Gaps in Oncology and Palliative Care

Virote Sriuranpong, MD, PhD
Medical Oncology Unit
Department of Medicine
Chulalongkorn University and The King Chulalongkorn Memorial Hospital

What is "palliative care"

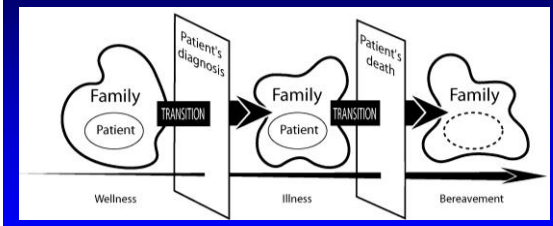
- Specialized care for people with serious illness
- Focus on relieving symptoms, improving QoL
- Appropriate at any age/stage, even along with active cancer treatment
- Provided by trained subspecialists
- Not the same as the "primary palliative care" we all do as oncologists
- Not a euphemism for hospice, or end of life care

Le Blanc ASCO 2016

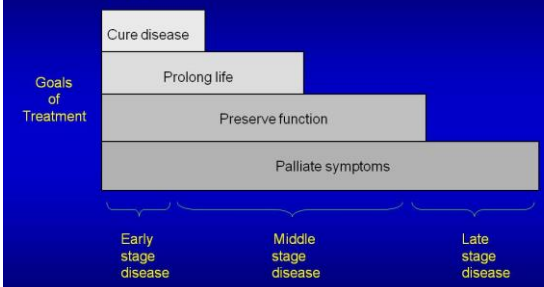
What does it do?

- Outcome improvements include:
  - Symptoms
  - Quality of life (QoL)
  - Mood (patients and caregivers)
  - Prognostic understanding
  - Survival
  - Satisfaction
  - Resource utilization
  - End-of-life outcomes

Patient/Family Transitions



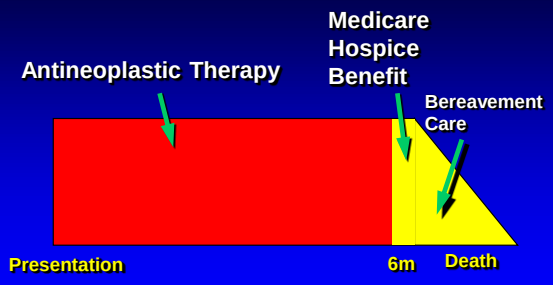
Common treatment goals during the course of a progressive disease



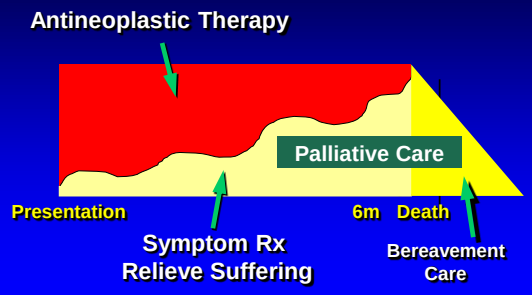
Goals of Care (especially toward the end of life)
1. Be cured
2. Live longer
3. Improve or maintain function/quality of life/independence
4. Be comfortable
5. Achieve life goals
Preparation for death/achievement of a good death
Remain at home
Strengthening relationships
Accomplish a particular personal goal
Spiritual needs
6. Provide support for family/caregiver
7. Clarify diagnosis or prognosis

Kaldjian et al. Goals of care toward the end of life: a structured literature review. *American Journal of Hospice & Palliative Medicine* 2009;25:501-511.
Haberle et al. Goals of care among hospitalized patients: a validation study. *American Journal of Hospice and Palliative Medicine* 2011;28:335-341.

Conventional cancer care



Comprehensive cancer care



Symptoms and Suffering of Cancer Patients

- Physical
  - Cancer
  - Treatment
  - Intercurrent illness
- Psychological distress
  - Anxiety, depression, worry, fear, hopelessness, etc
  - Worry about "being a burden"
- Social
  - Isolation
  - Caregiving
  - Financial

ASCO Survey in 1998

- 6645 oncologists; 118 questions
- N=3227 (48% response rate)
- No significant differences in answers based on oncology subspecialty

Source of information about palliative care

- 90% trial and error
- 73% colleagues and role models
- 38% traumatic experience
- Message: no formal teaching to oncologists

Inadequate education about palliative care

- 81% inadequate mentor or coaching in discussing poor prognosis (communication skills)
- 65% inadequate information about controlling symptoms (symptom control skills)

At least some influence

- 97% oncologists reluctant to “give up”
- 99% patient/family demands for antineoplastic therapy
- 80% chemotherapy is reimbursable
- 80% reluctance to talk about issues other than antineoplastic therapy
- 91% takes more time to do palliative care than give antineoplastic therapy

Personal failure

- 76% feel some sense of personal failure if patient dies of cancer
- 90% feel at least some anxiety discussing poor prognosis
- 75% feel at least some anxiety discussing symptom control with patients and families

Unrealistic expectations

- 29% patient
- 50% family
- 27% conflict

Professional satisfaction

- 98% feel some emotional satisfaction in providing palliative care
- 92% feel some intellectual satisfaction in providing palliative care
- Marked contrast with preparation and a cause for optimism

Gaps Between Oncology and Palliative Care

- Patients and family
  - Mismatched reality & expectation
- Physicians
  - Knowledges and skills
  - Time conflicts
  - Art and science reconciliation
- Healthcare system
  - Burden of disease
  - Budget optimization

Gaps From Patient Expectations

- Fears
  - Pain & suffering
  - Being a burden
  - Loss of control
  - Die in institution
- Desires
  - Be comfortable
  - Family able to cope
  - Sense of control
  - Die at home

Curriculum in Palliative Care Knowledge & Skills for Oncologist

Knowledge

- Familiarity with the role of multiple disciplines in the care of patients with advanced cancer
- Familiarity with how to screen patients for common symptoms and syndromes in routine practice and how to use scales to evaluate their severity
- Understanding of the main components of a comprehensive assessment of cancer symptoms and how to make a differential diagnosis
- Understanding of the pharmacology and toxicity of medications used for the control of main symptoms
- Familiarity with non-pharmacological interventions for symptom control such as counselling, nursing, physical, or music therapy, including their indications, efficacy, and side effects
- Familiarity with an integrated competencies-based management approach to common symptoms in patients with advanced cancer
- Familiarity with the evaluation and management of the complications of advanced and metastatic cancer, such as spinal cord compression, bowel obstruction, thrombosis, or bleeding
- Understanding of the main elements of a decisional process for invasive treatments and end-of-life care
- Familiarity with the different roles and burdens of family caregivers and supportive interventions
- Understanding of the main components of preparing for end-of-life such as legacy work, finishing business, legal preparation, premortal grief, post-mortal caregiver role, and place of death
- Understanding of the approach to conducting difficult conversations with patients and families
- Familiarity with the culturally-based preferences of patients and their families
- Understanding of the causes of burnout and potential approaches to prevent it

- Ability to discuss the role of post-curative, supportive, and palliative rehabilitation in the care of patients with advanced cancer and different models of out- and inpatient and home care
- Ability to demonstrate how a patient is characterised who is in need of specialised palliative care
- Ability to understand the causes of burnout and potential approaches to prevent it

Skill

- Ability to describe criteria for referral to specialised palliative care teams, such as triggers
- Ability to describe the mechanisms and pathophysiology of common cancer syndromes including pain, fatigue, weakness, anorexia, cachexia, anxiety, depression, breathlessness, and nausea
- Ability to contribute actively in a structured, competencies-aware, respectful way in a multidisciplinary team to plan and co-ordinate care for patients with advanced cancer and their families
- Ability to perform a comprehensive assessment of main symptoms (pain, fatigue, anorexia, anxiety, depression, breathlessness, and nausea), including the use of scales
- Ability to demonstrate understanding of the pharmacology of medications used to treat main symptoms by appropriately prescribing and titrating opioids, adjuvant analgesics, and other drugs
- Ability to demonstrate understanding of the toxicities of symptomatic medications by prescribing medications to prevent toxicities
- Ability to assess a patient with complex symptoms utilising cognitive assessment, symptom assessment scales, and modular assessments for main syndromes
- Ability to discuss the role of anticancer therapies for the relief of cancer-related symptoms, and to demonstrate how a patient can be prepared for the decisional encounter
- Ability to demonstrate a structured approach to making decisions for managing complications of metastatic/advanced cancer, and how to evaluate and manage the most common, including but not limited to spinal cord compression, bowel obstruction, thrombosis, or bleeding
- Ability to demonstrate the steps required for skilled and compassionate communication with patients and families, including breaking bad news, prognosis discussion, preparation for end-of-life, or family conflicts about care decisions
- Ability to discuss specific culturally-based preferences with patients and their families
- Ability to evaluate and manage psychological and existential symptoms and distress of having advanced cancer, including anxiety, depression, anger, and despair
- Ability to share a personal plan for self-care and to describe its importance for yourself

Presented By Timothy Gilligan at 2016 ASCO Annual Meeting

"Don't freak out—it's just a save-the-date."

Presented By Timothy Gilligan at 2016 ASCO Annual Meeting

Communication Strategies

Where to invest

- Clarifying the agenda
- Listening & inquiry
- Curiosity
- Empathy
- Understanding
- Supporting

What to avoid

- Defending
- Debating
- Arguing
- Persuading

Timothy Gilligan at 2016 ASCO Annual Meeting

Downsides of Chemotherapy at the EOL

- 1. Cost
- 2. Quality of Care
  - Associated with receiving other more intensive treatments, such as cardiopulmonary resuscitation
  - Downstream effects, include lack of planning for death and late/no referrals to hospice

Temel J. ASO 2105

Challenges in Stopping Chemotherapy

- Historical Challenges
  - Sometimes (rarely) we do not know when patients are in the last weeks or months of life
  - Sometimes (rarely) chemotherapy at the EOL is in line with patients goals and wishes
- Challenges in the Modern Era
  - Sometimes (and becoming often) there are new and exciting treatments available that have a good change of helping someone liver longer and feel better

New Challenges in Stopping Chemotherapy

- Cancer therapies are becoming more effective and less toxic
- Newer FDA approved therapies can be effective, even for patients with poor functional and performance status
  - Unclear if the “no chemotherapy for PS 3” rule is relevant for these newer therapies

Myths of Palliative Care

- Limited formal education available
- Balance of art and science
- Much research is needed to address several questions (searching for evidence based)
- At the end, we are human and prone to errors and biases
- Cross cultural applicability?

Hope this meeting will shed light on these issues

- “The physician’s duty is not to stave off death or return patients to their old lives, but to take into our arm a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of their own existence”

From When Breath Becomes Air, Paul Kalanithi

Timothy Gilligan at 2016 ASCO Annual Meeting