

Community-Based Primary Palliative Care Community of Practice Series 4

Palliative Care for Adolescents and Young Adults



Facilitator: Dr. Nadine Gebara

Guest Speakers: Drs Alexandra Saltman, Pamela Mosher & Sofia Canales Albarran

Date: June 25th, 2025

Territorial Honouring



The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness and their families.

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Objectives of this Series

After participating in this series, participants will be able to:

- Augment their primary-level palliative care skills with additional knowledge and expertise related to providing a palliative care approach.
- Connect with and learn from colleagues on how they are providing a palliative care approach.

Overview of Sessions

Session #	Session Title	Date/ Time
Session 1	Pain Management in the Delirious Patient	January 22, 2025 from 12 to 1pm ET
Session 2	Communication: Part 1	February 26, 2025 from 12 to 1pm ET
Session 3	Communication: Part 2	March 27, 2025 from 12 to 1pm ET
Session 4	Palliative Care for those Living with Dementia	April 23, 2025 from 12 to 1pm ET
Session 5	Gastrointestinal Symptoms in Palliative Care	May 28, 2025 from 12 to 1pm ET
Session 6	Palliative Care for Adolescents and Young Adults	June 25, 2025 from 12 to 1pm ET
Session 7	Interventions for symptom management; tubes and drains	July 3, 2025 from 12 to 1pm ET
Session 8	Intimacy and Sexuality in Advanced Serious Illness	August 27, 2025 from 12 to 1pm
Session 9	Tissue Donation at End of Life	September 24, 2025 from 12 to 1pm ET
Session 10	Supporting Caregivers	October 29, 2025 from 12 to 1pm ET

Welcome & Reminders

- Please introduce yourself in the chat! Let us know what province you are joining us from, your role and your work setting
- Your microphones are muted. There will be time during this session when you can unmute yourself for questions and discussion.
- You are welcome to use the chat function to ask questions and add comments throughout the session
- This session is being recorded and will be emailed to registrants within the next week.
- Remember not to disclose any Personal Health Information (PHI) during the session
- This 1-credit-per-hour Group Learning program has been certified by the College of Family Physicians of Canada for up to **10 Mainpro+** credits.

Disclosure

Relationship with Financial Sponsors:

Pallium Canada

- Not-for-profit
- Funded by Health Canada

Disclosure

This program has received financial support from:

- Health Canada in the form of a contribution program
- Generates funds to support operations and R&D from Pallium Pocketbook sales and course registration Fees

Facilitator/ Presenters:

- Dr. Nadine Gebara: Nothing to disclose
- Dr. Alexandra Saltman: Nothing to disclose
- Dr. Pamela Mosher: Nothing to disclose
- Dr. Sofia Canales Albarran: Nothing to disclose

Disclosure

Mitigating Potential Biases:

- The scientific planning committee had complete independent control over the development of course content

Introductions

Facilitator:

Dr. Nadine Gebara, MD CCFP- PC

Clinical co-lead of this ECHO series

Palliative Care Physician at Toronto Western Hospital, University Health Network

Family Physician at Gold Standard Health, Annex

Panelists:

Dr. Haley Draper, MD CCFP- PC

Clinical co-lead of this ECHO series

Palliative Care Physician at Toronto Western Hospital, University Health Network

Family Physician at Gold Standard Health, Annex

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Rev. Jennifer Holtslander, SCP-Associate, MRE, BTh

Spiritual Care Provider

Introductions

Guest Speakers:

Pamela Mosher, MD, MDiv

Staff Psychiatrist

Psychosocial Oncology, Supportive Care, and the Adolescent/Young Adult (AYA) Program

Princess Margaret Cancer Centre

Consultant Psychiatrist, SickKids Hospital Oncology and PACT Teams

Alexandra Saltman, MD, FRCPC

Palliative Care Physician, Princess Margaret Hospital, University Health Network

Rheumatologist, Mount Sinai Hospital

Assistant Professor, Department of Medicine, University of Toronto

Sofia Canales Albarran, MD

AYA Palliative Care Clinical/Research Fellow

University Health Network

Caring for Adolescent and Young Adults (AYA) in Palliative Care

Sofia Canales Albarran MD

Pamela J. Mosher, MD, MDiv

Alexandra Saltman, MD, FRCPC

Department of Supportive Care, Princess Margaret Cancer Centre

June 25, 2025

Learning Objectives:

1. List 3 “gaps” in AYA palliative care compared to care for "older" adults.
2. Identify 2-4 domains of disruption or needs AYAs with medical illness (e.g. cancer) often experience compared to older patients.
3. Name at least two community resources (and one national) for AYA patients with life-limiting cancer.

Top 5 "Take-Aways" From This Talk:

1. **AYAs have unique developmental needs** — one size does not fit all. Be flexible in how, when, and where you show up.
2. **Communication must empower the patient** — listen more than you speak.
3. **Build trust first** — then talk about hard things.
4. **Palliative care supports living fully** — not just dying well.
5. **Psychological and existential distress is often profound** and deserves proactive attention.

Who is an AYA?

- A. 13-24
- B. 15-24
- C. 15-29
- D. 15-39



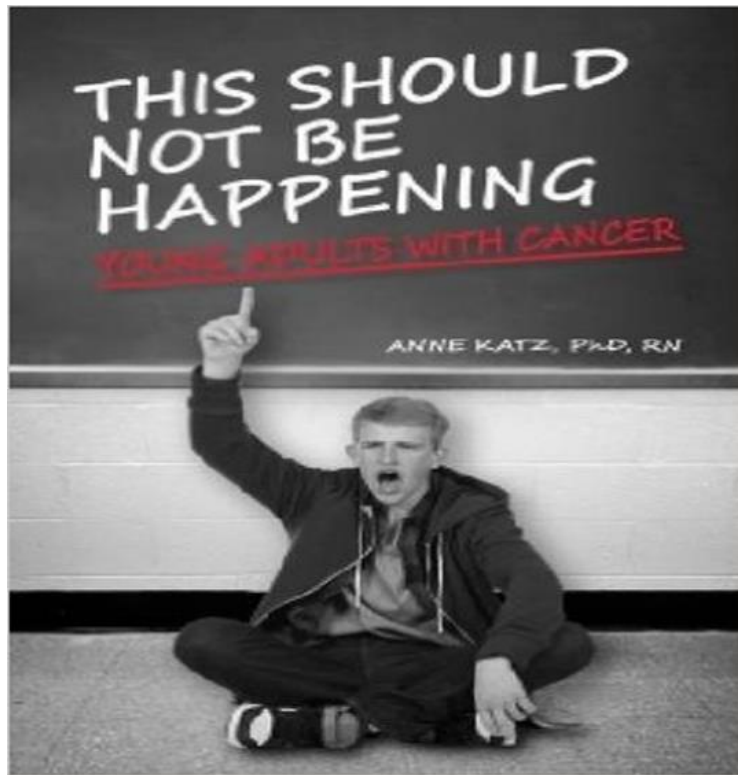
From ASCO website

Broad Age/Developmental Range



Why focus on AYAs?

- **Distinctive biology** from adult and pediatric cancers and other life-limiting illnesses.
- **Unique age-specific needs.**



Why focus on AYAs?



AYAs with cancer have **high palliative care needs** because of **poor survival**, **high symptom burden**, the **psychosocial impact of cancer**, and **unique communication challenges**.



Most AYAs survive their diagnoses, a sizeable minority do not.

In 2022, ~87,000 AYAs in the U.S. were diagnosed with cancer and > 9,000 died.



Recent **improvements in overall survival** among children and older adults with cancer have **not consistently extended to AYAs**.



Little to no data on AYAs with non-malignant life-limiting illnesses.

Why focus on AYAs?

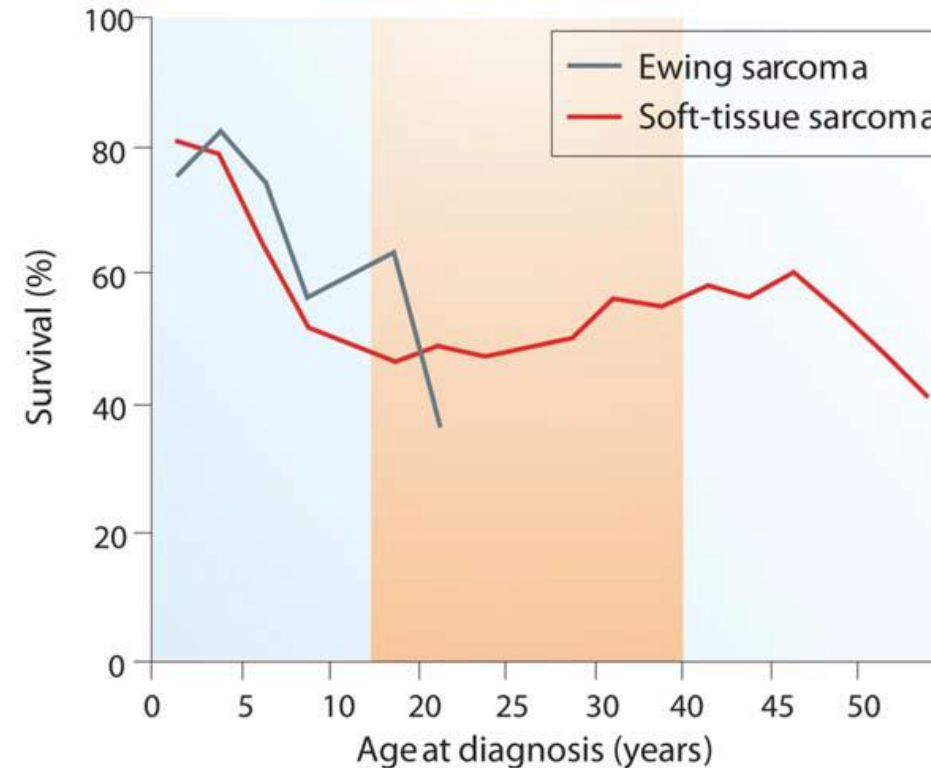


Between 1992 and 2013, there was an increase in the age-standardized incidence rate of cancer for the AYA population.

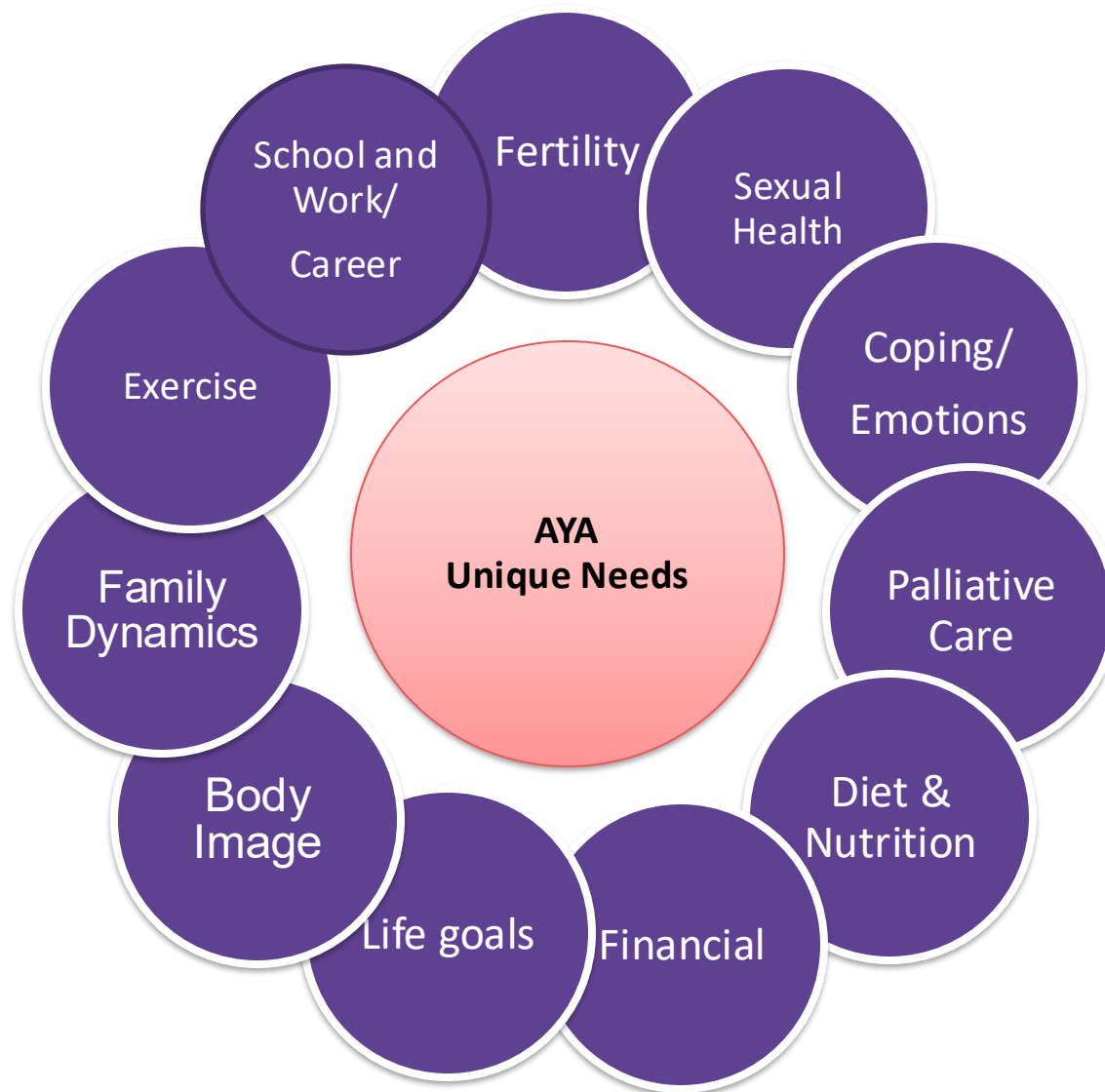


Distinctive biology of AYA cancers

- Soft tissue sarcoma has poorer prognosis compared to pediatric sarcoma
- Melanoma in AYA patients is distinct from adult melanoma histologically and clinically.
- Colorectal cancer has a poorer prognosis and exhibits more aggressive disease phenotype compared with older adult patients.



AYA: Many Areas of Need and Disruption



There is a lack of research investment dedicated to studying AYAs with cancer.^b

New cases:



of new cases of cancer diagnosed each year in Canada are in AYAs (aged 15–39 years).

Annual investment:



of the total cancer research investment in Canada was for AYA-specific^c cancer research. This represents an average annual investment of \$1.8 million between 2005 and 2013

Change in investment:



The average annual investment for AYA-specific research changed little from 2005 to 2013 despite an increase in total investment in cancer research in Canada.

Allocation of funding:



In 2013, the greatest proportion of AYA-specific research funding was for cancer control, survivorship and outcomes research.

1. AYAs have unique developmental needs — one size does not fit all. Be flexible in how, when, and where you show up.

- They are navigating identity, autonomy, relationships, and the future while also dealing with a life-threatening illness.
- Age-appropriate, developmentally attuned care is essential.
- AYA care requires creativity and adaptability — virtual visits, after-hours, emailing, etc.
- Complex cases need time, consistency, and out-of-the-box thinking.

2. Communication must empower the patient — listen more than you speak.

- Complex cases require time.
- Separate the patient from family.
- Don't impose the medical agenda.
 - AYAs may steer toward or away from certain topics.
 - Be patient, flexible, and attentive to when they're ready to go deeper.
 - Sometimes the most important moments come unexpectedly.

Case Example: JS

- 24 year old single man, living at home with mother (parents divorced), diagnosed with metastatic sarcoma
- Comorbid psychiatric history including ADHD and anxiety
- High physical and psychological symptom burden
- Very close parent-child relationship, but dynamic challenged in initial palliative care interactions by struggle between patient autonomy and parental perceptions of best interests

How would you approach this situation?

Case Example: JS

- As palliative team built rapport with patient and family over several visits, a breakthrough moment took place during hospital admission:
 - The patient was able to admit to his mother that he was only continuing chemotherapy in order to live longer to be by her side, and
 - The patient's mother reassured him that she would never ask him to suffer on her behalf, and that she would be okay.
- Palliative chemotherapy was subsequently discontinued in favour of a purely comfort-focused approach to care.

3. Build trust first — then talk about hard things.

NORMALIZE THEIR FEARS...

“So it really upset me when I was referred to palliative care because I still had hope [that I’d get better] ... but I feel like the word ‘palliative care’ is kind of a hopeless term.... There’s no way to get around palliative care without thinking about the end [death and dying].” (P015)

- Did you know you were going to be referred to our team?
- Do you know what palliative care entails?
- Helps to set expectations of consult and help patients "relax".

3. Build trust first — then talk about hard things.

Then get to know them!

- Prioritize building rapport
- Ask about pets, hobbies, partners, children, travels, weddings
- Listen
- Delayed diagnosis = not feeling heard

Specifics: Advanced Care Planning

- Developmentally dissonant but necessary
- 86% of AYAs report not only wanting to know about the terminal nature of their condition but also wanting to participate in discussions regarding EOL care.
- AYA will not establish trust if you push too hard in the first visit to discuss difficult topics, be honest but never harsh.
- These conversations affect how patients live at the end of their lives, how they die, and [how their families grieve](#).
- 56% of AYA cancer pt indicated that **not being able to discuss EOL** preferences was “a fate worse than death.”

Upshaw, 2020

Garvie et. Al
2013

Voicing My CHOICES™

A Planning Guide for
Adolescents & Young Adults



- Developmentally appropriate language.
- To be completed over time and filled together.
- Help an AYA's dying wishes be honored.
- Provides direction to parents, caregivers, and HCP regarding the AYA's wishes.

How I Wish To Be Remembered

If it is more comfortable, you may choose to let others decide about a funeral, a memorial service, and caring for your body after death. Or you can use these pages to voice your preferences.

My Remembrance

- ☐ I prefer not to be a part of planning my service.
- ☐ I prefer to plan my service. *(Please check all that apply)*

- ☐ The type of service(s)










I would like are:

- ☐ **Funeral**
- ☐ **Memorial service**
- ☐ **Celebration of my life**

I would like:

- ☐ To be **buried**
- ☐ To be **cremated**
- ☐ To **donate my body** to science
- ☐ To be an **organ donor**
- ☐ A **limited autopsy**
- ☐ A **standard autopsy**
- ☐ A **research protocol autopsy**
- ☐ I would like my healthcare agent to make the autopsy decision

Discussions About Goals of Care and Advance Care Planning Among Adolescents and Young Adults With Cancer Approaching the End of Life

Jennifer W. Mack, MD, MPH^{1,2} ; Colin Cernik, MS¹; Hajime Uno, PhD¹ ; Lanfang Xu, MS³; Cecile A. Laurent, MS⁴ ; Lauren Fisher, MS¹ ; Nancy Cannizzaro, BA⁵; Julie Munneke, BA⁴; Robert M. Cooper, MD⁶; Joshua R. Lakin, MD⁷ ; Corey M. Schwartz, MD⁸ ; Mallory Casperson, MS⁹; Andrea Altschuler, PhD⁴; Lori Wiener, PhD¹⁰ ; Lawrence Kushi, ScD⁴ ; and Chun R. Chao, PhD⁵ 

DOI <https://doi.org/10.1200/JCO.23.00641>

- High rates of medically intensive measures among AYAs near the end of life do not appear to be the result of a lack of discussions about goals of care and advance care planning

Case Example: KG

- 27 y.o. female with small bowel adenocarcinoma with liver and peritoneal mets
- Lived at home with husband and 2 children, 8-year-old girl and 2-year-old boy
- Referred to our clinic after multiple lines of treatment, mistrust on healthcare
- Admitted due to MBO, hospitalization was 3 months long.
- Developed colo-vaginal fistula, hydronephrosis requiring nephrostomy tubes, venting g-tube, ascites requiring frequent paracentesis .
- Complex pain management

Case Example: KG

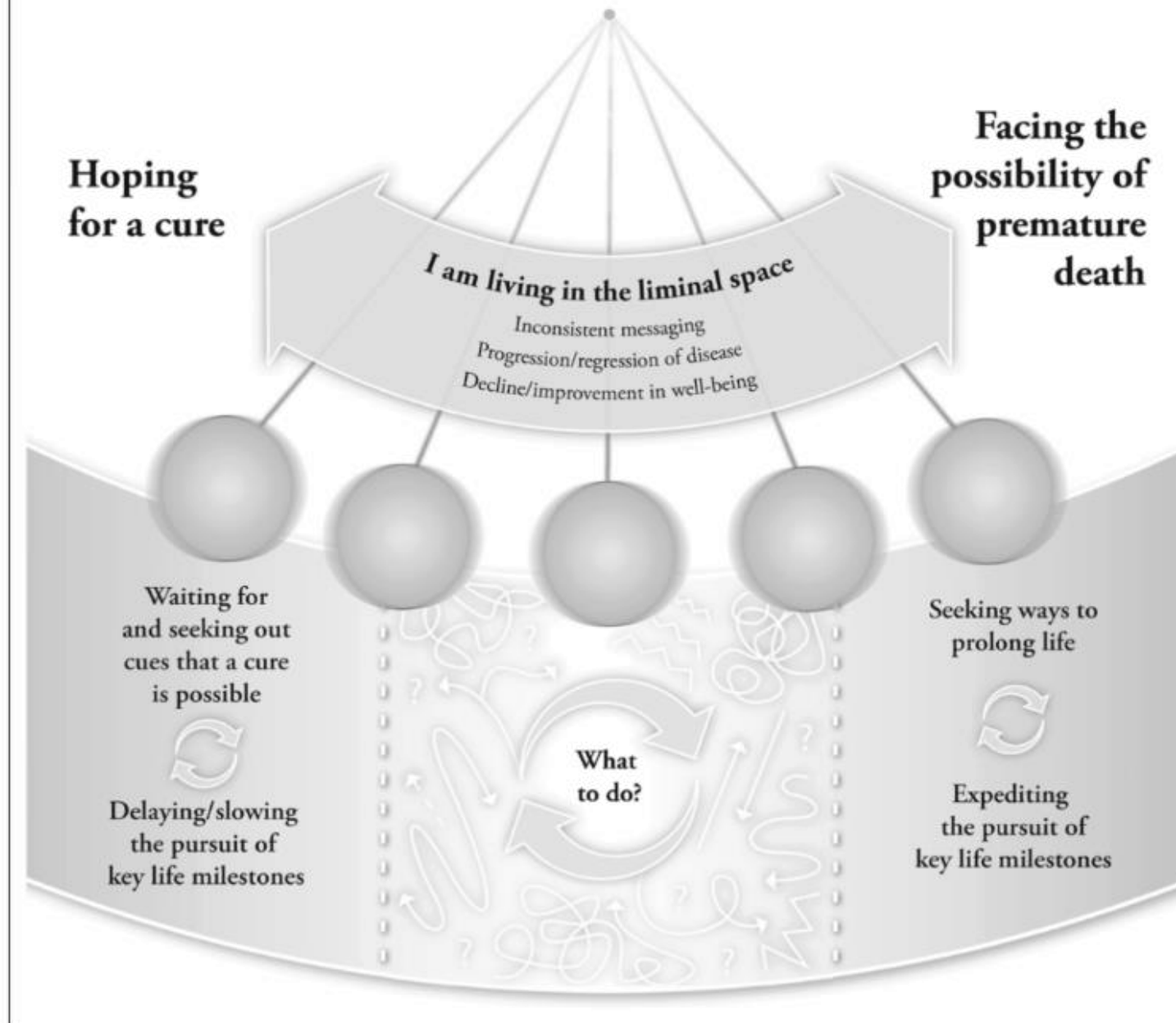
- We followed everyday during admission and built rapport
- Not open to having GOC conversations and was very clear about being full code.
- Disposition?
 - Couldn't go home because of high and complex care needs
 - Couldn't go to hospice because of being full code
 - Hospital hoping to free the bed
- Finally opened up to discussing code status

“I need to die in the ICU, I need to try resuscitation because I need my children to know that I never gave up”.

4. Palliative care supports living fully — not just dying well

- AYAs see themselves as healthy even with advanced cancer
- It's about prioritizing what matters most.
- For AYAs, this often means school, relationships, travel, creativity, and meaning.

Living with Advanced Cancer as a YA



Avery, 2024


Case Example: KM

- 21 y.o. female with a diagnosis of metastatic poorly differentiated mucinous ovarian cancer.
- Followed closely by our clinic
- Very rapid decline, big change from appointment to appointment
- School was a very important part of her life, bright student as part of her identity
- Completed 2 years of work as undergraduate student with full scholarship
- Wondered if she could have a certificate to acknowledge these 2 years

Case Example: KM

- Efforts from our clinic and cooperation from her university.
- The Provost, Chair and faculty members went to her home to personally deliver her certificate and coin
- Extremely meaningful experience for her and her family
- Last appointments asked if she could be buried with some belongings.

I want to be buried with my special coin



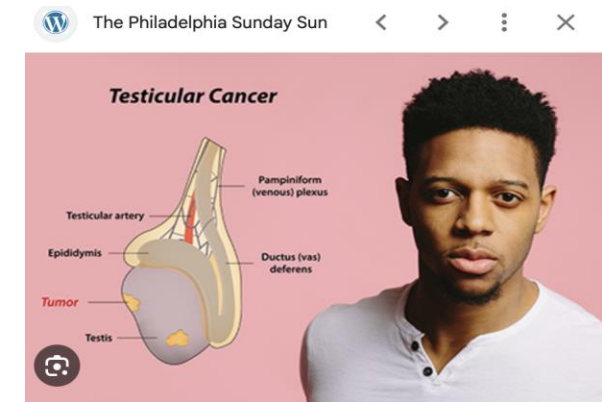
Holding complex, flexible, and diverse hopes enables patients to believe in the unlikely while simultaneously accepting the inevitable. The role of clinicians is to support both.

Rosenberg et al. 2021, JAMA.

5. Psychological and existential distress is often profound and deserves proactive attention.

Psychological and Emotional Considerations in Palliative Care for AYA

Dr. Pamela Mosher



Canadian Task Force Recommendations: Journal of Adolescent and Young Adult Oncology (JAYAO 2011)

1 Active Therapy and Supportive Care

Services must be provided to address the unique needs of AYA with cancer and survivors of cancer in childhood, adolescence, and young adulthood in order to redress inequities in their care relative to both younger and older patients.

2 Psychosocial Needs

AYA with cancer have unique psychosocial needs that must be met to enable each one to reach their full potential as productive, functioning members of society.

3 Palliation and Symptom Management

The challenge of providing palliative care to AYA patients, with their special needs related to their developmental stage, must be addressed.

4 Survivorship

Implementation of life-long monitoring and follow-up of survivors of cancer in childhood, adolescence, and young adulthood will provide economic and other societal benefits and help mitigate late- or long-term treatment effects.

5 Research and Metrics

Research and the establishment of outcome metrics are required to investigate issues critical to AYA with cancer and survivors of cancer in childhood, adolescence, and young adulthood in order to target interventions and health-care policy to improve all phases of the cancer journey.

6 Awareness and Leadership-Building

Awareness of issues specific to AYA with cancer must be improved and leadership efforts to increase awareness and advocate for change must be nurtured.

Fernandez C, Fraser GA, Freeman C, Grunfeld E, Gupta A, Mery LS, De Pauw S, Schacter B. Principles and Recommendations for the Provision of Healthcare in Canada to Adolescent and Young Adult-Aged Cancer Patients and Survivors. *J Adolesc Young Adult Oncol*. 2011 Apr;1(1):53-59.

AYA PSO “Gaps”/needs

- AYA's have larger delay between symptom onset and diagnosis.
- AYA Cancer biology is different, more aggressive
- AYA have poorer survival rates vs. Children/Older Adults
- Clinical trials typically target pediatric or later adulthood populations (ie, AYA have less access to clinical trials)
- Major gaps in accessing psychosocial and palliative care early on in cancer trajectory
- Transition from pediatric to adult care introduces additional gaps due to different volumes and models of care; AYAs are at risk of falling through cracks

NCCN guidelines 2018

AYA Oncology

“Referral to palliative care is appropriate when patients are being treated ***with curative intent*** and can be initiated at the time of initial diagnosis.”



Concepts from Paediatrics/PPC may help PC Clinicians

Approaches re: in AYAs' Emotional Distress

- Peds Palliative Care “from diagnosis until death”; alongside curative/active treatment.
- “The family is our patient”—like kids, AYA exist within an ecosystem→ pay attn to who is in that ecosystem and what is happening (eg communication, isolation, strain)-->mental health
- Family protection fallacy—AYA, like kids, are very good at protecting parents/partners and not sharing how much they are suffering. This means many topics may not have been discussed→ can create emotional distress eg, mood disruption, heightened anxiety, insomnia.
- Don't be afraid to separate pt from parents/spouse; private conversations can be vital, esp unanswered questions (esp the “what if's”)→ cause fear and emotional suffering for patients and caregivers alike
- Goal of 1st appt: focus on Rapport-building and helping a symptom (i.e., don't always jump straight to Advance Care Planning or fear of death; can exacerbate sadness or anxiety in certain pts; take your time)
- Stay flexible, allow time per visit; give choices; AYA can require more frequent follow up; takes a village

Psychological/Emotional Considerations in AYA Pall Care

- **Broad Developmental Range** = wide range of emotional coping skills— (neural/synaptic pruning doesn't finish until late 20's); your tx recommendations need to be flexible/varied
- **Not normal!** Every AYA with diagnosis of potential life-limiting disease will experience the impact on their mind and heart, not just body. ie, there is always some worry, sadness, irritability, mood changes, insomnia, etc. Name this to normalize it. This can be 1st step in getting them to open up re: symptoms.

Psychological/Emotional Considerations in AYA Pall Care

- **Take a Developmental lens** → the entire focus for young patients is about moving forward (next educational or professional step; next relationship step; living independently; buying a car, partnering, having a dog, kids, etc.), thus it is:
 - ***Developmentally appropriate*** to resist the idea of death at a young age or not be fully keen to accept/discuss, but it doesn't mean they don't wonder and don't have questions/fears that are driving emotional distress
 - ***Developmentally appropriate*** to think, plan and talk re: future (re: trips, weddings, etc.) even if this conflicts with MRP's prognosis or what MD/NP/PA think they relayed to the AYA patient. Avoid pathologizing/judging, but aim to understand and support

Psychological/Emotional Considerations in AYA Pall Care

- **Grief** is often unaddressed/unspoken-- several losses across domains (physical capacity, social life, job/work, romantic/sexual experiences, independence, finances, etc.) for AYA experiencing advanced illness (Kierkegaard quote). Acknowledging, validating, naming it as grief—can help provide relief + reduce symptoms
- **Clinicians' Perspectives/Biases/Grief** in treating AYA→ affect AYA mental health; pts sense it. Hard for many MRP's (in our case Oncologists) to deliver difficult news to AYA --> unclear Prognosis; late referrals to PC; increased fear/anx/depression



Your practice—how do you approach AYA Psychological Distress?

- You will see the typical mental health issues and then some
- Emotional/Mental Health Disruptions are common, so assess and target them like any other ESAS symptom—reduce suffering with medications and non-pharm strategies (we don't let pts suffer in pain so we shouldn't let them suffer from low mood, anxiety, insomnia, delirium)
- Do you ask re: emotional symptoms/coping at each appt with AYA? Reflect re: how comfortable you feel discussing mood/anxiety and overall coping? Even though some PC clinicians may tend (or want) to skip this part, instead “lean in” and ask at every appt
- What do you do if an AYA says they are depressed? Or anxious?
- How comfortable do you feel starting meds for anxiety/depression in young people based on prognosis? (e.g. SSRI's or stimulants), cross-tapering them, or discontinuing them?
- Pick a few medications and strategies you become comfortable/facile with based on Px
- Ensure you have a psychiatry or MH colleague to call (phone a friend)

Our efforts to address AYA Gaps/Needs at Princess Margaret resulted in the creation of an integrated care clinic model combining Palliative Care and Psychiatry

PM Cancer Centre Combined AYA Supportive and Palliative Care Clinic

- Our goals:
- Bridge some of the primary AYA gaps in Palliative and Psychosocial needs
- Provide better care for AYA population/better meet needs
- Increase capacity in each other and our trainees so we can all improve the way we address the physical + emotional needs



Article

Supporting the Needs of Adolescents and Young Adults: Integrated Palliative Care and Psychiatry Clinic for Adolescents and Young Adults with Cancer

Mohamed Abdelaal ^{1,2,3}, Pamela J. Mosher ^{1,2,4,5}, Abha Gupta ^{2,6,7}, Breffni Hannon ^{1,2,3,6}, Christine Cameron ², Malka Berman ², Rahim Moineddin ⁸, Jonathan Avery ⁹, Laura Mitchell ², Madeline Li ^{1,2,5}, Camilla Zimmermann ^{1,2,3,6} and Ahmed al-Awamer ^{1,2,3,8,*}

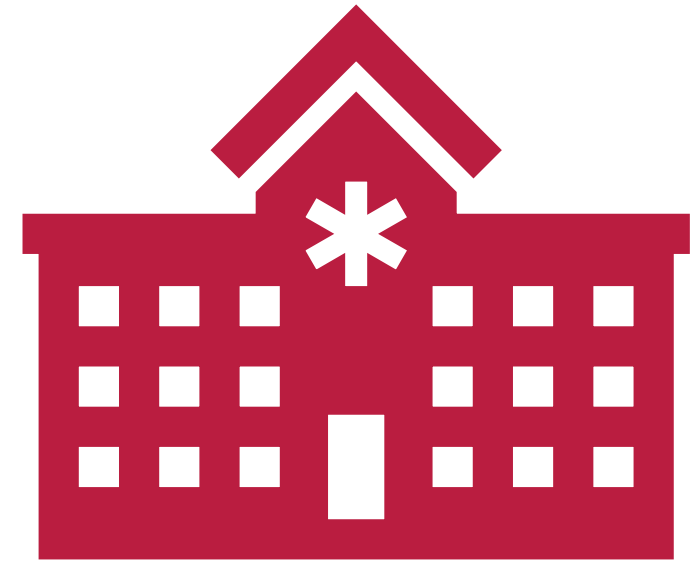
CARE DELIVERY

Young Adult Experience in an Outpatient Interdisciplinary Palliative Care Cancer Clinic

Jonathan Avery, PhD^{1,2}; Pamela J. Mosher, MD, MDiv¹⁻³; Alisha Kassam, MD, MPH⁴⁻⁶; Amirtha Srikanthan, MD, MHSc⁷; Norma D'Agostino, PhD¹; Camilla Zimmermann, MD, PhD^{1,8}; Yan Castaldo, BA²; Rachel Aubrey, BSc²; Caroline M. Rodrigues²; Adrian Thavaratnam²; Mahsa Samadi, MD²; Ahmed Al-Awamer, MBBS, MHSc^{1,9}; and Abha Gupta, MD, MSc^{1,2,6,10}

PMCC Combined AYA Supportive and Palliative Care Clinic

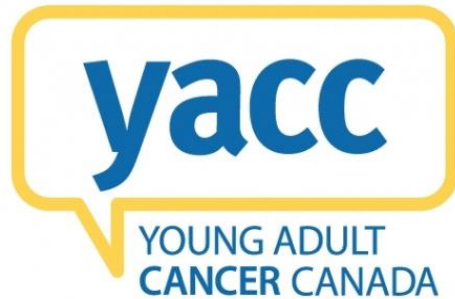
- Started May 2017 by Drs. Al-Awamer and Mosher, now co-led by Drs. Saltman and Mosher
- AYA Patients referred to Palliative Care are triaged to our combined AYA Supportive and Palliative Care Clinic
- A palliative care MD and psychiatrist assess all AYA patients together, which underscores the importance of psychosocial support as a standard of care for AYAs in our hospital
- One-stop shopping/integrated care; reduces appointment #'s for AYA
- Some family support is possible
- A clinic RN and trainees are involved
- Clinic occurs one day/week
- Virtual appointments are an option for patients who are unable to attend in person due to symptoms or distance.



Lessons Learned: Thoughts to Take Home

- AYA have unique psychosocial and palliative care needs
- Listen, Listen, Listen
- Don't lead from OUR agenda
- Complex cases; require time and flexibility
- Let them steer; watch carefully for opportunistic moment/s to ask re: GOC
- Do ACP/EOL planning in doses as AYA tolerates
- Patients know they need to talk ACP and EOL but it is very hard for them, and dissonant developmentally
- EOL conversations with AYA are most fruitful in relationships of trust; may need to occur over time in the outpatient setting (HBPC is different)
- Providers bringing up these issues too early (1st visit) may heighten fear, disrupt trust
- AYAs will do things that don't make sense to us.
- Separating patient from family/support people can be essential to help ease distress for all
- AYA and caregivers can hold both hope for miracles/survival while hearing the statistics/prognostic fears
- Age-appropriate psychosocial and palliative supports should be available for all AYA cancer patients
- Prioritize building rapport and trust
- Stay flexible (video visits, sometimes email/text or other technology, afternoon appts, etc.); admins not calling early in the morning.

AYA Community Peer Support Programs (cancer-related)





**Thank you for
your attention!**

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Session Wrap Up

- Please fill out our feedback survey, a link has been added into the chat.
- A recording of this session will be emailed to registrants within the next week.
- Join us for our next session on July 23rd, 2025, from 12-1pm ET on **Interventions for symptom management; tubes and drains.**

Thank You



Stay Connected
www.echopalliative.com