NYU School of Medicine
Reproductive Health
Communication and Adolescent-Young Adults Patients with Cancer

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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
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
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
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,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
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?

**Possible Choices:**
- Donating to other infertile women/couples
- Donating to medical research
- Thawing without donating – “compassionate transfer”
- Postponing the decision
Adoption is an option?

• Extra obstacles for cancer survivors

• Was this your second choice?

• Timing
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
- Points to consider:
  - 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?
**A transgender woman banking sperm**

- Elisa - transgender woman taking hormones for several years
- 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

**Points to consider:**
- Prejudice/discrimination when visiting fertility clinics
- Return of male features after stopping hormones
- Hormonal damage to sperm
- Need for prior discussion about fertility preservation
Policy and Guidelines
Policy Issues

• ASCO
• NCCN
• APA
Reproductive Health Discussions Along the Cancer Care Continuum

**Map Icon Key**

- **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 suppression, fertility sparing surgeries, testicular shielding, and nerve sparing surgeries). Refer interested patients to reproductive specialists. It is ideal to discuss these options before cancer treatment begins.

- **Sexual functioning**: Stress, fatigue, and treatment side effects can affect 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 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
Enriching Communication Skills for Health Professionals in Oncofertility (ECHO)
Success of ENRICH-ECHO

Original Article
Adoption and Care Act
Gwendolyn P. Quinn, PhD

BACKGROUND: To the authors’ knowledge, there are very few studies that have addressed these issues.

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Fertility and Fertility Preservation: Scripts to Support Oncology Nurses in Discussions with Adolescent and Young Adults
Susan T. Vadaparampil, MD, MPH, Joanne Kelch, MSN, Fran Schor, MD, MPH, and Gwendolyn P. Quinn, PhD, M

ABSTRACT

Objectives: 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 tym and frequently updated questions sheet. The script and supplementary materials were then vetted by oncology nurses who participated in the Education Nurses about Pre-reproductive Health Issues in Cancer Care (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.

Reflective practice

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

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What is ECHO?

Eriching 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.

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