

"Care of Adolescent & Young Adult HSCT Patients"

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Disclosure

I have no conflict of interest to disclose.

Objectives

- Identify unique stressors and challenges related to developmental stage for the AYA during HSCT.
- List various techniques to promote coping for AYA and families.

Objectives

Age Divisions

PEDIATRICS **ADULTS**

Neonate Adolescence Young Adults Geriatrics

BIRTH 15 18-21 YRS 39 > 65 YRS

Adolescent and Young Adults (AYA)

- In the United States
 - SEER 15–29
 - Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG) National Cancer Institute (NCI) JAYAO. 15–39
- Canada: 15–29
- Australia: 15–25
- United Kingdom (Teenage Cancer Trust) 13–24
- European (EUROCARE) 15–24

USE OF DEVELOPMENTAL STAGE TO IDENTIFY CONFLICT/STRESSOR

Stages of Psychosocial Development

- Infant
- Toddler
- Pre-schooler
- Grade-schooler
- Teenager
- Young Adult
- Middle-age Adult
- Older Adult

Proposed by Erik Erikson

ERIKSON'S STAGES OF DEVELOPMENT

Approximate Age	Psycho Social Crisis
Infant - 18 months	Trust vs. Mistrust
18 months - 3 years	Autonomy vs. Shame & Doubt
3 - 5 years	Initiative vs. Guilt
5 - 13 years	Industry vs. Inferiority
13 - 21 years	Identity vs. Role Confusion
21 - 39 years	Intimacy vs. Isolation
40 - 65 years	Generativity vs. Stagnation
65 and older	Ego Integrity vs. Despair

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Developmental Issues in AYA

AGE	STAGE	QUESTION	RELATIONS
>13	Identity vs Role Confusion	Who am I?	Peers, Role Model
>19	Intimacy vs Isolation	Can I love?	Friends, Partner
>25	Generativity vs Stagnation	Can I make my life count?	Household Workmates

Common Issues in AYA

COGNITIVE **PHYSICAL**

DEPENDENCE **SELF IMAGE**

PEER RELATIONSHIP

SOCIAL

MAJOR AGE DIVISION IN AYA

Early Young Adulthood (15-18) Young Adulthood (25-24) Late Young Adulthood (25-39)

15 18 24 39

Fertility → Infertility (PHYSICAL CHANGES)

Dependence → Independence (SOCIAL)

Concrete → Abstract (PSYCHOLOGICAL)


TRANSPLANT SPECIFIC ISSUES IN AYA

FINANCIAL **SEXUALITY**

DEPENDENCY ADHERENCE **PSYCHO SOCIAL** **PHYSICAL** **FERTILITY**


LOSS OR ROLE **COPING DEPRESSION** **FEAR OF FUTURE** **RELIGION/SPIRITUALITY** **QUALITY OF LIFE**

FATIGUE **PAIN**




PHYSICAL: SEXUALITY AND FERTILITY

- **SEXUALITY**
 “Many of the patients brought up sexual concerns with the intervention nurses, but felt uncomfortable with the MD”




PHYSICAL: FERTILITY

- Priority – Top quality of life concern
- 76% of childless cancer survivors desire children
- Biological offspring are preferred
- Infertility associated with increased risk of psychological distress
- Sperm banking associated with psychological relief
- Cancer patients may choose less toxic treatments in order to preserve fertility




FERTILITY OPTIONS

	FERTILITY OPTIONS	
FEMALE	Donor Embryos	Donated by a couple Done in conjunction with IVF Donor Eggs
	Donor Eggs	Donor chosen on preferences & donor's eggs are fertilized with partner's sperm
	Gestational Surrogacy	Woman carries pregnancy for another woman or couple
MALE	Donor Sperm	Patient can choose donor based on wide range of characteristics




Fertility Preservation-

	ESTABLISHED	EXPERIMENTAL
FEMALE	<ul style="list-style-type: none"> • RADIATION SHIELDING • OVARIAN TRANSPOSITION 	<u>OCYTE PRESERVATION AND CRYOPRESERVATION</u> -
MALE	<ul style="list-style-type: none"> • RADIATION SHIELDING • SPERM CRYOPRESERVATION 	<u>SPERM CRYOPRESERVATION</u> <u>SPERM CRYOPRESERVATION</u> <u>POST TREATMENT</u>



Fertility Preservation- Female

PROCEDURE	PROS	CONS
RADIATION SHIELDING Reduce radiation scatter to ovaries	<ul style="list-style-type: none"> • Easily implemented • No cost of RT • Low risk • Appropriate for all ages 	Does not protect against effects of chemotherapy
OVARIAN TRANSPOSITION Surgical repositioning of the ovaries outside of the radiation field	<ul style="list-style-type: none"> • Established procedure (50% success rate) • Sometimes covered by insurance • Used in both pre and post pubertal females 	<ul style="list-style-type: none"> • Outpatient surgery • Expertise in oophorectomy • Prior to RT



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Fertility Preservation- female

PROCEDURE	PROS	CONS
Oocyte Cryopreservation Harvesting and freezing of unfertilized eggs	<ul style="list-style-type: none"> Outcomes are improving Appropriate for adolescent females 	<ul style="list-style-type: none"> Hormone therapy harvesting 10-14 d post menses Outpatient surgery Costs: \$12,000 /cycle storage & implantation Time delay for treatment
Ovarian Tissue Freezing and Grafting Laparoscopic removal and freezing of ovarian tissue Reimplantation after cancer treatment	<ul style="list-style-type: none"> No time delay Appropriate for adolescent females with no partner 	<ul style="list-style-type: none"> ~ 10 live births reported using this technique Outpatient surgical procedure Cost: \$12,000 procedure, storage & implantation Tumor cell transmission?

Fertility Preservation- Male

PROCEDURE	PROS	CONS
RADIATION SHIELDING Reduce radiation scatter to testes	<ul style="list-style-type: none"> Easily implemented No cost of RT Low risk Appropriate for all ages 	<ul style="list-style-type: none"> Does not protect against effects of chemotherapy
SPERM CRYOPRESERVATION Traditional Method Alternative: sedated electroejaculation	<ul style="list-style-type: none"> Easily implemented Low risk Higher risk for sedation 	<ul style="list-style-type: none"> Referral prior treatment Upfront costs Physical and psychosexual development
SPERM CRYOPRESERVATION POST TREATMENT Biopsy to obtain individual sperm from testicular tissue	<ul style="list-style-type: none"> Option for semen contains no sperm Patients who are post treatment 	<ul style="list-style-type: none"> Costs Volume of material is less than traditional methods of collection

PHYSICAL: FATIGUE & PAIN

- FATIGUE**
Frustration with fatigue
- PAIN**
Pain threshold decrease with fear
Metabolism similar to adults

PSYCHOLOGICAL - COPING


- DEPRESSION**
Many patient experience and verbalize depressive symptoms only a few met criteria for clinical depression.
- USING TECHNOLOGY FOR DISTRACTION**
Majority of patients use phones, texting, social media, music to as a form of coping.

PSYCHOLOGICAL CONT

- DEPENDENCY**
 - Majority of AYA continue to have a primary care giver.
 - Mothers were most common
 - Dependence and independence balance
- ADHERENCE ISSUES**
 - Mask, clinic times and medication
 - Form of dependence


SOCIAL

- CHANGES IN ROLES & RELATIONSHIP**
 - Majority of relationships are affected and roles are changed or shifted.
 - Relations: Parents, siblings, significant other
 - Independent AYA to dependence
- LOSS "BEING IN LIMBO"**
 - Need to catch up with friends/peer
 - Become productive member of society




SOCIAL CONT

- **SCHOOL & EDUCATION**
 - Major *identity* for AYA and most patients are very motivated to return to school
- **FINANCIAL**
 - According to 2010 CDC report, AYA are twice as likely to be without insurance compared to adults
- **TRANSITION OF CARE**

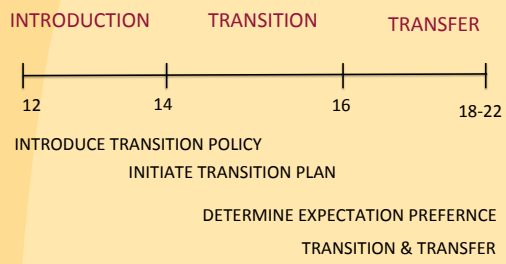


Social: Importance of Transition

- High “Importance Score” by expert panel on quality of care
- NIH identifies transition as an important step in the care of the developing patient




TRANSITION MILESTONE



INTRODUCTION TRANSITION TRANSFER

12 14 16 18-22

INTRODUCE TRANSITION POLICY
INITIATE TRANSITION PLAN
DETERMINE EXPECTATION PREFERENCE
TRANSITION & TRANSFER




TRANSITION REFERENCES

- AAP, AAFP, ACP: A Consensus Statement on Health Care Transition for Young Adults with Special Health Care Needs. *Pediatrics*, 2002, 110:6, 1304
- AAP, AAFP, ACP: Clinical Report—Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics*, July, 2011
- White, PH, McManus, MA, McAllister, JW, Cooley, WC. A primary care quality improvement approach to health care transition. *Pediatric Annals*, May 2012, 41:5




TRANSITION RESOURCES

- www.gottransition.org
- <http://www.syntiro.org/hrtw/>
- <http://jaxhats.ufl.edu>
- www.mahec.net/quality/chat.aspx?a=10
- Join the National Health Care Transition Center on Facebook – search GotTransition




SPIRITUAL

- RELIGION & SPIRITUALITY
- FEAR OF UNCERTAINTY (FUTURE)
- MEANING OF LIFE AND ROLE IN LIFE




TREATMENT RECOMMENDATION

- Changing Systems accommodate teaching and health delivery
- Survivorship and transition of care
- Psychological Support
- Dedicated Staff
- End of Life issues



TREATMENT RECOMMENDATION

- Peer to peer connection
- Recognition of Independence/Dependence Struggle
- Dedicated AYA Support Group
- Parental/Caregiver Support
- Awareness of AYA Culture



- *Psychosocial Care for AYA HCT Transplant Patients*
Cooke et al. J Psychosoc Oncol 2011
- *Role of Palliative Care in AYA Oncology*
Wein et al. JCO 2010

