PALLIATIVE CARE IN THE AYA POPULATION

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Objectives

Following this presentation, the audience will be able to:

- Define ‘Palliative Care’ and ‘AYA.’
- List three developmental considerations for the AYA population.
- Describe the importance of Palliative Care in the AYA population.
Palliative Care

- **National Cancer Institute:**
  - “Palliative care is given throughout a patient’s experience with cancer. It should begin at diagnosis and continue through treatment, follow-up care, and the end of life.”

- **World Health Organization:**
  - “…is the active total care of the (patient’s) body, mind, and spirit, and also involves giving support to the family.”

- **American Cancer Society:**
  - “…(palliative care) can help provide a better quality of life for your child and family by focusing on relieving the pain, symptoms, and stress associated with cancer and its treatment. It can help you and family find your way.”
Palliative Care

• Life-threatening or Life-limiting condition
• Starts at diagnosis & continues throughout illness
• Services
  – Symptom management
  – Communication
  – Advance care planning
  – Goals of care
  – Care coordination
  – Additional layer of support
• Goal: Improve Quality of Life
• Consult team
• Across the continuum of care

Palliative Care

Old Concept

Curative Care  Palliative Care/ Hospice

New and Improved Concept

Curative Care  Palliative Care  Hospice  Bereavement
AYA Oncology

- **Adolescent and Young Adult**
- 15-39 yrs
- 70,000 AYA CA diagnoses/yr
  - New dx every 7.5 mins
  - 6x the rate of children
  - Incidences > with age
  - Leading cause of disease-related death

AYA Oncology

Common Types of Cancer Affecting AYAs

• Less improvements
  – Delays in dx
  – Insurance coverage
  – Same therapy but different outcomes
  – Biological factors
  – Poor accrual in clinical trials 1/50

Figure 1: Improvement in 5-year relative survival of patients diagnosed with any invasive cancer except Kaposi sarcoma from 1973-1985 to 1986-1995 and from 1986-1995 to 1996-2005, US Surveillance, Epidemiology and End-Results (SEER) Program. Kaposi sarcoma is excluded because the HIV era during the late 1980s and early 1990s and the associated transient Kaposi sarcoma epidemic skews the overall results in 20 to 49 year-olds.

• Significant improvements in QOL
• Cost savings
• Patients that received palliative care:
  – Had better symptom control
  – Chose less aggressive care & chemo at EOL, but... had longer survival
  – Had less anxiety/depression
  – Felt higher levels of hope
Developmental Considerations

Development:
- Individual identity
- Independence & Autonomy

Challenges with CA:
- Loss of independence
- Regression
- Delayed or missed milestones
- Disruption in social lives/isolation
- Educational/professional repercussions
- Loss of fertility
- Money/Insurance issues
- Alteration in appearance
- Physical consequences

AYA Patient
Palliative Care in the AYA Population

• Assessing the whole person and family
  – Physical
    • Symptom management
  – Psychological and Emotional
    • Communication
    • Planning
  – Social
    • Relationships
    • Coordination of services
    • Insurance/Finances
  – Spiritual and Cultural
    • Legacy/Memory making

Physical

• **Frequency**
  - Fatigue: 57-86%
  - Reduced mobility 76%
  - Pain 73%
  - Poor appetite 71%
  - Dyspnea 6-21%

• **Distressing symptoms**
  - Nonpharmacological interventions
  - Integrative medicine
  - Pharmacological interventions
Psychological & Emotional

• Distressing symptoms
  – Nonpharmacological interventions
  – Integrative medicine
  – Referrals
  – Pharmacological interventions

• Coping
  – Avoid possible threats to life
  – Maintain a positive attitude
  – Maintain a normal life

stupidcancer.org, ulmanfund.org, cancercare.org

Communication

• Pt/Family goals of care
  – What is your understanding of…
  – Based on your understanding of…
    • What are you expecting from…
  – What is most important to you?
  – Hopes?
  – Worries?

tellingkidsaboutcancer.com, cancer.net

Advance Care Planning

• What if…
• Ask permission
• Give opportunities
  – Not talking about it ≠ Not thinking about it
• Benefits
  – Have a voice
  – Give a gift
  – Legacy leaving
  – Helps families honor wishes
  – Facilitates growth and development
  – Build trust and hope

palliativedoctors.org, capc.org, hpna.org, caringinfo.org, idph.iowa.gov/ipost, iowabar.org

• What are YOUR goals if you become very sick?
Fertility

• Start BEFORE treatment
• Explain the process
  – Men: Sperm banking
  – Women: Embryo, egg freezing, Lupron
  – Fertility sparing surgery
  – Radiation shielding

• Referral
• Continue the conversation

myoncofertility.org oncofertility.northwestern.edu vernaspurse.org

Social

- Practical issues
- Home issues
- Coordination of services
- Community resources
- Financial concerns
- Relationships

Cancerandcareers.org, planet cancer.org, 15-40.org

Insurance

• Limited access
  – Lowest percentage of insurance coverage
    • ACA Impact
  – Delays in diagnosis
  – Presentation with later stage disease
  – Least likely to have a ‘usual place to go’

patientadvocate.org, panfoundation.org, copays.org, criticalmass.org

**Spiritual & Cultural**

- **Belief System**
  - FICA
    - Faith, Belief, Meaning
    - Importance & Influence
    - Community
    - Address

- How would you describe your family?

- Traditions & Cultural Considerations

- Legacy & Memory Making

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The Future

• **Survivorship-remission**
  - Long-term follow-up
  - Screening to monitor and manage
    • Reoccurrence
    • Metastasis
    • Late effects

• **AYA & PC programs in IA**
  - UnityPoint, University of Iowa, & Mercy
  - Blank/John Stoddard
    • rachel.dow@unitypoint.org
  - UI Childrens/Peds Onc/Holden Cancer Center
    • kristin-j-foster@uiowa.edu

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Clinical Pearls

• Establish and maintain a relationship
  – Be consistent
  – Take your time
  – Be flexible with firmness
  – Establish patient’s Goals of Care
  – Be honest
  – Use your IDT

• What do AYAs want?
  – To be recognized as an individual
  – To be supported in maintaining normalcy
  – To have a voice
  – To understand their condition
  – To be treated with respect, maintain hope, and feel supported

Thank You!

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