



Palliative Care in Adolescents and Young Adults Needs, Obstacles and Opportunities

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Objectives

- Define palliative care and provide a brief update of recent research in the area of palliative oncology care
- Describe the additional complexities of integrating palliative care in the AYA age group
- Learn practical approaches for communicating with AYA about palliative care issues
- Provide “Clinical Pearls” for working with this complex patient population



What is Palliative Care?

NCI Definition

- Comfort care for a patient who has a serious disease
- ***Starts at diagnosis*** and continues throughout the illness
- A specialist team working alongside patient's primary team
- Multiple locations of care delivery – hospital, clinic, home, etc.
- Improves the quality of life of patients and family members by addressing emotional, physical, practical and spiritual issues

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Does integrating palliative care make a difference?

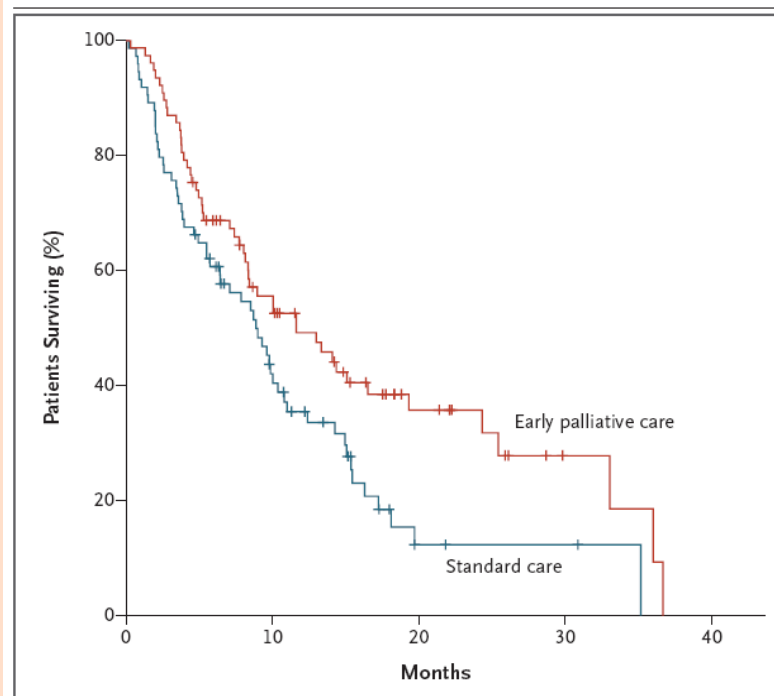
The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

N ENGL J MED 363;8 NEJM.ORG AUGUST 19, 2010



Better Quality of Life

Less Anxiety and Depression

Fewer Hospital Resources

Less Chemo Last 2 months of Life

Lived longer

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American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care

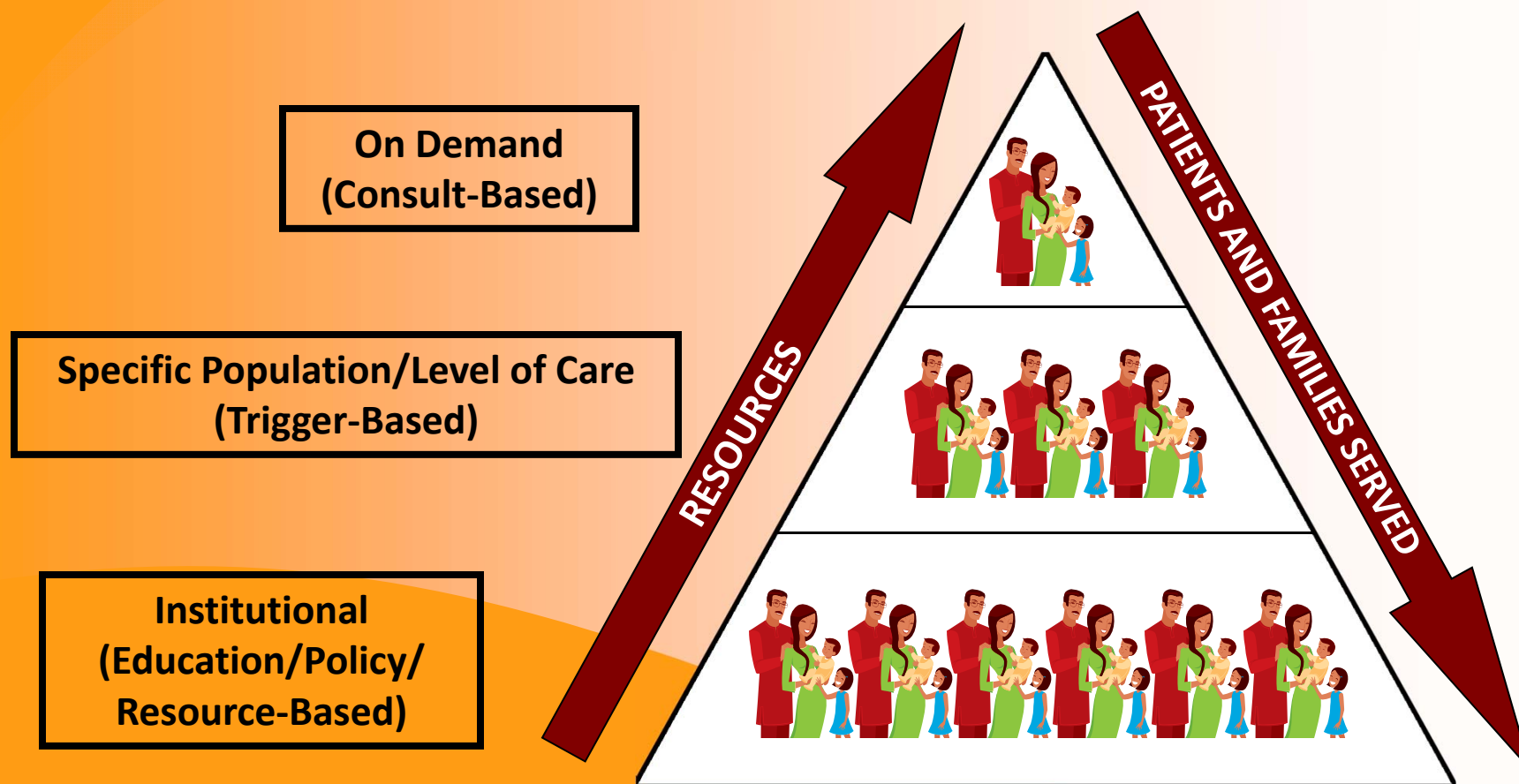
Thomas J. Smith, Sarah Temin, Erin R. Alesi, Amy P. Abernethy, Tracy A. Balboni, Ethan M. Basch, Betty R. Ferrell, Matt Loscalzo, Diane E. Meier, Judith A. Paice, Jeffrey M. Peppercorn, Mark Somerfield, Ellen Stovall, and Jamie H. Von Roenn

- “It is the panel’s expert consensus that ***combined standard oncology care and palliative care*** should be considered ***early in the course of illness*** for any patient with metastatic cancer and/or high symptom burden.”
- “Strategies to optimize concurrent palliative care and standard oncology care, with evaluation of its impact on important patient and caregiver outcomes (eg, QOL, survival, health care services utilization, and costs) and on society, should be an area of intense research.”

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Levels of Palliative Care Integration



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Clinical domains of AYA Palliative Oncology Care

- Sociologic
 - Parents
 - Ethical unit
 - Family *v individual*
 - Decision making and truth telling
 - Support outside hospital
 - Family or friend; partners and peers
 - A wish to die at home
 - Hospital-in-the-home service
 - Home in the hospital
 - Computers and other technology
- Physical
 - Tumor symptoms
 - Treatment adverse effects
 - Body changes
 - Appearance due to tumor
 - Appearance due to being AYA



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Clinical domains of AYA Palliative Oncology Care

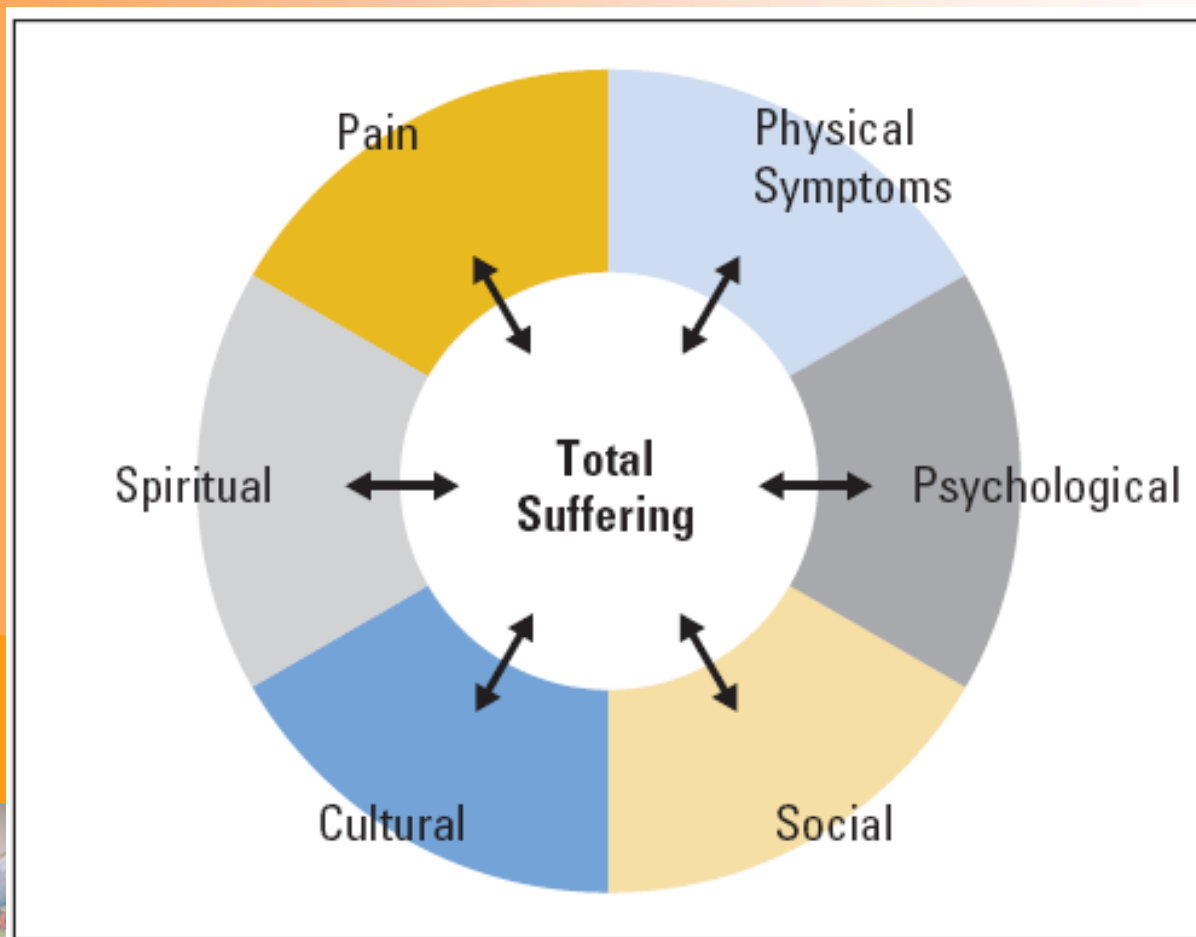
- Psychological
 - Compliance
 - Fear of death
 - Loneliness
 - Independence/Regression
 - Guilt
 - Depression
- Physiologic
 - Adult
 - Healthy organs
 - Sexuality and fertility
- Pharmacologic
 - Pharmacodynamics
 - Illicit drug use
 - Opioiphobia



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Total Suffering in AYA Palliative Oncology Care



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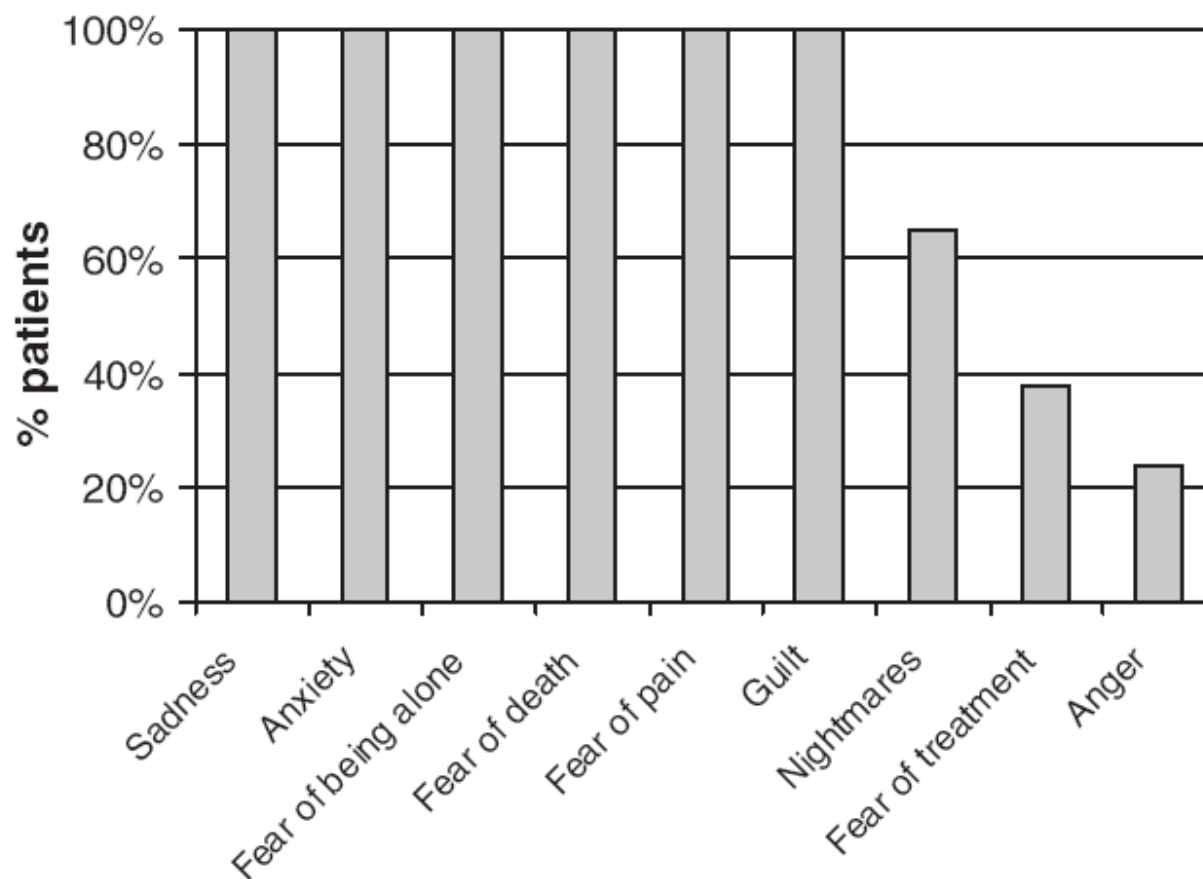


Pain and Other Symptoms

- The symptom presentation of AYAs at end of life is largely determined by the cancer
- Symptoms should be treated as for any adult or pediatric cancer patient
- 89% of patients experience distressing symptoms
- More than 50% experiencing three or more symptoms
 - Pain > Dyspnea > Fatigue > Rehab issues



Psychological Symptoms Last month of life



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Psychosocial Needs

- The emotional and social needs of AYA patients with a terminal illness are complex and vary considerably
- Severe illness often results in loss of newly gained independence
- **Peer support** is crucially important at this stage of life
 - Feel isolated from their regular peers at school or work because of their illness
 - Other AYA oncology patients → important support network
- The process of transitioning to palliative care may again isolate AYA patients from their new peers who are still on a “curative path”
- **Psychosocial isolation** is debilitating for AYA and facilitating peer interaction is an extremely important aspect of their care
- Professional psychosocial support and **interdisciplinary care** are critical

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AYA Grief and Bereavement Death Anxiety

- 23% of adolescents identified loss of close friend in previous year
- Grief experience can increase death anxiety
 - Death Anxiety → anticipating state of death/experiencing fear of dying
- Manifestations of problems with grief/bereavement/death anxiety
 - Shock, Depression, Fear, Loneliness, etc
- Adolescents are frequently disappointed in parents' reactions
 - Uncomfortable talking with parents about feelings
 - Expected more support from parents
- AYA oncology patients view subject as taboo with parents & feel pressured not to raise subject
- Prefer to seek out peers when experiencing death of peer, particularly others who were also close to deceased



AYA Grief and Bereavement Death Anxiety

Coping Strategies Employed by AYAs (n=80)

	#	%
Talking about it	17	21.3%
Don't know/remember	16	20.0%
Distraction (hobbies, school, work, being with people)	13	16.3%
Religious beliefs/prayer	9	11.3%
Not thinking about it	7	8.8%
Time passing	7	8.8%
Reminiscing	4	5.0%
Knowing it was coming	3	3.8%
Left blank	2	2.5%
Sarcastic Comment	1	1.3%
Being by myself	1	1.3%



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What hindered you (got in the way or made it hard) in coping with this loss? *

My actual situation dealing with an illness and worries
because my friend's family ~~were~~ was so devastating

What hindered you (got in the way or made it hard) in coping with this loss? *

I think that what made it harder for me to cope
with this loss was the thought of something happening to me
or to other people who were in my same situation, since
some of these deaths occurred doctors and other professionals
told them they were "fine".

**"Sometimes his mother posted really depressing things
about her grief on FaceBook."**

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Advance Care Planning Helps!

ONLINE FIRST

Family-Centered Advance Care Planning for Teens With Cancer

Maureen E. Lyon, PhD; Shana Jacobs, MD; Linda Briggs, MS, MA, RN;
Yao Iris Cheng, MS; Jichuan Wang, PhD

JAMA Pediatrics
Formerly Archives of Pediatrics & Adolescent Medicine

Results

- An ACP intervention significantly increased EoL congruence
- Intervention adolescents (100%) wanted their families to do what is best at the time, whereas fewer control adolescents (62%) gave families this leeway
- Intervention adolescents were significantly better informed about end-of-life decisions

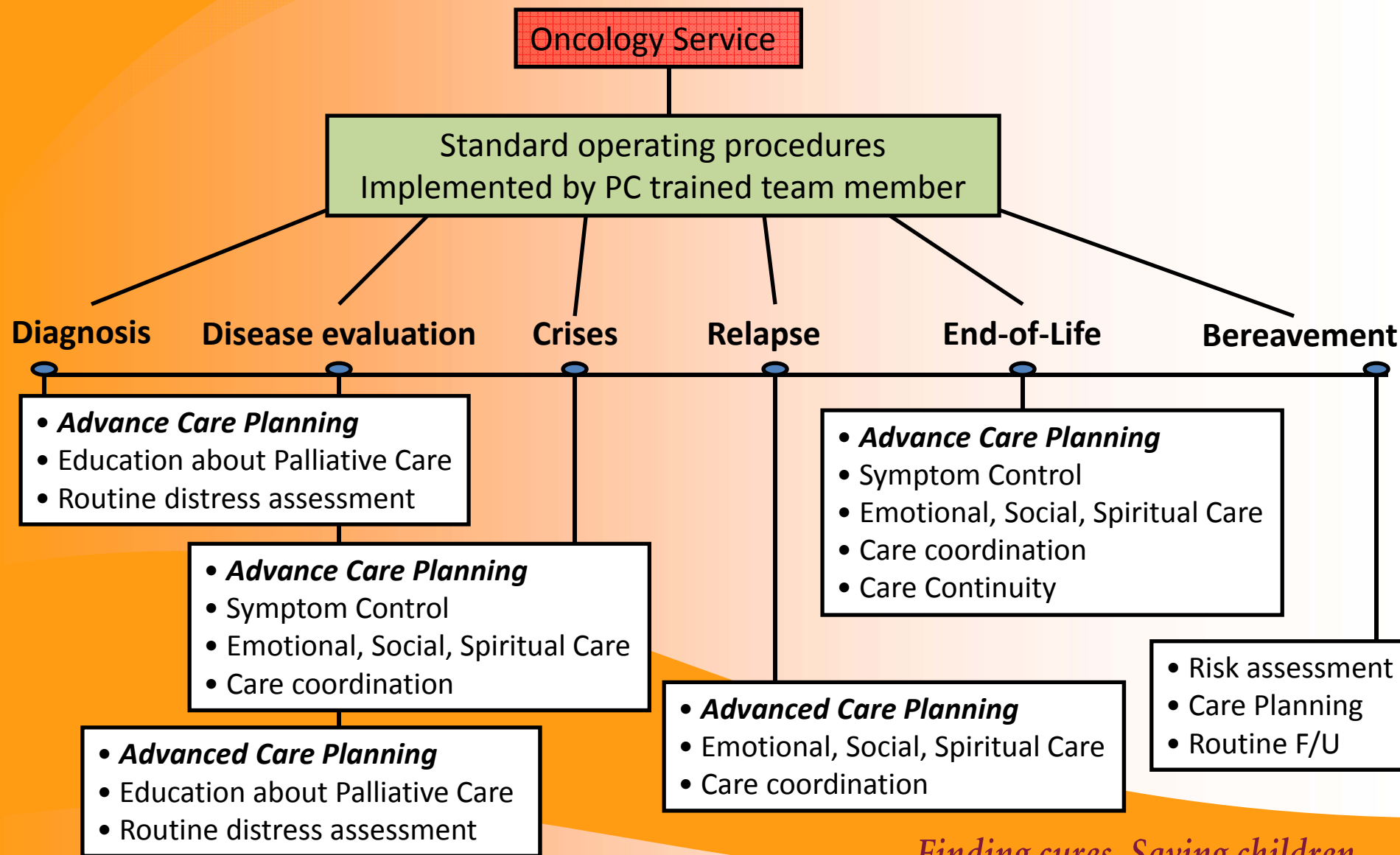
Conclusions

- Advance care planning enabled families to better understand and honor their adolescents' wishes

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“Embedded Expert” model of integration



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USE A “WHAT IF” CONVERSATIONS WHENEVER FAMILIES AND AYAS WANT TO DISCUSS ACP ISSUES!



End of Life Care



- The AYA population cognitively understands that death is permanent and irreversible
- The sense of immortality may act as a defense mechanism and may cause a delay in discussions
- Acceptance may appear in response to the fatigue and exhaustion of the disease journey
- Do not to assume that just because AYAs do not ask about death that they are not thinking about it

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End of Life Care

- Effort **MUST** be made to work toward a “good death”
 - Management of symptoms
 - Spiritual and personal growth
 - Care in a familiar setting surrounded by loved ones
 - Provision of understandable evidence to guide decision-making and planning
 - Confidence that there will not be financial, emotional, or physical burden to family members
 - The right of self-determination and control of treatment



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Quick Pearls - *Trust*

- To win the trust and confidence of AYAs is particularly important and challenging
 - ***ESTABLISH and MAINTAIN A THERAPEUTIC ALLIANCE***
- Interactions with the health care team may be lengthy and require innovative therapeutic compromises
- AYA compliance with medications and procedures can become a battleground as they assert independence
- Rigid discipline is contraindicated, whereas flexibility with firmness builds trust and confidence (Partnering not paternalism)

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Quick Pearls

Interdisciplinary Team

- The interdisciplinary team meeting is critical
 - Coordinate information
 - Update goals of care and create individualized plan of care
 - Debrief and support one another/prevent burnout
- Recommended membership of a PC AYA team should be a nurse, a social worker, a psychologist, an HPM physician, and an oncologist
- Creation of a flexible multidisciplinary palliative care team with extra training in the needs of the AYA patient
 - Provide support within both the pediatric and the adult facilities, as well as support for home care

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Quick Pearls

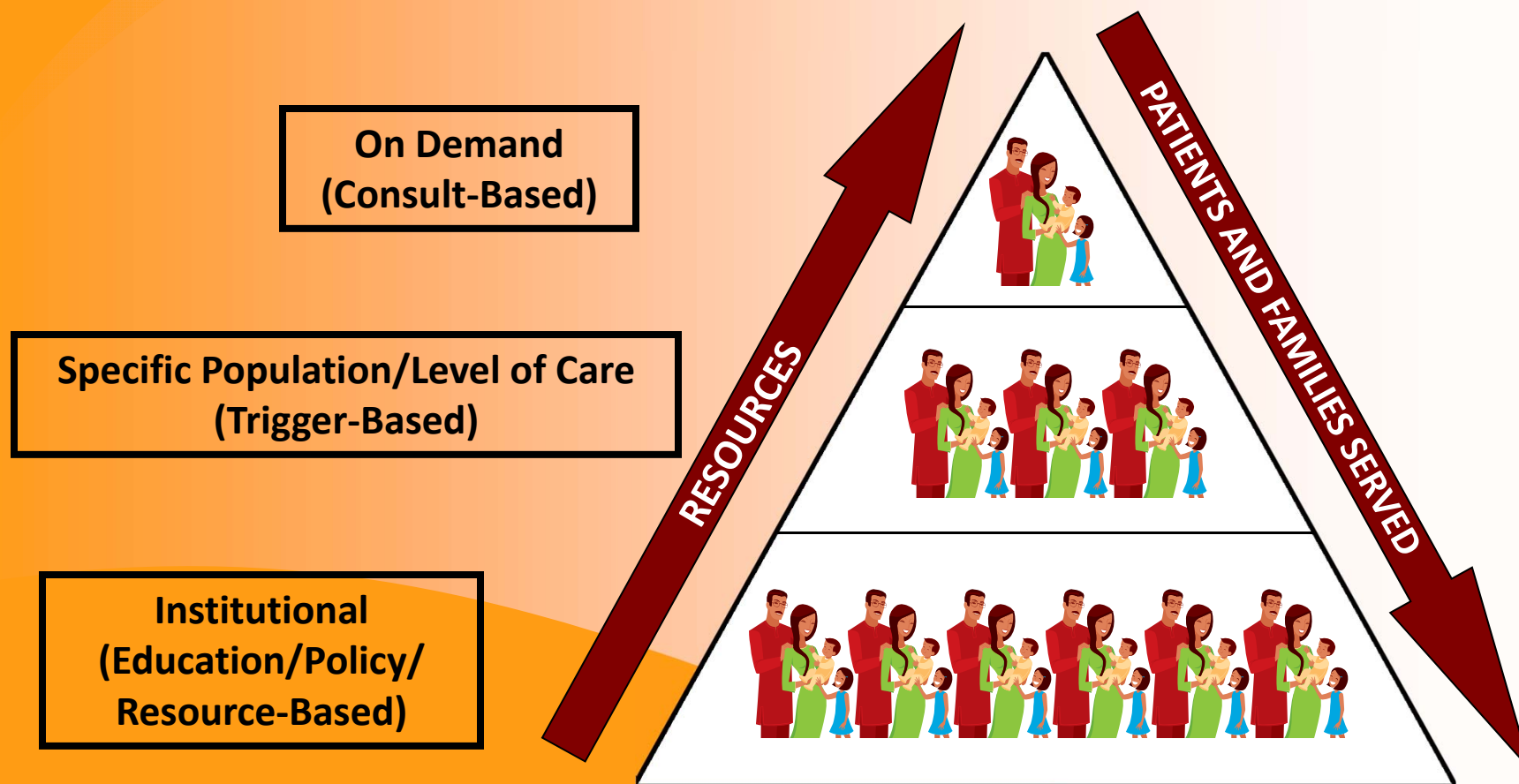
Introducing Palliative Care

- Initiate routine and regular screening for anxiety and psychosocial concerns by using a standardized questionnaire
- Screening questionnaires can also be used for early detection of other symptoms such as pain, nausea, or sleep disturbance
- “Embedded Expert” model of triggered assessments and education
- Early concurrent involvement of the PC team (alongside the primary oncologist) in AYA cases with complex symptoms and/or poor prognosis
 - Facilitates achieving optimal symptom control
 - Helps in later transition to end of life care
- The problem of late referrals to PC by the primary treating team is managed by integrating PC into the AYA team

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Levels of Palliative Care Integration

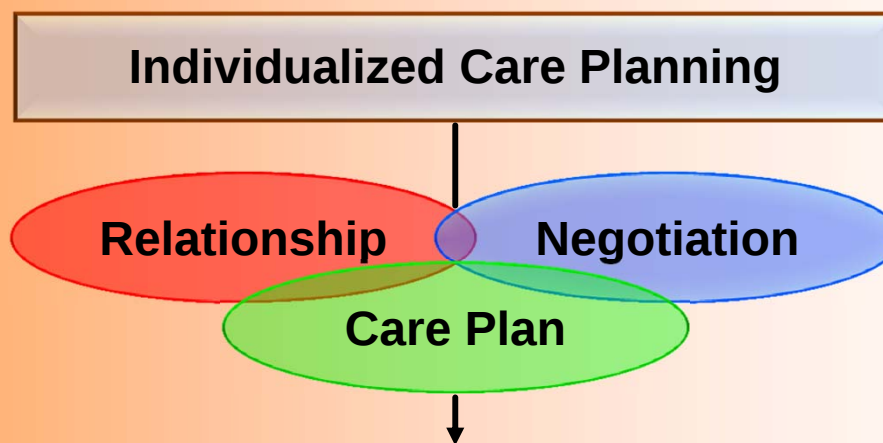


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Quality of Life in AYA Palliative Care

The ICPC Model



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Summary

- The principles of PC are readily transferrable to AYAs, but the interplay with psychosocial and existential issues characterizes this special subgroup of PC
- AYAs with cancer should have access to palliative care services to support and relieve physical and emotional suffering from the point of diagnosis
 - **INTEGRATION IS KEY**
- Create a clinical AYA team that includes palliative care experts
- Culture of care is critical
 - Early referrals and trigger-based SOPs
 - Education and policy development
 - Patient and family-centered care
- Properly integrated multidisciplinary PC will help support the patient and family and help facilitate a “good death”



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