Palliative Care
Impact on Patients with Breast Cancer

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Board Certified in Hospice and Palliative Care
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What do We Know?
Cancer as a Disease Experience

- Survival rates are increasing
- Breast cancer is transforming from an acute life threatening illness into a chronic illness
- Focus naturally being placed on facilitating quality of life.
How Common is This Cancer?

Number of New Cases and Deaths

<table>
<thead>
<tr>
<th>Common Types of Cancer</th>
<th>Estimated New Cases 2016</th>
<th>Estimated Deaths 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Breast Cancer (Female)</td>
<td>246,660</td>
<td>40,450</td>
</tr>
<tr>
<td>2. Lung and Bronchus Cancer</td>
<td>224,390</td>
<td>158,080</td>
</tr>
<tr>
<td>3. Prostate Cancer</td>
<td>180,890</td>
<td>26,120</td>
</tr>
<tr>
<td>4. Colon and Rectum Cancer</td>
<td>134,490</td>
<td>49,190</td>
</tr>
<tr>
<td>5. Bladder Cancer</td>
<td>76,960</td>
<td>16,390</td>
</tr>
<tr>
<td>6. Melanoma of the Skin</td>
<td>76,380</td>
<td>10,130</td>
</tr>
<tr>
<td>7. Non-Hodgkin Lymphoma</td>
<td>72,580</td>
<td>20,150</td>
</tr>
<tr>
<td>8. Thyroid Cancer</td>
<td>64,300</td>
<td>1,980</td>
</tr>
<tr>
<td>10. Leukemia</td>
<td>60,140</td>
<td>24,400</td>
</tr>
</tbody>
</table>

Female breast cancer represents 14.6% of all new cancer cases in the U.S.
US Cancer Prevalence: 15 Million+

Approximately one-fourth are breast cancer survivors

- Female breast: 23%
- Prostate: 8%
- Colorectal cancer: 8%
- Gynecologic: 3%
- Other genitourinary: 7%
- Hematologic: 6%
- Melanoma: 3%
- Lung: 21%
- Other: 15%
Statistics at a Glance
Breast Cancer

<table>
<thead>
<tr>
<th>Estimated New Cases in 2016</th>
<th>246,660</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of All New Cancer Cases</td>
<td>14.6%</td>
</tr>
<tr>
<td>Estimated Deaths in 2016</td>
<td>40,450</td>
</tr>
<tr>
<td>% of All Cancer Deaths</td>
<td>6.8%</td>
</tr>
</tbody>
</table>

Percent Surviving 5 Years
89.7%
2006-2012

5 Year Relative Survival by Stage at Diagnosis: Female Breast Cancer

Survival Rates:
- Localized: 98.8%
- Regional: 85.2%
- Distant: 26.3%
- Unstaged: 52.5%

Source:
Estimated Complete Prevalence Counts on 2015. NCI, DCCPS, released
Goals of People with Cancer

• Old days
  – Get affairs in order
  – Comfort
  – Say good bye

• Now a days
  – Continue work, like interests, hobbies
  – Maintain sense of self and identity
  – Continue to play important family roles
Challenges of Cancer Survivorship

• At risk for late physical effects of their primary treatment

• Highly symptomatic:
  – Average in hospital patient has 10 distressing symptoms
  – Average outpatient has 5 distressing symptoms

• Cancer survivors have increased burden of illness:
  – Days lost from work, inability to work
  – Self Identity
  – Need for help with daily activities
  – Physical symptoms

The Relationship of Symptoms to Quality of Life

• Quality of Life = sense of well being
• Physical Pain is common but not inevitable
• Fatigue, GI upset, and psychosocial problems are more prevalent, but **PAIN is the #1** feared aspect of cancer for most patients
• Patients want to be seen as a **WHOLE**
• Maintaining dignity: preserving autonomy, spirituality, and self esteem
Palliative Care
Interdisciplinary Team

• Can occur at any point in the journey from early stage diagnosis to end of life care.

• Complex symptom management
  • Pain, Dyspnea, GI Symptoms, Anxiety, Depression, Delirium

• Communication/collaboration with patient and families in overcoming barriers:
  • Support System
  • Decision making (Family conflict, unrealistic expectations)
  • Mobilization of resources to meet their goals for care
  • Advance care planning

• Grief and Loss Caregivers

• Spiritual Support and Cultural Competency
Palliative Care
Comfort Level and Expertise

Complex symptom management

- Pain
- Breathlessness/Dyspnea
- GI Symptoms:
  - Nausea, Vomiting, Constipation, Diarrhea
- Anxiety, Depression, Insomnia
- Anorexia
- Non-operable Obstruction
- Terminal Delirium
## Symptoms Associated with Metastatic Breast Cancer

<table>
<thead>
<tr>
<th>Metastatic Site</th>
<th>Associated Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>Fatigue, Sleeping difficulties, Depression</td>
</tr>
<tr>
<td>Bone</td>
<td>Pain, hypercalcemia, pathologic fracture, loss of mobility</td>
</tr>
<tr>
<td>CNS (Brain, leptomeningeal, spine)</td>
<td>Headache, confusion, weakness, seizures, speech impairment</td>
</tr>
<tr>
<td>Skin</td>
<td>Infection, bleeding, pain</td>
</tr>
<tr>
<td>GI (liver, ascites, peritoneum)</td>
<td>Nausea, vomiting, diarrhea, early satiety, jaundice,</td>
</tr>
<tr>
<td>Pulmonary</td>
<td>Pain, dyspnea, hemoptysis, cough</td>
</tr>
<tr>
<td>Lymph Nodes</td>
<td>Brachial plexopathies, pain</td>
</tr>
</tbody>
</table>

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**The Marks of Breast Cancer**

- **Gamma Knife Scars**: November 2010
- **First surgery**: 2011
- **Chemotherapy port placed**: April 2011
- **Lung biopsy**: July 2013
- **Right Hip Repair plate & screws**: October 2010
- **Repair Hip Fracture Compression screws**: August 2013
- **2nd surgery**: 2012

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**The Marks of Breast Cancer**

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“Disease occurs in organs; illness, which is the individuals experience of pain, occurs in people”

Geoffrey Dunn, MD, FACS
Board Certified in Palliative Care
Palliative Care

Comfort Level and Expertise

**Recognition of Psycho-Social Issues**

- **Concerns**
  - Relationship tension
  - Caregiver burden
  - Coping skills
  - Effect on children
  - Financial
  - Loss of independence, control

- **Emotions**
  - Fear
  - Anxiety
  - Anger
  - Sadness
  - Hopelessness
  - Loneliness
What do patients know about their disease *JAMA 2008*

- Cohort 332 terminally ill cancer pts who died a median of 4.4 months after enrollment.
- 123/332 (37%) patients reports having EOL Discussion with their physician at baseline.

**WHY?**
- Pts frequently misunderstand or fail to recall
- Doctors and patients ambivalence about talking about death
- Communicate euphemistically or delay discussions

*Wright A, et al, JAMA 2008*
Palliative Care

Goals of Care in Advanced Disease

- Cannot predict who will survive serious or critical illness and who will not
- Neither clinicians nor patients/families can make an abrupt shift from one exclusive set of care goals to another
- Patients and families want both disease-modifying treatment and palliative care
What Do Patients With Serious Illness Want?

- Pain and symptom control
- Relief of burdens on family
- Strengthen relationships with loved ones
- Achieve a sense of understanding and control
- Avoid a premature death
- Avoid inappropriate prolongation of the dying process

Barriers to Palliative Care

- Lack of knowledge
- Unwillingness to acknowledge advanced stage of illness
- Fear of taking away hope
- Uneasiness with evolving clinical situation

“Don’t freak out—it’s just a save-the-date.”
Role of Palliative Provider

• Address fears and concerns
• Help the patient and family
  – Elucidate their values
  – Understand the facts and dispel misconceptions
• Establish realistic goals of care
  – What patient experiences ≠ what onlookers see
• Discuss all options: risks versus benefits, and conservative options
• Assure comfort and non-abandonment
• Discuss advance care planning
Address fear of loss of control

- Select surrogate:
- Prepare advance directives
- Make a commitment to help patient maintain as much control as possible
- Clarifying Goals of care—whose goals we are trying to achieve
  - Medical team?
  - Family?
  - Patient?
What if’s??

• Who knows you the best and would be your voice
• How do I maintain my independence and control when I can’t speak for myself.
• Most American: 88% feel comfortable discussing issues relating to dying
• Yet only 42% have a living will.
What is an advance health care directive?

• A tool to communicate your choice
• A legal document with written instructions about future medical care
  – Only used if you are seriously ill and unable to speak for yourself
  – Includes Living will and Medical Power of Attorney
• Who has an Advance Directives?
  – 33% of cancer patients; *Spring: J Palliat Med. 2000*
Living will

• Legal document with your wishes about medical treatment
• You choose what you DO want
• What you DO NOT want
• Life Sustaining treatment, artificial nutrition/hydration, CPR, hemodialysis, organ donation
Medical Power of Attorney

• Legal form that authorizes a designated person to speak FOR you regarding medical decisions.

• Advantages:
  – You are in charge in making your own decisions
  – Documents can be changed at anytime
  – DO not need an attorney
How can an Advance Directive Help Me?

- Think about the care you want ahead of time.
- Have peace of mind because you wrote down your wishes.
- Help your loved ones. They don’t have to guess your wishes if you cannot tell them. And, they will have clear permission from you to speak your wishes.
Quality of Life with EOL Discussion

<table>
<thead>
<tr>
<th>EOL Discussion</th>
<th>No EOL Discussion</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Accept illness was terminal</td>
<td>• Received more aggressive medical care in final week of life</td>
</tr>
<tr>
<td>• Prefer medical treatment focused on comfort versus life extending therapies</td>
<td>• Bereaved Caregivers:</td>
</tr>
<tr>
<td>• Complete DNR</td>
<td>– Worse Quality of Life</td>
</tr>
<tr>
<td>• Were not associated with increased psychological distress</td>
<td>– More regret</td>
</tr>
<tr>
<td></td>
<td>– Higher risk of developing major Depressive Disorder</td>
</tr>
</tbody>
</table>
## POLST FORM

**Physician Order for Life Sustaining Treatment**

<table>
<thead>
<tr>
<th>TABLE 1</th>
<th>Differences between POLST and advance directives</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHARACTERISTICS</td>
<td>POLST</td>
</tr>
<tr>
<td>Population</td>
<td>For the seriously ill</td>
</tr>
<tr>
<td>Time frame</td>
<td>Current care</td>
</tr>
<tr>
<td>Who completes the form</td>
<td>Health care professionals</td>
</tr>
<tr>
<td>Resulting form</td>
<td>Medical orders (POLST)</td>
</tr>
<tr>
<td>Health care agent or surrogate role</td>
<td>Can engage in discussion if patient lacks capacity</td>
</tr>
<tr>
<td>Portability</td>
<td>Provider responsibility</td>
</tr>
<tr>
<td>Periodic review</td>
<td>Provider responsibility</td>
</tr>
</tbody>
</table>

POLST = Physician Orders for Life-Sustaining Treatment
HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTHCARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

First follow these orders, then contact physician. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. POLST complements an Advance Directive and is not intended to replace that document.

A. CARDIOPULMONARY RESUSCITATION (CPR):
   - If patient has no pulse and is not breathing.
   - If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.

   ☐ Attempt Resuscitation/CPR (Selecting CPR in Section A requires selecting Full Treatment in Section B)
   ☐ Do Not Attempt Resuscitation/DNR (Allow Natural Death)

B. MEDICAL INTERVENTIONS:
   - If patient is found with a pulse and/or is breathing.

   ☐ Full Treatment – primary goal of prolonging life by all medically effective means.
   - In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.
   - ☐ Trial Period of Full Treatment.

   ☐ Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.
   - In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.
   - ☐ Request transfer to hospital only if comfort needs cannot be met in current location.

   ☐ Comfort-Focused Treatment – primary goal of maximizing comfort.
   - Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. Request transfer to hospital only if comfort needs cannot be met in current location.

   Additional Orders:

C. ARTIFICIALLY ADMINISTERED NUTRITION:
   - Offer food by mouth if feasible and desired.

   ☐ Long-term artificial nutrition, including feeding tubes. Additional Orders:
   - ☐ Trial period of artificial nutrition, including feeding tubes.
   - ☐ No artificial means of nutrition, including feeding tubes.

D. INFORMATION AND SIGNATURES:

   Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker
   - ☐ Advance Directive dated ______ _, available and reviewed → Healthcare Agent if named in Advance Directive:
   - ☐ Advance Directive not available
   - ☐ No Advance Directive

   Signature of Physician
   - My signature below indicates to the best of my knowledge that these orders are consistent with the patient’s medical condition and preferences.
   - Print Physician Name: ____________________________
   - Physician Signature: ____________________________
   - Date: ____________________________
   - Physician Phone Number: ____________________________
   - Physician License Number: ____________________________

   Signature of Patient or Legally Recognized Decisionmaker
   - I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the patient who is the subject of the form.
   - Print Name: ____________________________
   - Relationship: (write self if patient)
   - Signature: ____________________________
   - Date: ____________________________
   - Mailing Address (street/city/state/zip): ____________________________
   - Phone Number: ____________________________
   - Office Use Only

SEND FORM WITH PATIENT WHenever TRANSFERRED OR DISCHARGED

*Form versions with effective dates of 1/1/2009 or 4/1/2011 are also valid
It’s About How you LIVE
Integrative Palliative Care

• Disparity between the way people die versus the way they want to die
• Maintaining Dignity Becomes Key
• 2 distinct needs:
  – To Know and Understand
  – To Feel known and Understood
• Integrative Care Model:  (Temel; NEJM 2010)
  – Better QOL
  – Higher satisfactions
  – Fewer depressive symptoms
  – Less unnecessary invasive measures in EOL
  – HIGHER SURVIVAL
Project ENABLE
Educate, Nurture, Advise, Before Life Ends
Palliative Care versus Hospice

Palliative Care

Hospice
Old versus New Approach

Old

Life Prolonging Care

Medicare Hospice Benefit

Disease Progression

Diagnosis of serious illness

Death

New

Life Prolonging Care

Palliative Care

Hospice Care

Bereavement
Hospice Care

1. Palliative care for patient at end of life
   • *Death would be more likely be < than 6 months, if the illness runs it’s expected course*
   • *Determined by two physicians*
2. A benefit elected by the patient/family
3. Primarily focuses on symptom support and comfort
4. Available in all patient settings - but primarily provided in the home
5. Bereavement support for family
<table>
<thead>
<tr>
<th>Palliative Care</th>
<th>Hospice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does not require a prognosis of less than 6 months</td>
<td>Requires a prognosis of 6 months or less certified by two physicians</td>
</tr>
<tr>
<td>Curative/aggressive measures can be maintained</td>
<td>Goal of comfort care versus curative/aggressive intent</td>
</tr>
<tr>
<td><strong>Physician managements of symptoms.</strong></td>
<td>Services provided by interdisciplinary team</td>
</tr>
<tr>
<td>Interdisciplinary team for psychosocial and spiritual support</td>
<td>Care can be provided anywhere and operate 24/7</td>
</tr>
<tr>
<td>Provide counseling for goals of care, advance care planning.</td>
<td>Bereavement care</td>
</tr>
</tbody>
</table>
Role of Hospice

**Will be able to Do:**
- Pain medications: oral, IV, SQ
- Equipment
- Nursing care, bathing
- Respite care
- Continuous care when patient actively dying or having crisis
- Does not have to be DNR in order to enroll
- Inpatient Hospice Care

**Will Not Be Able to Do:**
- Chemotherapy
- Blood transfusions
- Long term TPN nutrition
- Long term IVF Hydration
- Long term ionotrope therapy
- *Provide 24 hour care
- *Lab draws
- *XRT

*(certain exceptions)*
Goals of Hospice

- Offers a Familiar Environment
- Provides Comprehensive Plan with Healthcare Professionals
- Offers personalized care and support
- Give patients a Sense of Dignity
- Respects Patients Wishes
- Lessens Financial Burdens
- Provides Family Counseling
The most beautiful people we have known are those who have known defeat, known suffering, known struggle, known loss, and have found their way out of the depths. These persons have an appreciation, a sensitivity, and an understanding of life that fills them with compassion, gentleness, and a deep loving concern. Beautiful people do not just happen.”

Elisabeth Kubler-Ross