

15th Malaysian Hospice Council Congress @Sibu, Sarawak

Bridging the Gap in Palliative Care for Adolescents and Young Adults

**Paediatrics Palliative Care Symposium
26 July 2024**

Chong Lee Ai leeai@um.edu.my

Pain and Palliative Care Unit

Universiti Malaya, Kuala Lumpur



Content

the challenges and opportunities to enhance palliative care
for this vulnerable population

Adolescents and Young Adults

- ‘Stress levels perceived to be healthy’ :
 - teens reporting **higher stress levels** than adults
- Stress -> feeling : **overwhelmed** - 31%
depressed or sad - 30%
- Stress **impacting their lives**:
 - teens 54% vs adults 39%

Bethune S, Teen stress rivals that of adults. American Psychological Association 2014; 45(4):20
The Stress in America online survey (1,950 adults and 1,018 teens, (13 to 17yo)

Adolescents and Young Adults

- Sandwiched between childhood and adulthood
- Developmental tasks are complex - layered on continued physical and cognitive growth
 - issues of self-identity, body image
 - evolving intimacy, relationships, sexuality
 - evolving interdependence (dependence-independence-interdependence)
 - redefinition of roles in family, among peers, in society, career

Clark JK, Fasciano K. Young adult palliative care: challenges and opportunities.
Am J Hosp Palliat Care. 2015 Feb;32(1):101-11

15th Malaysian Hospice Council Congress @Sibu, Sarawak

Challenges with acquired illness

- Progress in illness -> children living past 21st birthday

- median life expectancy increasing...

- eg. cystic fibrosis = **36.8years**

Clark JK, Fasciano K. Young adult palliative care: challenges and opportunities. Am J Hosp Palliat Care. 2015 Feb;32(1):101-11

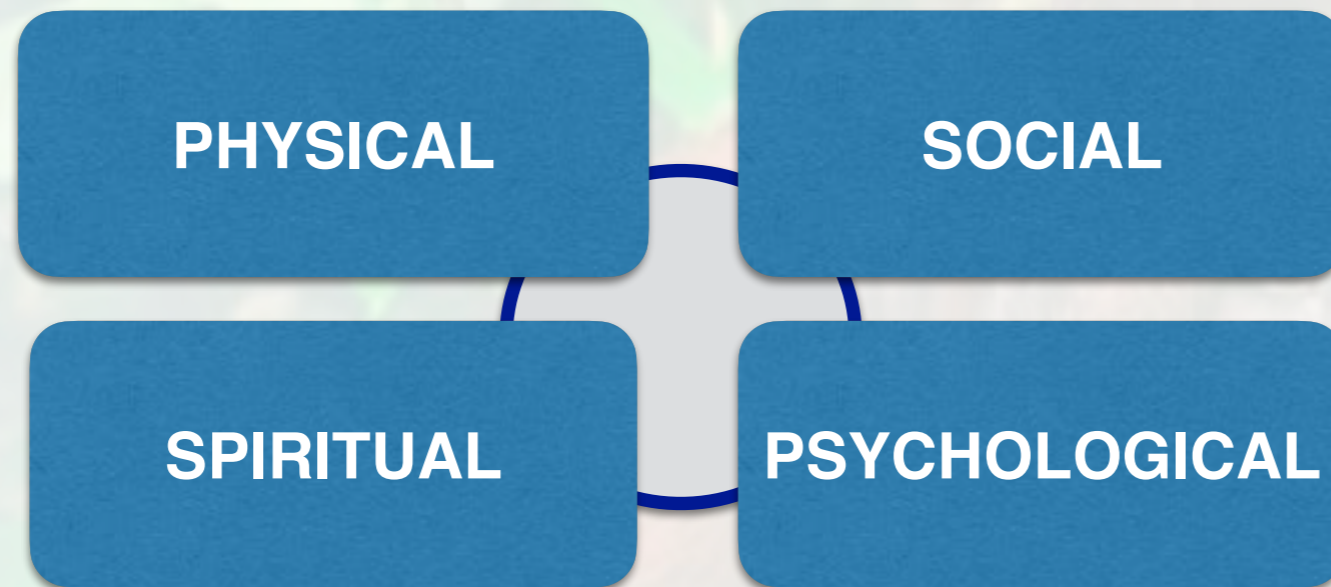
- congenital heart diseases = **75 +/-11 years** (smoking, illicit drugs, oral hygiene)

Reid GJ, Webb GD, McCrindle BW, Irvine MJ, Siu SC. Health behaviors among adolescents and young adults with congenital heart disease. Congenit Heart Dis. 2008;3(1):16-25.

- Duchenne muscular dystrophy **28.1 years**

Broomfield J et al. Life Expectancy in Duchenne Muscular Dystrophy: Reproduced Individual Patient Data Meta-analysis. Neurology. 2021 7;97(23)

The gaps in palliative care for AYA



- **Evolving cognitive, psychological, social, and spiritual development on each domain**
- Strategies utilized for children or adults often miss the complex needs

Anderson C. The Challenge of Palliative Care for Adolescents and Young Adults. Evidence-Based Oncology 2015; 21(SP14)

15th Malaysian Hospice Council Congress @Sibu, Sarawak

Challenges with acquired illness

- **Need for privacy and autonomy** -> invasive procedures, hospitalizations and increased reliance on parents
- **Development of self-esteem and positive body image** -> amputation, hair loss, and weight loss or weight gain
- **Develop independence, peer relations and sexual identity** -> limited/prevented from achieving these milestones, uncertainty

Anderson C. The Challenge of Palliative Care for Adolescents and Young Adults. Evidence-Based Oncology 2015; 21(SP14)

15th Malaysian Hospice Council Congress @Sibu, Sarawak

Challenges and Opportunities for Palliative Care

Physical Domain

Cognitive Domain

Social Domain

Ethical and Legal

Psychological

Social

Spiritual

Health care systems

Challenges and Opportunities for Palliative Care :

Physical Domain - symptom management

- symptoms at EOL - more severe (several disease models)
- maintain independence - foregoing debilitating side effects of treatments
- Total suffering worsened : psychological & spiritual developmental tasks with physical symptoms
- needs higher doses and adjuvants, frequent assessment and rapid titration
- non-pharmacological modalities

Clark JK, Fasciano K. Young adult palliative care: challenges and opportunities. Am J Hosp Palliat Care. 2015 Feb;32(1):101-11

15th Malaysian Hospice Council Congress @Sibu, Sarawak

Challenges and Opportunities for Palliative Care : Physical Domain - body image

- peak reproductive and sexual years, growth velocity
- Illness: delay/alteration -> demoralizing
- self identity is rooted in physical growth
- actively address threats to hormonal, sexual and reproductive health
- anticipated physical changes

Clark JK, Fasciano K. Young adult palliative care: challenges and opportunities.
Am J Hosp Palliat Care. 2015 Feb;32(1):101-11

15th Malaysian Hospice Council Congress @Sibu, Sarawak

Challenges and Opportunities for Palliative Care : Cognitive Domain - decision-making

- prefrontal cortex : skills in calibration of risk and reward, problem solving, prioritizing, planning, self-evaluation, and regulation of emotions
- Illness - complex medical decision making -> regression to more concrete or child-like thinking
- -> unable to cope with uncertainty and assess treatment options
- foster independent thinking, assurance they are not alone
- formation and maintenance of ACP
- anticipated fluctuations in goals of care (parents have poor understanding of AYA's values)

Friebert S et al. Congruence Gaps Between Adolescents With Cancer and Their Families Regarding Values, Goals, and Beliefs About End-of-Life Care. *JAMA Network Open*. 2020;3(5):e205424

Clark JK, Fasciano K. Young adult palliative care: challenges and opportunities. *Am J Hosp Palliat Care*. 2015 Feb;32(1):101-11

15th Malaysian Hospice Council Congress @Sibu, Sarawak

Challenges and Opportunities for Palliative Care : ethical and legal

- lack legal authority to make binding medical decisions (eg. discontinuation of treatment)
- shared decision-making model -> help with clinical uncertainty and nonadherence
- functional criteria for having capacity -> consider to allow young adolescent's treatment preferences

Freyer D. Care of the Dying Adolescent: Special Considerations. Pediatrics
2004; 113(2):381-388

15th Malaysian Hospice Council Congress @Sibu, Sarawak

Challenges and Opportunities for Palliative Care : psychological

- illness-> isolation from peers, cope with complex emotions, coping with uncertainty, a sense of little to no control
- taking risks can be positively associated with increased levels of independence, responsibility and autonomy
- ask for reasons for risk-taking behaviour - provide clear assignment of responsibilities and consequences

Clark JK, Fasciano K. Young adult palliative care: challenges and opportunities.
Am J Hosp Palliat Care. 2015 Feb;32(1):101-11

15th Malaysian Hospice Council Congress @Sibu, Sarawak

Challenges and Opportunities for Palliative Care : Social

- disclosure of illness and the uncertainty of response = threaten to developing self-identity
- who is of social importance can vary and change over time
- provide 'stock' answers for disclosure
- ascertain permission to communicate to family members , set expectations for dr-pt confidentiality
- develop healthy coping skills to reduce high risk behaviour
- protective factors: cohesive family, good role models, spiritual strength

Anderson C. The Challenge of Palliative Care for Adolescents and Young Adults. Evidence-Based Oncology 2015; 21(SP14)

Clark JK, Fasciano K. Young adult palliative care: challenges and opportunities. Am J Hosp Palliat Care. 2015 Feb;32(1):101-11

15th Malaysian Hospice Council Congress @Sibu, Sarawak

Challenges for Palliative Care : Spiritual Domain

- struggle with defining personal spiritual and religious beliefs and practices
- religious practice less important
- illness-> face own mortality
- if 'acting out' consider existential crisis
- facilitate conversations to define/ conceptualize personal spiritual beliefs and practices
- assist their struggle with personal death awareness
- identifies fears

Anderson C. The Challenge of Palliative Care for Adolescents and Young Adults. Evidence-Based Oncology 2015; 21(SP14)

Clark JK, Fasciano K. Young adult palliative care: challenges and opportunities. Am J Hosp Palliat Care. 2015 Feb;32(1):101-11

15th Malaysian Hospice Council Congress @Sibu, Sarawak

Challenges from Health care systems

- Paediatric and Adult services - binary health care system
- Training : discrete adult-oriented or child-oriented programmes

Abdelaal M et al. Palliative care for adolescents and young adults with advanced illness: A scoping review. Palliat Med. 2023 Jan;37(1):88-107

Challenges from Health care systems

- AYA : need developmentally appropriate care
- Transition care : address gap in the medical continuum

Clark JK, Fasciano K. Young adult palliative care: challenges and opportunities. Am J Hosp Palliat Care. 2015 Feb;32(1):101-11

- Referral for PC: during the last month of life : 7-17%,
last day of life : 18%, no palliative care referral : 43%

Abdelaal M et al. Palliative care for adolescents and young adults with advanced illness: A scoping review. Palliat Med. 2023 Jan;37(1):88-107

Gaps in Research

Definition of the age group

WHO :-

Adolescent : person aged 10-19yo

Young adolescents : children aged 10-15yo

Child : birth to 15yo

Young people : 10-24yo

most publications in Nth America AYA : 15-39yo

Research : predominantly cancer, 18% on non-malignant

Standards for improving the quality of care for children and young adolescents in health facilities.

Geneva: World Health Organization; 2018

<https://www.who.int/southeastasia/health-topics/adolescent-health>

Abdelaal M et al. Palliative care for adolescents and young adults with advanced illness: A scoping review. Palliat Med. 2023 Jan;37(1):88-107

Take Home Message

- Adolescent and Young Adults are a vulnerable group

“neither here nor there”

- Evolving developmental tasks
- Unique approaches