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Kids deserve the best.

BETWEEN TWO WORLDS-

UNIQUE CARE CONSIDERATIONS IN THE ADOLESCENT AND YOUNG ADULT (AYA) PATIENT POPULATION

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Objectives

- Highlight defining characteristics of the adolescent and young adult (AYA) population
- Outline unique palliative care considerations for the AYA population
- Describe provider challenges relating to end-of-life and palliative care for the AYA population

How do we define the AYA population?

- Technically via age range
 - Starts at age 15
 - Inconsistent upper cut off: 24-39 years old
- Based upon unique needs
 - Developmental needs
 - Advance care planning needs
 - Psychosocial needs



Demographics of the HPM work force

- January 2016: 6400 active HPM physicians
- Younger than general workforce
 - 20.9% of all providers in field and 26.1% of those who do only palliative care are under 40 years old
 - 36% HPM over 55 versus 43% all active physicians
- Majority female (53-64.7%)
 - 61.7% of fellows are female
 - Women are majority for HPM providers less than 50 years old

Remainder of presentation...

- Three topics important when considering the AYA population
 - Developmental considerations when terminal illness diagnosed in childhood
 - Unique palliative care models
 - Including advance care planning models
 - Provider challenges
 - Relatability to patient demographic
 - Lack of training for this population
- Case-based discussion
- Review the history and current status of the Child Life program at Froedtert
- Will have time for questions and discussion!

The image features four stylized silhouettes of children in various stages of development, set against a white background with a green ground line at the bottom. From left to right: 1. An orange silhouette of a child crawling on all fours. 2. A purple silhouette of a child walking, with a small orange ball on the ground in front of them. 3. A light green silhouette of a child jumping rope, with a long green loop in the air above them. 4. A teal silhouette of a child sitting on the ground, holding a teal ball. The text "Developmental Considerations" is overlaid in the center of the image.

Developmental Considerations

19 year old male with cystic fibrosis

- John was diagnosed with CF via newborn screen
- Grew up over 3 hours away from closest CF center
- Started with frequent lung infections in childhood that required prolonged hospitalizations, Mom primary caretaker
- Has one younger and two older siblings who do not have CF
- Parents divorced when John was 13
- John transitioned to the adult hospital at age 18, which was challenging for John and his family
- Admitted to the ICU with acute respiratory failure



Outline: Unique PC considerations for the AYA population

- Patients in process of aging out of pediatric and into adult care setting
- Care considerations must be related to developmental stages and are further impacted by ongoing illness that can affect development
- Outline the influences of above on PC strategies and approaches

Developmental considerations

- Time of great potential and significant instability
 - Magnified for AYA living with complex and serious illness
- Phase of life is typically one of great growth and change (physical, spiritual, psychological, social)
 - Living with a serious illness markedly impacts and interrupts this progression
 - “Patient identity” must be integrated with the new person they are becoming

Developmental considerations

- Key developmental tasks include negotiating and cultivating intimacy, vulnerability, dependence, and control
 - Assigning caregivers
 - Patient education
 - Encourage the AYA's voice
 - Provide “normalcy”
 - Reintegration to the community
 - Conversations regarding the future

Developmental considerations

- AYA with life-limiting conditions represent a wide range of diseases
 - Genetic or congenital that they have lived with for their entire life (muscular dystrophy, CP)
 - Others diagnosed or contracted in teen years or later (cancers, HIV/AIDS)
- This requires even more of an individualized approach for each AYA and his/her family

Developmental considerations

- Brain maturation and growth occurs into young adulthood along with advancements in executive functioning, planning, and abstract thinking
 - Helps one develop autonomy
- With serious illness in AYA, this developmental progression can be stunted
- Higher onset of mental health issues compared to those younger and older (most notably schizophrenia & depression)
- AYA also cope with multiple losses and anticipatory grief throughout the illness trajectory

Developmental considerations

- The AYA with a serious illness may not be participating in typical social outlets (work, school) and may be worried about how others will react to disclosure of diagnosis
 - May need to devise innovative ways to connect with peers and school
- This can lead to sense of isolation

Development – From pediatrics to adult medicine

- AYA designated “a unique and vulnerable population” worthy of specific mention by the National Cancer Institute and in the Affordable Care Act (ACA)
- Transitioning is acknowledged as a challenging time yet there is little support for it in practice
- Providers often inadequately trained to treat AYA for both medical and psychosocial needs

Concurrent Care for Pediatric Patients

- Under the Affordable Care Act (ACA), children with life-threatening health problems who are enrolled in Medicaid can get both curative treatment and hospice care (up to age 21).
- This part of the ACA is called Concurrent Care for Children (or Section 2302).
- Before the ACA became law, children with life-threatening health problems couldn't get both curative treatment and hospice care at the same time. For a child to get hospice care, the child's family first had to agree to stop all curative treatment.

AYA and fertility – Our approach

- New diagnosis of cancer or other serious illness → provider first broaches the topic of fertility with the patient
 - Including what options may be before, during, or after treatment
- More specific information is provided by our Clinical Nurse Leaders
 - Process of fertility preservation
 - Introduction of the role of Reproductive Medicine specialists
- Patients can meet personally with Reproductive Medicine in person, via video visit, or phone.
- Much support provided: financial counselors, counseling, physicians

Take home points- Developmental considerations

- AYA is a time of great potential and significant instability during which most negotiate and complete key developmental tasks
- AYA living with complex and serious illnesses often have great struggles related to achievement of autonomy and independence
- Transitioning from pediatric to adult medicine poses additional challenges for patients, families and providers



Unique AYA Palliative Care Models

20 year old female with osteosarcoma

- Presented at 19 years old after progressing through multiple lines of chemo
 - On clinical trial at that time
- Course complicated by malignant pericardial effusion and severe pain
- Eventually developed pulmonary tumor burden with tracheal compression
- Mother at bedside throughout course
 - Mother is a nurse
- Continued to decline- was actively dying
- Did not want to talk about it- deferred decisions to mom

Adult palliative care models

- Interdisciplinary model focusing on family unit, but more patient oriented
 - Variety in team structure:
 - Physicians, PA/NP, nurses, social workers, case workers, chaplains, child life specialists, music therapists, psychologists, volunteers, etc...
- Generally provide consultation in hospital setting
 - Also can assume primary care or be in clinic setting
- Newer models focus on community-based palliative care
- Provided concurrently with curative or life-prolonging interventions
- Over 85% of mid-large size hospitals have palliative care teams

Pediatric palliative care models

- Palliative care not as universally available as adult world
- American Academy of Pediatrics (AAP) supports an integrated model
 - PC offered at time of diagnosis or discussion of phase 1 clinical trial
 - Continues until outcome of cure or death
- Total family approach
 - Caregiver support
 - Patients with varying support and symptom management needs
 - Variable ages/development and diagnoses
- Interdisciplinary team

Transitioning from pediatric to adult world

- Family- to adult-oriented model
 - Although adult model now is more family-focused
 - Family centered versus patient centered care
- Common issues:
 - Who is decision maker?
 - Nursing support is different in adult hospital
 - PC generally involved later in disease course
 - Hospital looks different!
- No palliative care specific transition model



Lack of education relating to caring for this population

- Loss of AYA in the gap between pediatric and adult health care
- >50% residents report training on adolescent population is inadequate



Unique AYA care model

- Area needing more research
- Lack of specific training model
- Concurrent Care model discussed earlier

Recommend next steps

- Ongoing, multidisciplinary training programs for providers
- Consider the following:
 - Experiential Learning at the bedside
 - Didactic & day to day training
 - Shared clinician visits – ex. Joint visit -oncology with palliative care
 - Bereaved family members as educators
 - Online learning
- Consider collaboration with adult & pediatric providers

Advance care planning barriers

- Pediatricians cite feeling uncomfortable with ACP- “don’t know what to say”
 - Discussions therefore become incomplete
 - Significant patient misunderstanding
- Barriers to ACP in young AYA patients include
 - Unrealistic parent expectations
 - Differences between clinician and patient/parent understanding of prognosis
 - Lack of parent readiness to have discussion
- Lack of developmentally-appropriate documents

Advance care planning logistics

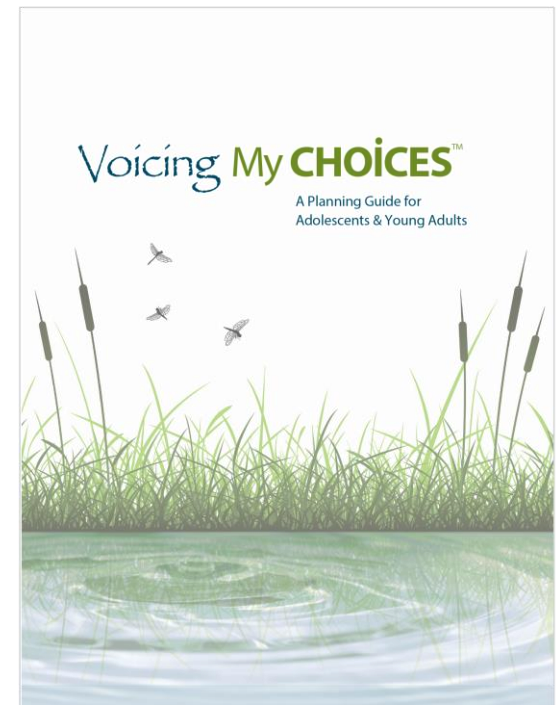
- Early ACP recommended
- Patients request that professionals play an active role
- Should be facilitated by trained professionals
- Lyon 2013 RCT: Survey, interview, and document completion
 - Family-centered discussions
 - Did not require prognostic awareness
 - Focused on family values
 - More likely to have wishes honored when faced with medical decisions later on
 - Utilize hypothetical scenarios

Advance care planning- Unique models

- Family-Centered ACP for Teens with Cancer (Lyon)
 - Family-centered ACP survey → Respecting Choices[®] planning interview → Five Wishes[®] document
- FOOT PRINTS program (Toce and Collins)
 - Hospital based “continuity physician”
 - ACP at time of enrollment and reassessed over time
 - Interdisciplinary care conference
- “My Thoughts, My Wishes, My Voice” (Wiener)
 - 2 agents and 2 alternates, less text
 - No scenarios
 - More check box selections
 - Sections for spiritual preferences, personal concerns, and letters to family

Voicing My CHOICES®

- ACP document designed for AYA
- Available for purchase on Five Wishes® webpage
- Includes choices on: comfort, support, medical care decisions, family/friends to know, spiritual, remembrance, belongings
- Numerous write in response questions to make it very specific to the individual



Take home points- Care models and ACP

- Care model is unique as compared to pediatric and adult models
- AYA population palliative care needs requires additional research and education
- Advance care planning discussions are of utmost importance
- Consider use of AYA-specific ACP document



Unique Provider Challenges

29 year old mother of two with cancer

- Diagnosed at age 29 with appendiceal cancer with peritoneal disease
- Poor pain control from diagnosis
- Met palliative care at diagnosis/transfer to academic medical center
- Chemo, plan for surgical resection/hyperthermic intraperitoneal chemotherapy (HIPEC)
- Unable to resect due to extensive disease burden
- Refractory pain and nausea/vomiting
- Eventual transition home with hospice support
- Peaceful death at home

Outline: Provider challenges related to EOL and PC for the AYA population

- Unique provider challenges relating to care for AYA population in terms of both medical care considerations and provider factors
- Highlight these challenges AND strategies to mitigate these issues

AYA and EOL - Medical care considerations

- Providers often feel ill-equipped
 - To care for the AYA population specifically
 - To care for most patients at EOL in general
- AYA often experience a more intense symptom burden at EOL compared to other age groups (and require more medications) yet may forgo treatment to maintain a clear mind and independence
- For some cancers, survival is worse in AYA compared to younger children and those over 40

AYA and EOL- Spiritual care considerations

- During AYA patient is forming personal spiritual belief system and may have little experience with death as they face their own mortality
- With AYA, there is a “perceived sense of unfairness in the early end of life circumstances for patient and family” (Pritchard)
- Even AYA facing death may express ordinary adolescent plans and wishes for the future.
 - This does not mean that they are in denial

Spiritual crisis or existential loss

- Major theme
- Loss of self, future dreams and goals
- Important to address spiritual needs beyond religious beliefs/practice
- Sexuality as a component in this population
- Acting out may be a sign of existential crisis

AYA and EOL- Provider factors

- Maintaining professional boundaries can be difficult with AYA population
- Providers who are early in their career may view AYA patients more as peers/friends and those who are more advanced may view AYA patients more as their own child
- Social media and online forums between patients and health care team members are an evolving frontier

Strategies to mitigate these issues at EOL . . .



- “The avoidance or lack of conversation about impending death by adults around them creates a sense of isolation, fear and anxiety.”
- Importance of compassionate, sensitive, and honest communication
- Provider consistency when possible

Family appreciation



.... “thank you for being real with me in the hospital, it helped us as a family better prepare while we could.”

Take home points- Provider challenges

- AYA EOL is difficult for patients, families and providers in large part due to perceived sense of unfairness and lack of training.
- PC providers can help the most by fostering communication and ACP using AYA specific tools.
- Through difficult conversations and aid of Child Life there is great opportunity for memory making, meaningful interactions, and peace at EOL for AYA.

Child Life at Froedtert Hospital

History of Child Life at Froedtert Hospital

- Bachelor's or Master's Prepared
 - Required full-semester internship
 - National certification exam
 - Continuing education hours to maintain certification
 - Members of multidisciplinary team
 - Document in medical record
-
- Collaboration with CW contracted services
 - 2009 FH approves Child Life Program 20 hours/week
 - 2011 FH Foundation Grant awarded for additional 20 hours/week!
 - 2016 Continued growth of patients supported, increases position to a 1.5 FTE
 - 2022 Program increased to 2.0 FTE consisting of 1 FTE and two @ 0.5 FTE

Child Life? We have adult patients.....

Consults for children ages 0-18 years old whose family member or loved one is...

- Hospitalized following traumatic injury
- Newly diagnosed with a life-threatening illness
- Including the whole family through diagnosis & hospitalization
- AYA transitioning to the adult hospital setting
- Experiencing changes in treatment or transitioning to comfort care
- Facing end of life care- memory-making and initiation of grief work

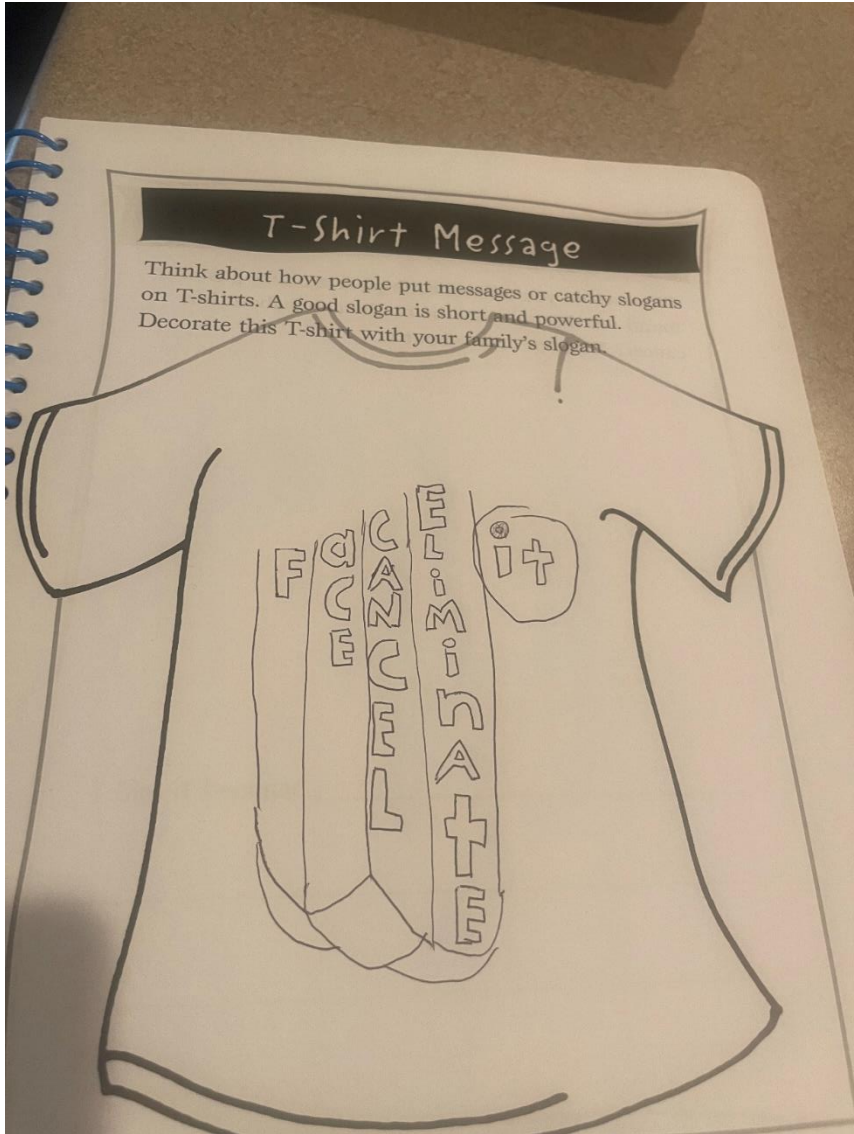
Child Life at CW

- CW has 28 Child Life Specialists (CLS) at CW between our Milwaukee and Fox Valley locations
- Our CLS do help younger children in many ways and are a wonderful resource for our AYA patients and their families.
- They can help facilitate communication between AYA patients, their parents and primary team. This can be especially important for disclosure and truth telling for all patients, most of all those at end of life.

Ongoing Psychosocial Care of Patient, Family & Friends



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Conclusions

Conclusions

- AYA population has unique care considerations
 - Developmental factors of particular importance
- Unique care model needs to be developed
 - Neither pediatric nor adult in their care needs
- More education and research is required
- Utilize individualized and AYA appropriate ACP documents



Questions and/or comments?

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The image features a light gray background with a subtle, circular, embossed-like pattern in the center. The corners of the image are decorated with several realistic water droplets of various sizes, some overlapping, creating a clean and modern aesthetic.

QUESTIONS?