Goals of Care Coalition of New Jersey's Inaugural Summit

Discuss, Decide, Document: An Interprofessional Summit on Advance Care Planning

Thursday, April 18, 2019
4:45 p.m. – 8:45 p.m.

JFK Conference Center
70 James St.
Edison, NJ 08820
(across the street from the hospital)

Co-Provided by:

Hackensack Meridian Health JFK Medical Center
Goals of Care Coalition of New Jersey
Faculty and Planning Committee:

*Explanation of Abbreviations
F = Faculty; P = Planning Committee; R = Reviewer

Barile, David, MD, Geriatric Medicine & Palliative Care, Penn Medicine Princeton Health; Founder and Chief Medical Officer, Goals of Care Coalition of New Jersey, Princeton, NJ.  F

Brown, Jessica, Chief Operating Officer, Goals of Care Coalition of New Jersey, Princeton, NJ.  P

Collins, Harry, MD, Medical Director, Hackensack Meridian Health, JFK Haven Hospice & Palliative Care Program, Hackensack Meridian Health, JFK Medical Center, Edison, NJ  F

Duberstein, Paul, PhD, Chair, Department of Health Behavior, Society and Policy, Rutgers School of Public Health, Rutgers Biomedical and Health Sciences, Piscataway, NJ.  F

Duttaroy, Pragati, PT, DPT, Clinical Director & Clinical Education Coordinator/Physical Therapy, Professional Development & CME; Hackensack Meridian Health, JFK Johnson Rehabilitation Institute, Edison, NJ  P

Feldstein, Lori, CEO and Executive Director, Goals of Care Coalition of New Jersey, Princeton, NJ.  F, P

Grafton, Tracy, LCSW, ACHP-SW, Social Worker, Hackensack Meridian Health, JFK Haven Hospice & Palliative Care Program, Hackensack Meridian Health, JFK Medical Center, Edison, NJ.  F, P

Griessl, Rev. Annari, Ph.D., BCCC, BCPC, FHPC, Director, Pastoral Care Services & Clinical Pastoral Education; Diplomate in Clinical Pastoral Supervision (CPSP), Hackensack Meridian Health, JFK Medical Center, Edison, NJ.  P

Kolber, Carole, Ph.D., Administrative Director, Professional Development & CME; Hackensack Meridian Health, JFK Johnson Rehabilitation Institute; Clinical Assistant Professor, Seton Hall University School of Health & Medical Science, South Orange, NJ.  F, P, R

Owusu-Ansah, Rev. Donna, M.Div., Chaplain, Hackensack Meridian Health, JFK Haven Hospice & Palliative Care Program, Hackensack Meridian Health, JFK Medical Center, Edison, NJ.  F

Winter, Robin, MD, Director of the JFK Family Medicine Residency Program; Medical Director of JFK Hartwyck Nursing, Convalescent and Rehabilitation Centers; Hackensack Meridian Health, JFK Medical Center; Professor and Founding Chair of the Department of Family Medicine for The Hackensack Meridian School of Medicine at Seton Hall University, Nutley, NJ.  F, P

Program:

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>4:45 - 5:15 pm</td>
<td>Registration &amp; Light Dinner</td>
</tr>
<tr>
<td>5:15 - 5:25</td>
<td>Welcome &amp; Opening Remarks – Robin Winter, M.D.</td>
</tr>
<tr>
<td>5:25 - 5:55</td>
<td>NJ: The Worst State to Die in ... Why and What We Can Do About It – Lori Feldstein</td>
</tr>
<tr>
<td>5:55 - 6:15</td>
<td>A Daughter’s Story-Adina Avery Grossman Introduction– Lori Feldstein</td>
</tr>
<tr>
<td>6:15 - 6:35</td>
<td>Practicing Good Medicine: What Everyone Needs to Know About Supportive, Palliative &amp; Hospice Care – Harry Collins, MD</td>
</tr>
<tr>
<td>6:35 - 6:45</td>
<td>BREAK</td>
</tr>
<tr>
<td>6:45 - 7:15</td>
<td>Advance Care Planning: Facilitating Effective Conversations for all New Jerseyans – David Barile, M.D.</td>
</tr>
<tr>
<td>7:15 - 7:45</td>
<td>Patient-Provider Relationship: Overcoming Obstacles to Open Dialogue about End-of-Life Care – Paul Duberstein, Ph.D.</td>
</tr>
<tr>
<td>8:05 - 8:35</td>
<td>Integrating Advance Care Planning into Your Practice – Tracy Grafton, LCSW, ACHP-SW</td>
</tr>
<tr>
<td>8:35 - 8:45</td>
<td>Question &amp; Answers; Closing Remarks – Lori Feldstein</td>
</tr>
</tbody>
</table>
Robin O. Winter, MD, MMM

Robin O. Winter, MD, MMM has been Director of the JFK Family Medicine Residency Program since 1989. After receiving a BA from Haverford College and a medical degree from Albert Einstein College of Medicine, Dr. Winter did his Family Medicine Residency at Hunterdon Medical Center in Flemington, New Jersey. To pursue his interest in the biopsychosocial model, he obtained a Certificate in Family Therapy from Trinity Counseling Service in Princeton, New Jersey. Board certified in both Family Medicine and Geriatric Medicine, Dr. Winter earned a Master of Medical Management degree at Carnegie Mellon University. He is Medical Director of JFK Hartwyck Nursing, Convalescent and Rehabilitation Centers, and sits on their Board. Dr. Winter is Professor and Founding Chair of the Department of Family Medicine for Hackensack Meridian School of Medicine at Seton Hall University. He is also a Clinical Professor in the Department of Family Medicine and Community Health at Rutgers Robert Wood Johnson Medical School and an Associate Professor at St. George's University School of Medicine.

A long-standing member of the Society of Teachers of Family Medicine (STFM), Dr. Winter is currently on the Editorial Board of their Journal, Family Medicine. He is a Past-President of the Association of Family Medicine Residency Directors, a fellow of the American Academy of Family Physicians and served a seven-year term on the Family Medicine Residency Review Committee of the Accreditation Council for Graduate Medical Education (ACGME). In addition to various research papers, Dr. Winter has published a number of articles on the use of literature and the humanities in Family Medicine residency education.
NJ: The Worse State to Die In
Why & What Can We Do About It

Lori Feldstein

Lori Feldstein, CEO and Executive Director of the nonprofit, Goals of Care Coalition of NJ (GOCCNJ), is responsible for directing the organization's efforts to improve shared decision-making between healthcare providers and patients and their families to ensure that decisions about care align with the patient's values and goals. After losing both of her parents to cancer, Lori realized that the way we, especially in NJ, deal with serious advanced illness and end-of-life care needed to be rethought. She became intent on changing the way we think and act when dealing with a life limiting illness and facing impending death. Because of her experience, she is more determined than ever to make certain that healthcare providers, patients and family members talk honestly and frequently about diagnosis, prognosis and the patient and family's goals of care so that patients get the care they want and no less and the care they need and no more! Prior to joining GOCCNJ, Lori was the founder of Cogent Medical Marketing in Princeton, NJ. Her experience in developing and implementing professional communication strategies for the pharmaceutical industry, focusing in such areas as market access, key opinion leader development, medical education, and advocacy prepared her well for the work she now does on behalf of GOCCNJ. A graduate of Muhlenberg College, she is a member of the Healthcare Communication and Marketing Association and the Healthcare Businesswomen's Association. She is also President of AJC's Central NJ Chapter and is a member of their National Board of Governors. Lori also serves on the on the National Council for AIPAC and is part of the AIPAC Princeton Leadership Council. In her spare time, Lori also is a volunteer with Greenwood House Hospice and enjoys time with her husband Michael and their three children, Peri (20), Jacob (18) and Carly (15). She loves to travel, run, practice yoga, read and cook.
NJ: The Worst State to Die In
Why & What Can We Do About It

Lori Feldstein
CEO & Executive Director
Goals of Care Coalition of New Jersey
Objectives

Discuss
how NJ ranks in providing person-centered end-of-life care

Identify
some of the factors that contribute to NJ's poor performance

Describe
what it will take to change the status quo in NJ

2016 State Performance Level Index

CTAC ACT Index, presented to GOCCNJ, February 2019
2016 State Performance Level Index

CTAC ACT Index, presented to GOCCNJ, February 2019

Database Sources for the 2017 National ACT Index Measures

<table>
<thead>
<tr>
<th>Source</th>
<th>Number of Measures in 2017 National ACT Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Health and Aging Trends Study (NHATS)</td>
<td>9</td>
</tr>
<tr>
<td>Dartmouth Atlas of Healthcare (DA)</td>
<td>8</td>
</tr>
<tr>
<td>Health and Retirement Study (HRS)</td>
<td>4</td>
</tr>
<tr>
<td>Agency for Healthcare Research and Quality (AHRQ)</td>
<td>2</td>
</tr>
<tr>
<td>Center to Advance Palliative Care (CAPC)</td>
<td>1</td>
</tr>
<tr>
<td>Center for Disease Control and Prevention (CDC)</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
</tr>
</tbody>
</table>

CTAC ACT Index, presented to GOCCNJ, February 2019
### New Jersey Index Measures 2016 Compared to US Index Average (Preliminary Draft)

**New Jersey Measures**

<table>
<thead>
<tr>
<th>Index Measure</th>
<th>2016 measure for the state</th>
<th>2016 measure for the US</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Medicare spending per decedent during the last two years of life</td>
<td>$88,495.58</td>
<td>$71,428.57</td>
</tr>
<tr>
<td>Hospital days per decedent during the last two years of life</td>
<td>18.259</td>
<td>16.418</td>
</tr>
<tr>
<td>Intensive care days per decedent during the last two years of life</td>
<td>8,900</td>
<td>5,400</td>
</tr>
<tr>
<td>Home health agency visits per decedent during the last two years of life</td>
<td>7,715</td>
<td>26.015</td>
</tr>
<tr>
<td>Percent enrolled in hospice during the last six months of life</td>
<td>49.1%</td>
<td>54.4%</td>
</tr>
<tr>
<td>Hospice days per decedent during the last six months of life</td>
<td>20.2</td>
<td>24.5</td>
</tr>
<tr>
<td>Average co-payments per decedent during the last two years of life - Total</td>
<td>$5,471.85</td>
<td>$4,075.66</td>
</tr>
<tr>
<td>Percent of Deaths Occurring at Home</td>
<td>28.4%</td>
<td>29.4%</td>
</tr>
<tr>
<td>Percent of hospital patients in medical cohort readmitted within 30 days of discharge</td>
<td>16.2%</td>
<td>14.9%</td>
</tr>
<tr>
<td>Percent of hospitals with a palliative care program</td>
<td>92.3%</td>
<td>96.5%</td>
</tr>
</tbody>
</table>

In the chart above, a red block indicates that the score is lower than the U.S. average. A yellow block indicates that the score is about the same as the U.S. average. A green block indicates that the score is greater than the U.S. average.

4/18/2016 © Goals of Care Coalition of New Jersey
### 10 Measures Included in the 2016 State-Level ACT Index Prototype
(Preliminary Data)

<table>
<thead>
<tr>
<th>ACT Performance Level Index Measures for 2016</th>
<th>Lowest Ranked State</th>
<th>Value</th>
<th>Highest Ranked State</th>
<th>Value</th>
<th>Highest/Lowest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home health agency visits per decedent in last two years</td>
<td>ND</td>
<td>5.3</td>
<td>UT</td>
<td>47.4</td>
<td>8.94</td>
</tr>
<tr>
<td>Intensive care days per decedent during the last two years of life</td>
<td>NJ</td>
<td>8.9</td>
<td>ND</td>
<td>1.8</td>
<td>4.94</td>
</tr>
<tr>
<td>Percent of hospitals with a palliative care program</td>
<td>AK</td>
<td>25.0%</td>
<td>NH, VT &amp; WV</td>
<td>100%</td>
<td>4.00</td>
</tr>
<tr>
<td>Hospice days per decedent</td>
<td>WY</td>
<td>10.1</td>
<td>UT</td>
<td>38.1</td>
<td>3.77</td>
</tr>
<tr>
<td>Percent deaths at home</td>
<td>ND</td>
<td>17.1%</td>
<td>UT</td>
<td>54.2%</td>
<td>3.17</td>
</tr>
<tr>
<td>Hospital days per decedent during the last two years of life</td>
<td>NY</td>
<td>20.1</td>
<td>UT</td>
<td>7.6</td>
<td>2.64</td>
</tr>
</tbody>
</table>

1. Two measures previously reported in the prior year’s CTAC State data are no longer being reported: “Hospice patients who received care consistent with their wishes” and “Hospice patients who received care consistent with their wishes without a hospice.” All measures are consistent with their previous year data in this presentation have been adjusted to remove these measures from any of the reported information.
2. CTAC is presently reviewing an additional 34 (increasing our index to 34 measures) state level reported measures for the purpose of adding them to our index.

4/7/2019

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<th>Highest Ranked State</th>
<th>Value</th>
<th>Highest/Lowest</th>
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<tr>
<td>Average co-payments: last two years of life</td>
<td>NJ</td>
<td>$5,472</td>
<td>MT</td>
<td>$2,252</td>
<td>2.43</td>
</tr>
<tr>
<td>Percent enrolled in hospice</td>
<td>ND</td>
<td>28.2%</td>
<td>UT</td>
<td>67.1%</td>
<td>2.38</td>
</tr>
<tr>
<td>Total Medicare spend: last two years of life</td>
<td>CA</td>
<td>$89,285</td>
<td>MT</td>
<td>$50,000</td>
<td>1.79</td>
</tr>
<tr>
<td>Percent readmitted within 30 days of discharge</td>
<td>NV</td>
<td>15.6%</td>
<td>UT</td>
<td>12.0%</td>
<td>1.30</td>
</tr>
</tbody>
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1. Two measures previously reported in the prior year's CTAC data are no longer being reported: "Caregivers who received patient's case assignment to hospice at the right time" and "Hospice patients who received care consistent with their stated end-of-life wishes." All previous year data in the presentation have been adjusted to remove these measures from any of the reported information.

2. CTAC is presently reviewing an additional 24 (increasing our index to 34 measures) state-level reported measures for the purpose of adding them to our index.

CTAC ACT Index, presented to GOCCNL, February 2016

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<th>Ranked State</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Medicare spend: last two years of life</td>
<td>CA</td>
<td>$80,265</td>
<td>NJ</td>
<td>$88,465</td>
</tr>
</tbody>
</table>

≥ $800 difference

1. Two measures previously reported in the prior year’s CTAC State data are no longer being reported: “Caregiver who provided patient was referred to hospice at the right time” and “Hospice patients who received care consistent with their stated wishes.” All previously year data in this presentation have been adjusted to remove these measures. For any of the reported information.

2. CTAC is presently reviewing an additional 24 (increasing the index to 26 measures) data trend reported measures for the purpose of adding them to our index.

CTAC ACT Index, presented to DOCCC, February 2019

Objectives

Identify

some of the factors that contribute to NJs poor performance
### Challenges

**Where do they exist?**

<table>
<thead>
<tr>
<th>Patients</th>
<th>Practitioners</th>
<th>System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cultural Diversity</td>
<td>Cultural Diversity</td>
<td>EMR</td>
</tr>
<tr>
<td>Poverty</td>
<td>Specialists</td>
<td>Hospitalist Movement</td>
</tr>
<tr>
<td>Insurance</td>
<td>Avoiding</td>
<td>Fragmentation</td>
</tr>
<tr>
<td>Dr. Google</td>
<td>Prognostication</td>
<td>Wrong Incentives</td>
</tr>
<tr>
<td>Family Dynamics</td>
<td>Defensive Medicine</td>
<td>Geography</td>
</tr>
<tr>
<td>Prior Trauma</td>
<td>Time</td>
<td>Medical Directives</td>
</tr>
<tr>
<td></td>
<td>Money</td>
<td>others</td>
</tr>
</tbody>
</table>

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### Challenges

**Factors Contributing to NJ's Poor Performance**
Challenges Cultural Diversity

3  1

third most culturally diverse state  the most culturally diverse amongst physicians

Challenges Cultural Diversity

third most culturally diverse state  the most culturally diverse amongst physicians
Challenges  
Lack of Communication

• 90% of people say that talking with their loved ones about end-of-life care is important
  27% have actually done so

• 80% of people say that if seriously ill, they would want to talk with their doctor about wishes for medical treatment toward the end of their life
  7% report having had the conversation with their doctor

• 82% of people say it’s important to put their wishes in writing
  23% of people have actually done it

1. The Dementia Project, National Survey, 2013
2. Survey of Californians by CAHF

Challenges  
Lack of Communication

• 99% of physicians who regularly treat patients 65 and older report that they believe that having advance care planning conversations are important
  14% have actually billed Medicare for the conversation

• 29% of physicians report having any formal training on how to talk with patients and families about end-of-life care
  46% of physicians say they feel unsure of what to say during those conversations

Imagine how much more difficult these conversations are when we don’t understand each other’s culture.

Where are the primary care doctors?

1 for every 2,500 people in NJ
### Challenges

**Specialists**

- Psychiatry
- Neurology
- Endocrine
- Pulmonary
- Cardiology
- Gastro
- Nephrology
- Surgery

### Hospitalists

![Arrow Pointing Up]

### Primary Care

![Arrow Pointing Down]
Challenges
Wrong Financial Incentives

Challenges
Changing the Culture

Treatment Preferences
Shared
Hope
Decision
Making

Satisfaction with Decision Process
Dignity

I don't want to live in a nursing home

Avoid Nursing Home
Decision Context

I don't want to be a vegetable
Decision Influences

Surrogate-Patient Concordance
Regret

Satisfaction with Decision Outcome
Prognosis

Burden on Family
Religion and Spirituality

Mistrust of Medical System

Overwhelmed In a Fog
Objectives

Describe what it will take to change the status quo in NJ

2019-2020 Initiatives
Resources

goalsofcare.org

ACP Guide
Leads you through the process of Advance Care Planning as you discuss, decide, and document your wishes for care at the end of your life.

4Step iCarePlan
Goals of Care Coalition of NJ

4SICP
Individualized, simple, 4-step approach to help patients make difficult medical decisions and to assist healthcare providers in having the conversation.

POLST
Specific medical orders, known as Practitioner Orders for Life-Sustaining Treatment, to be honored by healthcare providers during a medical crisis.

Stay in touch: goalsofcare.org Facebook.com/goalsofcare @goalsofcare

Goals of Care Coalition of New Jersey

Thank you
lfeldstein@goalsofcare.org
www.goalsofcare.org

Follow Us

Stay in touch:
facebook.com/goalsofcare @goalsofcare

© Goals of Care Coalition of New Jersey
A Daughter's Story

Adina Avery-Grossman

Adina Avery-Grossman is brand and licensing professional and founding partner of Brandgenuity, a trademark licensing agency with offices in NY, London, Munich and Hong Kong. She is a graduate of Princeton University and Columbia Business School. She lives in Bergen County with her husband Harman. Adina sits on several volunteer boards where her focus is marketing and development.
Hospice and Palliative Care

Harry Collins, MD

_Harry Collins, MD_ is Medical Director, JFK Medical Center Haven-Hospice Program and in private family practice in Edison, NJ. Dr. Collins is also Clinical Associate Professor, Department of Family Practice, Robert Wood Johnson Medical School. He graduated from Hahnemann Medical College, Philadelphia, PA and completed his residency in family practice at Medical College of Virginia, Richmond, VA. Dr. Collins is board certified in family medicine as well as hospice & palliative care. He graduated from the Temple University School of Pharmacy. He was a past recipient of both "Physician of the Year Award from the Middlesex County-Home Health Development" and the "NJ Hospice Medical Director of the Year." Dr. Collins has been principal investigator in many clinical trials. He is a member of numerous professional organizations, has authored several publications, and has presented on topics related to palliative care.
THE DIFFERENCE BETWEEN PALLIATIVE AND HOSPICE CARE

PALLIATIVE CARE
Palliative care is a comprehensive approach to improving the quality of life for people who are living with serious or potentially life-limiting illnesses. Palliative care programs at UPMC are made up of a multidisciplinary team of doctors, nurses, therapists, counselors, and social workers. The team works in collaboration with a patient's entire care team of physicians and nurses, and with the patient and their family to provide medical, emotional, and social support needed to cope with the burdens of a serious illness.

Since no two patients are alike, palliative care treatments are tailored to the individual based on his or her medical needs and his or her wishes for how they want to be treated - physically, psychologically, and spiritually.

Palliative care is a resource available for anyone with a serious or life-limiting illness. Some types of conditions that may be appropriate to receive palliative care include cancer, congestive heart failure, chronic obstructive pulmonary disease (COPD), Parkinson's disease, Alzheimer's disease, dementia, liver failure or end-stage kidney disease.

Palliative care provides treatments for symptoms even if the underlying disease cannot be cured. The main goals of palliative care are to relieve the pain and suffering and discomfort associated with an illness and to reduce patient and family members' stress.

Palliative care can be provided in a number of care settings including a patient's home, outpatient palliative care clinics, in nursing homes, hospitals, or other specialized clinics.

Since no two patients are alike, palliative care treatments are tailored to the individual based on his or her medical needs and his or her wishes for how they want to be treated - physically, psychologically, and spiritually.

HOSPICE CARE
While palliative care is available to any patient with a serious illness, hospice care is a specialized type of palliative care for patients suffering from an incurable illness or multiple illnesses with a life expectancy of six months or less. Hospice care is focused on improving quality of life, maintaining dignity, and making patients as comfortable as possible during the time they have remaining. The hospice care team is a multidisciplinary team made up of doctors, nurses, social workers, trained volunteers, and spiritual advisors. Hospice care can be provided in the home or in a facility such as a hospital, nursing home, or a dedicated hospice care facility.

Patients entering hospice care understand that their illness or disease is not responding to medical treatment. By entering hospice, attempts to cure the patient's underlying illness are stopped. Stopping curative treatment does not mean discontinuing all treatment. For example, if a patient is being treated for high blood pressure with medication, he or she will continue receiving those treatments in addition to the treatments they are receiving to manage the symptoms of their terminal illness.

Patients can elect to leave hospice care at any time if he or she decides that they want to resume curative treatments. Patients may also leave hospice care if their condition improves.
Hospice and Palliative Care

Harry Collins, MD
Medical Director

Haven Hospice & Palliative Care
Hackensack Meridian Health/
JFK Medical Center

History

- From the Latin term “hospes” meaning guest
- Origin from Middle Ages
- Likely developed when sick/wounded were cared for during the Crusades
- Modern hospice movement driven by Dame Cicely Saunders in Great Britain
History (cont.)

- Came to US in early 1970s.
- One hospice in US in 1974
- No formal funding avail. until 1983
- 4300 certified hospices in 2016
- 1.4 million people elected hospice care in 2016 (25,000 in 1982)

Hospice Care

- Interdisciplinary team-oriented approach in the provision of providing expert medical care, pain management, emotional and spiritual support of those patients and families experiencing a terminal illness

Adapted from NHPCO, (2017).
**Palliative Care**

- Care provided to treat any symptoms during the course of illness
- Palliative care can begin at diagnosis
- May be provided in conjunction with curative treatments
- Often a precursor to hospice care
- "alleviate symptoms of a disease without curing it"


---

**Interdisciplinary Team**

- Attending MD
- Hospice Medical Director
- Nurse Practitioner
- RN
- MSW
- CHHA
- Clergy
- Physical Therapy, Occupational Therapy
- Speech
- Audiology
- Dietician
- Volunteers (specially trained)
- Bereavement MSW
Locations/Levels of Care

- Home Hospice
- Nursing Home
- Assisted Living
- Inpatient Hospice
- Continuous Care
- Respite Care

Myths, Misperceptions

- You are "put" on hospice
- All medicines are stopped
- You cannot pursue curative care
- All hospices are the same
- You cannot see your doctor
- Everyone is on morphine

ALL WRONG!!
More myths and misperceptions

- Hospice does not feed or hydrate you
- You cannot have oxygen
- If you “come off” hospice you cannot come back
- If you break your leg we will not treat you
- We give the “magic shot”

ALL WRONG!!

Symptom Management

- Pain
- Nausea/ Vomiting
- Constipation
- Anxiety/ Agitation
- Increased respiratory secretions
- Insomnia
- Shortness of Breath
PAIN

- Pain “Is whatever the patient says it is”
- World Health Organization’s Pain Relief Ladder
- “Start Low and Go Slow” motto
- New Hospice regulations with quality measure pain indicators on every patient within 48-72 hours
- HIS (Hospice Item Set)
- Extractions/CMS
- ICD 10 codes

Pain Assessment & Reassessment

- Where is your pain?
- Describe your pain for me.
- When did the pain start? How long have you had it?
- Do you have other symptoms just before, during, or after your pain?
- Does the pain affect you activities of daily living?
- What do you usually do to try to help the pain go away?
Location of Pain

- Referred pain:
- Phantom pain
- Somatic pain
- Visceral pain
- Neuropathic pain
- Pain Control Involves Three Steps:
  - Detailed assessment
  - Plan of management
  - Monitoring

WHO Analgesic Ladder

ABPI. (2012). The WHO analgesic ladder.
**Character of Pain**

- Intense
- Stinging
- Shooting
- Dull
- Rubbing
- Sharp
- Pressing
- Throbbing
- Aching
- Searing

---

**Pain Medications**

- Non-narcotic analgesics - aspirin, acetaminophen, ibuprofen
- Narcotic analgesic - morphine, dilaudid, oxycodone, fentanyl
Alternatives/ Complementary Therapy

- Guided Imagery
- Positioning
- Pet Therapy
- Aroma Therapy
- Reiki
- Calm, quiet room
- Massage
- Soft music
- Distraction

Nausea/ Vomiting

Medications commonly used:

Zofran, Haldol, Reglan, Cannabinoids, Prochlorperazine, Antihistamines, Scopolamine, Steroids, Lorazepam, Zofran
**Constipation**

- Causes
- Assessment- includes a bowel history
- Treatments- most patients on opioids will need a daily bowel program. Start with a stool softener plus a laxative.
  - Senekot S
  - Mirilax
  - Lactulose
  - Dulcolax
  - Fleets enema

**Anxiety/Agitation**

- **Medications for Anxiety:**
  - Benzodiazepines ex: Ativan
  - Neuroleptics ex: Haldol
  - Phenobarbital
  - Antidepressants-SSRI’s ex: Zoloft
  - Tricyclic's ex: Pamelor
Increased Respiratory Congestion

- Positioning with HOB elevated
- Pillows under arms to raise diaphragm
- Medications: Scopolamine, Levsin, Atropine Eye Drops given orally, Morphine
- Oxygen- assess if patient receiving too much humidity with O2.
- AVOID SUCTIONING-MAY BE DISTRESSFUL

Insomnia

- Calm, quiet, darkened room
- Decrease daytime naps
- Increase daytime activities
- Medications: Ambien, Restoril, Ativan, Benadryl
**Shortness of Breath**

- Positioning- with HOB elevated
- Oxygen as ordered
- Fan in room, cool air
- Nebulizer Treatments as ordered
- Medications: Morphine, Ativan

---

**Psychosocial Aspects at End-of Life**
The Needs of the Dying Individual

- To be heard and validated
- To be respected
- To be allowed to experience the full range of feelings; grieving is normal!
- To have knowledgeable health care professionals caring for them
- To have an unbiased health professional
- To be included (if they wish) in all important conversations
- To have the opportunity to engage in life review

The Five Messages

- I love you
- Forgive me
- I forgive you
- Thank you
- Goodbye

Ask Yourself....

○ Is this care prolonging life or prolonging the dying?
○ Not, should death occur? Rather, when it does, what should it look like?
○ What can I do to stay strong for this patient and family?

References

○ Fox Chase Cancer Center (2014) Hospice and Palliative Care Continuing Nursing Education Manual.
Advance Care Planning:
Facilitating Effective Conversations for all New Jerseyans

David Barile, MD

David Barile, MD, is the Founder and Medical Director of the Goals of Care Coalition of New Jersey, a non-profit entity devoted to improving end of life care for residents of New Jersey. In addition to his roll with Goals of Care, he is chief of the Section of Geriatric Medicine and Medical Director of the Acute Care for the Elderly (ACE) unit at the Penn Medicine in Princeton. Dr. Barile completed his undergraduate education at University of California at Santa Cruz and received his Doctorate of Medicine from Eastern Virginia Medical School. He completed his Internship and Residency at Beth Israel Medical Center in New York City and a two-year Geriatric Fellowship at Mount Sinai School of Medicine. He received Internal Medicine board certification in 1999, Geriatric Medicine certification in 2001 and Hospice/Palliative Medicine certification in 2005. He has been in clinical practice since 2000.
Advance Care Planning:
Facilitating Effective Conversations for all New Jerseyans

David Barile, M.D.
CMO and Founder, Goals of Care Coalition of New Jersey
Intro

Past: people, laws, states

Present: current directives and POLST
Intro

Past: people, laws, states

Present: current directives and POLST

Future: emPOLST and other examples
Past: Luis Kutner

Past: Karen Ann Quinlan
Past: Nancy Cruzan

Past: Terri Schiavo
Past: History of New Jersey 1991
Present: directives

Present: New Jersey directive
Present: 5 wishes directive

do they work?
**Present: POLST**

goals of care
Present: POLST

scope of care

Present: POLST

artificial nutrition
Present: POLST

- code status

Present: POLST

- surrogates
Present: POLST

Which one?

Present: POLST

Advance directive
A legal form

POLST forms
A medical order
Present: POLST

- advance directive
- a legal form
- adults over 18

POLST forms
- a medical order
- prognosis of ~2yrs

Present: POLST

- advance directive
- a legal form
- adults over 18
- not actionable

POLST forms
- a medical order
- prognosis of ~2yrs
- actionable order
**Present: POLST**

- advance directive
- a legal form
- adults over 18
- not actionable
- completed by patient

- POLST forms
- a medical order
- prognosis of ~2 yrs
- actionable order
- by practitioner

**Present: billing**

- advance directive
- POLST forms
### Present: billing

<table>
<thead>
<tr>
<th>advance directive</th>
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</thead>
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<td>99497 <em>first</em> 30 min (16 min)</td>
<td>$85.00</td>
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<td>99498 third 30 min (16 min)</td>
<td>$85.00</td>
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<tr>
<td>76 min</td>
<td>$255.00</td>
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</table>
Present: directives

do they work?

Present: directives

legal transaction model
do they work?
Present: directives

legal transaction model
few use legal tools

Present: directives

legal transaction model
few use legal tools
not well understood
Present: directives

legal transaction model
few use legal tools
not well understood
no guidance

goals may change
Present: directives

legal transaction model

few use legal tools
not well understood
no guidance
goals may change
do surrogates know?
Present: directives

legal transaction model  \rightarrow  communication model

Present: directives

"advance care planning"  \rightarrow  communication model
Present: cultural issues

"advance care planning"

Present: cultural intelligence

"Stop teaching about cultural differences!"
David Livermore

Knowledge...
...without curiosity leads to stereotypes.
...without cultural humility leads to arrogance.
...without intersectionality leads to irrelevance.
...without skills leads to ineffectiveness.
Present: cultural intelligence

Drive
How can I adapt?
Interest (both intrinsic and extrinsic), motivation, and confidence.

Knowledge
How is this similar to my other experiences?
Cognition, understanding, values and norms, leadership.

Cultural Intelligence (CQ)
The ability to function effectively in culturally diverse settings

Action
How do I behave?
Speech acts, verbal, non-verbal, behaviors.

Strategy
How can I plan?
Awareness, meta-cognition, planning, checking.

Present: cultural intelligence

high yield questions:

What’s your understanding of your condition?

How are decisions made in your family?
Future: cake
Future: video directives

In my own words:
video advance directive recording service

Future: video directives

MyDirectives™ MOBILE™
The first app of its kind to be integrated with Apple’s new iOS® platform. Digitize a consumer’s voice and thoughts in a secure, legal advance care plan. Lets consumers give their doctors access to vital information right from their iPhone’s lock screen.
Future: emPOLST

emPOLST
ENABLING A PROVIDER-PATIENT CONNECTION IN END-OF-LIFE CARE
Patients facing a life-limiting illness want and deserve care that meets their end-of-life wishes.
The new emPOLST app helps healthcare providers facilitate and preserve patients' expressed wishes in an easily accessible database.

Present: decision making

Does this patient have capacity?
Yes  No

28/19
Present: decision making

Does this patient have capacity?
Yes  No
   ↓
Is there a POA?
Yes  No
   ↓

Present: decision making

Does this patient have capacity?
Yes  No
   ↓
Is there a POA?
Yes  No
   ↓
Is there a directive that can guide us?
**Present: decision making**

Does this patient have capacity?
Yes  No

↓

Is there a POA?
Yes  No

↓

Is there a directive that can guide us?
Yes  No

↓

what would the patient instruct us to do?
Present: decision making

Does this patient have capacity?

Yes  No

↓

Is there a POA?

Yes  No

↓

Is there a directive that can guide us?

Yes  No

↓

what would the patient instruct us to do?

Thank you

talk more
Patient-Provider Relationships: 
Overcoming Obstacles to Open Dialogue about End-of-Life Care

Paul Duberstein, Ph.D.

Dr. Paul Duberstein is a public health psychologist and chair of the Department of Health Behavior, Society, and Policy at the Rutgers School of Public Health. Prior to joining the Rutgers faculty in November 2018, he was a Professor at the University of Rochester School of Medicine and Dentistry where he held appointments in the Departments of Psychiatry (primary), Medicine, and Family Medicine. At Rochester, he served as Co-Director of the Rochester Center for Mind-Body Research, Co-Director of the Center for the Study and Prevention of Suicide, and Director of Research in the Department of Medicine’s Division of Palliative Care. Dr. Duberstein has published more than 240 scientific papers and has received awards in recognition of his contributions to personality psychology, suicidology, faculty mentorship, and community outreach.

Dr. Duberstein’s current research aims to improve the lives of older adults and their caregivers; he is particularly interested in mitigating disparities related to race, educational attainment, and poverty. His collaborative research projects have been funded by many public and private sources, including the American Foundation for Suicide Prevention, the Centers for Medicare and Medicaid Services, the US Department of Defense, the National Cancer Institute, the National Center for Injury Prevention and Control, the National Institute on Aging, the National Institute on Alcohol Abuse and Alcoholism, the National Institute of Mental Health, and the National Multiple Sclerosis Society.

A native of the NY metropolitan area, Dr. Duberstein received his undergraduate degree from the University of Pennsylvania. He completed graduate training in clinical and community psychology at SUNY Buffalo, advanced training in clinical psychology at McLean Hospital/Harvard Medical School and postdoctoral research training in geriatric mental health at the University of Rochester. He resides in Princeton, NJ with his wife, clinical psychologist Nancy Talbot. They have two daughters, Zoe and Eliza.
Patient-Provider Relationships: Overcoming Obstacles to Open Dialogue about End-of-Life Care

Paul R Duberstein, PhD
Professor and Chair
Department of Health Behavior, Society and Policy
Rutgers School of Public Health
"Keeping the Public in Public Health"

National Healthcare Decisions Day
Goals of Care Coalition of NJ Inaugural Summit
April 18, 2019

Problem:
Clinician-Centered Decision Making

↑ Healthcare costs
↓ Patient quality of life
↓ Caregiver bereavement course
Problem:
Clinician-Centered Decision Making

36% of spending on end-of-life (EOL) treatments can be explained by "physician beliefs unsupported by clinical evidence."


Power Asymmetries in Health Care Encounters

- Healthcare encounters are characterized by **power asymmetries** (Mishler et al., 1981)
- Clinicians are **powerful authorities**; patients and caregivers are not (Wirtz, Cribb, & Barber, 2006)
- Power asymmetries **impede patient/caregiver involvement** in decision-making and could **undermine** health outcomes
A Solution: Person-Centeredness

- Clinicians offer person-centered care to patients and caregivers when they:
  - elicit and consider priorities
  - explore treatment preferences
  - offer opportunities to participate actively in care
  - take steps to enhance the therapeutic alliance

- The key clinical procedure: good conversation
Good conversations are not the norm in advanced cancer care.

Major national organizations have called for improved patient-caregiver-clinician communication in the context of serious and life-limiting illnesses.

Wanted

An intervention that improves person-centered communication by:
- helping oncologists engage patients and caregivers in difficult conversations (e.g., about prognosis)
- reducing power asymmetries
- empowering and enabling patients and caregivers to take a more active role in their care
Values and Options In Cancer Care
R01 CA40419
Pls: R.M. Epstein, MD (U Rochester)
R.L. Kravitz, MD, MSPH (U California-Davis)
J. J. Fenton, MD, MPH (U California-Davis)

VOICE Caregiver Study
R01 CA168387
Pls: P.R. Duberstein, PhD (U Rochester)
H.G. Prigerson, PhD (Harvard/Dana Farber)

The trial is registered with ClinicalTrials.gov (NCT01485627)
Annual Z. Stanley Stys Memorial Lecture

Improving communication in cancer care: Necessary but insufficient

Paul R Duberstein, PhD
Professor and Chair
Department of Health Behavior, Society and Policy
Rutgers School of Public Health
"Keeping the Public in Public Health"

April 30, 2019
8:00 - 9:00 am
Penn Medicine Princeton Health
1 Plainsboro Road
Plainsboro, NJ

Main VOICE Findings

- The VOICE intervention improved communication between oncologists and patients/caregivers.

- The intervention had no statistically significant effects on patient-reported quality of life or health care utilization at the end of life.
IMPROVED COMMUNICATION, WHILE STRENGTHENING THE THERAPEUTIC ALLIANCE
Change in Therapeutic Alliance Following Prognostic Discussion (PD) With Oncologists

3 Months After Audio-Recorded Visit (n=216)

<table>
<thead>
<tr>
<th>Change in Measure 1-Unit Increase in PD (95% CI)</th>
<th></th>
<th>Change in Measure With Two-SD Increase in PD (95% CI)</th>
<th></th>
<th>Standardized Effect Size for Two-SD Increase in PD (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.18 (0.02 to 0.35)</td>
<td>.029</td>
<td>1.43 (0.15 to 2.72)</td>
<td>.24 (0.02 to 0.45)</td>
<td></td>
</tr>
<tr>
<td>-0.04 (-0.26 to 0.18)</td>
<td>.73</td>
<td>-0.30 (-2.04 to 1.44)</td>
<td>-0.04 (-0.33 to 0.23)</td>
<td></td>
</tr>
</tbody>
</table>

- Even though the intervention improved communication and strengthened the therapeutic alliance, it did not improve patient quality of life or reduce treatment intensity (chemotherapy in the last 30 days of life, ED visits, inpatient stays)

- Why?
- Patient preference?
- Oncologist attitudes and behaviors?
Oncologist comfort with medical paternalism

- At study entry, oncologists were administered a modified version of the Control Preference Scale.
- "Physicians have varying levels of comfort making decisions about treatments with their patients. Overall, how comfortable would you feel if a patient requested that you make the decisions using all that is known about the treatments?"
- Response options ranged from 1 (Not at all Comfortable) to 5 (Very Comfortable).
- Higher scores were presumed to reflect greater comfort with medical paternalism.

Patient-reported treatment preferences

- "If your cancer doctor advised you that there is no further anti-cancer treatment available that would be helpful, which of the following would you want?"
- Experimental treatments – such as experimental chemotherapy with unknown benefit for your disease
- Life support – a breathing machine, a tube for feeding or electric shock to the heart
- Palliative care – which is comfort care, focus on quality of life but not cure

Response options ranged from 1 (definitely no) to 5 (definitely yes)
### Outcome Variables:
Chemotherapy, ED/inpatient admissions, Last 30 Days

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chemotherapy</strong></td>
<td>• ≤ 14 days of death (2 points)</td>
</tr>
<tr>
<td>Initiation or continuation of IV or oral chemotherapy, excluding hormonal therapy</td>
<td>• 15-30 days (1 point)</td>
</tr>
<tr>
<td></td>
<td>• not at all (0 points)</td>
</tr>
<tr>
<td><strong>Emergency department or hospital admission</strong></td>
<td>• more than two (2 points)</td>
</tr>
<tr>
<td>Admission to Emergency Department or any unit in hospital except a palliative/hospice unit</td>
<td>• two (1 point)</td>
</tr>
<tr>
<td></td>
<td>• none or one (0 points)</td>
</tr>
</tbody>
</table>

### RESULTS
### Covariates vs. Mortality Status

<table>
<thead>
<tr>
<th>Covariates</th>
<th>Mortality Status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Deceased N=151</td>
</tr>
<tr>
<td>Randomization arm. n (%)</td>
<td></td>
</tr>
<tr>
<td>Intervention</td>
<td>71 (47%)</td>
</tr>
<tr>
<td>Control</td>
<td>80 (53%)</td>
</tr>
<tr>
<td>Site. n (%)</td>
<td></td>
</tr>
<tr>
<td>Sacramento, CA</td>
<td>38 (25%)</td>
</tr>
<tr>
<td>Western NY</td>
<td>113 (75%)</td>
</tr>
<tr>
<td>Breast cancer oncologist. n (%)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>126 (83%)</td>
</tr>
<tr>
<td>Yes</td>
<td>25 (17%)</td>
</tr>
<tr>
<td>Cancer aggressiveness. n (%)</td>
<td></td>
</tr>
<tr>
<td>Aggressive</td>
<td>89 (59%)</td>
</tr>
<tr>
<td>Less aggressive</td>
<td>62 (41%)</td>
</tr>
</tbody>
</table>

### More Covariates vs. Mortality Status

<table>
<thead>
<tr>
<th>More Covariates</th>
<th>Mortality Status</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Deceased N=151</td>
</tr>
<tr>
<td>Patient age, mean (SD)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>65.2 (10.6)</td>
</tr>
<tr>
<td>Gender. n (%)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>69 (46%)</td>
</tr>
<tr>
<td>Female</td>
<td>82 (54%)</td>
</tr>
<tr>
<td>Patient education. n (%)</td>
<td></td>
</tr>
<tr>
<td>HS or less</td>
<td>44 (29%)</td>
</tr>
<tr>
<td>Some college or more</td>
<td>107 (71%)</td>
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</table>
### Multivariable Analyses Predicting Chemotherapy and ED/Hospital admissions, Last Month of Life

<table>
<thead>
<tr>
<th></th>
<th>Chemotherapy</th>
<th>ED/ Hospital Admissions</th>
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<tbody>
<tr>
<td>Patient prefers experimental treatments</td>
<td>.295 (.081, 508)</td>
<td>.027 (.157, .21)</td>
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<tr>
<td>Patient prefers life support</td>
<td>-.174 (-.52, .173)</td>
<td>-.101 (-.387, .185)</td>
</tr>
<tr>
<td>Patient does not prefer palliative care</td>
<td>.342 (.108, .575)</td>
<td>.158 (-.045, .362)</td>
</tr>
<tr>
<td>Oncologist comfort with paternalism</td>
<td>.094 (.019, .170)</td>
<td>.059 (.073, .136)</td>
</tr>
</tbody>
</table>
Standardized effect sizes of oncologist comfort with paternalism ranged from .33 to .37

Effect Sizes, Luck, and Ethics

- Standardized effects of physician comfort with medical paternalism quantify variation in EoL care (chemotherapy, hospital stays) attributable to oncologists' responses to a hypothetical patient who requests that the oncologist make decisions about treatments.
- Wilkinson and Truog (2013) have written about the “luck of the draw”
  - The general idea is that patients are “assigned” to particular physicians by chance, not choice.
  - Even in the outpatient setting, patients are often assigned to physicians based on availability and sub specialization, not choice.
  - The “luck of the draw” poses ethical dilemmas because effect sizes reported here and elsewhere (36% of EoL Costs!) are not ignorable.


**Discussion**

- The findings raise troubling ethical questions about unwarranted variation in care.
- Patients of physicians who report being very comfortable with paternalism were more likely to receive chemotherapy in the final month and use costly ED or inpatient services.
- Patients who expressed a preference for experimental treatments were more likely to receive chemotherapy in the final month of life.
- The effects of patient preference and physician comfort with medical paternalism are independent.
- There was no evidence that the effect of oncologist comfort with medical paternalism was influenced by patient preference, or vice versa.

**Limitations**

- Generalizability is limited by the cohort, which was relatively small for utilization research, disproportionately white, relatively well-educated, and comprised of patients and oncologists in NY and CA who were willing to enter a clinical trial to improve communication.
- The parent VOICE trial was not designed or powered to examine predictors of health care utilization at the end of life.
- The assessment of physician comfort with medical paternalism is limited.
Conclusion

- Findings underscore the limitations of piecemeal efforts targeting oncologists alone or patients alone in efforts to improve EoL care.
- Greater research, clinical, and policy attention to patient treatment preferences and physician comfort with medical paternalism could lead to improvements in care of patients with advanced disease.

Thank You

To the patients, caregivers, and physicians who participated in the study, the NIH, the University of Rochester Department of Psychiatry Hendershot Endowment, dedicated study staff (Sandra Plumb, Martha Tuttle, and Camille Cipri) and our research assistants.
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Rev. Annari Griesel, PhD, BCCC, BCPC, FHP C

Rev. Annari Griesel, Ph.D., BCCC, BCPC, FHP C, is the Director of Pastoral Care for Hackensack Meridian Health, JFK Medical Center in New Jersey. She supervises Clinical Pastoral Education Chaplain Interns and develops hospital-community relations. She received her Ph.D. from Princeton Theological Seminary in Pastoral Theology. She is an ordained minister of the Presbyterian Church (USA) and serves as an Adjunct Faculty member at New Brunswick Theological Seminary. Dr. Griesel is currently the President of the Metuchen-Edison Area Interfaith Clergy Association. As a native South African and as a Chaplain for over 25 years, she brings an understanding and love of culturally and religiously diverse populations. Over these years she has provided pastoral support to many patients, family members and staff who were distraught, grieving and dealing with loss.
Compassionate Consent
How Spirituality, Religion, and Culture Inform Medical Decision Making

Rev. Donna Olivia Owusu-Ansah, M.Div.

Reverend Donna Olivia Owusu-Ansah is a preacher, chaplain, teacher, artist, writer, thinker, and dreamer who loves to study the Word of God, encourage others, and worship God.

In April 2007, Rev. Owusu-Ansah answered her call to ministry and was licensed to preach the Gospel of Jesus Christ in June 2008 at the Bethesda Baptist Church of New Rochelle, NY under the leadership of the Reverend Dr. Allen Paul Weaver, Jr. Rev. Owusu-Ansah was ordained to the Gospel ministry in August 2010. She served as the Assistant-to-the Pastor at the Bethesda Baptist Church from June 2010 until June 2012. Currently, Rev. Owusu-Ansah works as a Chaplain at Haven Hospice located at Hackensack Meridian Health, JFK Medical Center in Edison, NJ and is an Associate Minister at the New Hope Baptist Church in Metuchen, NJ under the leadership of the Reverend Dr. Ronald L. Owens. Rev. Owusu-Ansah serves at the Minister of Church Life at New Hope.

Rev. Owusu-Ansah graduated from New York University in 1999 (Bachelor of Science, Studio Art) and Howard University in 2004 (Master of Fine Art, Photography). In 2007 she enrolled in the Theological School at Drew University and graduated in May 2010 (Master of Divinity, Pastoral Theology). In May 2017, she completed four units of Clinical Pastoral Education (CPE) at JFK Medical Center, Edison, NJ.

Rev. Owusu-Ansah has always been interested in the way in which words and images can be used to bring forth new life, heal individuals, and grow communities. She is passionate about issues of social justice, diversity, and inclusion. In addition to ministry, she is an avid runner, completing the Philadelphia Marathon in 2017.
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Location
I want to locate myself in the work, so you know who I am and how I arrived here;
Presuppositions
I want to make clear my presuppositions that I bring to the room;

Orientation
I want talk about the title I’ve selected and why it matters;
"Compassion is a verb."
— Thich Nhat Hanh

On Compassion

* "Love and compassion are necessities, not luxuries. Without them, humanity cannot survive." — Dalai Lama XIV, The Art of Happiness

* "Listening is such a simple act. It requires us to be present, and that takes practice, but we don’t have to do anything else. We don’t have to advise, or coach, or sound wise. We just have to be willing to sit there and listen." — Margaret J. Wheatley
Compassionate Consent
And finally, that will lead us into the heart—also a word chosen intentionally—of our discussion.

"...from the time of our birth we are cultural beings."
—Patty Lane
On Culture, Religion, and Spirituality

"Our culture shapes who we are, what we believe and how we behave. At no point in our human interactions do we take off our culture and set it aside. It is always with us in all of our relationships, in all of our thinking and our processing of the world around us." —Patty Lane

On Culture

- Objective: eye contact, greetings, volume, initiative, food, clothing, time consciousness.

- Subjective: values, feelings, authority roles, concept of truth, motivations, assumptions, belief about gender roles.

- Open to change based on: age, community, religion/faith, education, employment, English proficiency.
On Spirituality

- Dynamic and Intrinsic;
- Meaning making;
- Purpose seeking;
- Experience of relationships;
- Expressed through beliefs, values, traditions, and practices.

On Religion

- Subset of spirituality;
- Systems of beliefs;
- Observed practices;
- Communal;
- Expressed through rituals that acknowledge, worship, communicate with and approach the Sacred.
On Culture, Religion and Spirituality

- Be mindful that there are nuances within cultures and faith based on region, generations, and family systems.

- Be mindful of prejudices or comfort level within a cultural or religious group that may help or hinder receptivity to the presence of a particular group.

- Never assume patient/family follows all or any of the rituals, traditions or beliefs of their culture, religion, or spiritual identification.

On Vulnerability and Suffering

Young and old, foolish and wise, rich and poor, all keep dying. As a potter’s clay vessel, large and small, bent and unbroken, all end up broken. So too soon life leads to death.

—The Buddha
On Vulnerability and Suffering

You are dust,
and to dust you shall return
—Genesis 3:19b

On Vulnerability and Suffering

Sooner or later we stop and we turn toward the suffering. The we learn what it has to teach us. We come to understand that suffering gives rise to compassion. —Frank Otakeki

"Although the world is full of suffering, it is also full of the overcoming of it."
—Helen Keller

On Consent

+ Provide personal human connection—present, tender, relational, warm, not to assure there is no danger, but to acknowledge the danger;
+ Meet patients and families where they are;
+ Educate patients, families, and care providers about implications of decisions;
+ Ask questions, listen deeply and ask clarifying questions;
+ Guide based on cultural, religious, and spiritual values.
On Consent

✦ How are you feeling?
✦ What is important to you?
✦ What are your goals and hopes?
✦ What are you afraid of?
✦ What does ______ mean to you?
Images:

- "Unknown Title" by Neomi Rapoport
- "Mixed Media Cartogram" by Val Britton
- "Unknown Title" by Alma Thomas
- "Karuna-The Compassion" by Community Arts Group
- Illustration from "I am Loved" by Ashley Bryan
- "Love and Knowledge Series" by Arlene Dubo
- "Asian Funeral Drawing" by Zozozjen
- "A Hand to Hold" by Shelby McQuilkin
- "Compass+Passion" by Katie Wilson
Integrating Advance Care Planning Into Your Practice: A Call to Action

Tracy Grafton, LCSW, ACHP-SW

Tracy Grafton, LCSW, ACHP-SW, is a social worker at Hackensack Meridian Health, JFK Haven Hospice & Palliative Care since 2000. She received her MSW from Rutgers, The State University of New Jersey. She has taught as an Adjunct Faculty member at the Rutgers Graduate School of Social Work and The College of New Jersey on the subjects of aging, oncology, end-of-life care, and bereavement. Tracy is passionate about advance care planning and active with The Conversation Project, National Healthcare Decisions Day, and NJHCQI’s “Conversation of Your Life” task force.
Integrating Advance Care Planning into your practice: A Call to Action

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Advance Care Planning: the numbers tell the story:

80% of Americans state that having these conversations are an important thing to do yet only 25% actually take the time to complete some form of advance directive.

According to a recent Health Matters poll, 60% of New Jerseyans believe that it's important to discuss aging with your doctor yet 60% of NJ do not have anything in writing.

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A Public Health Crisis

10,000 people a day turn 65

75% of people in the ICU cannot participate in their own health care decision making

In 2010, there were 5.8 million Americans aged 85+

By 2050, that number will be 19 million
"It is thornlike in appearance, but I need to order a battery of tests."

THINK BIG
START SMALL
& BE PATIENT
ABOVE
Living  the Line &  Embracing our HMH values!

- **HRO (High Reliability Organization)** - A shared decision-making process conveys respect and improves the alignment of care with goals at EOL which helps ensure that we are not doing more care or less care than what the patient desires
- The 4 “C’s”:
  - **Courageous** - embrace the positive and take a step outside our comfort zone and start a new program!
  - **Collaborative** - Foster a spirit of community & recognize that we are stronger together in our efforts!
  - **Creative** - Doing our part to making things better by championing new ideas!
  - **Compassionate** - Having meaningful conversations and making moments matter!

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Strategies for Advancing the “Conversation” in your practice:

- Start with completing your own advance directive!
- Place signage in your office & in languages commonly used in your service area; normalize it!
- Have translators on staff or use a service for interpretation
- Make it a routine part of your assessment/intake form
- Provide written and verbal education on what exactly is an advance directive and a POLST, when to have one
- Host an occasional Advance Care Planning education program in your office breaking down CPR, intubation, artificial nutrition and hydration, the importance of planning ahead
- Keep resources accessible and up-to-date
- Use multi-modal resources
- Practice communication! There is a plethora of on-line tools to help you.
**Conversation Starters:**

- What makes your life most meaningful? What matters to you most?
- What is your understanding of your illness/diagnosis?
- What is your understanding of your prognosis (explain what this means)?
- Have you had any experiences that have shaped the way you think about disability and/or death?
- If you were very sick, are there any specific medical treatments that might be too much for you?
- Who do you trust that knows your wishes and would be the best person to speak up for you when you can’t? Are they aware of when it is ok to stop giving life support?
- In what circumstances would you rather not be alive?
- How honest do you want your physician or family to be with you? Have you told them this?
- In presenting the POLST, use the stoplight analogy (Red light, yellow light, green light)
- Best Case, Worst Case, Most Likely to happen
- Keep in mind the average American reads at an 8th grade level & 25% of Americans cannot read the newspaper

**The “Imagine” Scenario:**

Imagine **TODAY** that something has happened either suddenly or gradually that has led you to be in the care of medical professionals. You do not know who you are, where you are or who is caring for you. You are unable to participate in decisions about your care. Everything that can be done for you is being done to keep you alive. At what point are you ok with stopping this care? Who has the authority and ability to communicate this on your behalf?
Resources Are Available to Help You:

- Palliative Care Consultants afford you the expertise of social workers, chaplains, nurses and doctors with special training in having these conversations & are available to assist you with family meetings
- Goalsofcare.org
- Theconversationproject.org
- Use the Ask, Tell, Ask method of communication (http://www.ihi.org/education/IHIOpenSchool/resources/Pages/AudioandVideo/ConnieDavis-WhatsAskTellAsk.aspx)

- Acpdecisions.org
- The Conversation Project by Angelo Volandes, MD
- Being Mortal by Atul Gawande, MD
- “Physicians Guide to End-of-Life Care” article by Richard Balaban, MD
- Advance Directives and End-of-Life Decisions, a free downloadable publication from the National Hospice & Palliative Care Organization
- The Conversation Starter Kit, free and downloadable from theconversationproject.org

Establishing Priorities:
“People have priorities besides just living longer.”
- Atul Gawande

Dr. Gawande’s 5 Questions:
- What is your understanding of where you are and of your illness?
- Your fears or worries for the future
- Your goals and priorities
- What outcomes are unacceptable to you? What are you willing to sacrifice and not?
- What would a good day look like?
- What is too much for you?
Ariadne Labs - "Serious Illness Conversation Guide"

• A new collaborative aims to improve communication between clinicians and patients with serious illness
• Offers:
  - Communication skills training
  - Implementation strategies

Ariadnelabs.org

Cross-Cultural Interview Questions Regarding Serious Illness and End-of-Life Care:

"Some people want to know everything about their medical condition, and others do not. What is your preference?"

"Do you prefer to make medical decisions about future tests or treatments for yourself, or would you prefer that someone else make them for you?"

To patients who request that the physician discuss their condition with family members: "Would you be more comfortable if I spoke with your (brother, son, daughter) alone, or would you like to be present?" If the patient chooses not to be present: "If you change your mind at any point and would like more information, please let me know. I will answer any questions you have." (This exchange should be documented in the medical record.)

When discussing medical issues with family members, particularly through a translator, it is often helpful to confirm their understanding: "I want to be sure that I am explaining your mother’s treatment options accurately. Could you explain to me what you understand about your mother’s condition and the treatment that we are recommending?"

"Is there anything that would be helpful for me to know about how your family/community/religious faith views serious illness and treatment?"

"Sometimes people are uncomfortable discussing these issues with a doctor who is of a different race or cultural background. Are you comfortable with me treating you? Will you please let me know if there is anything about your background that would be helpful for me to know in working with you or your (mother, father, sister, brother)?"

Forest Park Hospital Family Medicine Residency Program, St. Louis, Missouri, American Family Physician. 2008 Feb 1;71(3):515-522.
Creative Programming:
Book Discussions
NHDD Events
Professional Conferences & Learn
Mayor’s Advance Directive Signing Event
Facilitated Film Screenings

Community Discussions
Activity: Go Wish & My Gift of Grace

"Coffee & Conversation" cards distributed at all outpatient access points, acute care floors, physician offices & at community presentations

Since program began in May 2016:
# conversations = 344
# advance directives completed = 225 (65%)
Average # attendees ea. month = 11
Other exciting COYL task force activities:

* 8-week ACP series at Rossmoor senior living community
* ACP in the workplace pilot fall 2019
* HMH JFK Pilot project May – Sept. 2018

Advance Care Planning Pilot Project

* May 2018

Using "Conversation Ready Principles", we will:

* Engage with our patients and families to understand what matters most to them at the end of life
* Steward this information as reliably as we do allergy information
* Respect people's wishes for care at the end of life by partnering to develop shared goals of care
* Exemplify this work in our own lives so that we understand the benefits and challenges
* Connect in a manner that is culturally and individually respectful of each patient.
Documentation:

• Honoring the "Allergy Analogy" best practice recommendation, green translucent inserts for "Advance Care Planning Documents" were placed in the front of the medical chart and documents were placed in file (the advance directive, copy of POLST labeled "COPY" and any ACP progress notes). A copy of the ACP progress note was also be placed into the ACP binder on the unit for team follow-up purposes after discharge.

• ACP team member documented patient/family encounters on the progress note

Pilot Project Results/Data:

• May 14 – August 31, 2018 (Monday through Friday) = 76 days
• (n) = 218 people met screening criteria (avg. of 4 per day)
• # conversations = 163 (75% of total actually seen)
• 25% not seen = off floor, sleeping, lacking mental capacity, ACP staff unavailable
• # Advance Directives/POLSTs completed = 96 (59%)
• # conversations refused = 2
• # known deaths during pilot = 4
• # complaints from staff, patients or physicians = 0
Pilot Project Results/Data:

- **AGE:**
  Range = 33 – 100 y.o.
  Mean = 72 y.o.

- **GENDER:** Female = 60%
  Male = 40%

- **RACE:** Caucasian = 56%
  African-American = 24%
  Hispanic/Other = 13%
  Asian = 7%

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2017 U.S. Average Life Expectancy
Males = 76 y.o.
Females = 81 y.o.

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Friday Chart Review

% of patients with ACP documentation in Chart

* = ACP Staffing issues
Observations:

- Pilot project up & running smoothly within one week
- Very engaged & committed unit staff
- Registration information often incorrect
- MDs willing to refer; did not know mechanism/process
- LTC settings not sending the POLST or AD as required, not being obtained.
- Who are the MDs having the conversation with re: DNR/DNI?
- Heather’s code blue story
- Nurse Manager thoughts – has kept the approach post-pilot project
- Addition of ACP documentation to ISBAR during daily rounds vs. code status
- Learned POLST can be completed with VERBAL consent
- Dual responsibilities of ACP facilitators who volunteered worked OT any day they were assigned to the project schedule (under-resourced)

"What can you do by next Tuesday?"
Questions?