The Growing Landscape of Palliative Care

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Scientist, Billings Clinic

PI, Montana Cancer Consortium

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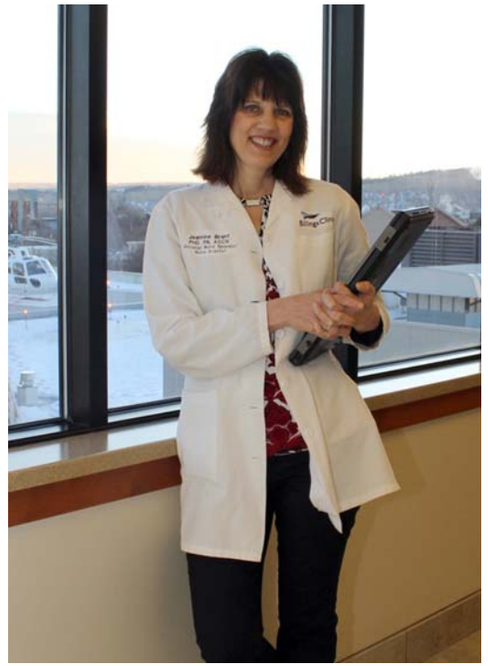

Health Care, Education and Research

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.”

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Overview

- Palliative Care Background and Statistics
- Key Considerations in Palliative Care Practice and Research
- Global Lessons

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Our Best Teachers

Our Personal Stories

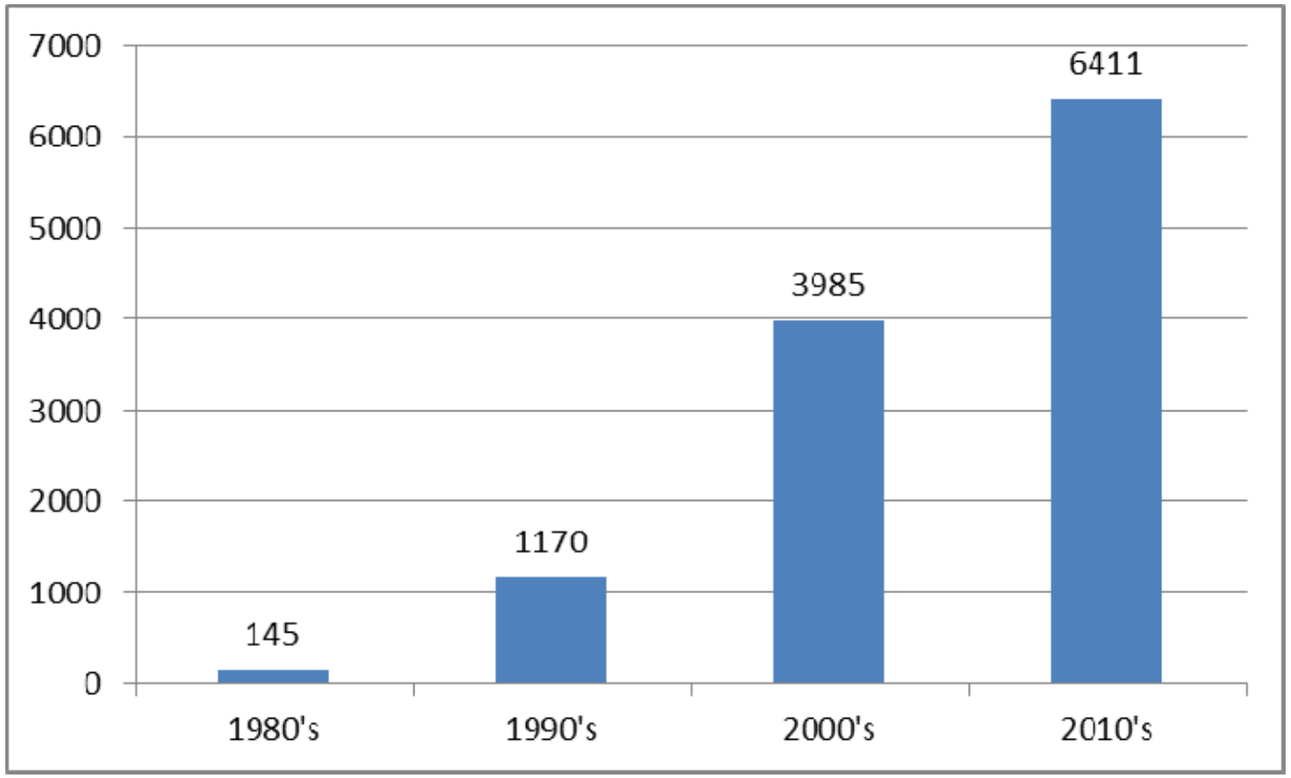
Most of us have cared for a loved one with a chronic or life-limiting illness. Palliative care is personal!

Definition of Palliative Care

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



Palliative Care in the title of the manuscript

First palliative care service in US in 1985 – Wayne State
First palliative medicine program in US in 1987 – Cleveland Clinic

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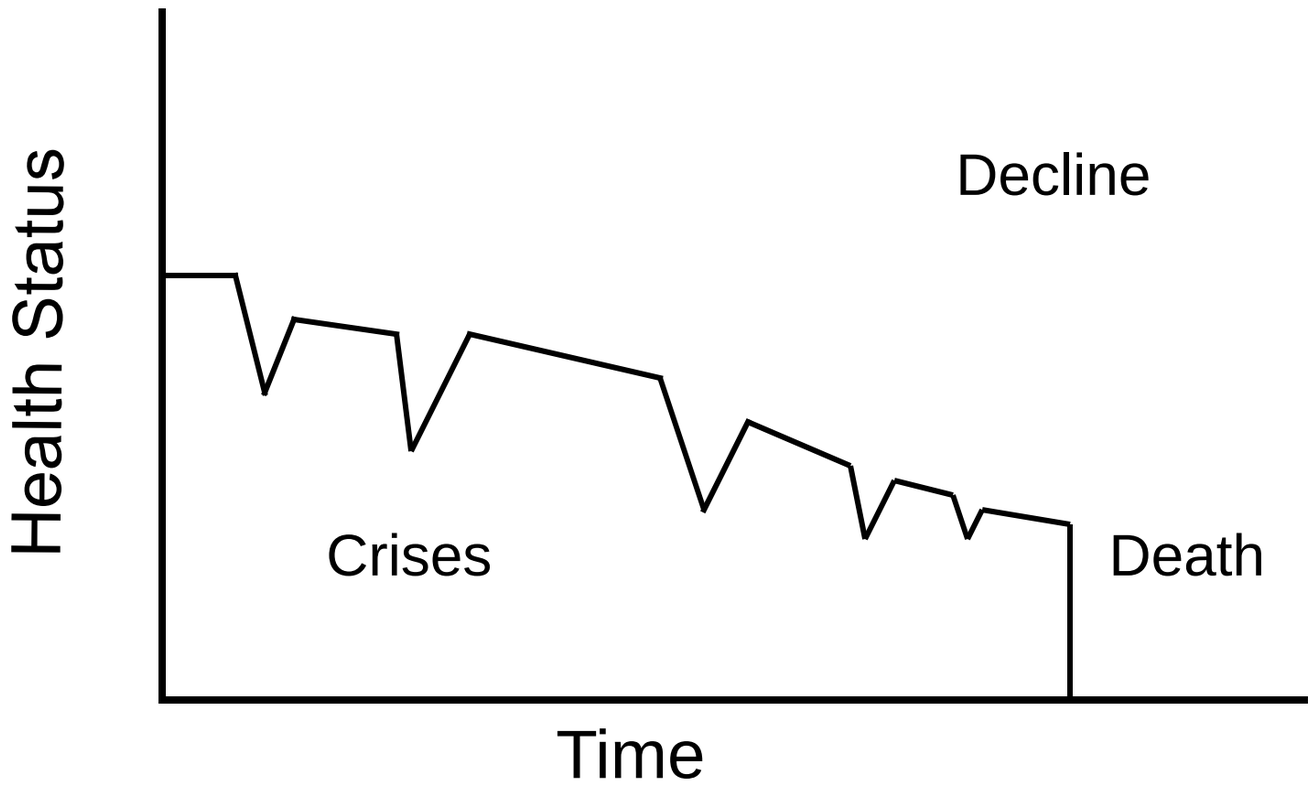
Palliative Care Trajectory Continuum?



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

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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.

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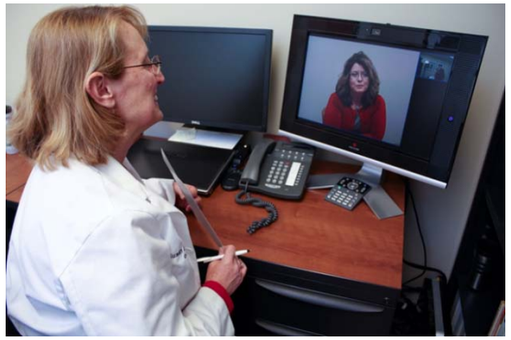
Celebrate Survivorship
Talk About Being Mortal

Growing Landscape

Hospital

Clinic

Home



Telemedicine/Telephone

Long-Term Care

Remote Rural Areas

Diagnosis → Survivorship → End of Life

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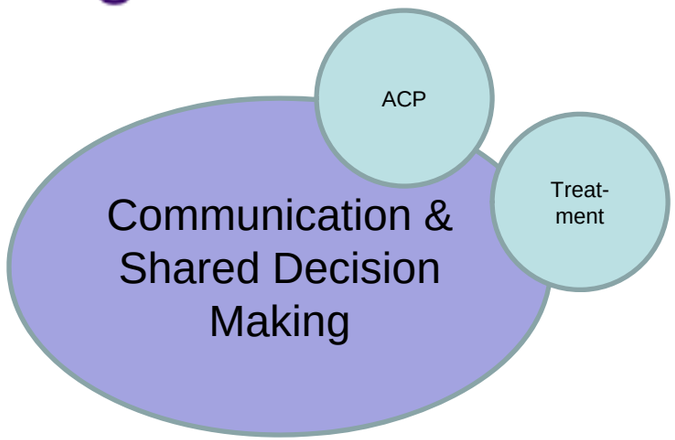
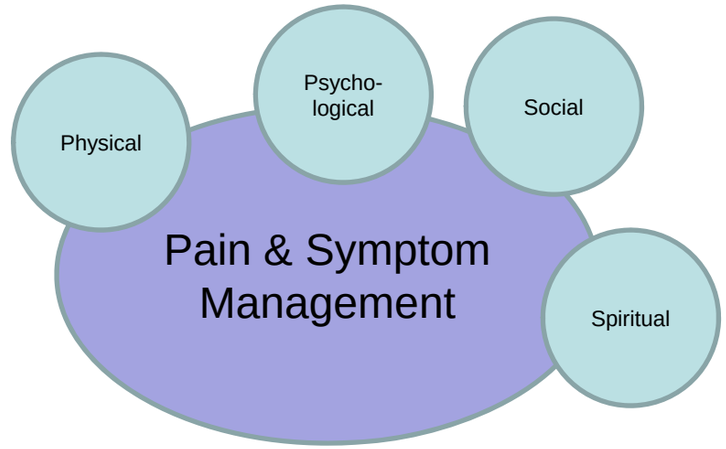
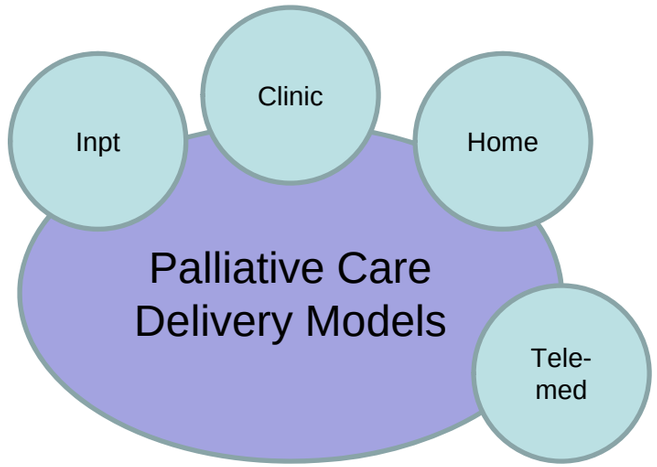
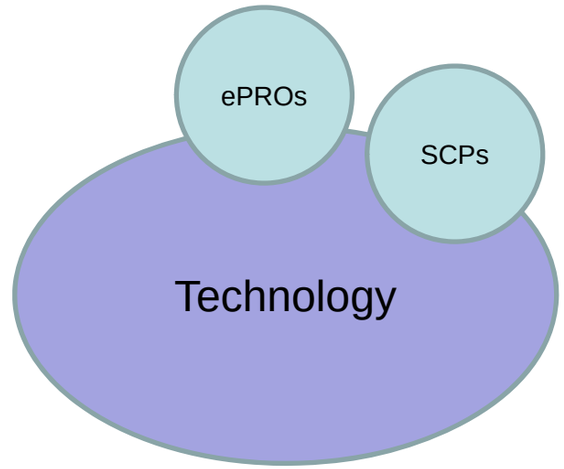
Key Considerations









Communication and Shared Decision Making

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Patients' Expectations about Effects of Chemotherapy for Advanced Cancer

Jane C. Weeks, M.D., Paul J. Catalano, Sc.D., Angel Cronin, M.S., Matthew D. Finkelman, Ph.D., Jennifer W. Mack, M.D., M.P.H., Nancy L. Keating, M.D., M.P.H., and Deborah Schrag, M.D., M.P.H.

From the Departments of Medical Oncology (J.C.W., A.C., D.S.), Biostatistics and Computational Biology (P.J.C.), and Pediatric Oncology (J.W.M.), Dana–Farber Cancer Institute, the Department of Public Health and Community Service, Tufts University School of Dental Medicine (M.D.F.), and the Department of Medicine, Brigham and Women's Hospital, and the Department of Health Care Policy, Harvard Medical School (N.L.K.) — all in Boston. Address reprint requests to Dr. Weeks at the Dana–Farber Cancer Institute, 450 Brookline Ave., Boston, MA 02215, or at jane_weeks@dfci.harvard.edu.

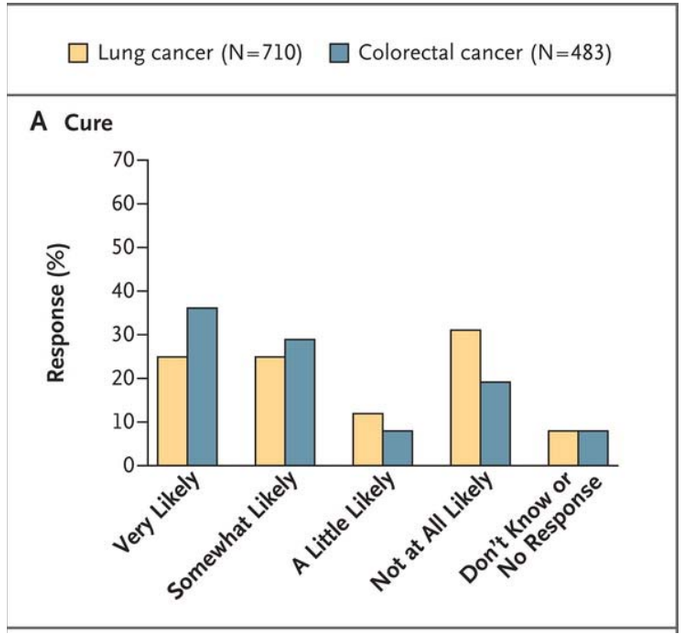
N Engl J Med 2012;367:1616-25.
DOI: 10.1056/NEJMoa1204410

ABSTRACT

BACKGROUND
Chemotherapy for metastatic lung or colorectal cancer can prolong life by weeks or months and may provide palliation, but it is not curative.

METHODS
We studied 1193 patients participating in the Cancer Care Outcomes Research and Surveillance (CanCORS) study (a national, prospective, observational cohort study) who were alive 4 months after diagnosis and received chemotherapy for newly diagnosed metastatic (stage IV) lung or colorectal cancer. We sought to characterize the prevalence of the expectation that chemotherapy might be curative and to identify the clinical, sociodemographic, and health-system factors associated with this expectation. Data were obtained from a patient survey by professional interviewers in addition to a comprehensive review of medical records.

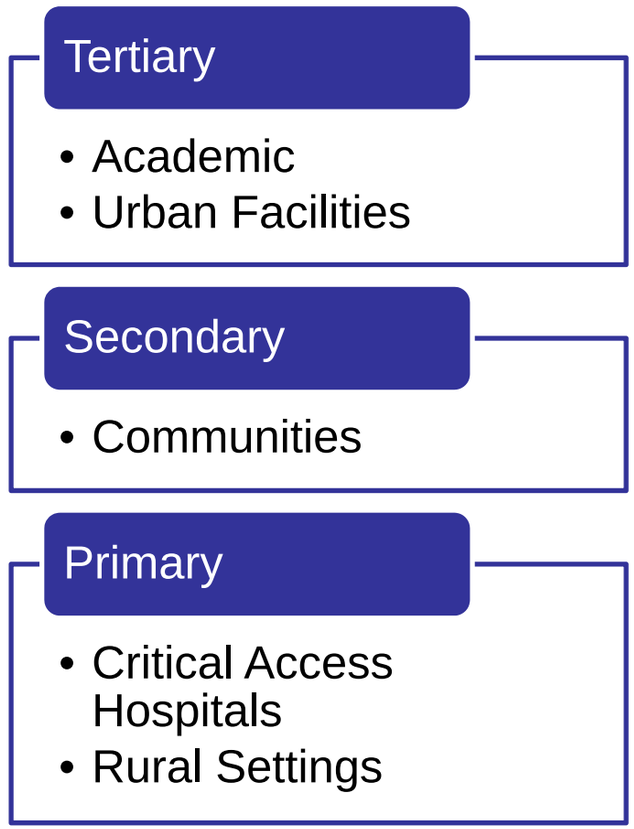
RESULTS
Overall, 69% of patients with lung cancer and 81% of those with colorectal cancer



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

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

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.

ABSTRACT

BACKGROUND

Patients with metastatic non–small-cell lung cancer have a substantial symptom burden and may receive aggressive care at the end of life. We examined the effect of introducing palliative care early after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease.

METHODS

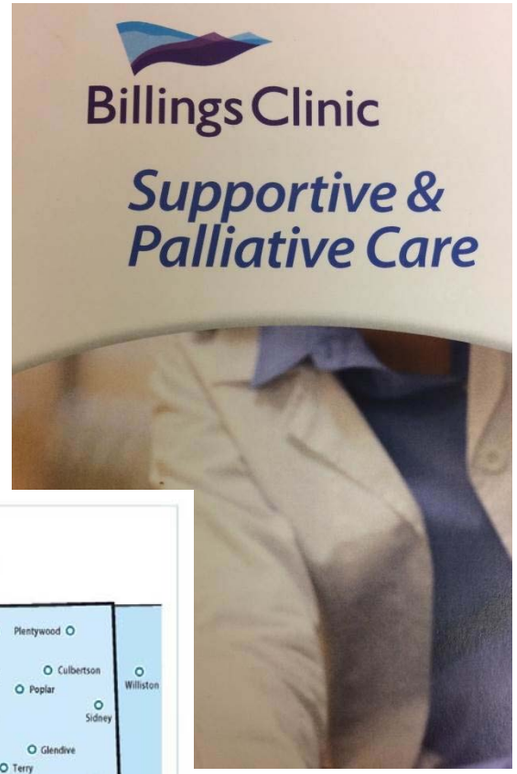
We randomly assigned patients with newly diagnosed metastatic non–small-cell lung cancer to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone. Quality of life and mood were assessed at baseline and at 12 weeks with the use of the Functional Assessment of Cancer Therapy–Lung (FACT-L) scale and the Hospital Anxiety and Depression Scale, respectively. The primary outcome was the change in the quality of life at 12 weeks. Data on end-of-life care were collected from electronic medical records.

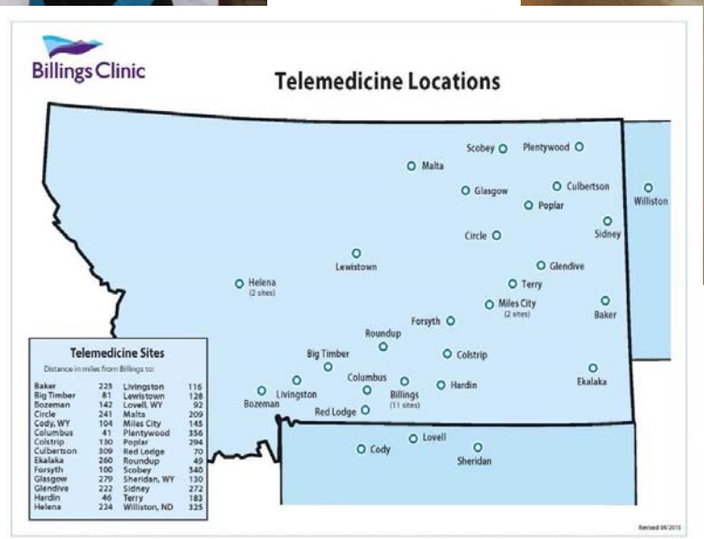
From Massachusetts General Hospital, Boston (J.S.T., J.A.G., A.M., E.R.G., V.A.J., C.M.D., J.J., W.F.P., J.A.B.); the State University of New York, Buffalo (S.A.); Adult Palliative Medicine, Department of Anesthesiology, Columbia University Medical Center, New York (C.D.B.); and Yale University, New Haven, CT (T.J.L.). Address reprint requests to Dr. Temel at Massachusetts General Hospital, 55 Fruit St., Yawkey 7B, Boston, MA 02114, or at jtemel@partners.org.

N Engl J Med 2010;363:733-42.

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?

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Survivorship Navigator

ARTICLE

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

Survivorship Navigator . . . . . Supportive Care Navigator

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

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Organizing Our Thoughts . . .

JAN JOURNAL OF ADVANCED NURSING

DISCUSSION PAPER

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

Jeannine M. Brant, Susan Beck & Christine Miaskowski

Accepted for publication 4 September 2009

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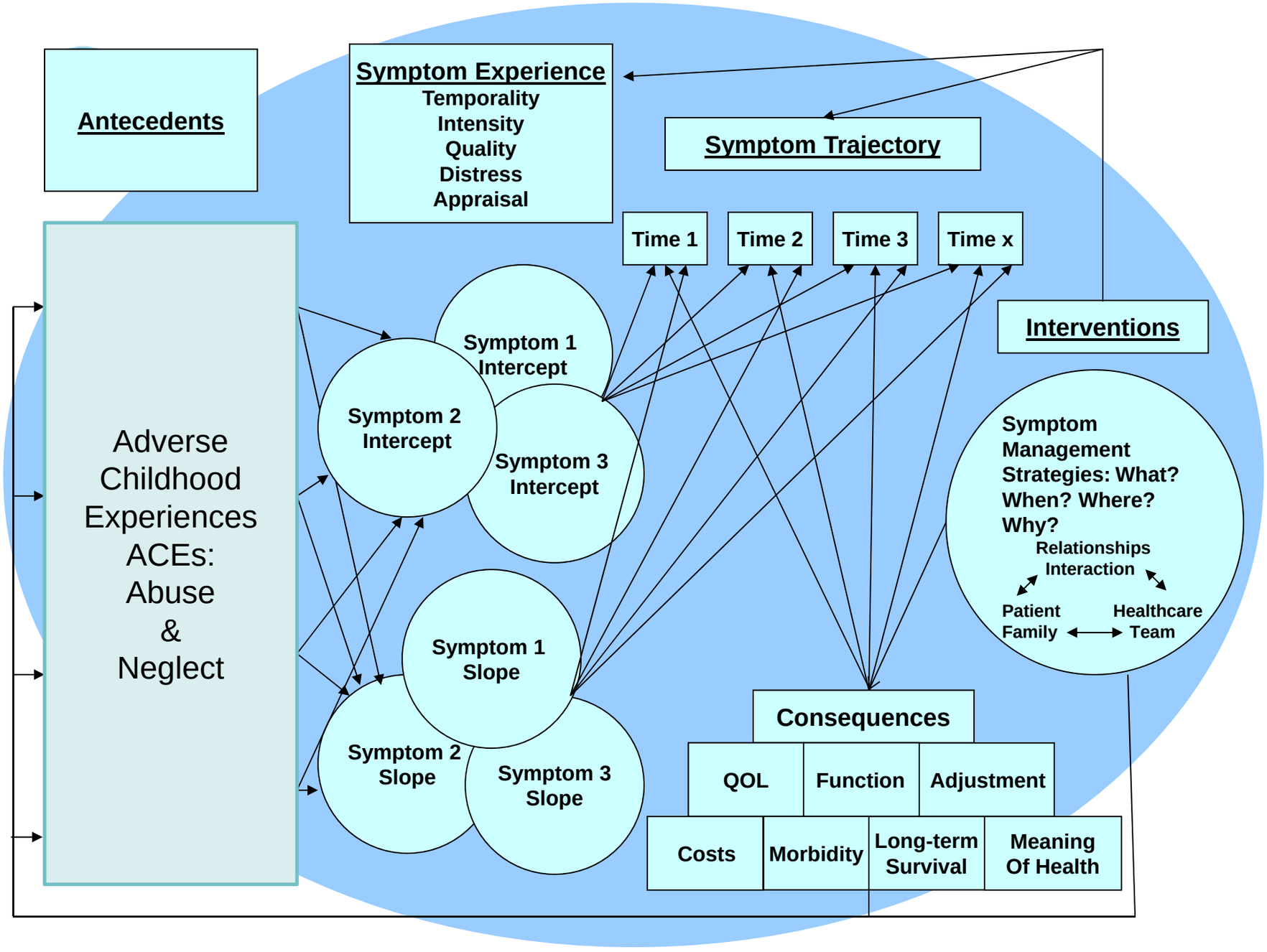
BRANT J.M., BECK S. & MIASKOWSKI C. (2010) Building dynamic models and theories to advance the science of symptom management research. *Journal of Advanced Nursing* 66(1), 228–240.
doi: 10.1111/j.1365-2648.2009.05179.x


Antecedents
Symptom Experience
Temporality
Intensity
Quality
Distress
Appraisal
Symptom Trajectory
Time 1
Time 2
Time 3
Time x
Interventions
Adverse Childhood Experiences ACEs: Abuse & Neglect
Symptom 1 Intercept
Symptom 2 Intercept
Symptom 3 Intercept
Symptom 1 Slope
Symptom 2 Slope
Symptom 3 Slope
Symptom Management Strategies: What? When? Where? Why?
Relationships
Interaction
Patient Family
Healthcare Team
Consequences
QOL
Function
Adjustment
Costs
Morbidity
Long-term Survival
Meaning Of Health

European Journal of Oncology Nursing 15 (2011) 470–477

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journal homepage: www.elsevier.com/locate/ejon

Symptom trajectories during chemotherapy in outpatients with lung cancer colorectal cancer, or lymphoma

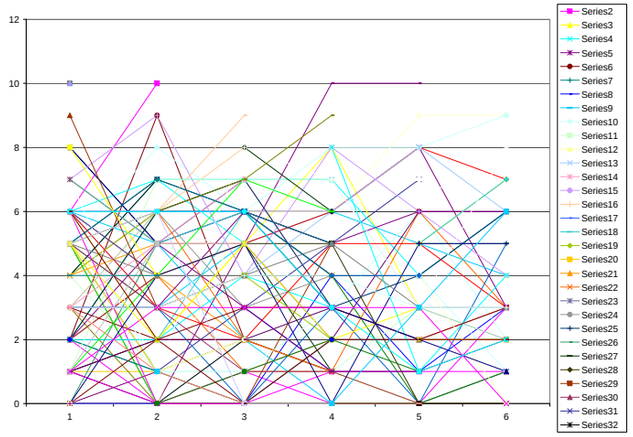
Jeannine M. Brant [a,b,*], Susan L. Beck [b], William N. Dudley [c], Patrick Cobb [d], Ginette Pepper [b], Christine Miaskowski [e]

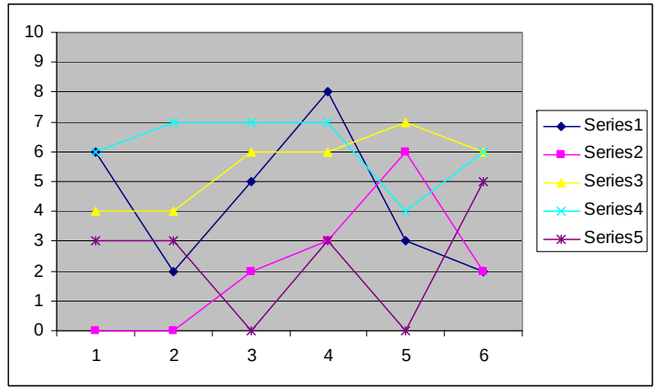
[a] Billings Clinic Cancer Center, Billings, MT, USA
[b] University of Utah, College of Nursing, USA
[c] University of North Carolina, Greensboro, USA
[d] Hematology Oncology Centers of the Northern Rockies, Billings, MT, USA
[e] University of California, San Francisco, USA

Keywords:
Chemotherapy
Symptoms

A B S T R A C T

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 chemo-





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

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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

CNE

Chronic and Refractory Pain

A systematic review of pharmacologic management in oncology

Jeannine M. Brant, PhD, APRN, AOCN®, FAAN, Lisa Keller, RN, OCN®, MS, Karen McLeod, MSN, RN, OCN®, CNL, Chao Yeh, PhD, RN, and Linda H. Eaton, PhD, RN, AOCN®

Many evidence-based pharmacologic and nonpharmacologic strategies exist to manage acute, chronic, refractory, and breakthrough cancer pain. This supplement includes an overview of cancer pain assessment, which is the foundation of pain management. Following the overview are four systematic reviews covering 462 studies on cancer pain management. The Oncology Nursing Society Putting Evidence Into Practice (PEP) expert panel summarized the evidence and provided recommendations for practice based on PEP guidelines.

AT A GLANCE

- Cancer-related pain is a significant problem that can be well managed when evidence-based strategies are implemented.
- Evidence-based interventions for cancer pain management fall into four categories: acute, chronic, refractory, and breakthrough.

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.

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Too Much to Do
Technology Can **Help!**

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

PRO-CTCAE

carevive

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

ePROs Extend Survival!

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2017 ASCO ANNUAL MEETING
Making a Difference in Cancer Care WITH YOU

ASCO DAILY NEWS

Online Tool for Reporting Symptoms Extends Survival

JUNE 4, 2017

Dr. Ethan M. Basch presents LBA2.

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, MSc, 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.

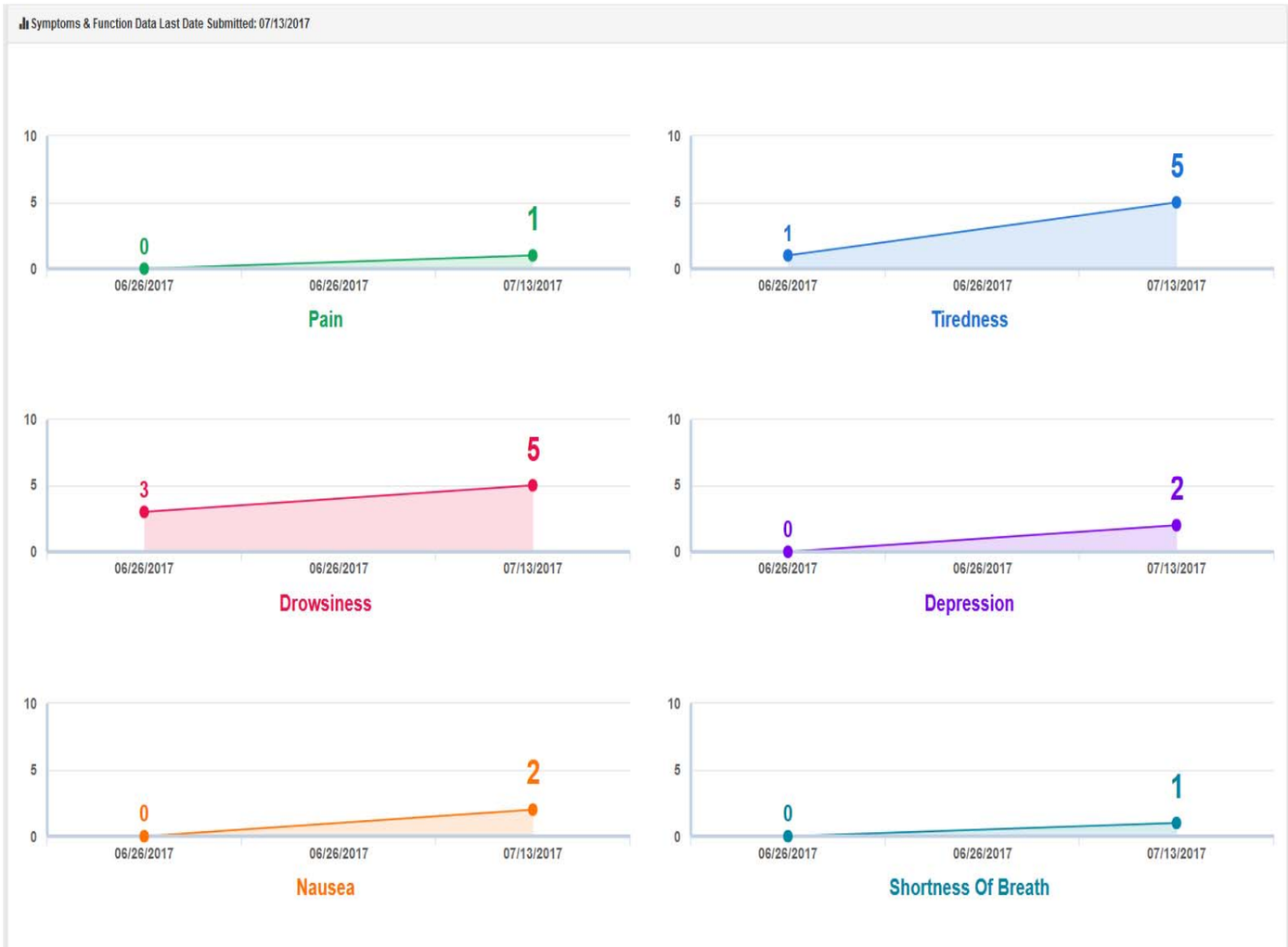
The standard model for reporting symptoms is a reactive approach in which patients must take the initiative to remember and report their symptoms to health professionals, who can then take action to alleviate the symptoms, Dr. Basch noted. In a proactive model, e-reminders can be sent periodically to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

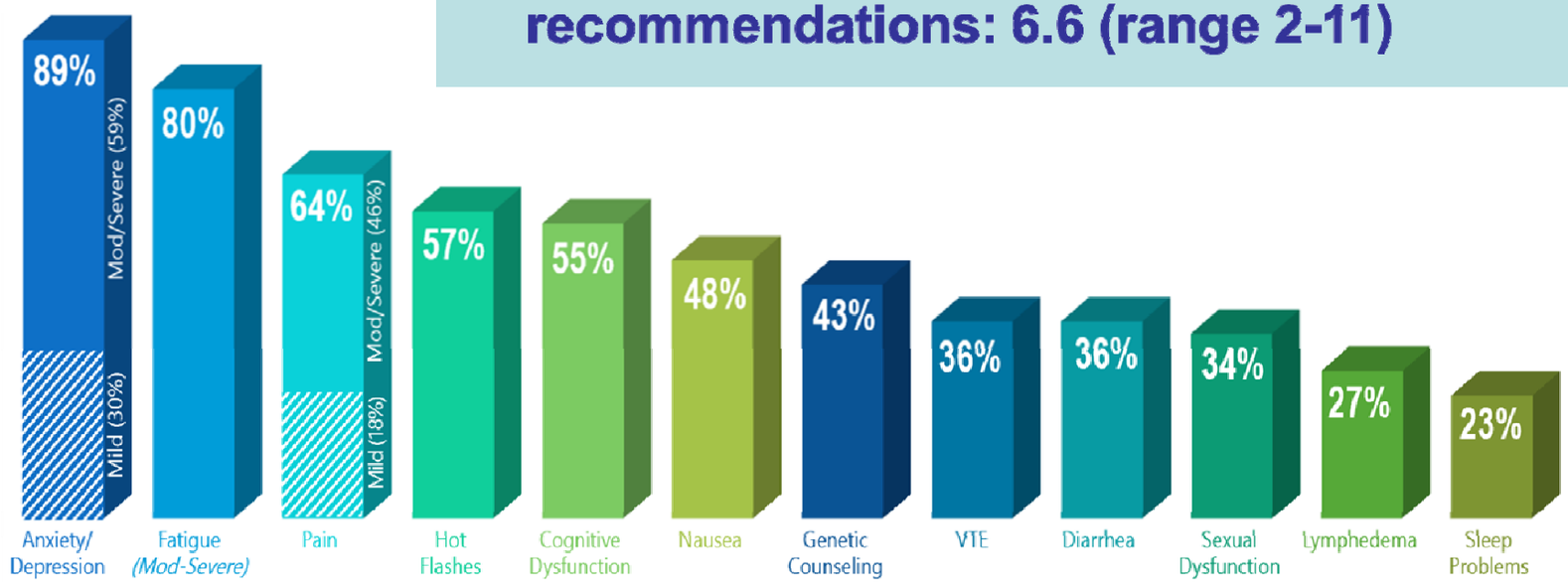
ASCO 2014 Poster Presentation

Tracking Symptoms Over Time



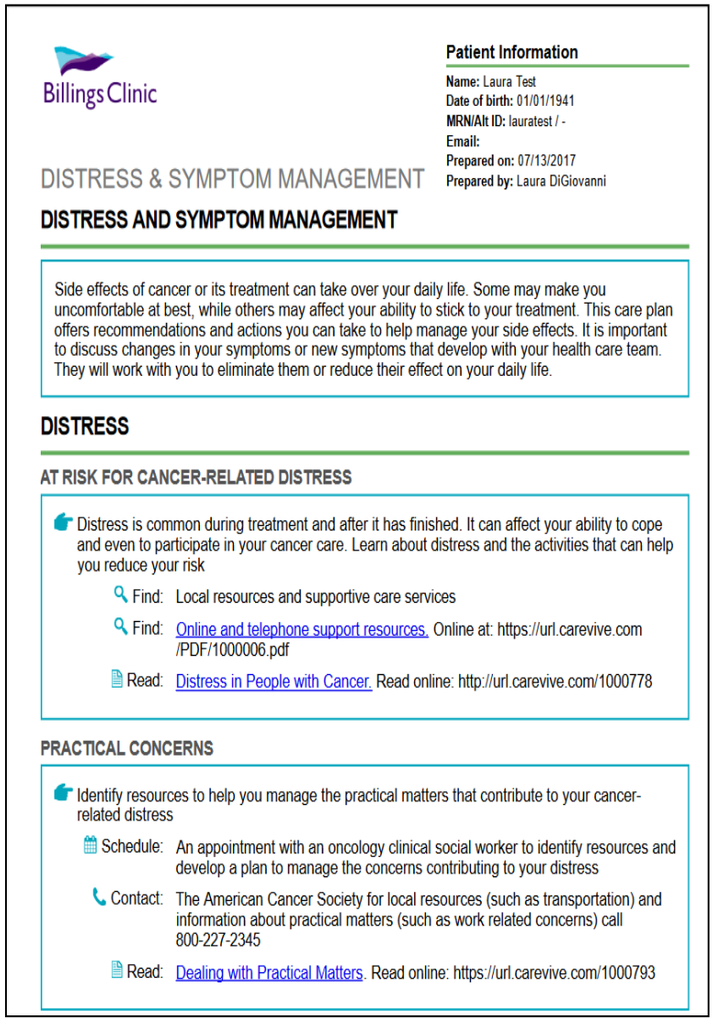
Care Plan Recommendations

- **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



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Patient Information
Name: Laura Test
Date of birth: 01/01/1941
MRN/Alt ID: lauratest / -
Email:
Prepared on: 07/13/2017
Prepared by: Laura DiGiovanni

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

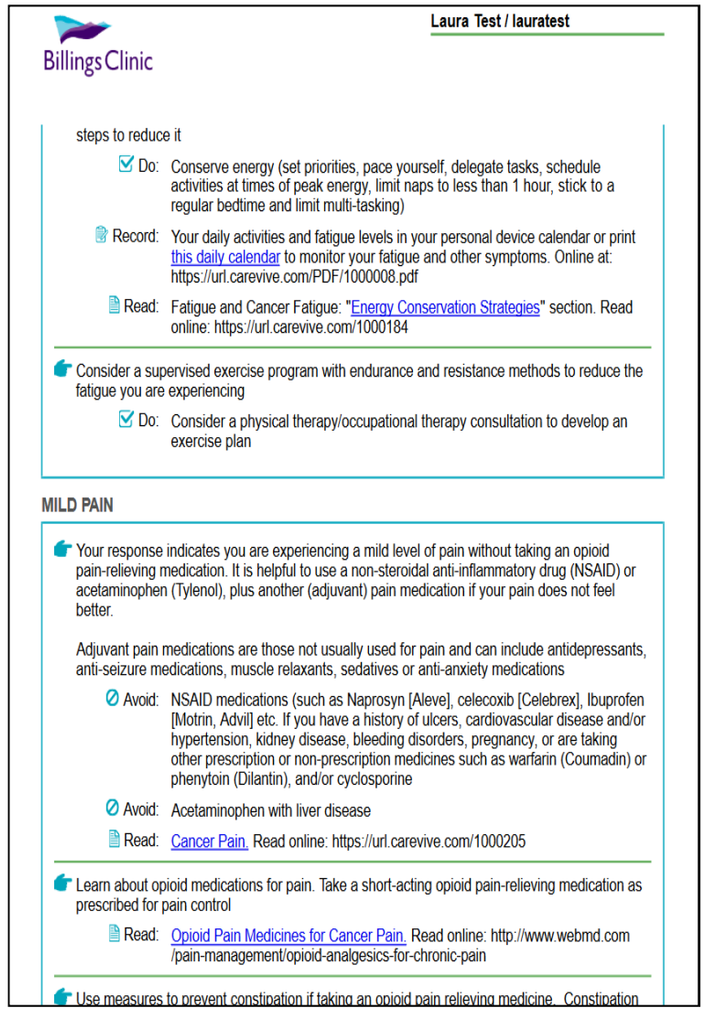
Distress is common during treatment and after it has finished. It can affect your ability to cope and even to participate in your cancer care. Learn about distress and the activities that can help you reduce your risk

- Find: Local resources and supportive care services
- Find: Online and telephone support resources. Online at: https://url.carevive.com/PDF/1000006.pdf
- Read: Distress in People with Cancer. Read online: http://url.carevive.com/1000778

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.carevive.com/1000793



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Laura Test / lauratest

steps to reduce it

- Do: Conserve energy (set priorities, pace yourself, delegate tasks, schedule activities at times of peak energy, limit naps to less than 1 hour, stick to a regular bedtime and limit multi-tasking)
- Record: Your daily activities and fatigue levels in your personal device calendar or print this daily calendar to monitor your fatigue and other symptoms. Online at: https://url.carevive.com/PDF/1000008.pdf
- Read: Fatigue and Cancer Fatigue: "Energy Conservation Strategies" section. Read online: https://url.carevive.com/1000184

Consider a supervised exercise program with endurance and resistance methods to reduce the fatigue you are experiencing

- Do: Consider a physical therapy/occupational therapy consultation to develop an exercise plan

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 (adjuvant) pain medication if your pain does not feel better.

Adjuvant pain medications are those not usually used for pain and can include antidepressants, anti-seizure medications, muscle relaxants, sedatives or anti-anxiety medications

- Avoid: NSAID medications (such as Naprosyn [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.carevive.com/1000205

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

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

Use measures to prevent constipation if taking an opioid pain relieving medicine. 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)

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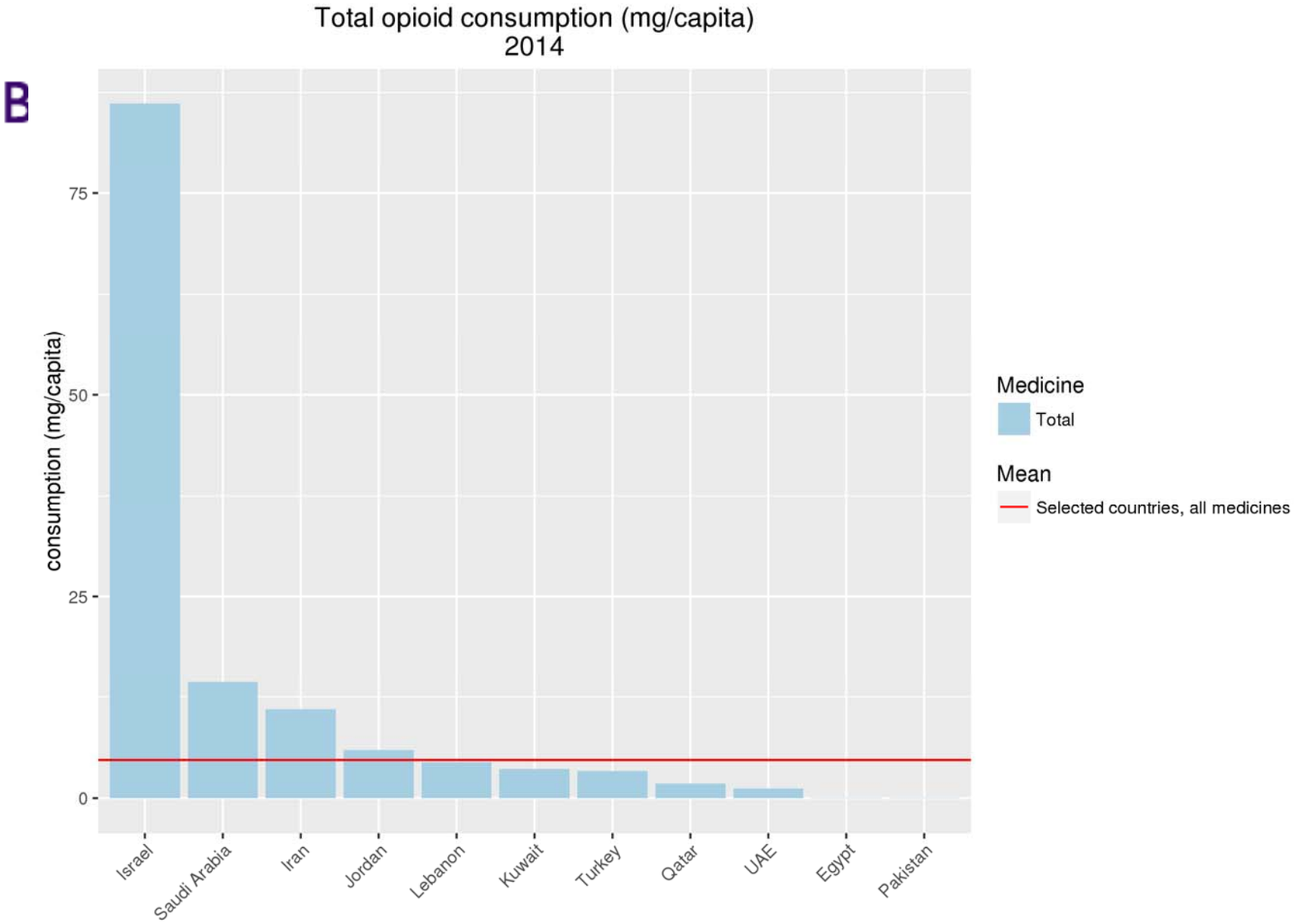

Sources: International Narcotics Control Board; World Health Organization population data

By: Pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Center, 2016

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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, Omani Cancer Association, and the Oncology Nursing Society to increase pain assessment and management capacity in the ME.

The Single Convention on Narcot- world's population), which con-

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"Palliative Care and Oncology: Time for Increased Collaboration and Integration"

Mini Review

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-

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We are more similar than we are different

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

Rodriguez NM[1], Brant JM[1], Pendharkar D[1], Arreola-Ornelas H[1], Bhadelia A[1], de Lima Lopes G Jr[1], Knaul FM[1].

⊕ **Author information**

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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and daughter, Ronit

OCA - Dr. Wahid AlKharusi
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