Metastatic Breast Cancer: Understanding Palliative Care

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Conceptual Shift for Palliative Care

Disease-Directed Therapies



Why Palliative Care?



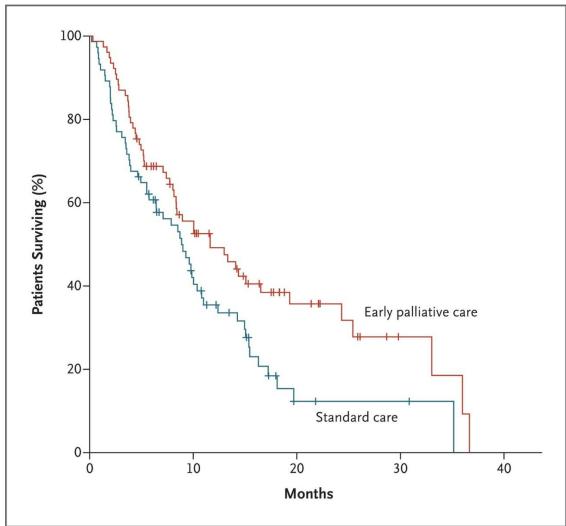
Early Palliative Care for Patients with Metastatic Non– Small-Cell Lung Cancer

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.

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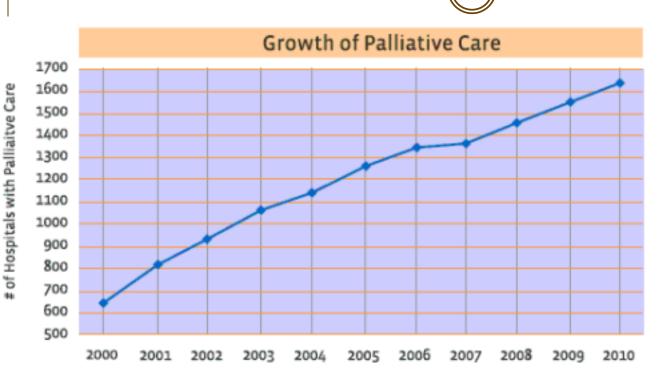
Kaplan–Meier Estimates of Survival According to Study Group



What is Palliative Care?

- Specialized medical care for people with serious illnesses at any age and at any stage
- Focused on providing patients with relief from the symptoms, pain, and stress of a serious illness
- Can be provided with curative treatment
- Delivered by an interdisciplinary team
- Goal: improve quality of life for both the patient and the family

Growth of US Hospital-based Palliative Care teams



Source: 2002 to 2012 American Hospital Association Annual Hospital Surveys for FY 2000 to 2010; and data from the Center toAdvance Palliative Care's (CAPC) National Palliative Care Registry: *

85% of US hospitals with >300 beds have a Palliative Care Program

HOW CAN WE HELP?

Tasks

- Comfort
- Communication
- Continuity



"Melanie"

45 yo former model with 2 children

Her breast cancer returned to her bones and the nerves going to her right arm; she will start chemotherapy next week

Pain 10/10, aching, burning, shooting down her right arm

Thin, anxious, sleepless



What has the pain done to her?

CANCER INHIBITS MOVEMENT, SLEEP, EATING, HUGGING

OUT OF WORK
NO BOOK CLUB
NO ROLE IN FAMILY

GUILT
HOPELESSNESS
HELPLESSNESS
FEAR OF DEATH

NO CHURCH
ESTRANGED FROM
FAITH?
PAIN = PUNISHMENT

What has the pain done to her?

PHYSICAL

CANCER INHIBITS MOVEMENT, SLEEP, EATING, HUGGING

SOCIAL

OUT OF WORK
NO BOOK CLUB
NO ROLE IN FAMILY

SUFFERING

PSYCHOLOGICAL

GUILT
HOPELESSNESS
HELPLESSNESS
FEAR OF DEATH

SPIRITUAL

NO CHURCH
ESTRANGED FROM
FAITH?
PAIN = PUNISHMENT

Unspoken concerns about Pain medications

- Will I get addicted?
- What will people think of me if I take narcotics for the pain?
- What will I do if the pain gets worse?

Answers

- Will I get addicted?
 - NO. Addicts want to get OUT of their lives
 - Melanie wants to get back INTO her life
- What will people think of me if I take narcotics for the pain?
 - They won't be able to tell any difference
- What will I do if the pain gets worse?
 - Take more or stronger medication
 - She cannot "use up" pain medication

Will the doctor think less of me if I complain of pain?

NO: SHE'LL CHANGE THE PAIN REGIMEN

Treatment for Cancer Patients in Pain

- Cancer pain can be relieved while its cause is being determined
- Cancer pain can be controlled even when the cancer itself cannot

Treatment for Cancer Patients in Pain

- Increasing doses of pain medications, including narcotics, are safe and well-tolerated by patients in uncontrolled pain
- Most side-effects caused by pain-relieving medications can be prevented or treated
- Other medications and practices can add significantly to pain relief

Family Barriers Her family asks:

IS SHE REALLY HAVING PAIN?





Behaviors that Pain Changes



- General activity
- o Mood
- Walking ability
- Work (home or outside)
- o Relationships with others
- o Sleep
- Enjoyment of life

Brief Pain Inventory

OBSTACLES TO PAIN RELIEF

- Obstacles Melanie presents
 - o Desire to be a "good" patient
 - Low expectation of relief
- Obstacles from both Melanie and her family
 - o Don't "see" the pain
 - o Fear of opioids
 - o Fear of "using up" opioids
 - o Increased pain = Progressive disease

What are Melanie's Goals and Purposes?

WHAT DOES SHE NEED TO BE ABLE TO DO??

Melanie's Primary Goals

- Tolerable pain
- No constipation
- Get through the chemo
- Be a mom to her kids and a wife to her husband
- Feel useful around the house
- Reconnect with her faith
- Teach

Narcotic medications

- Immediate acting
 - o Fentanyl lozenges, films, nasal spray
- Short acting pills/liquids
 - o Morphine, oxycodone, hydromorphone
- Time-release pills
 - o Morphine, oxycodone, hydromorphone oxymorphone
- Long-acting
 - o Methadone
- Skin patch: Fentanyl

Customizing Melanie's regimen

- Is the pain constant?
 - o Time-release, methadone, or skin patch and
 - Immediate or short-acting (for increases in pain between doses)
- Does the pain come and go?
 - o Immediate or short-acting medication
- Does the pain interfere with sleep?
 - o Time-release at night

When would Melanie's doctor change her narcotic?

- She has sleepiness that persists
- She has nausea that persists
- She is confused
- She wants to try something else

All narcotic pain relievers are equally constipating

She wants to minimize the pills she takes

- Acupuncture
- Massage, heat, cold
- Meditation or hypnosis

Her bones ache, and hurt when she moves

Oral Medications

- o Acetaminophen
- o NSAIDs (like ibuprofen)
- o Glucocorticoids (like dexamethasone)

Infusions

- o Bisphosphonates (like Zolendronic acid)
- o RANK-L inhibitors
- Radiation therapy
- Infusion of radioactive material
 - o E.g. Strontium, samarium

She has burning, shooting, or tingling pain

- Oral Medications
 - o Glucocorticoids (like dexamethasone)
 - o Drugs that "quiet" nerves (like pregabalin)
- Skin patch
 - Local anesthetic (like LidodermTM)
- Medications into the spinal fluid (like the "spinal" women get when in labor)
 - o Narcotics, local anesthetics, other

PREVENT CONSTIPATION

- Stop non-soluble fiber
- Start
 - o Stool softener
 - Motility agent
 - o Polyethylene glycol
 - o (Lactulose)

WHAT IF HER PAIN REMAINS INTOLERABLE?

Persistent Distress: Unasked Questions



- How do I talk with my children?
- Can I continue to work?
- What will happen to me, to my family?
- Who am I now?
- Why am I being punished?

Persistent Distress: Existential suffering

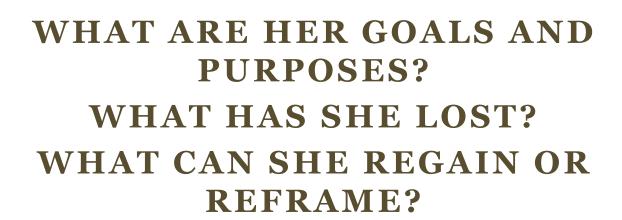
- Being a burden on others
- Meaninglessness of life
- Loss of recognizable, acceptable self
- Loss of purpose

Frankl VE: Man's search for meaning; 3rd edition; Simon and Shuster, NY 1984

Cassell E: The Nature of Suffering and the Goals of Medicine. 2nd edition, Oxford University Press, New York,

HOW CAN WE HELP?

FUNCTION



PRIMARY GOALS

- Tolerable pain
- No constipation
- Get through the chemo
- Be a mom to her kids and a wife to her husband
- Feel useful around the house
- Reconnect with her faith
- Teach

REFRAMED GOALS

- Melanie can find things to do that don't depend entirely on her right arm
 - o As a mom
 - o As a wife
 - o Around the house
- She might tutor if she can't teach at school

What are her sources of support?

CAN THEY BE ENHANCED / REGAINED?

Melanie's Support

CURRENT

- Family
- Colleagues at school

ENHANCEMENTS

- VNA / Health Aide
- Home PT
- Counselors for her kids
- Spiritual / social counselors for her/her husband

Reconnect With Her Faith

- Pastoral counseling about
 - o Guilt
 - Fears about dying
 - o Loss
 - Punishment
 - 0?

Meaning Of The Illness

PHYSICAL

DEBILITY

SOCIAL

ISOLATION

SUFFERING

WELL-BEING

PSYCHOLOGICAL

DEPRESSION FEAR OF DEATH

SPIRITUAL

PUNISHMENT

HEALING

PHYSICAL

PAIN TOLERABLE
KEY FUNCTIONS
RESTORED OR
LIMITATIONS ACCEPTED

SOCIAL

CONNECTION

WELL-BEING

SUFFERING

PSYCHOLOGICAL

MEANING MAKING TRUST REDIRECTED HOPE SPIRITUAL FORGIVENESS

Tasks

- Comfort
- Communication
- Continuity



Communication of Prognosis

Overly Optimistic

Realistic

Realistic

- Eliminates fear of MD abandonment
- True "informed consent" in clinical trials
- Redirects hope and energy to last goals
- Redefines purpose, sense of efficacy
- Allows for creation of Legacy and for Closure
- Enhances survival of the bereaved



"There's no easy way I can tell you this, so I'm sending you to someone who can."

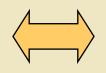
Advance Care Planning POLST form

	HIPAA PERMITS DISCLOSURE TO HEALTH CARE	PROFESSIONALS	AS NECESSARY FOR TREATMENT	
Physician Orders		Last Name/ First/ Middle Initial		
for Life-Sustaining Treatment (POLST)		Address		
rst follow these orders, then contact physician, NP, or PA. These		City/State/Zip		
ndi	al orders are based on the person's current medical tion and preferences. Any section not completed does not date the form and implies full treatment for that section.	Date of Birth (mm.	dd/yyyy) Last 4 SSN Gender M F	
	CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.			
L eck	Attempt Resuscitation/CPR Do Not Attempt Resuscitation/DNR (<u>A</u> llow <u>N</u> atural <u>D</u> eath)			
ne	When not in cardiopulmonary arrest, follow orders in B , C and D .			
	M EDICAL INTERVENTIONS: Person has pulse and/ <u>or</u> is breathing.			
} eck ne	Comfort Measures Only Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Do not transfer to hospital for life-sustaining treatment. Transfer if comfort needs cannot be met in current location.			
	Limited Additional Interventions Includes care described above. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). <i>Transfer to hospital if indicated. Avoid intensive care.</i>			
	Full Treatment Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. Transfer to hospital if indicated. Includes intensive care. Additional Orders:			
ANTIBIOTICS				
eck	No antibiotics. Use other measures to relieve symptoms.			
ne	Determine use or limitation of antibiotics when infection occurs.			
	Use antibiotics if medically indicated.			
	Additional Orders:			
)	ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food by mouth if feasible.			
eck	No artificial nutrition by tube.			
ne	Defined trial period of artificial nutrition by tube.			
	Long-term artificial nutrition by tube.			
	Additional Orders:			
\mathbb{E}	REASON FOR ORDERS AND SIGNATURES			
	My signature below indicates to the best of my knowledge that these orders are consistent with the person's current medical condition and preferences as indicated by the discussion with :			
	Patient Health Care Representative Parent of Minor			
	Court-Appointed Guardian Other			
	Print Primary Care Professional Name Office Use Only		Office Use Only	
-	Print Signing Physician / NP / PA Name and Phone Number	rint Signing Physician / NP / PA Name and Phone Number		
	()			
	Physician / NP / PA Signature (mandatory)			

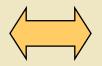
Continuity of Care



Hospital



Clinics

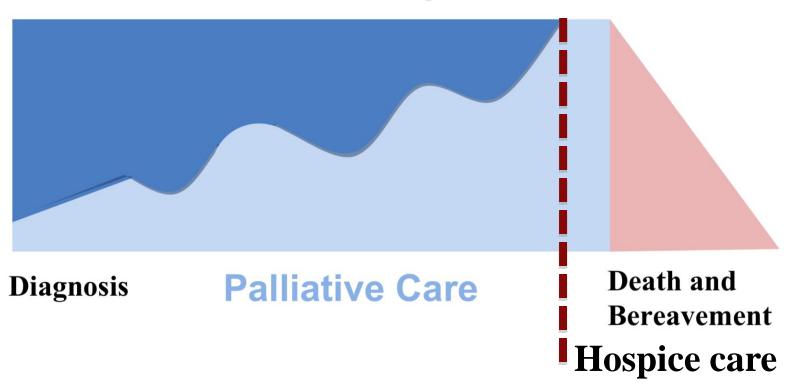


Home



Timing of Hospice Care

Disease-Directed Therapies



Hospice Eligibility

- Patients do not have to be "DNR"
- Patients do not give up their PCP or specialist primarily directing their care
- Patients cannot "use up" their hospice eligibility
- Patients who live alone can enroll in hospice
- Patients can be remain on hospice while they're rehospitalized
- Prognosis is thought to be 6 months or less if the disease takes its usual course...

Hospice Benefits

- Skilled team of nurses, health aide, social worker, chaplain and volunteers cares for patients at home
- All medications related to the terminal illness, oxygen, and durable medical equipment (a hospital bed, for example) are included and delivered to the home
- Telephone support is available 24/7 from skilled nurses, with extra home visits as needed
- Support for the family for 13 months after the death

Websites



- www.palliativedoctors.org
 - AAHPM website
- www.cancer.net
 - o the ASCO patient website
- www.cancercare.org
 - o on line, phone, and face-to-face SW support
- www.getpalliativecare.org
 - CAPC website
- LBBC

Books



- Abrahm JL. A Physician's Guide to Pain and Symptom Management, 2nd Edition, Johns Hopkins University Press, 2005.
- Cassell E: The Nature of Suffering and the Goals of Medicine. 2nd edition,
 Oxford University Press, New York, 2004
- Cassell E: The Nature of Healing. Oxford University Press, New York, 2013
- Frankl VE: Man's search for meaning; 3rd edition; Simon and Shuster, NY
 1984
- Miaskowski C, Cleary J, Burney R, et al. Guideline for the Management of Cancer Pain in Adults and Children, APS Clinical Practice Guidelines Series, No.3. Glenview, Ill.; American Pain Society, 2005

Palliative Care

- Comfort
- Communication
- Continuity

