

The Role of Palliative Care in the Continuum of Cancer Care

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The Good News in Cancer Care

- **New and more effective treatments are being developed regularly**
- **Cure rates are increasing**
- **Mortality rates are declining**
- **Longer life expectancy even when cancer is not curable**

Continuing Challenges

- **1.5 million new cancer cases projected for 2009 in the US.**
- **Over 500,000 deaths from cancer are predicted in 2009**
- **Patients with cancer still suffer -**
 - **Even if the cancer is ultimately curable**
 - **Especially if it is not**
- **What constitutes successful care for these patients?**

Goals of Medicine in the 16th Century

- To cure sometimes
- To relieve often
- To comfort always

What Has Changed During the Past 5 Centuries?

- **We focus on cure**
- **We still cure only sometimes.**
- **We now have the knowledge/tools to relieve almost always.**
- **Do we comfort always?**

Does It Matter?

**Does good medical care
still need to involve all these
components?**

... The alleviation of suffering is the warrant of medicine and its test of adequacy ...It is a test that contemporary medicine fails despite the brilliance of its science and its awesome technological power.

The Problem of Pain

- Many patients receive inadequate treatment for pain
- 50% of hospitalized terminal patients suffered moderate to severe pain at least half the time during the last few days of life.

*SUPPORT Study, JAMA 1995; 274:1591-1598

Challenges to Successful Pain Management

- **Potential for opioid abuse**
- **Regulatory issues**
- **Neurophysiologic response to anti-nociceptive measures**
- **Opioid-induced hyperalgesia**
- **Subjective nature of pain**

Believe the Patient?

For adult humans, the distress we describe as pain usually reflects a combination of:

- Nerve impulses arriving in the brain from the peripheral nervous system
- Crosslinking connections to centers of emotion
- Cortical interpretation of the meaning of the pain impulses.

Understanding Pain Sources

- **Pain is always a subjective experience.**
- **As healthcare professionals, we need to:**
 - **Listen to the patient's description of pain or suffering**
 - **Attempt to understand the source(s) of the pain**
 - **Offer treatments that address the major sources of pain and suffering**

Frequency of the Most Prevalent Symptoms in Advanced Cancer

Symptom % of patients

cachexia 72
pain 71
anorexia 65
xerostomia 54
asthenia 50
dyspnea 48

Symptom % of patients

constipation 47
cough 47
depression 47
nausea 40
vomiting 37
insomnia 32

Twycross, 1986, Ventafridda, 1990; Portenoy, 1994; Seamark, 1996, NG, 1998; Walsh, 2000

Symptoms In Hospice Patients

	<u>Frequency</u>	<u>Level of Distress</u> <u>(Scale 1-4)</u>
Lack of energy	95%	3.3
Pain	82%	2.2
Lack of Appetite	81%	2.2
Difficulty Concentrating	70%	2.2
Drowsiness	74%	2.0

Reported from 67 patients in the last assessment before death. Sadness (51%), sexual dysfunction (63%), change in self-image were earlier concerns.

Kutner, JS et al UCHSC, Denver CO. PoPCRN Study

Kutner, JS et al J. Pain & Symptom Mgt 21(6): 473-80, 2001

What is Suffering?

- **Suffering occurs when there is a threat to an individual's personhood.**
- **When an individual's intactness as a person is undermined.**
- **May involve injury or threat to defining relationships, future, dreams, self-esteem, identity or roles.**

The Complexity of Human Suffering

**The patient's interpretation of the
meaning of the disease or
symptoms may amplify the distress
and lead to suffering.**

Suffering

- **“Suffering may occur in the absence of any [physical] symptoms whatsoever, e.g. when one is forced to witness helplessly the pain of a loved one.**
- **Indeed, helplessness itself may be a source of suffering.”**

Sculptor, Age 35

- Breast cancer...treatment...disfigurement
.....*suffering.*
- Oophorectomy...hirsute, obese and no
libido*suffering.*
- Pathological fracture...disagreement about
sx management*suffering.*

Suffering in Life-Threatening Illness

- **Multiple sources of suffering:**
 - Physical distress
 - Pain, nausea, fatigue, dyspnea, weakness, anorexia
 - Emotional suffering
 - Depression, anxiety, fear, regrets, sadness
 - Social suffering
 - Loneliness, isolation, fear of being a burden or abandoned
 - Spiritual distress
 - Guilt, fear of the future, loss of hope and meaning

Treatment of Suffering

- **Most pain and other symptoms can be managed with use of effective medications.**
- **Identifying and caring for emotional, social and spiritual suffering can be more time-consuming.**
- **Sometimes physical symptoms are amplified by other sources of suffering.**

**“...Doctors do not treat
diseases or symptoms,
they treat patients.”**

Cassell 2004 p19

What do Cancer Patients Need?

- **Assurance symptoms can be managed**
- **Information about the disease, treatment and care options**
- **Support; a sense of being understood**
- **Hope – based on a realistic understanding of their disease**
- **A safe place to process and suffer**

The Search for Connection

“ Cancer is isolating, and the isolation can hurt far more than the treatment. Suddenly, you, the person with cancer, find yourself on one side of the wall, the sick side. Everyone else in your world is on the other side of that wall, the normal side.”

Jacquelyn Johnson 1987

Treatment of Suffering

- Requires more than the correct pharmaceutical agents.
- Requires professionals who will seek to:
 - understand the sources of the suffering
 - attend to the varied needs of the suffering patient.

**We recognize
the needs of suffering patients
often exceed the time
available to care for them.**

**Would it help to have a
team of professionals
with a variety of skills to
manage the needs
of the whole person?**

Palliative Care

- **Care delivered by an interdisciplinary team trained to address various types of suffering.**
- **May be provided anytime in the course of a life-limiting illness.**
- **Goal is to relieve suffering in people with life-limiting illnesses**
- **Focuses on providing comfort and hope whether or not cure is possible.**

Palliative Medicine

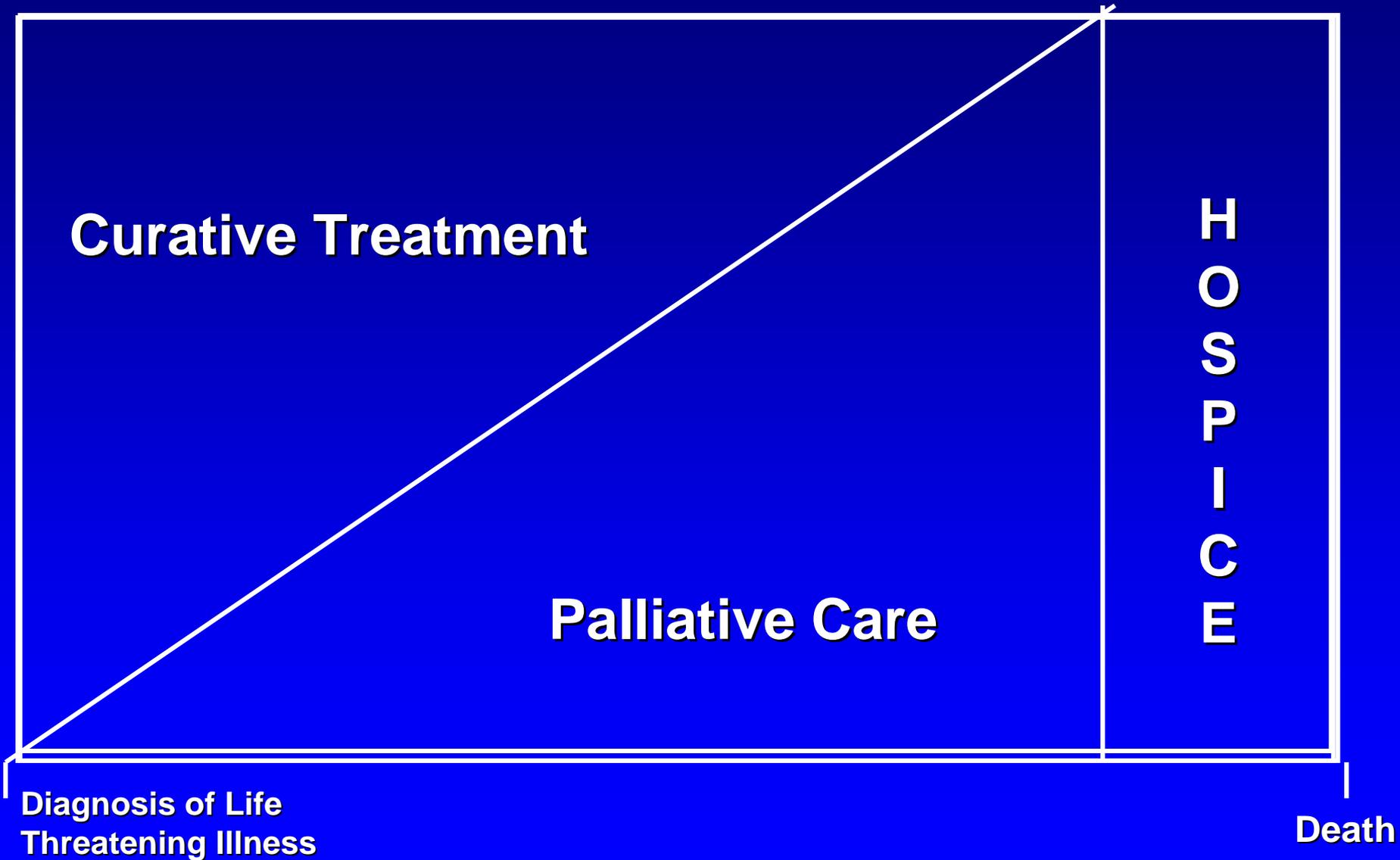
- **A new subspecialty of medicine – first recognized by the ABMS in Sept 2006**
- **Primarily based in hospitals or outpatient clinics.**
- **Usually a consulting service**
- **Physician billing is the only source of revenue.**

**What is the difference
between Palliative Care and
Hospice?**

Hospice

- **Also involves an interdisciplinary team skilled in management of symptoms and suffering**
- **Focuses on the final months of life.**
- **Primarily provided at the patient's residence.**
- **Medicare Part A pays hospice a per diem rate.**
 - Hospice pays for all services, drugs, treatment and equipment related to terminal diagnosis.**
- **Eligibility is defined by Medicare**

End of Life Care Continuum



Determining Hospice Eligibility

- 1. Does the patient have a life-threatening illness?**
- 2. Would you be surprised if the patient died within 6 months?**

Myths About Hospice

1. Hospice is about dying.

-Its about helping people live until they die

2. Hospice means there is nothing more that can be done.

-There's always more we can do.

3. Hospice is only important in the last few days of life.

-It often takes months to complete the final steps of life and find peace.

Components of End-of-life Care

1. Philosophical realignment with focus shifted from *finding a cure* to *finding peace*.
2. Treatment of symptoms and suffering
3. Support for completion of a life with dignity and acceptance.
4. Support in the process of finding new sources of hope and meaning.

When is Palliative Care Appropriate?

- A life-threatening or life-limiting diagnosis - regardless of the stage of the disease or treatment choices
- Suffering or challenging sx present
- Need to address:
 - a) Goals for life or treatment
 - b) Advance directive planning
 - c) Code status changes

What Can Palliative Care Offer?

- 1. Assistance in processing patient and family goals as disease progresses.**
- 2. Discussion of options**
- 3. Physical symptom management**
- 4. Support with emotional, spiritual, and social pain**
- 5. Support and education for family and care givers.**

Goals of Palliative Care

- 1. Empower patient/family decision-making process**
- 2. Optimal quality of life**
 - a) Relief of symptoms**
 - b) Maintaining function**
 - c) Preserving cognition**
- 3. Support in finding meaning and peace at each stage of life**

Models for Palliative Care in Treatment of Cancer

- Oncologist manages symptoms; oncology nurses support emotional needs.**
- Consult palliative care team for sx management or EOL discussion for selected patients while hospitalized.**

Models for Palliative Care in Treatment of Cancer

- Referral of selected patients to Palliative Care clinic.**
- Palliative care team based in cancer center or large oncology office**
- All patients with new cancer diagnosis seen by palliative care.**

Models for Palliative Care in Treatment of Cancer

- **Screening tools used to identify all patients who could benefit from palliative care.**
- **Facilitated support groups**
- **Nurse navigators**

Myth #1

**We should do
whatever we can
to prolong life.**

The Truth

**Sometimes our best
efforts to help just
prolong suffering**

**There often comes a time
when quality of life counts
for more than quantity.**

Myth #2

Once there's "no hope",
you might as well
get it over with quickly.

What Can We Offer Suffering Cancer Patients?

- 1. More effective palliative interventions**
- 2. Increased knowledge about symptom management**
- 3. Increased resources to support patients**

Opportunities for Healing When Cure Isn't Possible

“The aim of healing is not to be cured.

The aim of healing is not to survive.

The aim of healing is to become whole.”

Robert Twycross, 2004

Focusing on the Things that Really Matter

- **Quality-of-life matters when quantity is limited.**
- **Remaining time and energy should focus on things that matter to the individual:**
 - **Completing goals, bonding with loved ones**
 - **Finding peace and meaning**
 - **Saying the things to loved ones that don't get said in the normal course of life**

End-of-Life Completion: The Messages that Matter

“I love you”

“Forgive me”

“I forgive you”

“Thank you”

“Good-bye”

Man Aged 39 with AIDS

- “This last part of my life could have been very unpleasant, but it wasn’t. In many ways, it has been the best part of my life. I’ve had the opportunity to get to know my family again, a chance that few people have...”

Meaning in Suffering

A husband writes of his wife's illness:

“The suffering of a long and terminal illness is not all waste. Nothing that creates such tenderness can be all waste.”

Elisabeth Kubler-Ross

- **“Those who have the strength and the love to sit with a dying patient in the silence that goes beyond words will know that this moment is neither frightening nor painful, but a peaceful cessation of the functioning of the body.”**

- **“You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die.”**

*– Dr. Cicely Saunders, Founder of St Christopher’s Hospice,
London, 1967*

“Dying does not have to be horrifying. Pain can always be alleviated. Relief from physical distress is the first priority, but it is not the ultimate goal. Beyond morphine and skilled medical care it is possible to attend the dying in ways that honor and even celebrate their lives.”

Ira Byock, M.D.

Recommended Reading

1. Cassell, Eric J. The Nature of Suffering and The Goals of Medicine, 2nd Edition, Oxford University Press, Inc., NY, 2004
2. Groopman, Jerome. The Anatomy of Hope – How People Prevail in the Face of Illness, Random House, Inc., NY 2004
3. Byock, Ira, MD, Dying Well, The Berkley Publishing Group, NY, 1997
4. Twycross, Robert, MD, Introducing Palliative Care, Third Edition, Radcliffe Medical Press Ltd., UK, 1999