Services
- Psychosocial support services
- Patient education, aids, and tools

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Enriching Communication Skills for Health Professionals in Oncofertility (ECHO)

Success of ENRICH-ECHO

J Cancer Educ
DOI 10.1007/s13187-012-0435-z

Reproductive
Cancer Patie
for Oncology

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Gwendolyn P. Quinn

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Abstract In 2008, app
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practice-level change.

Original Article

Adoption and Ca
Ac

Gwendolyn P. Quinn, PhD[1,2]

BACKGROUND: To the authors' knowled
about their experiences negotiating a c
The current study describes the results
process for survivors with the goal of h
regarding adoption. METHODS: Training
ducted an interview using a semistructu
The authors examined responses to eac
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survivors would benefit from a health ca
decision about fertility and adoption. Ca

KEYWORDS: cancer, survivor, adoption,

Healio > Nursing > Journals > JCEN

ORIGINAL ARTICLE

Nurse Perspectives on Referrals for Oncology Patients to Reproductive Endocrinologists: Results of a Learning Activity

Susan T. Vadaparampil, PhD, MPH; Juliette Christie, PhD, MA; Meghan Bowman, BA; Ivana Sehovic, MPH; Cathy D. Meade, PhD, RN, FAAN; Clement K. Gwede, PhD, MPH, RN; Gwendolyn P. Quinn, PhD

The Journal of Conti
August 2016 - Volum
Posted August 3, 2016
DOI: 10.3928/00220124-201

READ/SUBMIT COMMENTS

Abstract Article

BACKGROUND:
Although concern about futu
reproductive endocrinologist
lack the knowledge and train
Issues in Cancer Healthcare

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What Do Surgical Oncology Nurses Know About ...
Factors Influencing Results

CONCLUSION:
Oncology nurses have an o
addressed.

J Contin Educ Nurs. 2016;47

Fertility and Fertility Preservation: Scripts to Support Oncology Nurses in Discussions with Adolescent and Y

Susan T. Vadaparampil, PhD, MPH, Joanne Kelvin, MSN, Ivana Sehovic, MPH, and Gwendolyn P. Quinn, PhD, M

ABSTRACT

- *Objective:* To describe a script-based approach to assist oncology nurses in fertility discussions with their adolescent and young adult (AYA) patients.
- *Methods:* Scripts were developed by a team that included experts in fertility and reproductive health, health education, health communication, and clinical care of AYA patients. Individual scripts for females, males, and survivors were created and accompanied by a flyer and frequently asked questions sheet. The script and supplementary materials were then vetted by oncology nurses who participated in the Educating Nurses about Reproductive Health Issues in Cancer Healthcare (ENRICH) training program.
- *Results:* The scripts were rated as helpful and socially appropriate with minor concerns noted about awkward wording and medical jargon.
- *Conclusion:* The updated scripts provide one approach for nurses to become more adept at discussing the topic of infertility and FP with AYA oncology patients and survivors.

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journal homepage: www.elsevier.com/locate/pateducou

Reflective practice

ENRICH: A promising oncology nurse training program to implement ASCO clinical practice guidelines on fertility for AYA cancer patients

Susan T. Vadaparampil[a,b,*], Clement K. Gwede[a], Cathy Meade[a], Joanne Kelvin[c], Richard R. Reich[a,d], Joyce Reinecke[e], Meghan Bowman[a], Ivana Sehovic[a], Gwendolyn P. Quinn[a,b], ENRICH RESEARCH GROUP

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ABSTRACT

Objective: We describe the impact of ENRICH (Educating Nurses about Reproductive Issues in Cancer Healthcare), a web-based communication-skill-building curriculum for oncology nurses regarding AYA fertility and other reproductive health issues.
Methods: Participants completed an 8-week course that incorporated didactic content, case studies, and interactive learning. Each learner completed a pre- and post-test assessing knowledge and a 6-month follow-up survey assessing learner behaviors and institutional changes.
Results: Out of 77 participants, the majority (72%) scored higher on the post-test. Fifty-four participants completed the follow-up survey: 41% reviewed current institutional practices, 20% formed a committee, and 37% gathered patient materials or financial resources (22%). Participants also reported new policies (30%), in-service education (37%), new patient education materials (26%), a patient navigator role (28%), and workplace collaborations with reproductive specialists (46%).
Conclusion: ENRICH improved nurses' knowledge and involvement in activities addressing fertility needs of oncology patients. Our study provides a readily accessible model to prepare oncology nurses to integrate American Society of Clinical Oncology guidelines and improve Quality Oncology Practice Initiative measures related to fertility.
Practice implications: Nurses will be better prepared to discuss important survivorship issues related to fertility and reproductive health, leading to improved quality of life outcomes for AYAs.

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Are you:

- **A psychologist or counselor, social worker, nurse, or APP who works with cancer patients ages 15-45?**
- **Interested in learning about fertility preservation, sexual health, contraception, and psychosocial issues?**

What is ECHO?

Enriching Communication Skills for Health Professionals in Oncofertility (ECHO) is a web-based training program focusing on building communication skills

Training Topics

- Risk of infertility
- Fertility preservation
- Sexual functioning
- Body image
- Ethical, social, and cultural considerations

Why participate?

- 17.75 FREE continuing education credits from APA, ASWB, ANCC, and AAPA
- Free educational materials
- Training facilitated by a national team of experts
- Certificate of completion

Apply Today!

Interested learners should submit their application on our website at: https://echo.rhoinstitute.org/2020-echo-application/. **Deadline to apply is November 22nd, 2019.** Course will run early January-mid March 2020.

Contact Information

For additional information or questions, please contact us at:
Phone: (813)745-6941
Email:ECHO@Moffitt.org
Web: www.echo.rhoinstitute.org

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