Interdisciplinary End of Life Symposium

Communication and Normalization of Hospice Care in the United States

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Disclosures

- I do not have any relevant financial relationships.

This presentation and/or comments will provide a balanced, non-promotional, and evidence-based approach to all diagnostic, therapeutic and/or research related content.

Cultural Linguistic Competency (CLC) & Implicit Bias (IB)

STATE LAW:

The California legislature has passed Assembly Bill (AB) 1195, which states that as of July 1, 2006, all Category 1 CME activities that relate to patient care must include a cultural diversity/linguistics component. It has also passed AB 241, which states that as of January 1, 2022, all continuing education courses for a physician and surgeon **must** contain curriculum that includes specified instruction in the understanding of implicit bias in medical treatment.

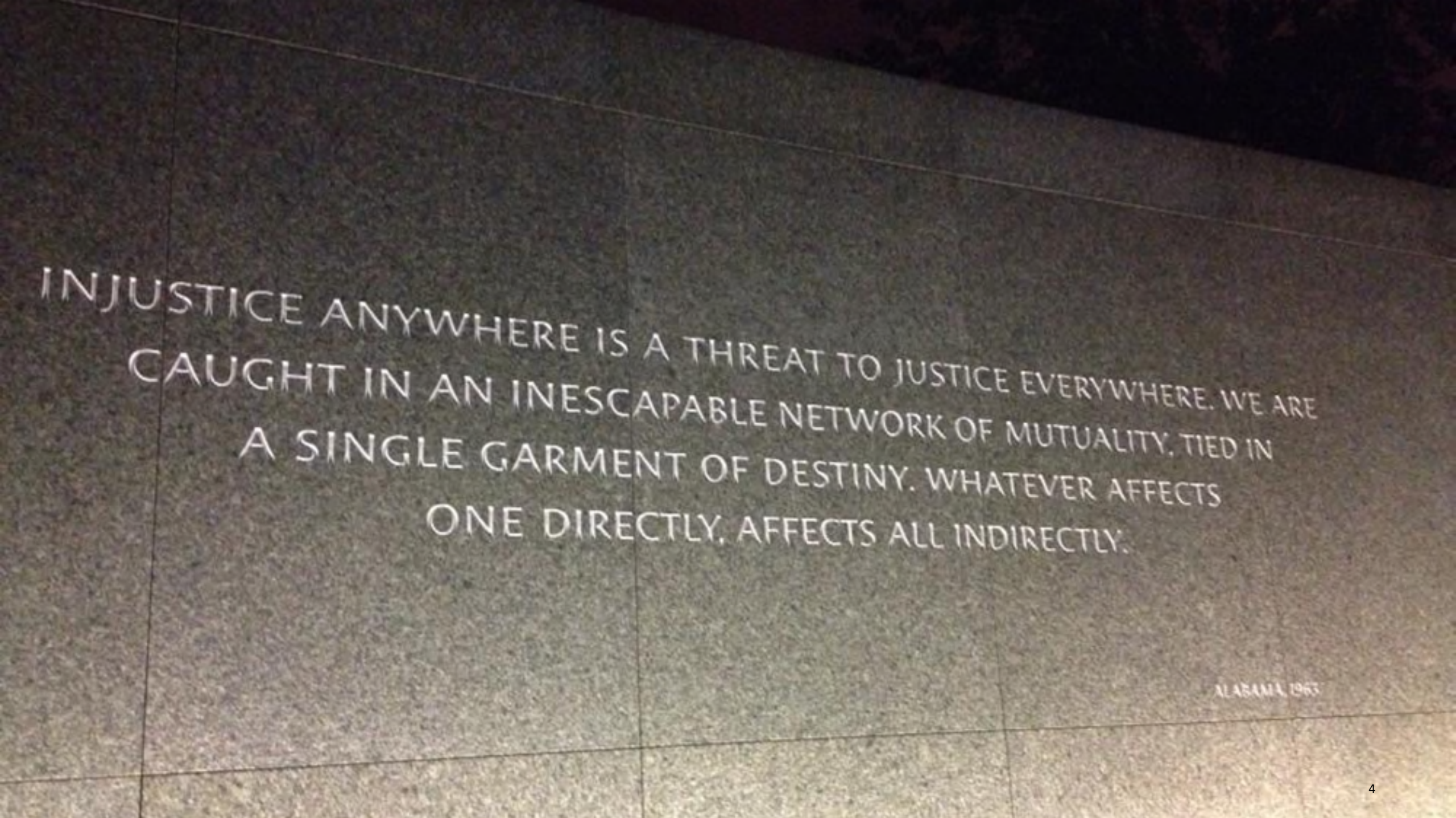
The cultural and linguistic competency (CLC) and implicit bias (IB) definitions reiterate how patients' diverse backgrounds may impact their access to care.

EXEMPTION:

Business and Professions Code 2190.1 exempts activities which are dedicated solely to research or other issues that do not contain a direct patient care component.

The following CLC & IB components will be addressed in this presentation:

- *Addressing language barriers, managing cultural differences and diversity, and modulating communication for various socioeconomic groups*
- *The well-known and studied implicit bias that Black and Brown people face prevents these vulnerable populations from accessing care and perpetuates healthcare disparities across medical sub-specialties, which likely contributes to the overall underutilization of hospice care.*


INJUSTICE ANYWHERE IS A THREAT TO JUSTICE EVERYWHERE. WE ARE
CAUGHT IN AN INESCAPABLE NETWORK OF MUTUALITY, TIED IN
A SINGLE GARMENT OF DESTINY. WHATEVER AFFECTS
ONE DIRECTLY, AFFECTS ALL INDIRECTLY.
ALABAMA, 1963

Hospice is Healthcare

- Shock value out of way…
- H-word, take fear out of it when we *Educate and Empower*
- President & Mrs. Carter on hospice care
- 27% of Americans
- Gap in knowledge about hospice eligibility guidelines across the healthcare system.
  - Patients and Families
  - Physician Specialists

Why I chose this title?

- Barriers of communication prevent people from **sharing EOL wishes**
- Hospice Care is **underutilized** in our country
- We must work **together** to address the challenges people face at the EOL
  - INTERDISCIPLINARY
  - As humans we will all encounter issues, regardless of HCW status

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Communication

What is Communication?

- Oxford Definition includes EXCHANGING of information or news
  - mutuality
- We SPECIALIZE in difficult conversations, EOL workers
  - **Necessary conversations**, avoided and delayed
- Varying degrees of communication skills and styles, further diversified by our personality and background

Communication in Healthcare

- Conversations about how people want to *live* until the end of life
  - **NHDD 2024** discuss diversity in our society and some cultures may find it taboo, superstitious or disrespectful to discuss death
- What Matters to you?
- Goals of care: values, hopes, preferences
- NHDD 2025 pledge…

Breaking Down Barriers of Communication in Healthcare

- **Barriers**, double-edged sword
  - Diversity of cultures in our society
    - Helped by Cultural Humility, curiosity
- Everyone has a role: **ALL disciplines**
  - Result? Breaking down barriers of communication can build mutual trust between the healthcare system, patients and families

A Communication tool: LISTEN

- **LISTEN & LET** them do most of the talking
- **INQUIRY & INTEREST** about their rich life experiences “What’s important to you?”
- **SIT** down as they SHARE their life stories. Share the insights you learn from the things they’re willing to share
- **TAKE** notes on the key aspects of their experience and the wisdom they share- helps teammates
- **EMPATHIZE** with their perspective on the challenges they have faced in life or pain they’re currently experiencing
- **Never** make assumptions about their needs. Ask permission to examine.

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Normalization

Normalization

- Define Hospice Care
- Who
- What
- Where
- When
- Why
- How

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Hospice Care

Hospice Care: Sustainability of Healthcare

- Save money: reduce healthcare costs the last year of life by 11% https://hospicenews.com/2023/03/29/hospice-length-of-stay-balancing-patient-needs-versus-regulatory-compliance/

Medicare: Eligibility 180 days (6 months)

- Average 77.9 days 2018 ; 92.1 days 2021 on the rise? https://hospicenews.com/2019/11/25/average-hospice-length-of-stay-rose-during-2018/
- **Median** (half/half)
  - Last five years was 18 days **now only 17 days**!
- We must help folks see the **advantages of hospice care**😇

Where does the time go at the EOL? 

- Second opinions (delays care, wastes precious time IMO)
- Advance care planning not in place
- Eligibility knowledge lacking by the general public WHY IS HOSPICE UNDERUSED IN THE US? “**only 27% of Americans** knew what hospice care was and what it entailed.” https://www.partnerplusmedia.com/latest-news/why-is-hospice-underused-in-the-us

NHPCO Facts and Figures Report 2023

- Released December 13, 2023 (slide deck available)
- https://www.nhpco.org/hospice-care-overview/hospice-facts-figures/
- **Hospice patient characteristics**
- Location and level of care
- Medicare hospice spending
- Hospice provider characteristics
- Volunteer and bereavement services info

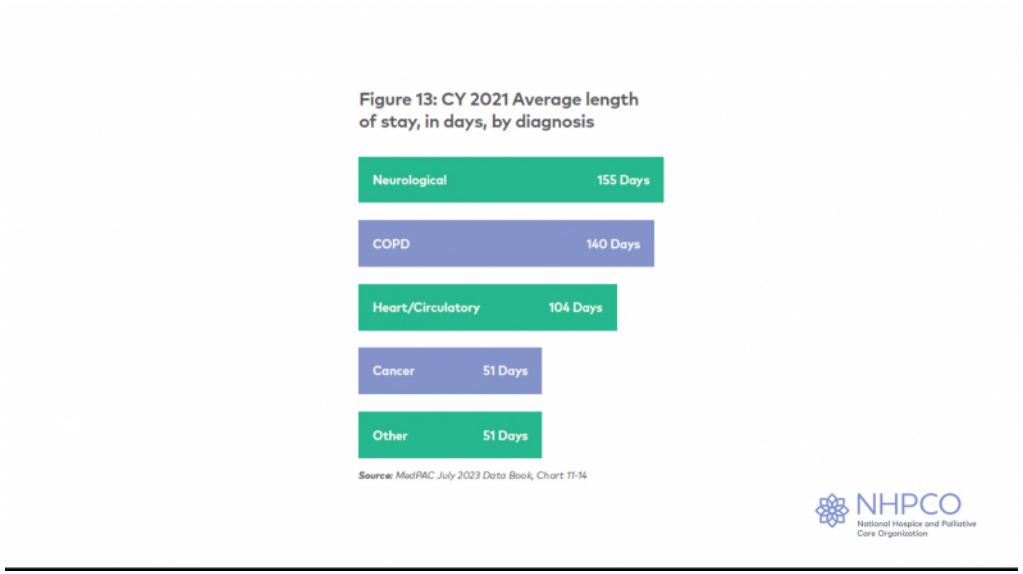
NHPCO Facts and Figures Report 2023 cont'd

- Medicare Beneficiaries **1.7million people** used Hospice
- Medicare decedents **47.3%** utilized hospice care (2.8 million people)
- "Focus on caring not curing"
- Principle Diagnosis 2022

Year	Average lifetime length of stay among decedents (in days)	Median lifetime length of stay among decedents (in days)	Number of Medicare decedents who used hospice (in millions)
2010	87.8	18	0.87
2019	92.5	18	1.20
2020	97.0	18	1.31
2021	92.1	17	1.29

Note: Note: "Lifetime length of stay" is calculated for decedents who were using hospice at the time of death or before death and reflects the total number of days the decedent was enrolled in the Medicare hospice benefit during their lifetime.

Source: *MedPAC March 2023 Report to Congress, Table 10-4*



NHPCO Facts and Figures Report 2023 cont'd

- Principle Diagnosis 2022

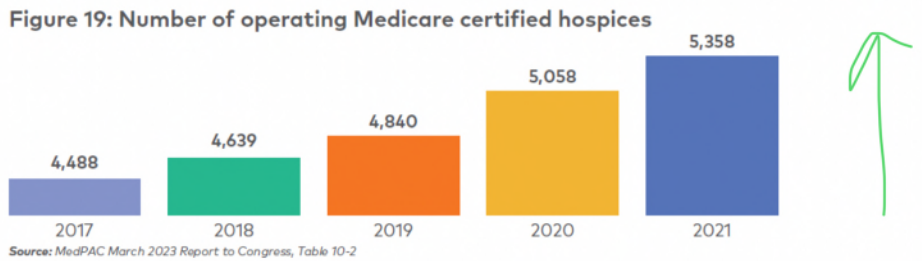
Table 2: FY 2022 Top 20 Principal Hospice Diagnoses, by ICD-10 code

Rank	"International Classification of Diseases, Tenth Revision (ICD-10)/Reported Principal Diagnosis"	Number of Beneficiaries	Percentage of all Reported Principal Diagnoses
1	G30.9-Alzheimer disease, unspecified	135,910	7.4%
2	G31.1-Senile degeneration of brain, not elsewhere classified	124,365	6.8%
3	J44.9-Chronic obstructive pulmonary disease, unspecified	78,630	4.3%
4	G30.1-Alzheimer disease with late onset	63,980	3.5%
5	I50.9-Heart failure, unspecified	52,375	2.8%
6	G20-Parkinson disease	52,155	2.8%
7	"I25.10-Atherosclerotic heart disease of native coronary artery withoutangina pectoris"	47,117	2.6%
8	"C34.90-Malignant neoplasm of unspecified part of unspecified bronchus or lung"	44,093	2.4%
9	U07.1-Emergency use of U07.1	43,505	2.4%
10	I67.2-Cerebral atherosclerosis	38,543	2.1%
11	I11.0-Hypertensive heart disease with (congestive) heart failure	36,860	2.0%
12	I67.9-Cerebrovascular disease, unspecified	35,120	1.9%
13	E43-Unspecified severe protein-energy malnutrition	33,111	1.8%
14	I63.9-Cerebral infarction, unspecified	29,291	1.6%
15	"I13.0-Hypertensive heart and renal disease with (congestive) heart failure"	27,455	1.5%
16	C61-Malignant neoplasm of prostate	24,806	1.3%
17	N18.6-End stage renal disease	24,565	1.3%
18	J96.01-Acute respiratory failure with hypoxia	23,329	1.3%
19	C25.9-Malignant neoplasm: Pancreas, unspecified	22,128	1.2%
20	"J44.1-Chronic obstructive pulmonary disease with acute exacerbation, unspecified"	20,928	1.1%

Source: *FY 2024 Hospice Wage Index and Quality Reporting Proposed Rule, Table 2*

NHPCO Facts and Figures Report 2023 cont'd

- More hospice agencies, less care



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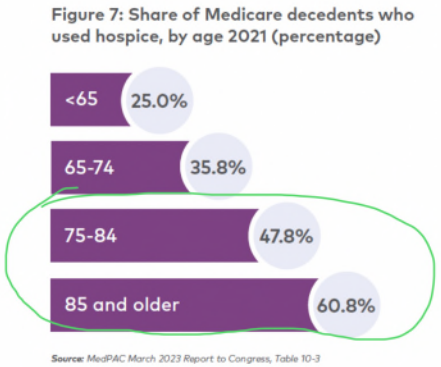
What are we doing wrong?

- How people initiate hospice care:
  - Direct from patient
  - PCP, primary care physicians
  - Hospital case managers (HOSPITALISTS)
  - Facilities
  - Specialists

A word about Primary Care: Where Physicians focus on prevention

- Internal Medicine and Family Medicine
- **United States Preventative Services Task Force USPSTF Screenings age groups outside of range: 75-84 47.8%; 85 60.8%**
- A & B Grade Recommendations https://www.uspreventiveservicestaskforce.org/uspstf/recommendation-topics/uspstf-a-and-b-recommendations
  - AAA
  - Colorectal cancer 45-49
  - Breast cancer Mammogram BRCA-Related (family history) 50-74 biennial
  - Cervical cancer 21-65
  - Prostate cancer
  - Lung cancer 50-80 (20 pk/yr, currently smoke, quit 15 years ago)
  - HCV 18-79
  - HIV 15-65 (PreP is A for adolescents and adults at risk)
  - Osteoporosis (prevent falls and fractures) women 65 and up



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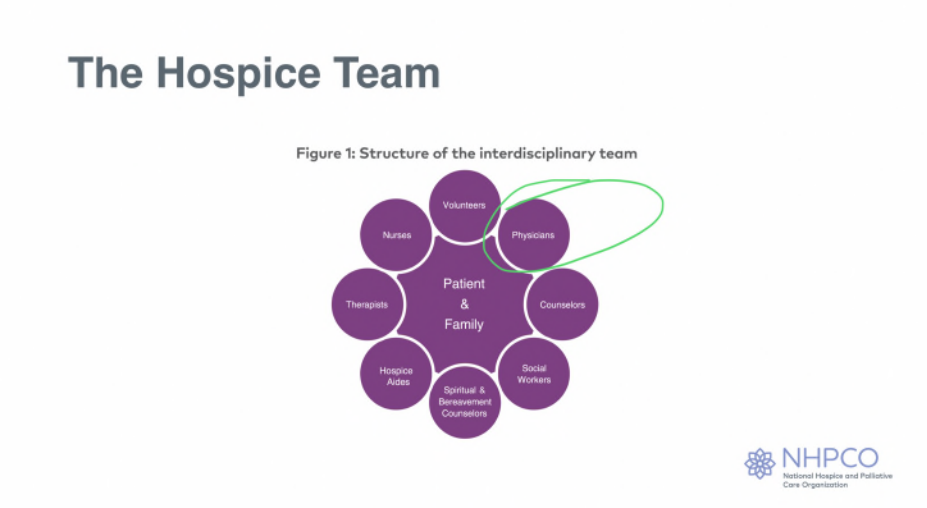
How Healthcare can look at the EOL

- Frequent hospitalizations!
- Things to “tune up”: hyponatremia and other metabolic derangements, dehydration, UTIs (pyelonephritis), infections can lead to sepsis (death)
- Wounds (skin failure) infections that lead to sepsis



Cultural Shift: End-of-Life Care for Specialists

- EOL care is not funeral arrangements or estate planning
  - Instructions for **death**
- **Late stages of life**, final 2-10 years, 70-90s, younger for some (cancer)
- **Palliative care**: “specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.” https://getpalliativecare.org/whatis/
- **Hospice care**—Our sacred work caring for **dying** people with terminal conditions: increased ADL dependence, reduced PPS%, nutrition and cognitive declines

Define Basics: When is Hospice Care needed?

- Serious illness
- Incurable disease
- Limited life expectancy, bleak prognosis
- Frequent hospitalizations, but getting weaker (function, nutrition, cognition)

A Valuable Resource: Educates & Empowers EVERYONE involved

- The Real Deal About Hospice: Short Stories Highlighting the Advantages of Hospice Care for Patients and Families Kaishauna Guidry, MD, HMDC and Sharon Harris, LVN, CHPLN, EOLD
- Cases discussed from this book published 11/05/2023
  - Each chapter with **disease-specific insights** on when to seek timely hospice care

Who are the Specialists in our communities?

- Cardiologists
- Infectious Disease Specialists
- Neurologists
- Pulmonologists/Critical Care Specialists
- Nephrologists
- Oncologists (have a better emoji?)
- Gastroenterologists
- HOSPITALISTS call consults on all of the above during hospitalizations

Helping Cardiologists

- Chapter 4: Heart Disease “Mr. Paul” didn’t know about hospice care, had 5 hospitalizations during final 9 months of life for heart failure exacerbations, CHF which can be managed at home with hospice care
  - 4 weeks on routine home care
- American Heart Month February Bonus podcast
- Congestive Heart Failure CHF, undiagnosed until late stages
  - Advanced Heart Failure, Stage D with NYHA Class 3 or 4 symptoms
- **Consider an inservice with hospice physician and local cardiology group**

Helping Infectious Disease Specialists 

- HIV
  - USPSTF Screening people ages 15-65
- Chapter 5: Beverly diagnosed with HIV many years ago, now a senior living in a SNF
- World AIDS Day 12/01
  - Consider a community event

Helping Neurologist 🧠
(Five of the Top 10 Principle Diagnosis)

- Chapter 1 ALS **Neurodegenerative**: Sal lost ability to move and communicate (quadriplegia), then muscles of respiration became too weak to support breathing.
  - Needed non-invasive positive pressure ventilation NIPPV
- Chapter 2 Alzheimer's disease (short LOS a non-issue)
  - Mr. Davey sundowning stresses family caregiver/daughter
- Chapter 9 Stroke & **Coma**
  - Mr. Henry with new decline after stroke

Helping Pulm/ Critical Care Specialist

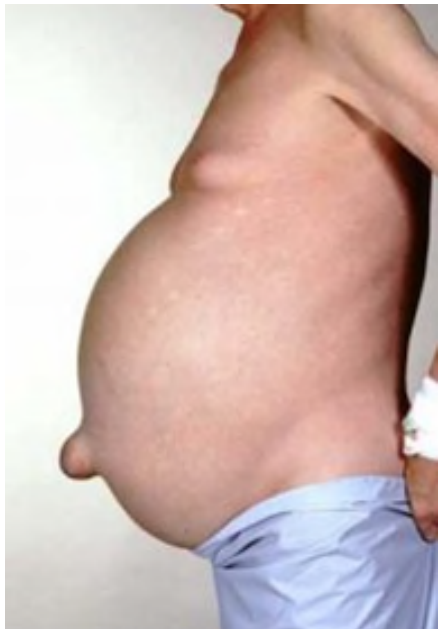
- Chapter 7 COPD- Chronic Obstructive Pulmonary Disease
  - Ms. Vivian: Oxygen dependent, maxed out treatment, frequently hospitalized for COPD exacerbations
- Chapter 9 Stroke and Coma - they’re on ventilators in the MICU
- Consider 3 wishes project collaboration
  - https://3wishesproject.com

Helping Nephrologists 

- Renal Disease: Chapter 8 Ms. Wilson faced with decision to stop dialysis for **end stage renal disease** (many etiologies)
  - Hemodialysis HD
  - Peritoneal dialysis PD
- When is it time to stop? Weak, unstable vitals, symptoms, coding!
- People die in 2-3 weeks after discontinuing dialysis
- Some people choose to NOT start dialysis
- Consider in-service with dialysis center

Helping Gastroenterologists 💩 (Hepatologist)

- Chapter 6 Liver Disease: Ruben with Jaundice, dyspnea, ascites, abdominal pain
  - Manage draining of refractory ascites at home
- HCV treatment failure, HCC
- Liver transplant lists (non-candidates)
- Paracentesis clinics
  - Increasing frequency



Helping Oncologists ☠️

- Patients diagnosed at advance stages
  - Outside of screening age range
  - Not treatment candidate (dementia or debility)
- The case of Mr. Turner: Chapter 3
- Lung cancer: dyspnea, malignant pleural effusion; Treatment complications causing hospitalizations
- Caregiver stress of daughter; **Delayed** hospice care choice until symptoms were severe
- Months of stress, only on hospice for 5 days

Helping HOSPITALISTS 

- Case managers huddle with them daily
- They may call directly from ED (don’t forget emergency room physicians and case managers)
- **HOSPITALISTS engage with all of the SPECIALISTS!**
- Consider National Hospitalist Day 03/07 event in your community

Help them SEE the Advantages of Hospice Care for Patients and Families

- Interdisciplinary care team with unique roles
- Ability to be home
- Medications and nursing staff available to adjust plan of care quickly
- Time and support to resolve family conflicts
- Resources readily available
- Many more….

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Thank you

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