Listening Session 2: *Optimizing the Mix of Palliative Care and End-of-Life Care in PB-TCOC Models*

Presenters:

Subject Matter Experts

- **Kurt Merkelz, MD, FAAHPM** – Senior Vice President and Chief Medical Officer, Compassus
- **Natalie C. Ernecoff, PhD, MPH** – Full Policy Researcher, RAND
- **Ira Byock, MD, FAAHPM** – Emeritus Professor of Medicine and Community & Family Medicine, Dartmouth Geisel School of Medicine
- **Betty Ferrell, RN, PhD** – Director and Professor, Division of Nursing Research and Education, Department of Population Sciences, City of Hope

Listening Session 2: *Optimizing the Mix of Palliative Care and End-of-Life Care in PB-TCOC Models*

Kurt Merkelz, MD, FAAHPM

Senior Vice President and Chief Medical Officer, Compassus

Opportunities for Enhancing Palliative Care and Related Outcomes in PB-TCOC Models

Kurt Merkelz, MD, FAAHPM
Chief Medical Officer
Compassus
June 11, 2024

Background: Kurt Merkelz, MD, FAAHPM

- MD (Practicing Palliative Care Physician, Geriatrician)
  - Chief Medical Officer Compassus
  - Right Care Foundation Member

- Applied Science/Research focused on supporting frail/chronically ill individuals in their homes (successful aging)
  - Substantive model of care that supports outcomes necessary for patients to be successful in their homes

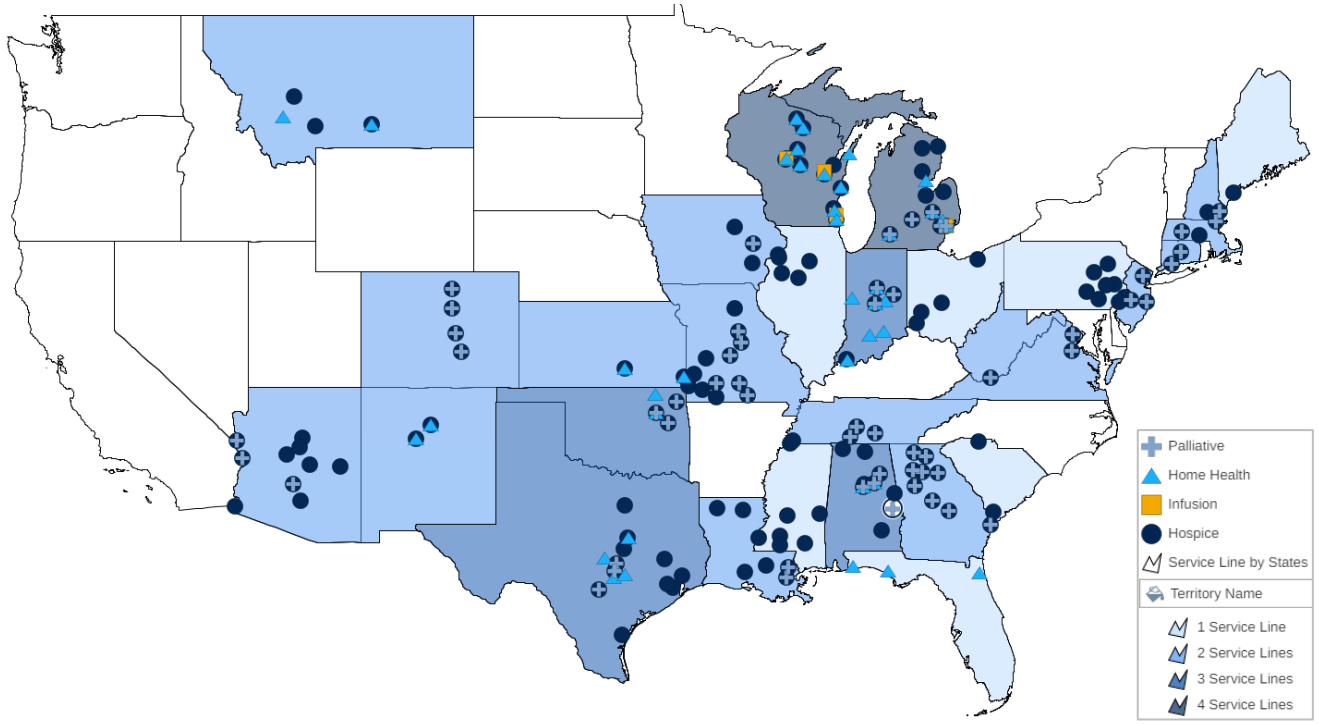
- Developed and implemented a system wide Care Delivery Model that supports successful aging at home
  - Trained over 10,000 clinicians in standardized best practices to support individualized care
  - Substantial improvement on HQRP metrics and HH Star ratings

"We need to redefine outcomes of success. Recovery, Restoration of function - should not be the measures of effectiveness and quality of care. Prior level of function (performance) is what led them to the hospitalization to begin with"

COMPASSUS®

Compassus Integrated Home-based Care

Compassus is a nationally-scaled provider of integrated home-based care to more than 100K patients annually. We are continually evaluating community needs nationwide for expansion and integration opportunities across service lines.



CORE SERVICE LINES

HOME HEALTH
49 programs

HOME INFUSION
3 programs

PALLIATIVE CARE
43 programs

HOSPICE
151 programs

Selection of value-added partnerships

VANTAGE HEALTH PLAN
DIVERSICARE
Ascension
VNS Health
Bon Secours Catholic health system
HEALTHTEXAS PRIMARY CARE DOCTORS
Complete Health™ Patients first... always.

COMPASSUS®

RIGHTCARE
FOUNDATION

Our Research

COMMUNITY BASED- grounded in the needs, issues, concerns, and strategies of communities and the community-based organizations that serve them. PARTICIPATORY-directly engaging communities and community knowledge in the research process and its outcomes. ACTION BASED AND ORIENTED-supporting and/or enhancing the strategic action that leads to community transformation and social change.

PB-TCOC Models Employing Palliative Care

- Improved symptom management
- Improved advance care planning
- Timely transition to hospice care, increased use of hospice care
- Reduced hospitalizations

EPIDEMIC OF RISK IN CARE FOR THE FRAIL, ELDERLY, and SERIOUSLY ILL IN OUR COMMUNITIES

individuals who have multiple complex chronic conditions, disability, and frailty are more highly associated with High Needs High Cost

References:

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4. Cassel, J. B., et al. (2016). The impact of palliative care consultation on healthcare outcomes in hospitalized patients. *Journal of Palliative Medicine*, 19(5), 555-560.
5. Temel, J. S., et al. (2017). Effects of early palliative care on patients with metastatic cancer. *The Lancet Oncology*, 18(3), 294-302.
6. Morrison, R. S., et al. (2011). Palliative care consultation teams cut hospital costs for Medicaid beneficiaries. *Health Affairs*, 30(3), 454-463.

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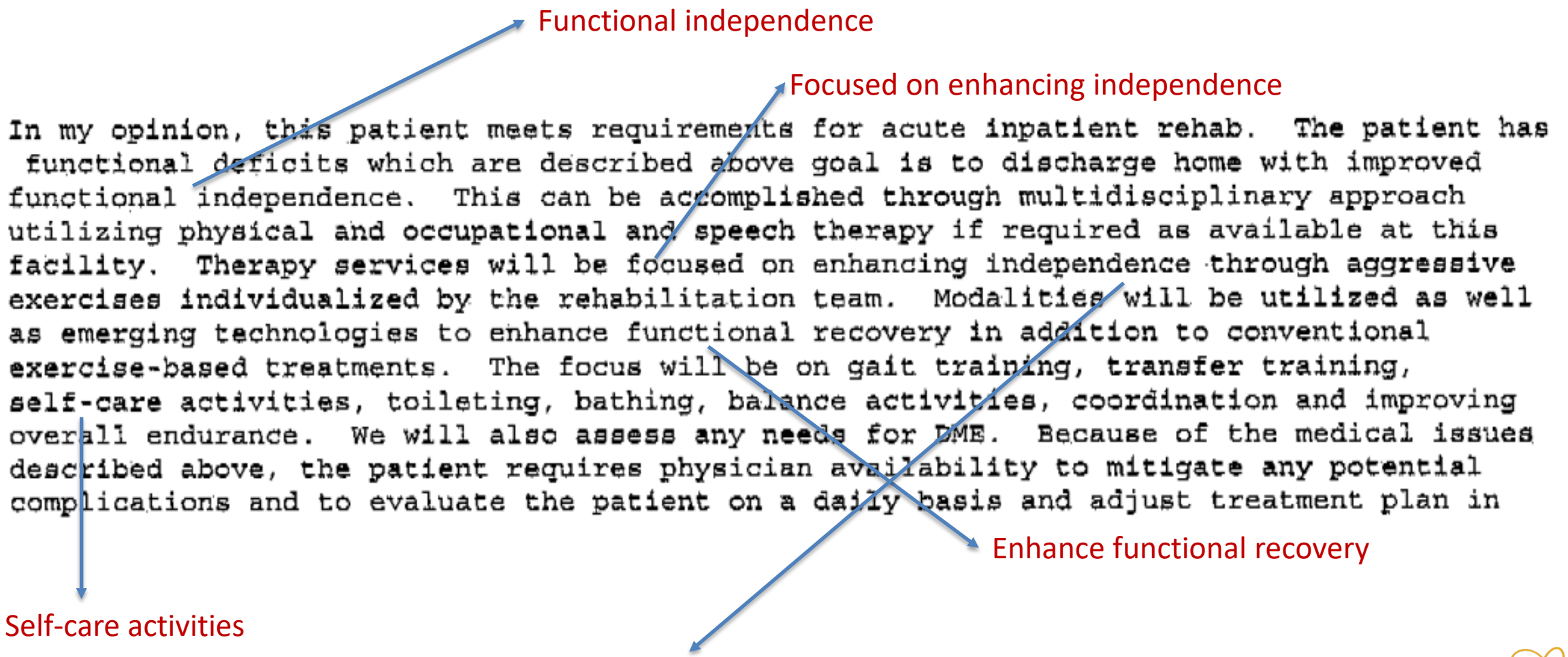
Current State of the Art: 92-year-old with chronic osteoarthritis, hip injury, cerebrovascular disease, hypertension, atrial fibrillation



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Evolution of the Definition of Independence

- Original understanding arose from veterans coming out of WWII
- Focus was on recovery of physical function – limb loss
- Current system continues to over-emphasize independent goal attainment
- Patients want AUTONOMY – NOT SELF-RELIANCE
- For the seriously ill the problem(s) are often never cured, never stable and results in lingering health issues.

Self-determination. The ability to have solutions/systems in place that meet the needs of the patient

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Treatment Plans

	N	Treatment Plans	Performance Components	Self-Reliance Activities	Safety Risk Reduction	Medical Condition Management	Autonomy	Burden of Care & Quality of Life
Rehab Hospitals	28	1,607	61%	36%	<1%	<3%	<1%	<1%
Skilled Nursing	113	9,712	70%	26%	<1%	<3%	<1%	<1%
LTACH	11	391	81%	16%	<1%	<3%	<1%	<1%
Home Health	34	11,388	54%	38%	<1%	<10%	<1%	<1%
	186	23,098	66.5%	29%	<1%	<5%	<1%	<1%

OUTCOMES	Net Outcome Through the Continuum
Safety	Net increase of 8 risks (avg >40) avg 62
Autonomy	34/51 (>30% chance of 6 month readmission. Basic needs not met in 5 of 13 categories on average)
Medical Condition	1 Yes 6 No's
Caregiver Burden	Net increase in Caregiver Burden
Quality of Life	Poor. No net gain.
Self-Reliance	Progressive decline over time, punctuated by steep declines. PLOF=readmission

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Integration of Palliative Care throughout the Continuum

- Current models of care are not designed to meet the needs of frail, seriously and chronically ill individuals.
- Community-based Palliative care for serious/chronically ill requires a new paradigm –current training does not address solutions/systems to meet the needs of the patient.
- Over-emphasis of symptom management, medications, acute medical care
- Most of the patients in need of specialized supportive care are not yet hospice appropriate.
- It’s not about prognosis, it’s about the success of the patient in 6 critical areas.
- The Palliative care clinician is perfectly situated to be integrated into the treatment team to support “quarterback” the care plan and outcomes.

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Redefining the Quality Equation – Driving the 6 Key Outcomes

Palliative care, deploying a outcomes-focused methodology, is the only high value care that will significantly impact people with serious illness

*Medical Condition Management * Safety * Autonomy * Burden of care * Aging in Place * Quality of Life*

$$\text{QUALITY} = \frac{\text{What the } \sout{\text{provider delivers}} \text{ patient receives}}{\text{What the } \sout{\text{system expects}} \text{ patient needs}}$$

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Compassus' Care Delivery Model

Six elements of the model support disease-specific clinical pathways and outcomes-driven accountability

RIGHT MEDS RIGHT TIME

- ✓ Decreased polypharmacy
- ✓ Elimination of potentially inappropriate Meds
- ✓ Reduced drug adverse events

TOTAL PAIN MANAGEMENT

- ✓ Standardized pain assessment
- ✓ HIS #1637: Pain Screen & Assessment
- ✓ Screening for Pain & Interviewing for Comfort

WHEN THEN SYMPTOM MANAGEMENT

- ✓ Comprehensive Symptom Management for your patients
- ✓ Edmonton Symptom Assessment System Score

#1 GREATEST CONCERN

- ✓ Individualized, Person-centered care
- ✓ Visits in Last Three Days of Life

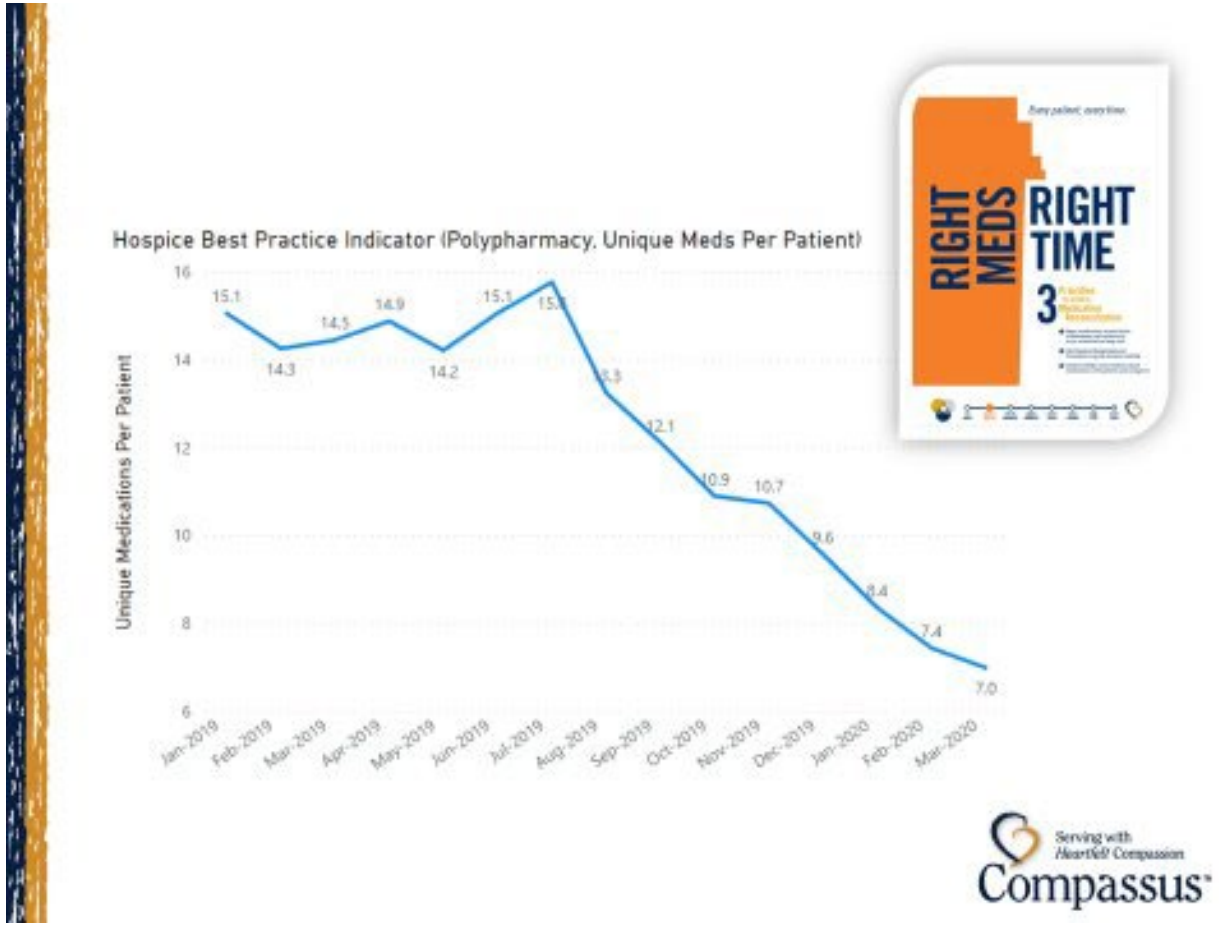
SAFETY & AUTONOMY

- ✓ Identification of Resident Safety Risks
- ✓ Hospice Best Practice Indicator – Rx per patient
- ✓ Drug Adverse Incidents per 1K patient days

QUALITY OF LIFE

- ✓ The One Thing
- ✓ Storyboard

Applying the Principles of Care Delivery Model



Medical Condition Management

There are 7 key goals

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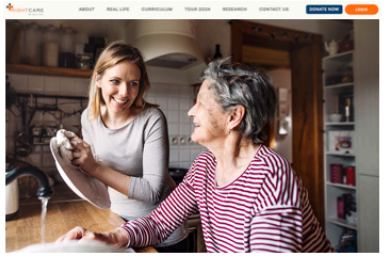
Community Engagement

What is RIGHTCARE currently doing with this advanced care methodology.

https://vimeo.com/manage/videos/840582293

RC CRR is equipping fire departments and their local healthcare and community with the tolls and resources necessary to reduce the epidemic of emergent call volume from the AIM and SIM population that is crippling emergency response around the country. This allows the entire local community to participate in advanced community risk reduction programming.



www.rightcareministry.org

RC is currently bringing a new model of senior ministry programming to multiple major denominations around the U.S. This gives seniors and their adult children necessary resources, tools, and support to change the mSDOH profile of seniors (parents) to one of success as they navigate the challenge that come with aging with these diseases.

SENIOR Helpers
LIFE PROFILE

https://www.seniorhelpers.com/services/life-profile-service/

RC has completed a national integration roll out of the mSDOH assessment and care planning into over 300 private duty locations, significantly changing the value proposition of private duty on total cost of care for at risk populations. This has also led to the first CHAP Certified Age Friendly Care at Home office in the country, with many more to follow.

Next Steps

RIGHTCARE FOUNDATION

CARE DELIVERY
The Compassus Way™

Innovative efforts most effective to improve palliative care services for patients with complex chronic conditions or serious illness

- Stop rearranging chairs and hoping for new outcome
  - Medicine works
  - The problem is everything else

- Clearly defined methodology that achieves substantive outcomes that are measurable
  - Outcomes that the payor source, clinician, and patient care about, can realize, and must achieve
  - Standardized best practice delivered in individualized ways
  - More focus on objective outcomes over subjective ratings of care

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Listening Session 2: *Optimizing the Mix of Palliative Care and End-of-Life Care in PB-TCOC Models*

Natalie C. Ernecoff, PhD, MPH
Full Policy Researcher, RAND

Lessons Learned about Providing Concurrent Hospice Services

Natalie C. Ernecoff, PhD, MPH

Full Policy Researcher

RAND

Pittsburgh, Pennsylvania

June 11, 2024

RAND CORPORATION

Overview

1. Background on hospice policy & concurrent care
2. Best practices for providing concurrent hospice services
3. How models of concurrent hospice services improve patient outcomes
4. Care coordination challenges

Hospice in the United States

- Medicare Hospice Benefit developed in cancer care
  - 6-month prognosis
  - Relatively inexpensive medications
  - Home-based care
- Does not cover related disease-directed therapies
- Intended to be *inclusive*

THE NEW YORK TIMES, WEDNESDAY, SEPTEMBER 1, 1982

Tax Measure Offers New Benefits For Hospice Care of Terminally Ill

WASHINGTON, Aug. 31 (UPI) — The tax bill recently passed by Congress contains a provision that is regarded as sure to strengthen a movement providing special care for the dying.

The hospice provision would allow Medicare to pay for the care of the dying at home instead of in the hospital.

In 1978 there were 59 organizations offering hospice care; by mid-1981, there were 440, according to the Congressional Budget Office. The $98.1 billion tax measure, which President Reagan is expected to sign soon, is scheduled to take effect Nov. 1, 1983.

The hospice provision is aimed at giving participants in Medicare, the Federal program of health care for the elderly, an alternative to sometimes costly hospital treatment.

Focus on Relief From Pain

Hospices care for the terminally ill chiefly by concentrating on relief from pain. Some hospices are in separate buildings, but that is more common in England, where the movement began.

The budget office estimates that hospice services care for 50,000 people in this country, about 10 percent of the potential users. Virtually all are cancer patients. The office predicts the measure will make it possible for an additional 109,000 people to seek hospice services.

The bill provides a comprehensive

"A hospice," she went on, "really provides not only competent care, but it provides a more loving and more compassionate and more appropriate care for the patient at this stage in the illness. The hospice recognizes when illness is no longer curable. A hospice just allows death to come naturally."

The hospice benefit would cover some items Medicare cannot pay for, such as counseling for the patient and family, outpatient drugs, medical supplies for a patient's comfort, the respite service and custodial home health care. The measure has an expiration date of Oct. 1, 1986, giving Congress time to evaluate the program and make changes.

After the costs of a transition period, the budget office estimates the program would save $48 million before it expires in 1986. In 1983, the budget office estimates, each hospice user would spend $1,100 less than in a hospital.

The Reagan Administration had opposed the program because it wanted to wait for results of a hospice study, expected to be completed in September 1983. But when Congress, in response to the lobbying of the hospice movement, indicated it might go ahead, the Administration assented.

Although most hospice care must be provided at home, a provision in the bill would allow Medicare benefits to be paid for care in an institutional hospice near New Haven, Conn.

Patients are forced to make the “terrible choice.”

- Hospices are unable to afford coverage of many disease-direct therapies, so they often require discontinuation before enrolling.
- E.g., palliative dialysis, blood transfusions, palliative radiation
- Patients who could benefit from disease-directed therapies are often forced to choose between therapies that can improve quality of life and hospice.

- Thus, fewer of those patients elect the hospice benefit.
- Those who do choose the hospice benefit often access these services very near the end of life with less opportunity to receive its intended benefits.

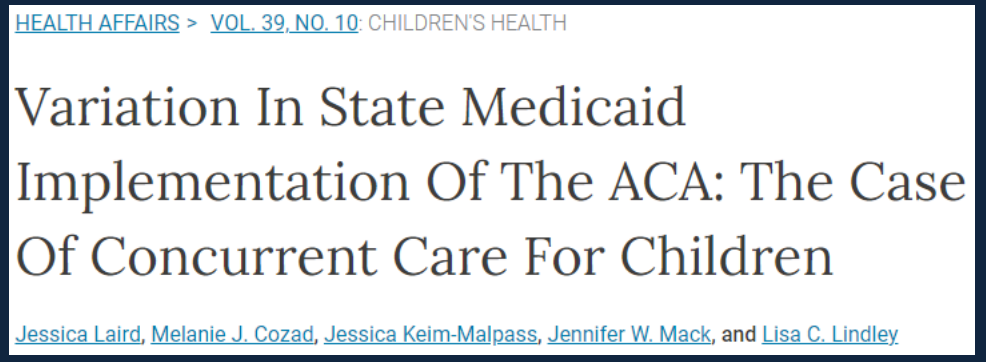
What is Concurrent Care?

- Continuation of disease-directed therapy upon enrollment in hospice to support patient goals near the end of life

1. Treatment motivated by symptom management rather than curative.
2. Potential benefits & burdens of treatment must balance with goals of care & quality of life.
3. Treatments must be reviewed regularly.

Utility of Concurrent Care: Pediatrics

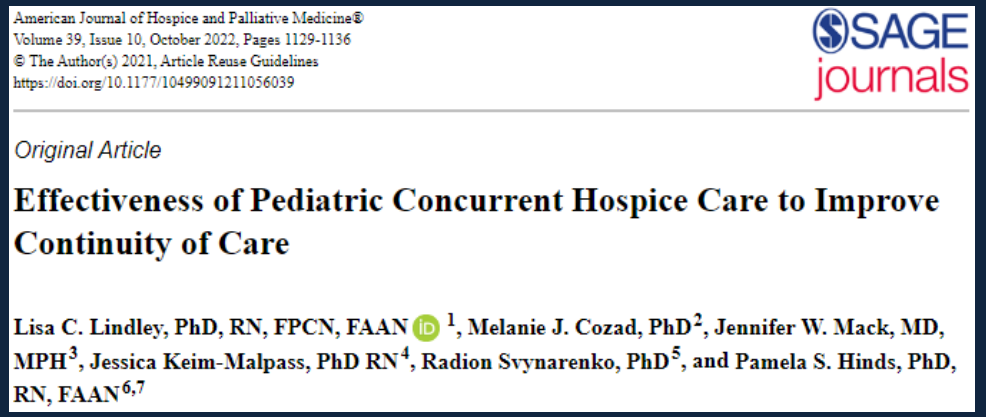
- **Context**
  - 2010: ACA Medicaid policy change
  - State-level variation
- **Findings**
  - ↑ hospice length of stay
  - ↓ live discharges from hospice



HEALTH AFFAIRS > VOL. 39, NO. 10: CHILDREN'S HEALTH

Variation In State Medicaid Implementation Of The ACA: The Case Of Concurrent Care For Children

Jessica Laird, Melanie J. Cozad, Jessica Keim-Malpass, Jennifer W. Mack, and Lisa C. Lindley



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https://doi.org/10.1177/10499091211056039

SAGE journals

Original Article

Effectiveness of Pediatric Concurrent Hospice Care to Improve Continuity of Care

Lisa C. Lindley, PhD, RN, FPCN, FAAN [1], Melanie J. Cozad, PhD[2], Jennifer W. Mack, MD, MPH[3], Jessica Keim-Malpass, PhD RN[4], Radion Svynarenko, PhD[5], and Pamela S. Hinds, PhD, RN, FAAN[6,7]

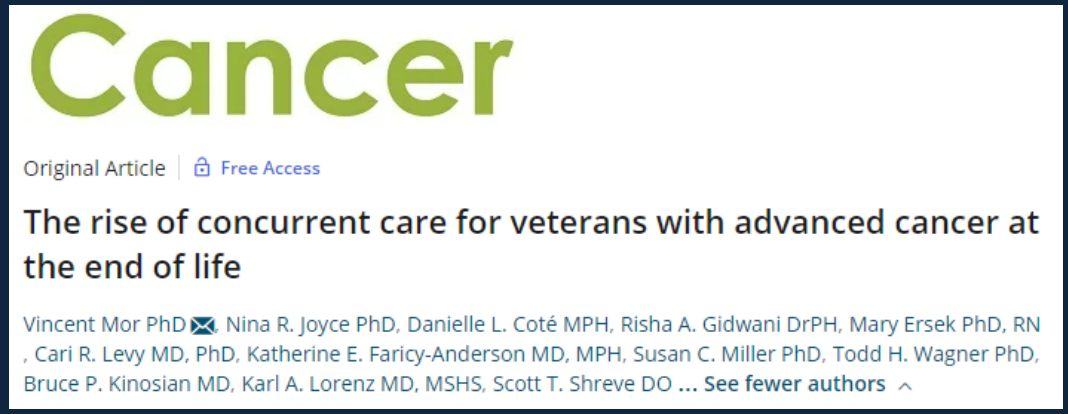
Utility of Concurrent Care: VA cancer care

- **Context**
  - 2000s: Low hospice enrollment
  - Non-Medicare rules
- **Findings**
  - Chemotherapy was used after hospice enrollment
  - Discontinued before death
  - Fewer ICU admissions
  - No change in survival

JAMA Oncology | Original Investigation

Association of Expanded VA Hospice Care With Aggressive Care and Cost for Veterans With Advanced Lung Cancer

Vincent Mor, PhD; Todd H. Wagner, PhD; Cari Levy, MD, PhD; Mary Ersek, PhD, RN; Susan C. Miller, PhD; Risha Gidwani-Marszowski, DrPh; Nina Joyce, PhD; Katherine Faricy-Anderson, MD, MPH; Emily A. Corneau, MPH; Karl Lorenz, MD, MSHS; Bruce Kinosian, MD; Scott Shreve, DO



Cancer

Original Article | Free Access

The rise of concurrent care for veterans with advanced cancer at the end of life

Vincent Mor PhD, Nina R. Joyce PhD, Danielle L. Coté MPH, Risha A. Gidwani DrPH, Mary Ersek PhD, RN, Cari R. Levy MD, PhD, Katherine E. Faricy-Anderson MD, MPH, Susan C. Miller PhD, Todd H. Wagner PhD, Bruce P. Kinosian MD, Karl A. Lorenz MD, MSHS, Scott T. Shreve DO ... See fewer authors

Utility of Concurrent Care: VA ESKD care

- Population
  - Veterans living with ESKD
- Findings
  - Median hospice length of stay:
    - 4 days among non-concurrent
    - 43 days among concurrent care


JAMA Health Forum™

Original Investigation

Association of Hospice Payer With Concurrent Receipt of Hospice and Dialysis Among US Veterans With End-stage Kidney Disease

A Retrospective Analysis of a National Cohort

Melissa W. Wachterman, MD, MSc, MPH; Emily E. Corneau, MPH; Ann M. O'Hare, MD, MA; Nancy L. Keating, MD, MPH; Vincent Mor, PhD

Utility of Concurrent Care: Hospice and Dialysis

- **Context**
  - Collaborative program between non-profit hospice & dialysis
  - Contracted rate
- **Findings**
  - ½ of concurrent enrollees did not use any dialysis
  - Mean hospice length of stay:
    - 12 days among all
    - 17 days among those who received any dialysis

This was a way for us to let his body decide.

-Family caregiver

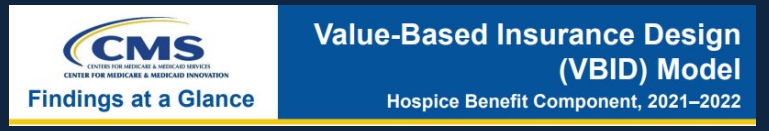
Policy Landscape: Medicare Care Choices Model

- **Context**
  - Hospices paid higher per capita fee
  - FFS Medicare covers disease-directed concurrent treatments
  - Hospices responsible for administrative burden (e.g., eligibility determination)
- **Population**
  - Eligible 1° diagnoses: cancer, COPD, CHF, or HIV/AIDS

- **Findings**
  - ↑ hospice enrollment
  - Hospice ~1 week earlier
  - ↓ inpatient care → ↓ lower costs
  - ↑ Caregiver-reported experience
  - Most enrollees were from large hospices
    - Many hospices withdrew from the model
    - Difficulties identifying eligible beneficiaries based on narrow criteria

Policy Landscape: Value-Based Insurance Design

- **Context**
  - Carves hospice into Medicare Advantage
  - Hospices can provide transitional concurrent care
    - Higher per capita fee in the first month of enrollment
    - Reimbursement for concurrent care related to terminal condition
    - Retain responsibility for treatment plans & care coordination
- **Population**
  - Medicare Advantage beneficiaries near the end of life
- **Findings** (ongoing, sunsetting 2024)
  - Low enrollment
  - No change in hospice utilization outcomes in first year



Components of Effective Concurrent Care

Patient identification and referral pathways must be clear.

From outpatient: nephrology/dialysis, oncology, primary care

From inpatient: hospitalists, specialty palliative care

Good communication & workflows foster interdisciplinary collaboration.

Education & engagement for clinicians, patients, & families facilitates the Program, including early and ongoing goals of care conversations.

Coordinated care leads to smooth transitions.

Lack of coordinated care leads to rough transitions.

Key Takeaways

- **Concurrent care is a feasible and effective option** to promote timely patient-centered care via hospice access near the end of life.
  - Feasibility is driven by interdisciplinary care coordination, clinician education, & clear referral pathways.

- **Payment models for concurrent care require operational clinical models.**
  - Clinical models include include modifiable care plans, interdisciplinary care coordination, clear workflows (including for referral), and education and ongoing communication between clinicians, patients, and families.

Natalie C. Ernecoff, PhD, MPH

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Disclosures

- I do not have conflicts of interest.
- Portions of this work were funded by the Palliative Care Research Collaboratory.

Appendix: References & Select Reading

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Listening Session 2: *Optimizing the Mix of Palliative Care and End-of-Life Care in PB-TCOC Models*

Ira Byock, MD, FAAHPM

Emeritus Professor of Medicine and Community & Family Medicine, Dartmouth Geisel School of Medicine

Patient Perspectives & Doctors' Roles in Caring Well Through the End of Life

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Emeritus Professor of Medicine & Community and Family Medicine
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Clinical Transformation Specialists, PLLC
IraByock.org

PTAC Public Meeting

June 11, 2024

Goals of Medicine

Problem-based, Transactional Medical Model

- Cure
- Longevity
- Rehabilitation
- Alleviating symptoms & suffering

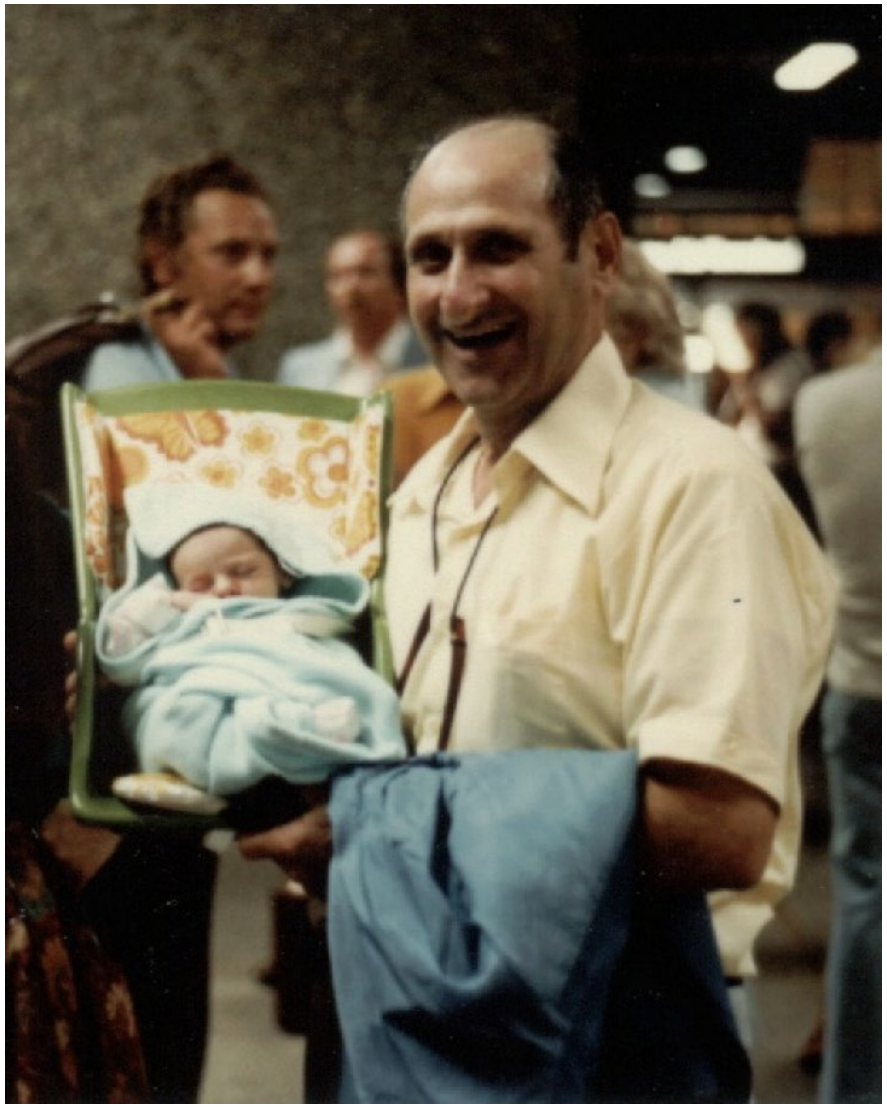
Goals of Medicine

Problem-based, Transactional Medical Model

- Cure
- Longevity
- Rehabilitation
- Alleviating symptoms & suffering

Problem	Everything the patient reports and doctor's findings which are regarded as problems
Subjective	History of the problem; what the patient feels or thinks about the problem
Objective	Doctors findings related with the problem
Assessment	Evaluation of the problem; the diff. diagnosis
Plan	Prescription, consultation, advice, control visit.

Health & Illness are *Personal!*



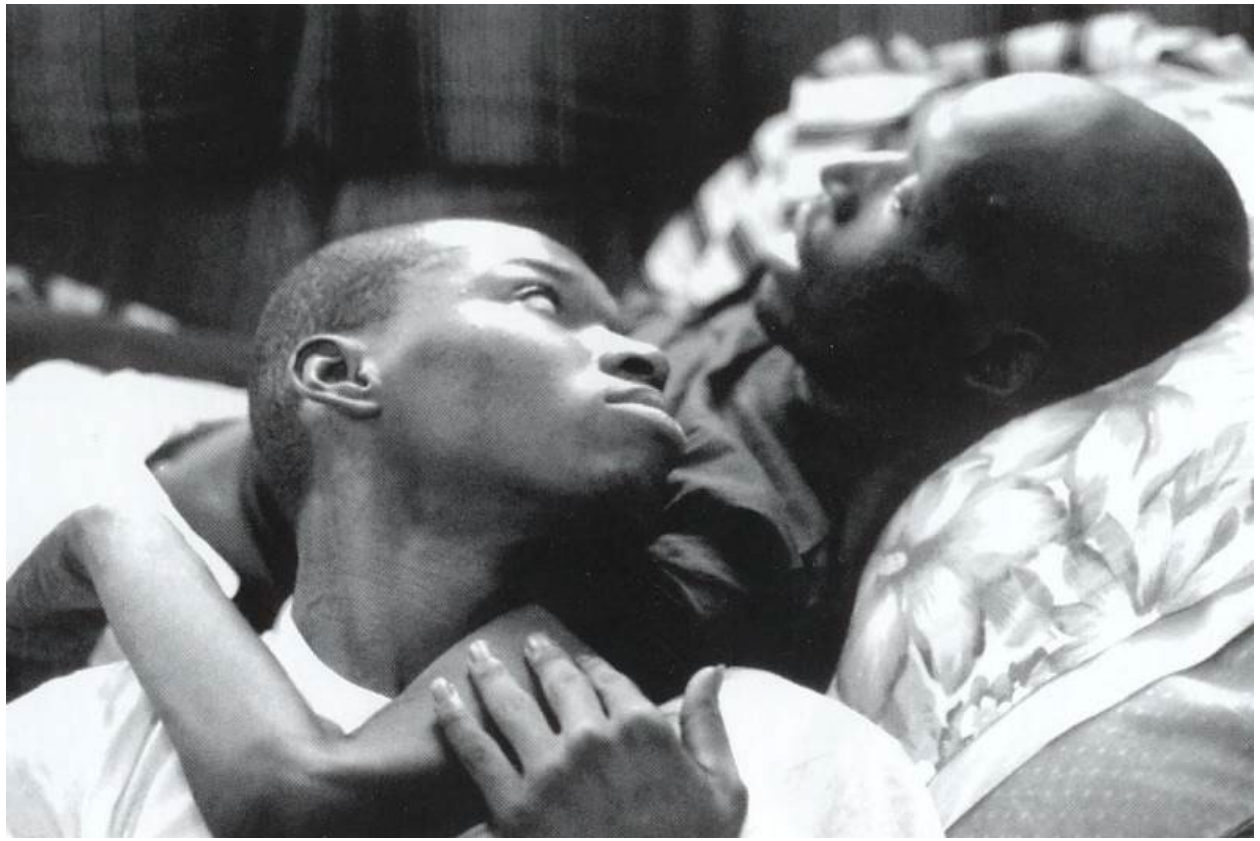
Seymour and Lila Byock

Health & Illness are *Personal!*

Whenever an individual receives a serious diagnosis, his or her family shares the illness.

Health & Illness are *Personal!*

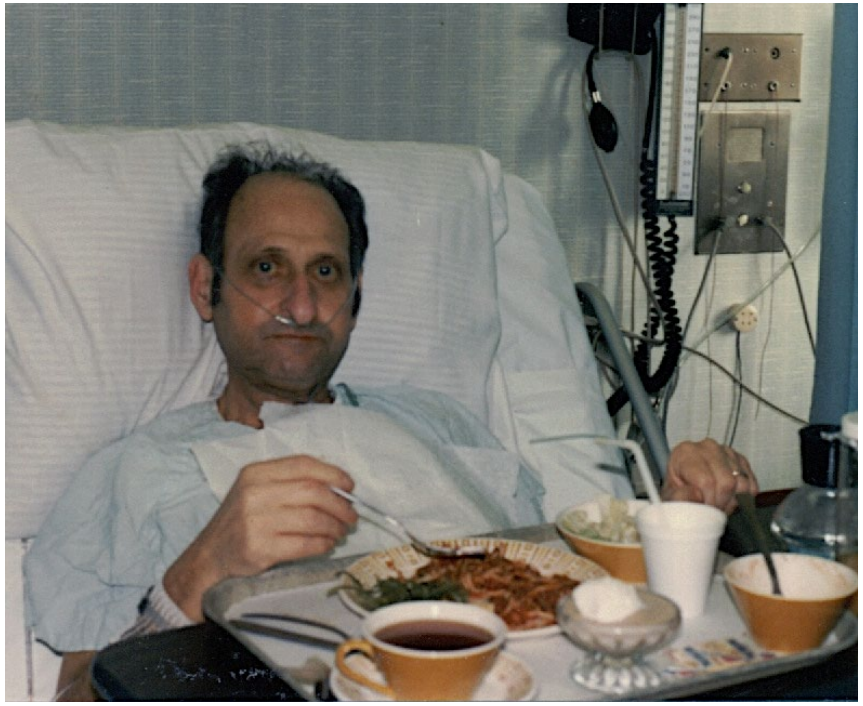
Whenever an individual receives a serious diagnosis, his or her family shares the illness.



Project on Death in America Jan 1998-2000

What Matters Most to People?

- Other people
- Not being a burden
- Retaining dignity
- Not suffering
- Feeling seen, heard and understood
- Not falling through cracks in system



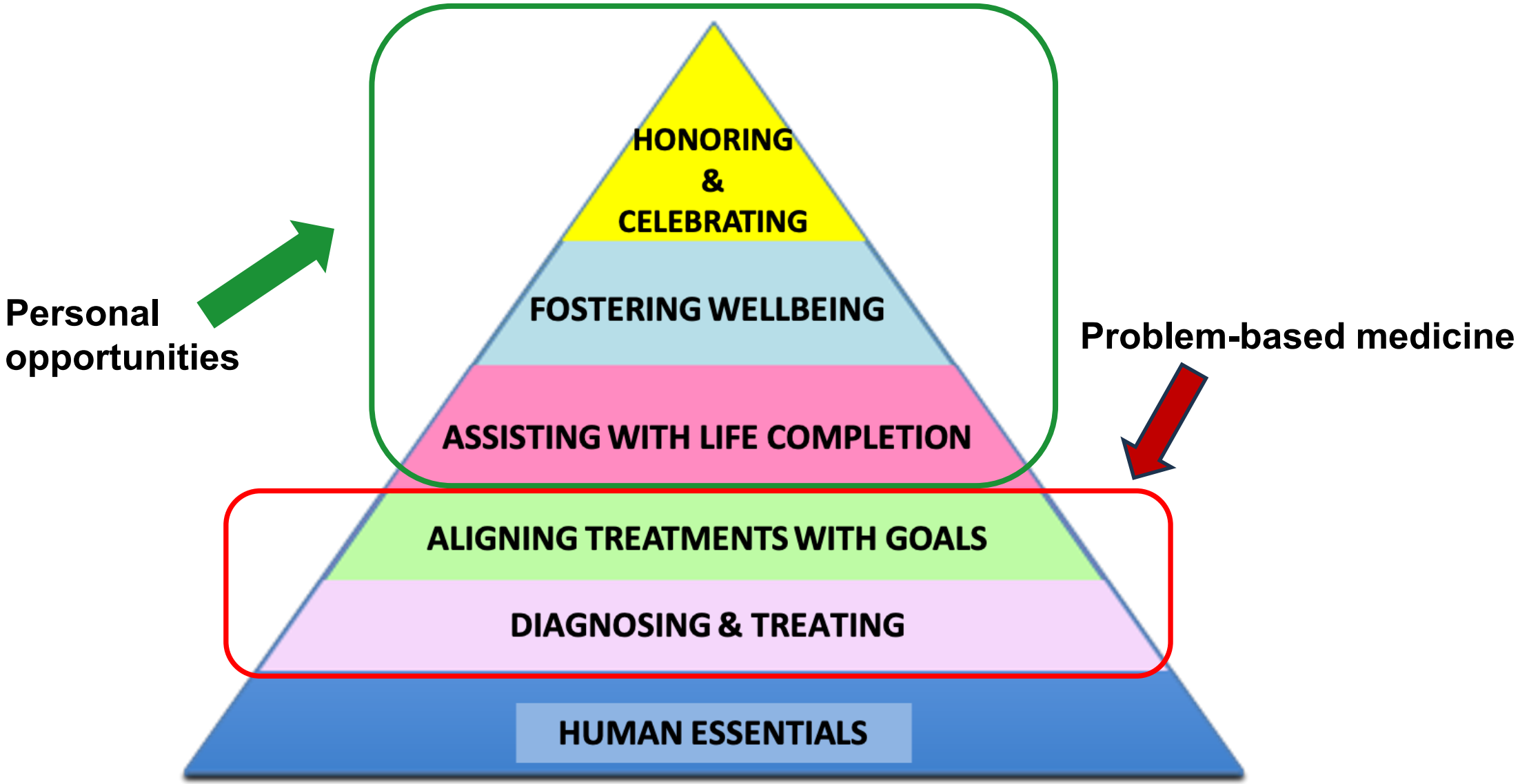
Caring for Whole Persons

- Cure
- Longevity
- Rehabilitation
- Alleviating symptoms & suffering

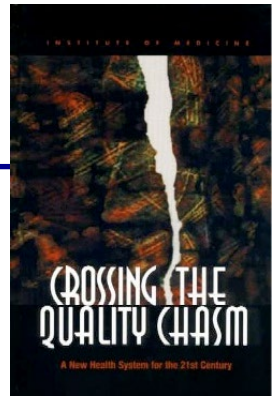
AND

Fostering personal wellbeing throughout life, including experiences with illness dying, caregiving, grieving

Caring for Whole Persons



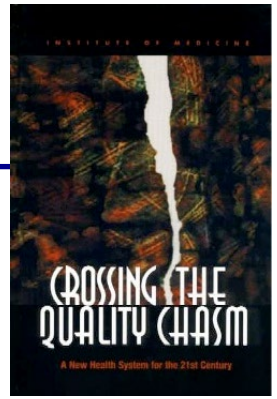
A Taxonomy of Quality



- Safe
- Effective
- Patient-centered
- Timely
- Efficient
- Equitable

Crossing the Quality Chasm:
A New Health System for the 21st Century
Institute of Medicine, March 2001

A Taxonomy of Quality



Defining patient-centered care:

"Healthcare that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care."

Crossing the Quality Chasm:
A New Health System for the 21st Century
Institute of Medicine, March 2001

ACP & GOC Conversations Can Be Hard Because They Involve Talking About Dying

- **We have an awkward relationship with death – that's true for almost all cultures**
- **Within Western medicine a patient's death can feel like failure**
- **Death is inevitable, suffering is not**
- **Dying is hard and unwanted. *And* it is a time of life that often holds value**
- **Conversations with clinicians can influence how our patients die and experience of families**
- **Skill-building and confidence can help make these conversations professionally satisfying**

Sonya Hebert / The Dallas Morning News / 12/13/08

ACP = advance care planning
GOC = goals of care

Normalizing ACP & GOC Conversations

"We ask everyone about their preferences – especially who they would want to speak for them – and ask them to complete an advance directive."

ACP = advance care planning
GOC = goals of care

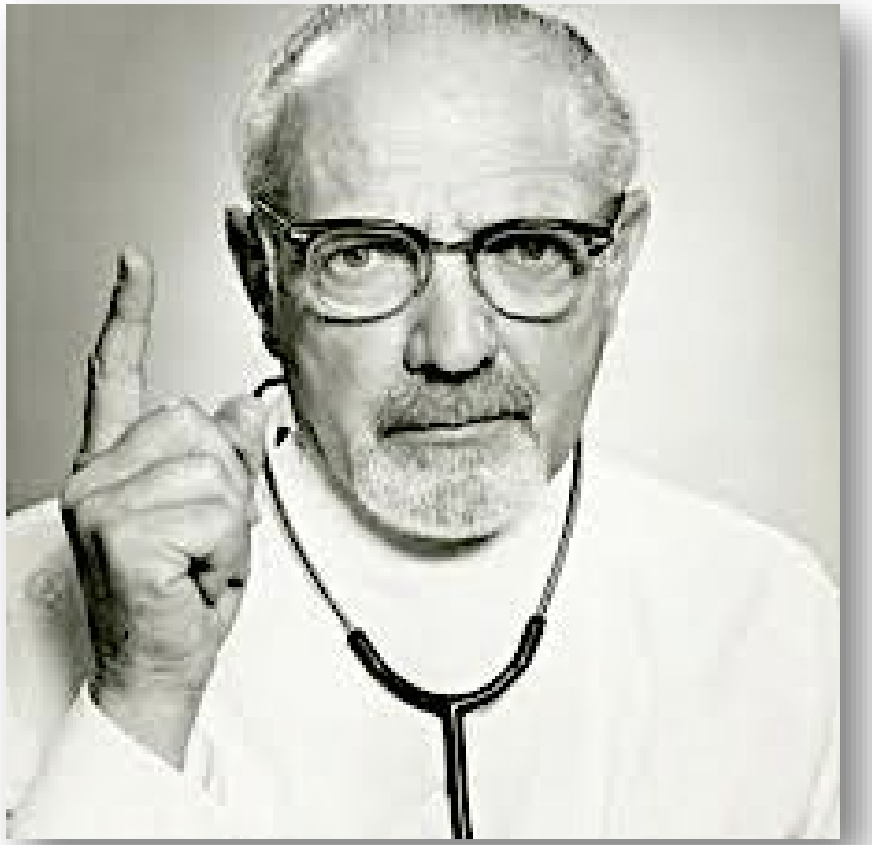
Normalizing ACP & GOC Conversations

“I have an advance directive – and so does every adult in my family.”

ACP = advance care planning
GOC = goals of care

Aligning Treatments with Personal Goals

Shared Decision Making – circa 1960



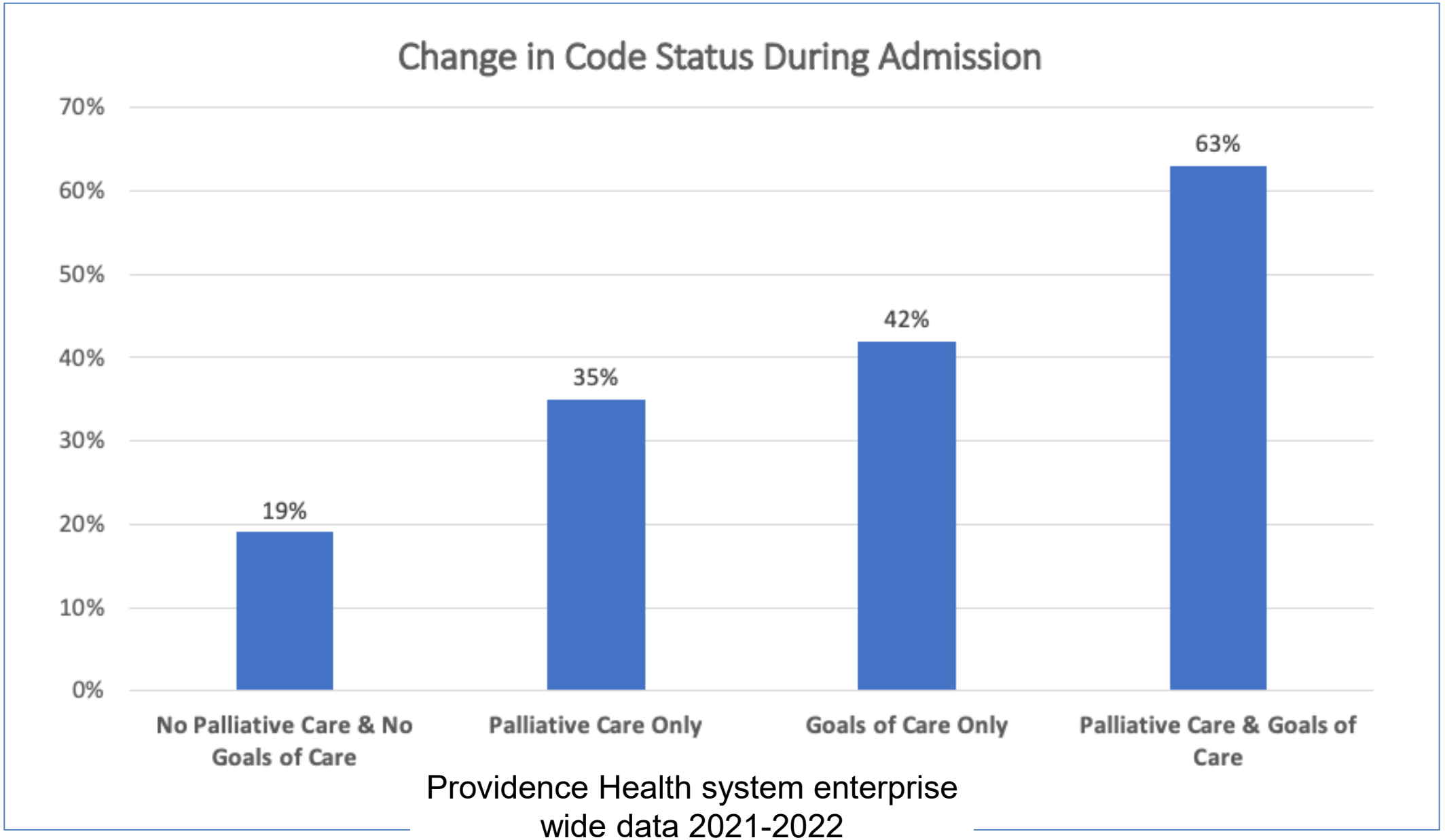
Aligning Treatments with Personal Goals

Shared Decision Making – circa 2024

Achievable health outcomes

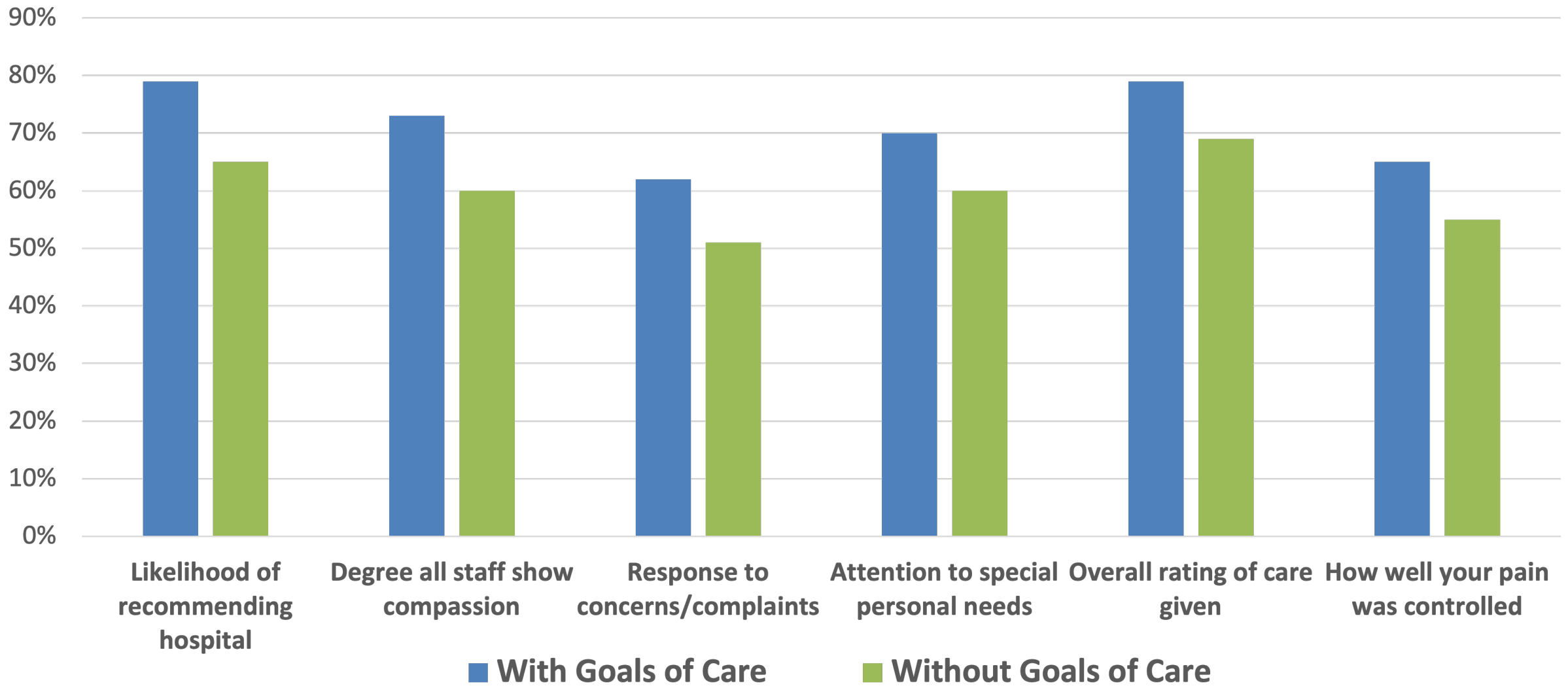
Personal values, preferences and priorities

Code Status Change: Hospitalized Patients with a Serious Illness



Providence Health system enterprise wide data 2021-2022

Improved Patient Experience with Goals of Care



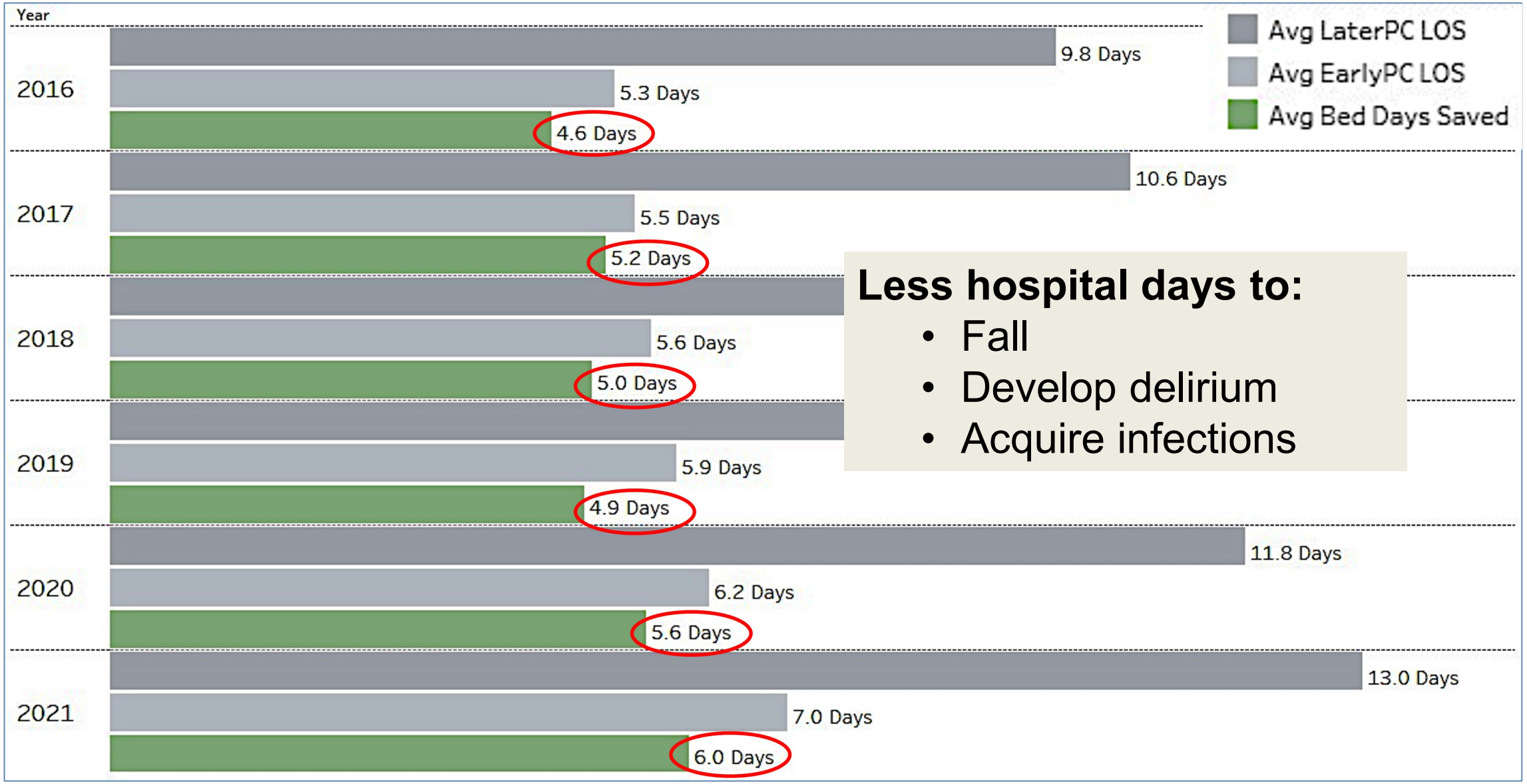
With GOC (N = 192) vs without GOC (N = 772); Top-box selection; single hospital 2020; Subset of all statistically significant results ($p < 0.05$) analyzed GOC conversations conducted by non-palliative care clinicians

Normalizing Early, Concurrent Palliative Care

“Our Palliative Care team is here to provide you and your family with an extra layer of support....”

Photo: Medical University of South Carolina
https://nursing.musc.edu/admissions/our-programs/palliative-care/practice

Impact on Bed Days of Early vs Later Palliative Care



Less hospital days to:

- Fall
- Develop delirium
- Acquire infections

What Doctors Are For

Problem-based Medical Model

- Saving lives
- Preventing injuries, diseases, disabilities
- Extending life, when cure is not possible
- Optimizing function & independence
- Alleviating symptoms & suffering

https://www.modernhealthcare.com/article/20171215/NEWS/171219912/higher-patient-satisfaction-linked-to-lower-readmissions

What Doctors Are For

Whole Person Caring Model

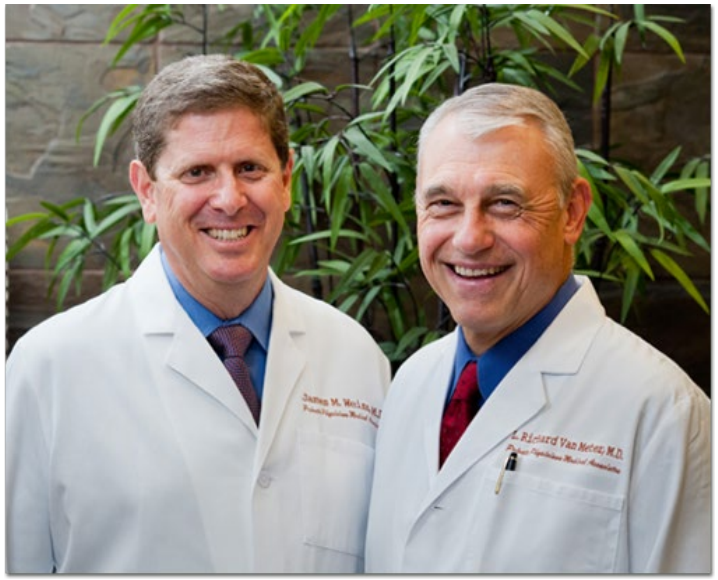
- Assisting in treatment decisions consistent with patients' personal priorities
- Accompanying people through difficult times of illness & disability
- Improving well-being of patients within families and communities
- Preserving & fostering patients' potential to grow individually and together with those they love

Reclaiming Primacy of Primary Care

Concierge Medicine

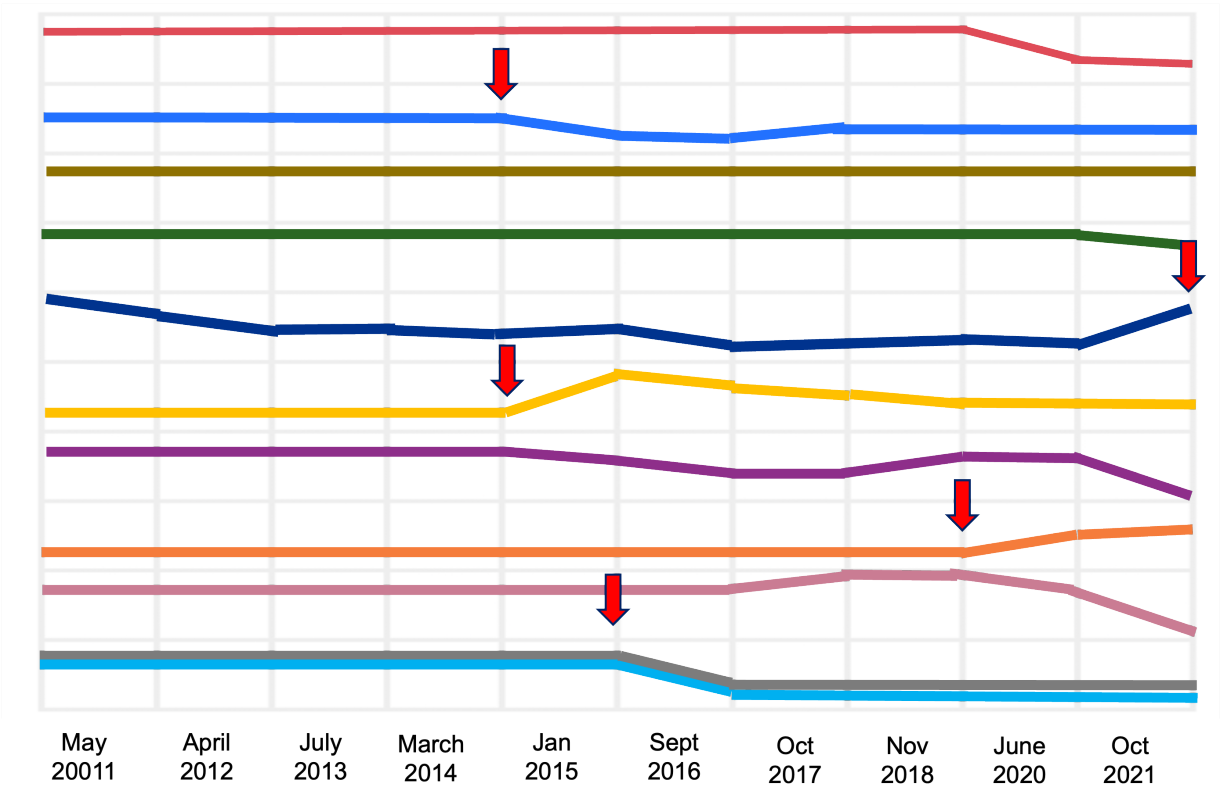
One model for improving clinician satisfaction & joy at work



If we had more time…

- **Personalizing the EHR**
- **AI enabled Patient Reported Information**
- **Whole person wellbeing dashboards**



Safe at home
Basic needs
ADLs
IADLs
Depression / anxiety
Pain
Spiritual wellbeing
Alcohol - substance
Soc network / Isolation
Intimacy - sex
Caregiving

APPENDIX

For further reading:

The Best Care Possible: A Physician's Quest to Transform Care Through the End of Life by Ira Byock 2012, Avery Penguin

Ira R. Byock, MD, FAAHPM
Emeritus Professor of Medicine & Community and Family Medicine
Dartmouth Geisel School of Medicine
IraByock.org

Listening Session 2: *Optimizing the Mix of Palliative Care and End-of-Life Care in PB-TCOC Models*

Betty Ferrell, RN, PhD

Director and Professor, Division of Nursing Research and Education,
Department of Population Sciences, City of Hope

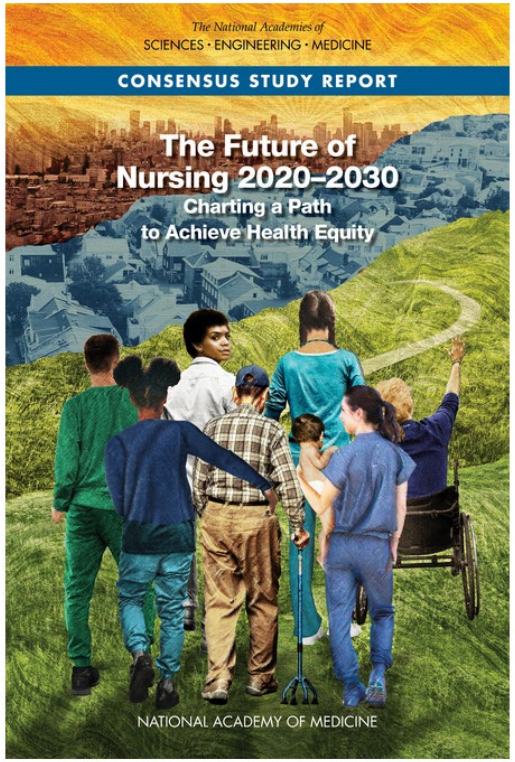
"Addressing the Workforce Challenges Related to Caring for Patients with Complex Chronic Conditions or Serious Illness through Clinical Leadership"

Betty Ferrell, PhD, RN, MA, CHPN, FAAN, FPCN
Professor and Director
Division of Nursing Research and Education
City of Hope
PI, End of Life Nursing Education Consortium (ELNEC)

Nurses are the predominant profession in health care, across all health care settings and all patient populations. They are central to patient and family understanding of illness, managing distressing symptoms, transitioning between health care systems, and they are present across all settings at the time of death.

Advanced Practice Nurses are underutilized in serious illness care and have untapped potential to manage patients with serious, complex illnesses.

Nurses are vital in providing initial assessment of needs of diverse populations, care during disease focused care, transition to palliative focused care, initiating hospice care, managing urgent needs, supporting family caregivers, providing telehealth, and care at the end of life.



What are Best Practices in Complex Care in Serious Illness?

Quality palliative care is the kind of care that you would want if you or someone you care about is seriously ill. Patient centered care in complex serious illness attends to physical, psychological, social and spiritual needs.

Best practices include:

- An assessment of the person and their family needs
- Assessment of symptoms and quality of life concerns
- A clear understanding of the goals of care
- Early integration of palliative care
- Early referral to hospice
- Access to support for symptoms and changing needs

The Generalist-Specialist Model of Nursing in Serious Illness Care

"Preparing Oncology Advanced Practice Nurses as Generalists in Palliative Care"

430 Oncology APRNs trained through ELNEC to integrate palliative care into their oncology practice.

12 month follow up documented changes in practice including increased family meetings, communicating with oncologists and with patients about patient prognosis and goals of care, referral of families for bereavement support and supporting clinical staff in end of life care.

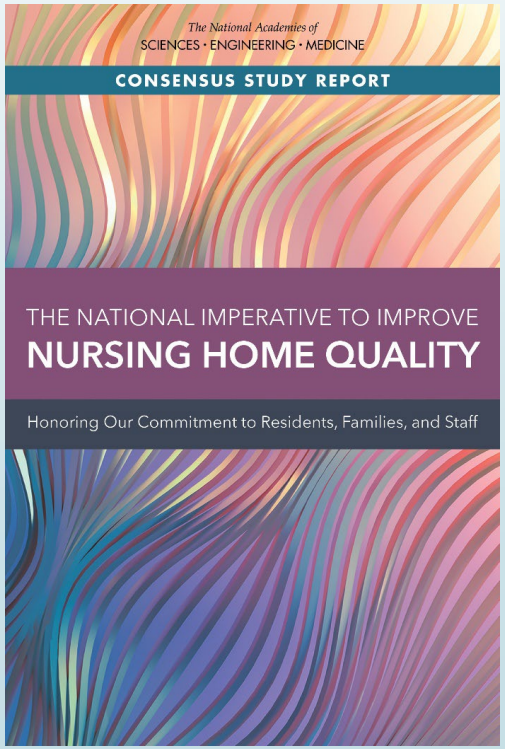
Journal of Palliative Medicine 26 (2) 2022

NCI Funded R25 CA217270 BFerrell, PI.

Goal 2 of the Report

Ensure a well-prepared, empowered, and appropriately compensated **workforce**.

www.nationalacademies.org/nursing-homes



Goal 2 : Recommendations

- Competitive wages and benefits
- Staffing standards and expertise
  - Full-time social worker
- Empowerment of certified nursing assistants
- Education and training
- Data collection and research

Palliative Care: Training Clinicians to Provide Quality Care in Serious Illness

ELNEC

END-OF-LIFE NURSING EDUCATION CONSORTIUM

Advancing Palliative Care

www.aacnnursing.org/elnec

City of Hope

American Association of Colleges of Nursing

ELNEC Content Addresses the Domains of the NCP Guidelines for Quality Palliative Care

- Palliative Care overview
- Pain Management
- Symptom Management
- Ethical Issues
- Cultural and Spiritual
- Communication
- Loss / Grief
- Final Hours / EOL

NCP - National Coalition for Hospice and Palliative Care

History of ELNEC

- Partnership between City of Hope and American Association of Colleges of Nursing (AACN)
- Began in 2000 with funding from the Robert Wood Johnson Foundation
- First Course: January 2001, Pasadena, CA
- January 2024 marked the 300th ELNEC Trainer Course!

City of Hope®

American Association of Colleges of Nursing

TODAY

- Over **47,532** ELNEC trainers through national courses
- These ELNEC Trainers have returned to their institutions/facilities and educated over **1,532,311** clinicians across disciplines. Presented in every US state and DC
- Thousands have completed ELNEC training online via Relias
- ELNEC Undergraduate (1,191) and Graduate (396) School of Nursing enrolled with 90,367 + 3,512 student online complete courses, respectively
- Taught in over 114 countries
- Translated into 12 languages

ELNEC Curricula

- Currently 8 ELNEC Curricula

  In person courses and Online:

  - ELNEC Core
  - ELNEC Geriatric (includes unlicensed staff)
  - ELNEC Pediatric (includes Neonatal Care)
  - ELNEC Critical Care
  - ELNEC APRN
  - ELNEC Oncology APRN (NCI, R25 Grant)
  - ELNEC Communication

  Online only:

  - ELNEC Undergraduate/New Grad (online)*
  - ELNEC Graduate (online)*

  *Supported by Cambia Health Foundation

The Nursing Workforce is Essential to Transforming Serious Illness Care