The Growing Landscape of Palliative Care

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Health Care, Education and Research
Disclosures

• Speaker’s Bureaus
  – Genentech
  – Insys
Harry Hynes, MD 1935-2000

• A native of Ireland who received his MD degree from the National University of Ireland in Dublin
• Trained in the US at the Mayo Clinic in hematology/oncology
• Established his oncology practice in Wichita Kansas and led the Wichita CCOP
• In 1993, Dr. Hynes received a Certificate of Merit from the National Cancer Institute for “Fostering the Growth of Clinical Trials Research in the Community.”
Overview

• Palliative Care Background and Statistics
• Key Considerations in Palliative Care Practice and Research
• Global Lessons
Our Best Teachers
Most of us have cared for a loved one with a chronic or life-limiting illness. Palliative care is personal!
Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

WHO, 2002
4 Decades of Palliative Care

First palliative care service in US in 1985 – Wayne State
First palliative medicine program in US in 1987 – Cleveland Clinic
Palliative Care Trajectory Continuum?

Health Status

Time

Crisis

Decline

Death
Palliative Care Continuum

- 1985 – dx. breast cancer
- 1995 – bone metastases
- 1998 – chest wall recurrence
- 2005 – vaginal wall recurrence – Her-2+
- 2008 – tumor around spinal cord
- 2009 - soft tissue mass abdomen
- 2010 – lung and liver metastases
- Died in November 2011

- Nausea and vomiting with oral opioids
- Bone pain
- Abdominal (visceral) pain
- Osteonecrosis of the jaw
- Herpes zoster and post-herpetic neuralgia
- Fatigue, weakness, lack of energy
- Anorexia
Societal View of Palliative Care

DEATH = FAILURE
Never Give Up

… fought bravely until the very end. Never let it be said that she lost her battle, for to lose is to give up and she never did.
Key Considerations

Communication & Shared Decision Making

- ACP
- Treatment

Palliative Care Delivery Models

- Inpt
- Clinic
- Home
- Tele-med

Pain & Symptom Management

- Physical
- Psychological
- Social
- Spiritual

Technology

- ePROs
- SCPs
Communication and Shared Decision Making

How to best communicate?
When to communicate?
How to communicate with diverse populations?
Palliative Care Delivery Models

- **Where?**
  - We have to go to where the patients are!
- **Which patients?**
- **How often? Dose?**
- **Which team members?**
  - Physician or Advanced Practitioner
  - Nurse
  - Social Worker
  - Chaplain
  - Others?
- **Model replication**
Early Palliative Care Improves Survival

A221303: Randomized study of early palliative care integrated with standard oncology care versus standard oncology care alone in patients with incurable lung or non-colorectal gastrointestinal malignancies
Rural Palliative Care Models

How can we reach remote and disparate populations?
Navigating the Transition From Cancer Care to Primary Care: Assistance of a Survivorship Care Plan

Jeannine M. Brant, PhD, APRN, AOCN®, FAAN, Karyl Blaseg, RN, MSN, OCN®, Kathy Aders, RN, BSN, Dona Oliver, RN, MSN, MBA, Evan Gray, and William N. Dudley, PhD

Brant is an oncology clinical nurse specialist and nurse scientist. Blaseg is director of cancer services, integrative medicine, and supportive care. Aders is a patient care navigator, and Oliver is a data analyst, all at the Billings Clinic in Montana. Gray is a customer services representative at CenterPoint Human Services in Winston-Salem, NC, and Dudley is a professor in the Department of Public Health Education at the University of North Carolina in Greensboro.

No financial relationships to disclose.

Purpose/Objectives: To examine symptom and quality-of-life (QOL) trajectories in breast cancer and lymphoma survivors enrolled in a survivorship navigation intervention and to explore patient, caregiver, and primary care provider (PCP) satisfaction with receipt of a survivorship care plan (SCP).

Design: Prospective, cohort, longitudinal.

Setting: The Billings Clinic, an integrated cancer center in Montana.

Sample: 67 patients with breast cancer or lymphoma who recently completed cancer treatment, along with 39 of their caregivers and 23 PCPs.

Methods: Data collection at one, three, and six months by the Functional Assessment of Patient Health
Complexity of Symptom Science
What Should We Study?

- Asthenia/Fatigue
- Anorexia
- Cognitive Impairment
- Constipation
- Diarrhea
- Dyspnea
- Lymphedema

- Pain
- Peripheral Neuropathy
- Nausea and Vomiting
- Sedation and Confusion
- Sexual Dysfunction
- Xerostomia
DISCUSSION PAPER

Building dynamic models and theories to advance the science of symptom management research

Jeannine M. Brant, Susan Beck & Christine Miaskowski

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Antecedents

Demographics:
- Age, gender, marital status, race, role, education, SES, genetics, developmental level

Disease Characteristics:
- Type of cancer, stage, Tx., comorbidities, Biomarkers, genomics

Individual Characteristics:
- Knowledge, values, Past experiences, ACE, Coping skills, self-care, Spirituality, support

Environment:
- Physical, Social, Cultural, Lifestyle

Symptom Experience
- Temporality
- Intensity
- Quality
- Distress
- Appraisal

Symptom Trajectory
- Time 1
- Time 2
- Time 3
- Time x

Interventions
- Relationships
- Interaction
- Patient
- Family
- Healthcare
- Team

Consequences
- QOL
- Function
- Adjustment
- Costs
- Morbidity
- Long-term Survival
- Meaning Of Health

Adverse Childhood Experiences
- ACEs: Abuse & Neglect

Symptom Experience
- Symptom 1 Intercept
- Symptom 2 Intercept
- Symptom 3 Intercept
- Symptom 1 Slope
- Symptom 2 Slope
- Symptom 3 Slope

Symptom Trajectory
- Symptom Experience
- Interventions
- Consequences

Symptom Experience
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Adverse Childhood Experiences
- ACEs: Abuse & Neglect
Symptom trajectories during chemotherapy in outpatients with lung cancer colorectal cancer, or lymphoma

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A B S T R A C T

Keywords: Chemotherapy
Symptoms

Purpose: Pain, depression, distress, fatigue, and sleep disturbance are common symptoms in oncology patients, but little data are available that examine the trajectories of these symptoms during chemotherapeutic interventions.

Graphs and tables showing symptom trajectories over time for different series.
Systematic Reviews of Symptoms

- Oncology Nursing Society Putting Evidence into Practice
  - Systematic reviews of 20 different symptoms
  - Identify gaps in science
  - Set directions for future research
- Clinical Journal of Oncology Nursing, June 2017 Issue – Pain Systematic Reviews

https://www.ons.org/practice-resources/pep
Cancer-Related Pain

Assessment and management with Putting Evidence Into Practice interventions

Jeannine M. Brant, PhD, APRN, AOCN®; FAAN; Linda H. Eaton, PhD, RN, AOCN®,
and Margaret M. Irwin, PhD, RN, MN

Chronic and Refractory Pain

A systematic review of pharmacologic management in oncology

Jeannine M. Brant, PhD, APRN, AOCN®, FAAN; Lisa Kelley, RN, OCN®, MS; Karen McLeod, MSN, RN, OCN®, CNS; Chao Yeh, PhD, RN,
and Linda H. Eaton, PhD, RN, AOCN®
Moonshot – Call for Symptom Management Research

Symptom management research.

- Support research to accelerate development of guidelines for management of patient-reported symptoms to improve quality of life and adherence to treatment regimens.
Too Much to Do
Technology Can Help!

- Patient-reported Outcomes
- Shared Decision Making
- Supportive Care Plans
- Survivorship Care Plans
- Home-based Monitoring
Standards Driving PROs

• Quality Oncology Practice Initiative (QOPI)
• “Commission on Cancer (CoC)
• Oncology Care Model
  – 12 performance metrics include pain assessment/Mx,
    Depression screening, hospital admissions/ER visits
Meet Mary

• Rectal cancer survivor
• One year follow-up visit
  – Clinic initiated distress screening
  – Patient rated distress at “8” due to unpredictable diarrhea and inability to run
  – Did not report earlier – “small trade off for my life”
• Supportive Care Team
  – Nutritional consult
  – Anti-diarrhea agents
• Running again and reports a high quality of life
The use of a web-based system that allowed patients to report symptoms to their clinicians remotely was associated with benefits including improved quality of life (QOL) and longer overall survival (OS), a randomized single-center trial found.

Ethan M. Basch, MD, MPH, FASCO, of the University of North Carolina at Chapel Hill, presented the findings of the study (Abstract LBA2) at the Plenary Session on June 4. "This approach should be considered for inclusion as a part of standard symptom management," Dr. Basch said. The results of the study were published in the Journal of the American Medical Association simultaneously with the presentation.

Symptoms are common in advanced cancer, and symptom management is a cornerstone of oncology practice to alleviate suffering and avoid downstream complications. However, numerous hurdles inhibit patient reporting of symptoms, and previous research has shown that up to half of symptoms are not reported to clinicians, Dr. Basch said. Research has also shown that systemic symptom monitoring can help close this gap, and that patients are willing and able to self-report, even when they are ill or close to death.

The standard model for reporting symptoms is a reactive approach in which patients must take the initiative to remember and report their symptoms to health professionals, who can then take action to alleviate the symptoms, Dr. Basch noted. In a proactive model, e-reminders can be sent periodically to patients prompting them to report symptoms, which are then conveyed to health professionals through e-alerts.

Investigators at Memorial Sloan Kettering Cancer Center, where Dr. Basch was practicing when the study was conducted, hypothesized that allowing patients to self-report their symptoms through an online portal would permit physicians to intervene earlier, improving symptom management, and thus improving outcomes. They recruited patients receiving chemotherapy for metastatic breast, lung, genitourinary, or gynecologic cancers.

Patients were randomly assigned to receive either standard symptom monitoring or the intervention in which they could self-report 12 common symptoms before and between visits. Patients received weekly email reminders, and when they reported symptoms, email alerts were sent to nurses. Oncologists received printed reports at visits.
Supportive care plans: Harnessing technology and patient-reported outcomes to drive quality care across the cancer continuum

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Tracking Symptoms Over Time
Care Plan Recommendations

- Mean duration of patient participation: 9 weeks (range 1-32)
- Mean number of care plans: 3 (range 1-7)
- Mean number of unique recommendations: 6.6 (range 2-11)

n=51 patients with gynecologic cancers
Customizable Care Plans

DISTRESS & SYMPTOM MANAGEMENT

DISTRESS AND SYMPTOM MANAGEMENT

Side effects of cancer or its treatment can take over your daily life. Some may make you uncomfortable at best, while others may affect your ability to stick to your treatment. This care plan offers recommendations and actions you can take to help manage your side effects. It is important to discuss changes in your symptoms or new symptoms that develop with your health care team. They will work with you to eliminate them or reduce their effect on your daily life.

DISTRESS

AT RISK FOR CANCER-RELATED DISTRESS

Distress is common during treatment and after it has finished. It can affect your ability to cope and even to participate in your cancer care. Learn about distress and the activities that can help you reduce your risk.

- Find Local resources and supportive care services:
  - Online and telephone support resources. Online at: https://url.carewire.com/PDF/1000051.pdf
  - Read: Distress in People with Cancer. Read online: http://url.carewire.com/100077B

PRACTICAL CONCERNS

Identify resources to help you manage the practical matters that contribute to your cancer-related distress.

- Schedule: An appointment with an oncology clinical social worker to identify resources and develop a plan to manage the concerns contributing to your distress.
  - Contact: The American Cancer Society for local resources (such as transportation) and information about practical matters (such as work-related concerns) call 800-227-2345
  - Read: Dealing with Practical Matters. Read online: https://url.carewire.com/1000793

MILD PAIN

Your response indicates you are experiencing a mild level of pain without taking an opioid pain-relieving medication. It is helpful to use a non-steroidal anti-inflammatory drug (NSAID) or acetaminophen (Tylenol), plus another (adjunct) pain medication if your pain does not feel better.

Adjuvant pain medications are those usually used for pain and can include antidepressants, anti-seizure medications, muscle relaxants, sedatives or anti-anxiety medications.

- Avoid: NSAID medications (such as Naproxen [Aleve], celecoxib [Celebrex], ibuprofen [Motrin, Advil] etc. if you have a history of ulcers, cardiovascular disease and/or hypertension, kidney disease, bleeding disorders, pregnancy, or are taking other prescription or non-prescription medicines such as warfarin [Coumadin] or phenytoin [Dilantin], and/or cyclosporine.
  - Avoid: Acetaminophen with liver disease
  - Read: Cancer Pain. Read online: https://url.carewire.com/1000225

Learn about opioid medications for pain. Take a short-acting opioid pain-relieving medication as prescribed for pain control.

- Read: Opioid Pain Medications for Cancer Pain. Read online: http://www.webmd.com/pain-management/opioid-anaesthesia-for-chronic-pain

Use measures to prevent constipation if taking an opioid pain reliever medication. Constipation...
Recommendations for Research

• Shared Decision Making
  – ACP
  – Disparities
• Models of Care
  – Dose, Who, When
  – Rural Populations
• Symptom Science
  – Pain!
  – Nonopioid strategies
  – Nonpharmacologic modalities
• Technology
  – How to measure impact on symptoms, costs, hospital utilization
Global Palliative Care Landscape

• More than 29 million people died in 2011 in need of palliative care (WHO Global Health Estimates, 2011)

• 34% of these people died from cancer (WPCA Global Atlas of Palliative Care at the End of Life, 2014)

• Over 18 million died in pain and distress (www.TWHPCA.org)
Total opioid consumption (mg/capita)
2014

Sources: International Narcotics Control Board; World Health Organization population data
By: Pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Center, 2016
Pain Management in the Middle East: Building Capacity With Global Partners

Jeannine M. Brant, PhD, APRN, AOCN®, FAAN, Susie Newton, MS, APRN, AOCN®, AOCNS®, and Martha A. Maurer, PhD, MSSW, MPH

The Middle East (ME) is an economically diverse region that includes countries in Central Asia and Northern Africa. Regardless, cancer is a major health concern in the ME, and pain management is an essential component of cancer care across the disease trajectory. This column will provide background on opioid use for pain management in the ME and highlight the collaborative work of the Middle Eastern Cancer Consortium, Omran Cancer Association, and the Oncology Nursing Society to increase pain assessment and management capacity in the ME.

The Single Convention on Narcotic Drugs, the world’s population, which includes countries in Central Asia and Northern Africa, sets standards for opioid use. In the Middle East, cancer is a major health concern, and pain management is essential for quality care.

PALLIATIVE MEDICINE AND HOSPICE CARE

Holistic Total Pain Management in Palliative Care: Cultural and Global Considerations

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ABSTRACT

Pain is a significant symptom in patients with chronic and life-threatening illness. While pain is traditionally thought of as a physiological experience, total pain recognizes the interplay of psychological, cognitive, social, spiritual, and cultural factors that influence the pain perception and total experience. Comprehensive pain assessment and management are foundational goals within the scope of palliative care, and optimal management depends on addressing each domain of the total pain experience. An overview of the total pain experience is provided, and clinicians should consider psychological, cognitive, social, spiritual, and cultural aspects in as-
We are more similar than we are different

Thinking Differently in Global Health in Oncology Using a Diagonal Approach: Harnessing Similarities, Improving Education, and Empowering an Alternative Oncology Workforce.

Rodriguez NM1, Brant JM2, Pangarkar D1, Arroyo-Orellas L1, Bhadelia A1, de Lima Lopes Guir1, Knaufl FM1

Abstract
Cancer is a leading global cause of death, and diverse and minority populations suffer worse outcomes compared with white people from Western societies. Within the United States, African Americans and other blacks, Hispanics, Asians, and American Indians have lower cancer survival rates than whites. In the rest of the world, those from low- and middle-income countries have the greatest disparities, but even those from non-Western high-income countries such as Oman and the United Arab Emirates are diagnosed with cancer at later stages and suffer increased mortality. Although considerable differences exist among these populations, similarities and synergies are also apparent. Challenges can be very similar in reaching these populations effectively for cancer control to improve outcomes, and innovative strategies are needed to effectively make change. In this review, the authors discuss new approaches to the prevention and early detection of cancer as well as the implementation of programs in global oncology and put in evidence cultural similarities and challenges of different populations, highlighting strategies to improve cancer survival and quality care around the world through innovations in training and education, empowerment of an alternative workforce, and a diagonal approach to cancer care using case studies drawn from the authors’ work and experience.

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Free full text
Global Partners

Oncology Nursing Society (ONS)
American Society of Clinical Oncology (ASCO)
Middle East Cancer Association (MECC)
Oman Cancer Association (OCA)
Chinese Psychosocial Oncology Society (CPOS)

MECC - Prof. Michael Silbermann and daughter, Ronit
OCA - Dr. Wahid AlKharusi and wife, Madame Yuthar
CPOS – Dr. Lili Tang
Beijing, China
Liberating Structures

- Engage participants
- Every voice is heard
- Capacity building
- Engage in critical conversations
- Develop relationships
Palliative Care Global Leaders
Turning Places Into People