

FOSTERING HOPE AND ALLEVIATING SUFFERING: THE ROLE OF PALLIATIVE CARE IN CANCER TREATMENT

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Objectives

- The Illness Experience
- What is Palliative Care? Is it different from Hospice?
- Common symptoms, treatments and support for people living with cancer

The Illness Experience

- Diagnosis of cancer → What happens next?...How do I cope?....Who am I now?....Will my family be OK?....Who can help me and my family now?...Who am I after my cancer treatment?



“The State of Illness”

- Disconnection from the world
- Loss of a sense of omnipotence: “I’m in control of my future”
- Loss of sense of omniscience: “I know what the future holds for me”

Loss of a sense of control and predictability...

Eric Cassell “The Nature of Suffering and the Goals of Medicine”

Suffering

- Suffering is the specific distress that happens when persons feel that their intactness as a person is threatened.
- Has different realms (physical, social, emotional, spiritual, existential, etc.), but...
 - ..Whatever happens to one part happens to the whole, and
 - People don't experience their suffering in a reductionist way

Eric Cassell "The Nature of Suffering and the Goals of Medicine"

Suffering

- Is always personal and particular = unique to the person experiencing it
- Can't necessarily be fixed with a pill or procedure
- The memory of the experience never goes away
- Pain \neq Suffering (Pain can cause suffering, but treatment of physical pain does not always end suffering....)

Eric Cassell "The Nature of Suffering and the Goals of Medicine"

Suffering

- Suffering
 - Can have a future orientation- “What will happen now?”
 - Is related to role expectations- “Am I the same person now as I was before I had cancer?”
 - Is lonely- “Can anyone understand what is happening to me?”
 - Often involves self-conflict: “I want to do all the things I used to, but now I feel too tired.”
- Suffering is *entirely related to meaning*
 - Why has this happened to me? What does it all mean?
 - “Man is not destroyed by suffering, but by suffering without meaning.”
Viktor Frankl “Man’s Search for Meaning”

Medical Culture: Disease vs. Illness

- Disease:
 - The medical problem- its name, symptoms, what the tests show...
“metastatic pancreatic cancer”
- Illness:
 - What this *unique patient* experiences.
 - 100 patients with the same tests will each have a unique “illness”
 - We used to think:
 - “*Know the disease and you know the illness. Cure the disease, you have cured the illness*”....
 - Maybe not so black and white, because each person is unique

Shifting Priorities and Expectations

- The goal of medicine is
 - ... "to cure sometimes, to relieve often and to comfort always."
19th Century Medicine
 - "to cure always, treat often, comfort if we have the time."
20th Century Medicine
 - *Can we focus on a cure, and also comfort and support at the same time?*
21st Century Medicine

Palliative Care

- If people suffer in many realms when they are ill, maybe they need a team to help them navigate through their illness journey
 - “Whole person care requires a whole person. Until one comes along, use your team.”

Balfour Mount, MD, founder of Palliative Care

What is Palliative Care?

- “An approach that improves the **quality of life** of patients and their families facing the problems associated with life threatening illness, through **prevention of and relief of suffering** by means of early identification and impeccable assessment and **treatment of pain and other problems, physical, psychological and spiritual**”

World Health Organization

Put the person and their experience and needs front and center....not only focus on the disease....

Palliative Care

- Palliative Care is a new **medical specialty** that offers care for patient and family that helps when someone has a serious and/or life threatening illness.
 - A medical specialty like oncology, geriatrics, cardiology, etc.
 - Provided by a team (doctors, nurses, social worker, chaplain, arts in medicine, others)- UNM team has 2 oncologists on team
- You don't need to choose between curative treatment and palliative care- **you can have *both at the same time***.
 - Palliative Care is not Hospice
 - Is not just for patients with cancer; any diagnosis
 - Any age at any stage
 - Does not hasten or prolong the dying process
 - *Prognosis does not matter....*

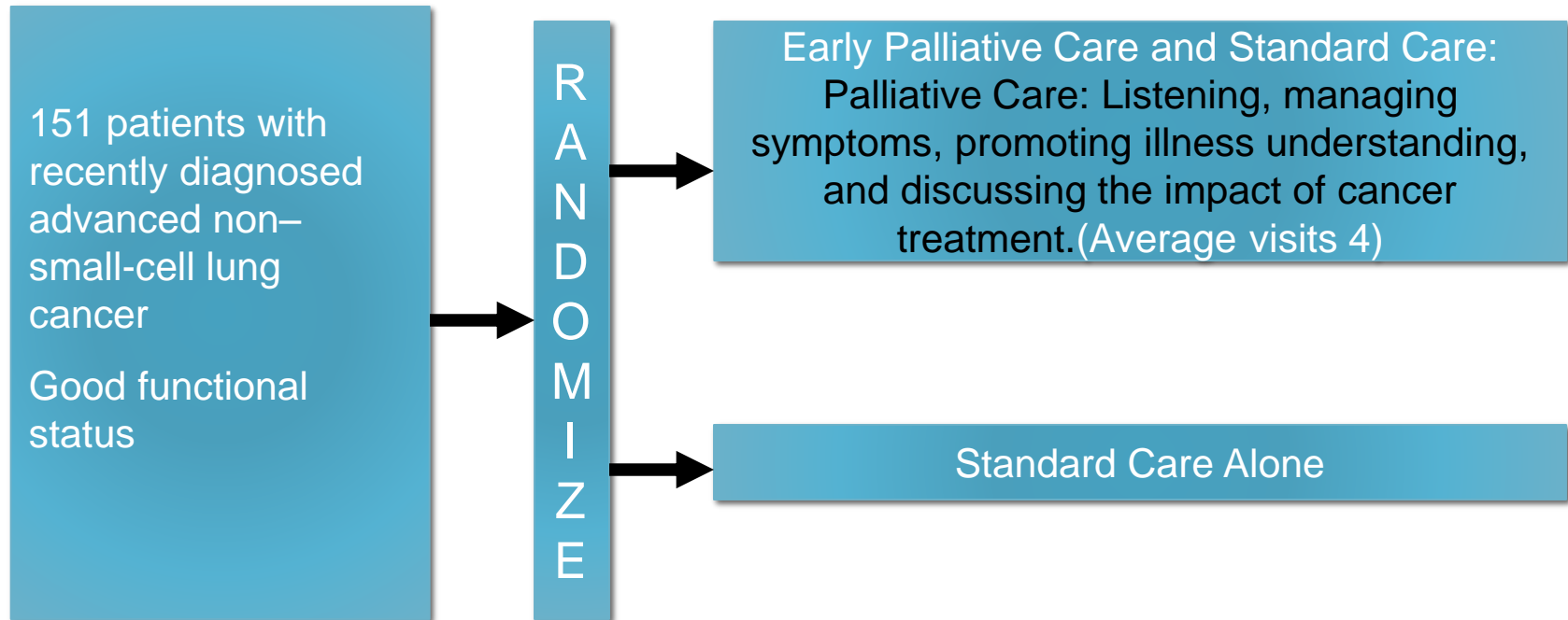
What does Palliative Care do?

- Expert symptom management
 - Pain, Nausea and vomiting, Shortness of breath, Depression, Fatigue, etc.
- Help with Difficult Decision Making
 - Coordinate and explain information from many different doctors.
 - Explore what is important to you
 - Review different treatment options and help you determine which option may best meet your needs
- Emotional and spiritual support for patients and families
- Practical help about resources for families facing serious illness
- Support your oncologist as s/he is trying to cure your cancer

Who can benefit from Palliative Care?

- Ask:
 - Do you feel you need help with pain or other symptom management?
 - Do you or your family feel you need more support in helping to cope with your cancer diagnosis?
 - Do you have questions about what the future may hold for you? Prognosis?
 - Do you need extra help making decisions about what you want to do?

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



Temel et al NEJM 2010

Early Palliative Care for Lung Cancer

- Early Palliative Care led to:
 - Better quality of life
 - Less depressive symptoms
- AND
 - Patients lived **2.7 months longer**....

*******So patients lived longer and felt better if they received Palliative Care along with standard Cancer treatments at the time of diagnosis compared to Cancer treatments alone.....***

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

- ***While evidence clarifying optimal delivery of Palliative Care to improve patient outcomes is evolving, no trials to date have demonstrated harm to patients and caregivers, or excessive costs, from early involvement of Palliative Care. Therefore, 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."***

What is Hospice?

- Hospice Care is a **Health Care Benefit**:
 - Medicare and Medicaid benefit since 1983; many private insurances have a “hospice benefit”
- Hospice is also a **type of or philosophy of care**:
 - People who have a life expectancy of 6 months or less ***if a disease runs its natural course***
 - Focus is on comfort and quality of life, not life prolongation- usually people ***not*** on cancer treatment
 - Also provided by a team of different providers (nurses, doctors, social worker, bereavement, chaplains, therapists, etc.) like Palliative Care
 - Usually provided at **home** (but can be provided in a NH or inpatient hospice....)
- **Prognosis matters**

“All Hospice Care is Palliative Care; not all Palliative Care is Hospice”

Hospice benefit:

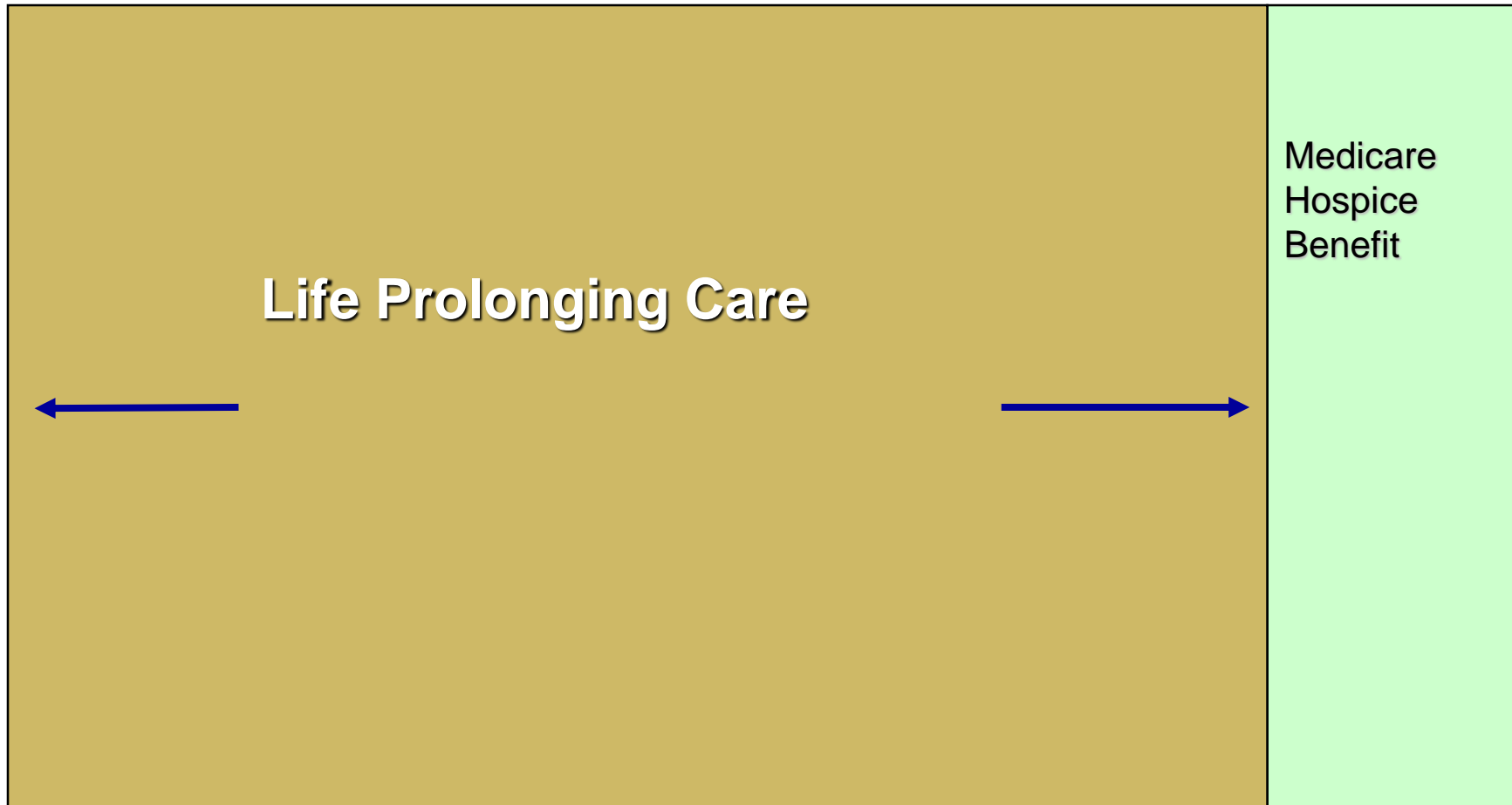
- Regular visits to you in your home plus 24/7 availability by phone; visit to home if needed at any time (= most support in the home you can have)
 - Not in home 24/7 care however; Hospice helps your family care for you in the home
 - Support for families, including bereavement care
- Respite care
- Medications for your illness; equipment needed
 - Remember: People can sign off Hospice; You can still see your doctor on Hospice.

Misperceptions about Hospice and Palliative Care

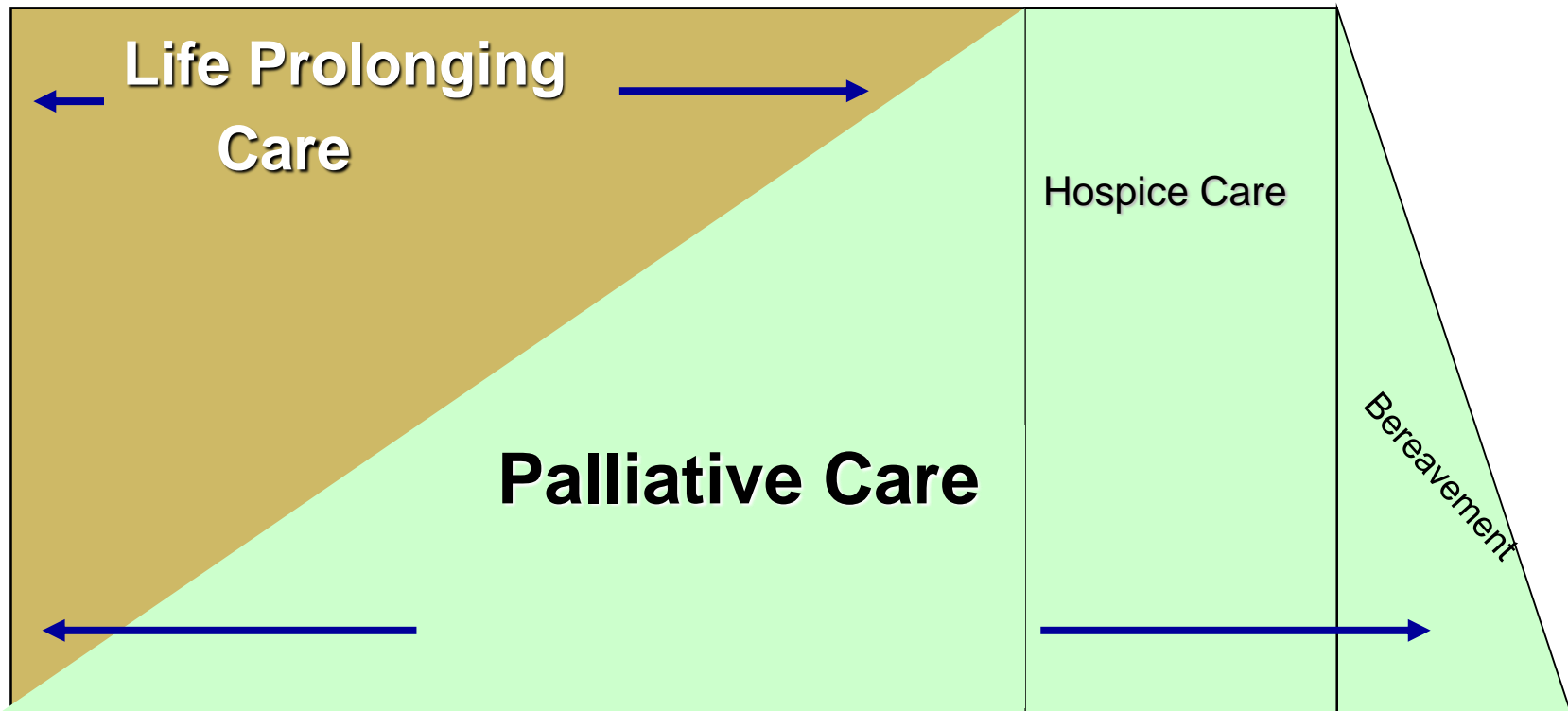
- Patient: “But I don’t want Palliative Care. I want to get better.”
- *OR*
- Doctor: “You don’t need Palliative Care. We still have treatments to offer you.”

Confusion about Palliative Care and Hospice....

Older Model of Medical Care



New Model of Palliative Care



How can I find out about Palliative or Hospice services where I live?

- <http://www.getpalliativecare.org>
 - Hospital-based Palliative Medicine services
- <http://www.caring.com/local/hospices-in-new-mexico>
 - Hospices serving your community
- <http://www.caringinfo.org>
 - Planning ahead
 - Caregiving
 - Living with an illness

PHYSICAL CAUSES OF SUFFERING

Basic Information about Cancer Pain and What Can Be
Done to Help

Pain Management....

- Is an important part of care for people who have cancer
 - 80-90% of patients with cancer have pain
- If you are in severe pain, you can't think of anything else, and the urgent goal is to help relieve pain
 - “Meaning” becomes “getting me out of this pain”!

Cancer Pain

- Uncontrolled pain *does not* go hand-in-hand with a diagnosis of cancer.
- Almost all pain can be decreased to a “tolerable level” with medications and other therapies.
- Sometimes this requires an expert in pain beyond your cancer doctor, such as Palliative Care, a Pain Service or Hospice services...

Pain Medications

- There are different types of medicines that treat pain coming from:
 - Muscles or Bones- metastases to the ribs....
 - Inner Organs- liver, bowels....
 - Damage to Nerves- hands, feet, other...may even be a result of chemotherapy....
- Many patients take several different medications to control their pain
- There may be some medicines that are not safe for you (because of differences in kidney function or interactions with other medicines that you take)

Opioid Pain Medications

- Some of the best pain medicines we have for moderate to severe pain
 - Examples: Morphine, Percocet, Fentanyl, Dilaudid, Oxycodone, Roxanol, etc.
- Some are short-acting and some are long-acting
 - Many patients with cancer need to use both a long- and short-acting medicine

Myths and Fears about Opioids:

Unfortunately many patients with cancer suffer with uncontrolled pain due to myths and fears of opioid medicines.....

Myths and Reality:

- **Myth:** Strong pain medicines are only used for people who are really sick or dying.
 - Not True: Opioids can help for people with pain no matter what stage of illness.....
- **Myth:** If I take pain medication now, then it won't work later when my pain gets really bad....
 - Not True: The doses of pain medication can be adjusted as needed, just like insulin is adjusted based on blood sugars....

Myths and Reality

- **Myth:** Everyone who takes morphine gets addicted.
 - Not True: People who do not have a history of addiction, or risk factors for addiction, rarely get “addicted” (<1%)
 - Addiction is a psychological need, NOT a physical need or physical dependence on the medication, which can occur for many medications that one takes regularly, like blood pressure medications....
- **Myth:** Allergies to opioids are very common.
 - Not true: Allergies to opioids are very rare. Side effects (such as constipation) are common, but these can be managed very well if they are anticipated and treated....

Many other therapies can help with pain

- Other types of medications (like nerve pain medicines)
- Topical treatments (lidocaine, capsaicin)
- Physical therapy
- Surgery
- Radiation
- “Interventional Procedures” often done by an anesthesiologist pain doctor – injecting pain medicine near a nerve or into the epidural space
- Complementary treatments- acupuncture, healing touch, massage, etc.

Many other “tools in the toolbox”....

Where can I learn more about the treatment of cancer pain and palliative care?

- <http://www.acscan.org/qualityoflife/resources>
- <http://www.cancer.org/treatment/treatmentsandsideeffects/palliativecare/index>
- <http://www.cancersupportivecare.com/pain.html>
 - Excellent resource for patients and families

HEALING AND HOPE

Hope

- What generates hope?
- Does talking about the future take away hope?



- Many studies tell us that people want to know about the future and what to expect
 - And yet many physicians don't discuss this. Why?
 - Perceived lack of training
 - Stress
 - Take away hope
 - No time to address emotional needs
 - Harm patients
 - Hurt our relationship with the patient
 - What if we're wrong? Uncertainty about prognosis
 - It's emotionally difficult
 - Explicit requests by patient/family not to discuss

Balancing Hope and Realism

- “I want to hope for the best, but I need to know what to expect so I can plan. I also want to know there are people to talk with if things aren’t going well, in any realm of my life.”

Research about Hope

- **Coping with Cancer Study** (2008) looking at patients with stage 4 cancer and their caregivers: *Have they had conversations about end of life issues with their doctors?*
 - People who have discussions about end of life issues did not report increased emotional distress or feel less “hopeful”
 - People often made different decisions about their health care at end of life (often, but not always, less aggressive)
 - Caregivers felt better prepared and had less depression, regret, better QOL after their loved one passed
 - QOL of caregiver was related to QOL of patient

How one is told is important

- Loved ones present (not all!)
- Adequate time
- Acknowledgment of emotional, spiritual, existential impact of having a life-limiting disease
- ‘Attitude’ of the clinician- focused on the patient and not just the disease
- Respect for patient’s emotional state

Hagerty Ann Onc 2005. Clayton Supp Care CA 2005. Curtis J Palliat Med 2008.

What will happen is important...

- ...And is just as important as time
- Near universal finding including:
 - Impact of illness & its treatment on their lives
 - What to expect – treatment and functional courses
 - True in Cancer, CHF, COPD, Dementia
 - Near the end of life...
 - Places of death, impact of death on family, help they can get

Hagerty et al Ann Oncol 2005. Curtis et al. Eur Resp J 2004. Curtis et al. Chest 2002. Knauff et al. Chest 2005.

Hope and Optimism

- Qualitative research:
 - Clayton *Cancer* 2005: Explored with advanced cancer patients how they see hope
 - Major themes
 - Emphasize what can be done
 - Emotional support, care, dignity, listening, non-abandonment
 - Practical support (help in home)/Discuss day-to-day living
 - Truth-telling but 'not blunt,' leaving space for the unanticipated....
 - Which as a physician, is the most humbling experience. We love when people surprise us.
- What takes away hope?
 - "Talking only about the disease, and not how it affects me as a person"

“Most patients...”

- ...means some patients want to talk about these things. Some:
 - Don't want to talk about the future
 - Don't want straight-forward assessments of the future
 - Don't want to talk about anything 'negative'
 - Want us to promise them cure, recovery
- We as medical providers need to let people determine the tempo of how we provide information.

Hope & Optimism

- “Hope” =
 - Receiving the best care possible= all the right things are being done,
 - Non-abandonment= we will be with you throughout this journey
 - Caring= I know my team cares for me
 - Completeness of information, measured as the patient and family want to receive it
- We can do this. We can treat the disease and care for the person at the same time
- This is healing....
 - Healing= “To make whole” = Whole Person Care
 - Healing may be different than Cure

How does one live with cancer?

- Use your team
 - Oncologist, nurses, therapists, pharmacists and all the people at your cancer treatment center
 - Best care possible
 - Palliative Care- a specialized team of people that work with your cancer doctor to help you and your family through your illness, with expertise in pain and symptom management
 - Family, friends and your personal support team, like the Cancer Support Network
 - Sometimes friends and family need you to tell them how to help

“Learn from yesterday, live for today, hope for tomorrow.”

Albert Einstein

Hope and Healing

- I wish all of you the best. I wish you and your family strength and courage through your journey. I wish you hope, healing and well-being.

Thank you

