Increased Relevance of Advanced Care Planning in the COVID-19 Era
May 21, 2020

J. Randall Curtis, MD, MPH, Harborview Medical Center, University of Washington
Pastor Corey L. Kennard, MACM, Amplify Christian Church; Manager, Patient Experience, Ascension St. John Hospital, Detroit, MI
Lauren Jodi Van Scoy, MD, Penn State Milton S. Hershey Medical Center

This program is made possible by the John and Wauna Harmon Foundation

Speaker Bios

J. Randall Curtis, MD, MPH
Rated as one of America’s Top Pulmonologists by US News & World Report, he also serves as the Chief of the Pulmonary Medicine Service at Harborview Medical Center. He was recently appointed as the Founding Director of the Cambia Palliative Care Center of Excellence at Harborview Medical Center. His research focuses on improving palliative care for patients with serious illness, as well as their families.

Corey L. Kennard, MACM
Pastor of Amplify Christian Church and Manager of Patient Experience at Ascension St. John Hospital, Detroit. He has a holistic approach (body, mind, and spirit) that serves as the foundation for his desire to see all human beings treated with dignity, honor, and respect.

LJ Van Scoy, MD
A pulmonary and critical care physician at Penn State Milton S. Hershey Medical Center, she is an Associate Professor of Medicine, Humanities and Public Health Sciences. Her research program focuses on end-of-life issues and includes advance care planning, communication, and end-of-life decision-making. She is also the Principal Investigator for several research studies and the Chair of Project Management for the Center for Palliative Care at Penn State College of Medicine. She has served as a consultant to numerous organizations and on a variety of committees, including the Department of Veterans Affairs and the National End-of-Life Care Research Network.

CAMBIA PALLIATIVE CARE CENTER OF EXCELLENCE
UNIVERSITY OF WASHINGTON

J. Randall Curtis, MD, MPH
Director, Cambia Palliative Care Center of Excellence
Harborview Medical Center, University of Washington
@JRandallCurtis1

www.uwpalliativecarecenter.com
Disclosures and Funding

- Disclosures
  - No financial conflict of interest
- Funding

Outline

- Advance care planning and goals-of-care discussions
- Modifications for COVID-19
- Palliative care during COVID-19
  - Supporting family
  - Role of palliative care specialists

Terminology: Advance Care Planning and Goals-of-care Discussions

- Advance care planning: discussions about values, goals, and preferences for future care
  - Healthy individuals
- Goals-of-care discussions: discussions about current goals and how they should inform current & future care
  - Chronic illness (early)
  - Imminently dying (late)
Randomized Trial of Advance Care Planning Among 309 Elderly

- Hospitalized patients age >80 randomized to ACP by trained facilitator vs. usual care
- 81% received ACP; 56% completed AD
  - Facilitator used “Respecting Patient Choices”
  - ACP in collaboration with physician
  - Families present for 72%
  - Sessions took median 60 minutes


<table>
<thead>
<tr>
<th>Outcome (%)</th>
<th>ACP</th>
<th>Control</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death in ICU</td>
<td>0</td>
<td>14</td>
<td>0.03</td>
</tr>
<tr>
<td>PTSD in family</td>
<td>0</td>
<td>14</td>
<td>0.03</td>
</tr>
<tr>
<td>Depression in family</td>
<td>0</td>
<td>30</td>
<td>0.002</td>
</tr>
<tr>
<td>Anxiety in family</td>
<td>0</td>
<td>19</td>
<td>0.02</td>
</tr>
<tr>
<td>Satisfied with death</td>
<td>80</td>
<td>68</td>
<td>0.02</td>
</tr>
<tr>
<td>Satisfied with care</td>
<td>93</td>
<td>65</td>
<td>0.001</td>
</tr>
</tbody>
</table>


EHR provides potential to measure quality of palliative care across the healthcare system

- Using Electronic Health Records for Quality Measurement and Accountability in Care of the Seriously Ill: Opportunities and Challenges
  - J. Randall Caro, MD, MPH,(1,2) Deborah Selth, MD,(1,2) Wendy Starks, PhD, MPH(1,3)
  - Robert M. Lee, MD,(1,2,*) Erin X. Knox, MD,(1,2,*) Luis Aviles, MD,(1,2) James Deyar, RN,(1,2) William Lubitz, MD,(1,2)
  - Elizabeth T. Loggen, MD,(1,2) James A. Fausto, MD,(1,2) Charlene Lovely, MD,(1,2) and Ruth N. Engberg, PhD(1,2)

JOURNAL OF PALLIATIVE MEDICINE
Volume 21, Number 6, 2018

- EHR provides potential to measure quality of palliative care across the healthcare system
- Assessing care of population served by UW Medicine
  - Intensity of care for patients with chronic life-limiting illness and documentation of advance care planning
  - Identified 23,096 patients with chronic illness who died 2010-2015 cared for by UW Medicine
Advance Directives and POLST Forms at UW Medicine

Hospitalizations in the Last 30 Days of Life at UW Medicine

ICU use in the Last 30 Days of Life at UW Medicine
Provision of Palliative Care

• Broad domains of palliative care
  – Symptoms (physical and psychological), communication, coordination, spiritual care
• Primary palliative care
  – Care provided by all clinicians caring for patients with serious illness
• Specialty palliative care
  – Care provided by palliative care specialists

Outline

• Advance care planning and goals-of-care discussions
• Modifications for COVID-19
• Palliative care during COVID-19
  – Role of palliative care specialists
  – Supporting family

What is different in our fundamental approach now with COVID-19?

NOTHING!!
Things Would Be Different if We Hit Crisis Standards of Care

- Three levels of care
  - Conventional – usual care with adequate resources
  - Contingency – strive for usual care under stress
  - Crisis – scarce resources limit care
- We are not in crisis standards
  - Able to avoid through public health measures
- If we were to hit crisis standards of care
  - Hospital triage teams make allocation decisions
  - Use of CPR may be included in those decisions

Curtis/Kress/Stepleton; JAMA 2020; Epub 3-27-20

Increased Importance of Addressing CPR During COVID-19

- Non-beneficial or unwanted CPR has always had risks for patients and family
  - Prolong patient suffering
  - Increase family distress
- Now CPR has increased risks for clinicians
  - Increased potential for exposure
  - Increased clinician distress
  - Increased use of limited PPE resources
- CPR will be even less effective in isolation
We need not discuss therapies that are not indicated.
CPR is an exception because of patient & family expectations.
Informed assent is an ethical option.
- Can help some patients or families who can’t make a decision for DNR but will let doctors decide.

Steps of Informed Assent When CPR is Judged Not to be Indicated

Assent Statement: “In this situation, we don’t use CPR”

Assess Understanding and Allow for Objection

NO – Proceed with Informed Assent

YES – Informed Assent Not Appropriate

Explain CPR won’t achieve patient’s goals

Consider unilateral DNR: Rare cases of true medical futility

Outline

- Advance care planning and goals-of-care discussions
- Modifications for COVID-19
- Palliative care during COVID-19
  - Role of palliative care specialists
  - Supporting family
Supporting Families Given Visitation Restrictions

- Don’t under-estimate the stress
  - Patients, families, clinicians
- Identify alternative communication
  - Daily phone or video-conference
- Create opportunities to allow family to see patients
  - Through the window into room
  - 1-2 family members in PPE for dying patients

Using Palliative Care Consult Services

- Palliative care consults ready to help
  - Prioritize high need patients and families
    - COVID-19 patients
    - ICU and ED settings
  - Available for coaching and brief or full consults
  - Developed plan for surge staffing
- Target key areas of need
  - Difficult goals of care & code status discussions
  - Moderate/severe symptoms
  - Spiritual assessment/support
- Support families with restricted visitation
COVID-19 Resources

• Clinician communication: www.vitaltalk.org

• Patients and families; Friends and relatives
  www.theconversationproject.org  www.prepareforyourcare.org

• UW Medicine Palliative Care Response Plan
  https://www.jpsmjournal.com/content/covid-19

Pastor Corey L. Kennard

www.CoreyLKennard.com
Twitter: @iampastorcorey
Instagram: @iampastorcorey
Facebook.com/CoreyLKennard
LinkedIn: Corey L. Kennard
Impact of COVID-19 in Detroit

- My Hospital – 200% increase in weekly death rate
- Wayne County – 11.5% death rate
- Black Community hit hard due to underlying health conditions
- Historical Health Inequities: Systematic and unjust distribution of social, economic, and environmental conditions needed for health

Causes of Staff Fatigue

- Volume of deaths
- Lack of PPE
- Shortage of staff due to sickness and stress
- *Family/household distance and concerns*

Virtual Visits

The overarching goal of virtual visits is to augment in-person visits and broaden access in the following ways:

- Increase patient engagement and satisfaction
- Improve clinician satisfaction and efficiency
- Provide immediate connection with clinicians and family members
- Enhance communication
- Resolve medication discrepancies
- Improve care quality and reduce hospital traffic
- Reinforce patient care with specialist consultations
- Reduce patient anxiety and feelings of loneliness
Barriers to Advance Care Planning in Communities of Color:

- Lack of ACP Knowledge
- Mistrust of Healthcare System
- Spiritual Beliefs
- Fear of Discussions Regarding Mortality
- Lack of Healthcare Interaction and Access
- Secrecy of Medical Condition (Health)

What Disparities Has COVID-19 Uncovered?
African-American Health Concerns prior to COVID-19 that have increased the mortality risk

- 44% more likely to die from stroke
- 40% more likely to die from breast cancer
- 25% more likely to die from heart disease
- 20% more likely to have asthma and 3x as likely to die from it
- 23% more likely to be obese
- 72% more likely to be diabetic
Role of Clergy in ACP

- Increase their awareness of the importance of Advance Care Planning (ACP)
- Explore their personal feelings and faith perspectives when it comes to ACP
- Embrace their consequential role of spiritually inspiring and leading their congregants as they consider important decisions impacting their health and well-being when they are not able to speak for themselves
- Learn how ACP can ease the worries and concerns of family and close friends of their congregants before a health crisis occurs
- Teach the Biblical Foundation of ACP, and include as a vital and natural part of their overall ministry

Advance Care Planning in the COVID-19 Era
Lauren Jodi Van Scoy, MD
Associate Professor of Medicine, Humanities and Public Health Sciences
Division of Pulmonary and Critical Care
lvanscoy@pennstatehealth.psu.edu
Twitter: @KnowYourWishes

A Happy Contrast

- 2-week lead time
- Drills
- Command center
- Years of training as an Ebola Treatment Center
- PPE available
- Drive by testing
- Current inpatient testing available within 2 hours
As of 5/18/20

- Patients actively inpatient at MSHMC: 17 inpatient, 1 on ventilator
- Dauphin County: 912
- State of PA: 60,622
- State of PA Deaths: 4,342
- Deaths in US: 1,401,948
- State of NY: 345,813

- TOTAL: Discharged 83 patients, 2 deaths

**Disparities in Hospitalization Rates**

<table>
<thead>
<tr>
<th>% Population</th>
<th>White Americans</th>
<th>African Americans</th>
<th>Latinx Americans</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Hospitalizations</td>
<td>59%</td>
<td>18%</td>
<td>14%</td>
</tr>
<tr>
<td></td>
<td>45%</td>
<td>33%</td>
<td>8%</td>
</tr>
</tbody>
</table>

This COVID-19–associated hospitalizations among persons of all ages in 99 counties in 14 states (California, Colorado, Connecticut, Georgia, Iowa, Maryland, Michigan, Minnesota, New Mexico, New York, Ohio, Oregon, Tennessee, and Utah). The catchment area represents approximately 10% of the U.S. population.

![Health Disparities exist in end-of-life care](image)

African Americans and Hispanic/Latinx patients are 3 times more likely than White Americans to die after a lengthy ICU stay and receive unwanted treatments.
60% US population have engaged in ACP

Yet...

<25% African American and Hispanic/Latinx populations engaging in ACP

Yet...

60% US population have engaged in ACP

African American and Hispanic/Latinx populations engaging in ACP

What’s been done?

One-on-one interventions with nurses, social workers, and education programs

Videos, online programs

POLST programs

EMT flags prompting PPOs to discuss ACP

Small to moderate effect sizes, labor and resource intense, and don’t address barriers...

ACP Tools

Created by Rebecca Sudore, MD
www.prepareforyourcare.org

Created by Michael Green, MD, Benjamin Levi, MD, PhD and Vital Decisions, LLC
www.mylivingvoice.com

What’s been done?

Small to moderate effect sizes, labor and resource intense, and don’t address barriers...

ACP Tools

Created by Rebecca Sudore, MD
www.prepareforyourcare.org

Created by Michael Green, MD, Benjamin Levi, MD, PhD and Vital Decisions, LLC
www.mylivingvoice.com
Underserved communities have unique barriers to ACP

- Access to resources
  - Financial
  - Health centers
  - Computers
  - PCPs
- Geography (rurality)
- Distrust of the healthcare system/research

Overcoming Barriers

- Games have been used to address emotionally laden topics (cancer, obesity, PTSD, anxiety)
- Games have successfully altered health-related behaviors (exercise, healthy eating, medication adherence)
- Games create a safe environment for role playing, trial and error, non-threatening forum
- Health games are easy to implement in community settings
- Psychological safety is fostered

Heavy questions

Lighter questions
Community-Based Delivery Model

National Scope

- 65 applications
- 53 host sites
- 27 states

 HOST

COMMUNITY CENTER

PROJECT TEAM
HFA, Project Talk

COMMUNITY CENTER
### On Site Recruitment

<table>
<thead>
<tr>
<th>Site</th>
<th>Venue Type</th>
<th>Region</th>
<th>Urban/Rural</th>
<th>No. of Attendees</th>
<th>No. Consented</th>
<th>Consent Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Broussard, LA</td>
<td>Place of worship</td>
<td>South</td>
<td>Rural</td>
<td>43</td>
<td>43</td>
<td>100%</td>
</tr>
<tr>
<td>Sodus, NY</td>
<td>Place of worship</td>
<td>Northeast</td>
<td>Rural</td>
<td>22</td>
<td>22</td>
<td>100%</td>
</tr>
<tr>
<td>Livingston, AL</td>
<td>University location</td>
<td>South</td>
<td>Rural</td>
<td>52</td>
<td>50</td>
<td>96%</td>
</tr>
<tr>
<td>Atlanta, GA</td>
<td>Health center</td>
<td>South</td>
<td>Urban</td>
<td>35</td>
<td>35</td>
<td>100%</td>
</tr>
<tr>
<td>Philadelphia, PA</td>
<td>Place of worship</td>
<td>Northeast</td>
<td>Urban</td>
<td>17</td>
<td>16</td>
<td>94%</td>
</tr>
<tr>
<td>Amarillo, TX</td>
<td>Community center</td>
<td>Midwest</td>
<td>Urban</td>
<td>20</td>
<td>20</td>
<td>100%</td>
</tr>
<tr>
<td>Las Vegas, NV</td>
<td>Place of worship</td>
<td>South</td>
<td>Urban</td>
<td>48</td>
<td>45</td>
<td>94%</td>
</tr>
<tr>
<td>Lakeland, FL</td>
<td>Health center</td>
<td>South</td>
<td>Urban</td>
<td>24</td>
<td>23</td>
<td>96%</td>
</tr>
<tr>
<td>Milwaukee, WI</td>
<td>Place of worship</td>
<td>Midwest</td>
<td>Urban</td>
<td>31</td>
<td>18</td>
<td>58%</td>
</tr>
<tr>
<td>Asheville, NC</td>
<td>Place of worship</td>
<td>South</td>
<td>Rural</td>
<td>24</td>
<td>24</td>
<td>100%</td>
</tr>
<tr>
<td>Chicago, IL</td>
<td>Place of worship</td>
<td>Midwest</td>
<td>Urban</td>
<td>32</td>
<td>13</td>
<td>41%</td>
</tr>
<tr>
<td>Battle Creek, MI</td>
<td>Place of worship</td>
<td>Midwest</td>
<td>Urban</td>
<td>6</td>
<td>6</td>
<td>100%</td>
</tr>
<tr>
<td>Palo Alto, CA</td>
<td>Place of worship</td>
<td>West</td>
<td>Urban</td>
<td>18</td>
<td>18</td>
<td>100%</td>
</tr>
<tr>
<td>St. Louis, MO</td>
<td>Senior center</td>
<td>Midwest</td>
<td>Urban</td>
<td>17</td>
<td>17</td>
<td>100%</td>
</tr>
</tbody>
</table>

**TOTALS** | 428 | 386 | 90%  

**Total project participants** = 1,122

---

**Since Game Day, have you...**

ACP behaviors at ~ 9 months

- **Completed a AD** 41%
- **Reviewed resources provided at Game Day** 56%
- **Completed 3+ behaviors** 67%
- **Completed 1+ behaviors** 98%
- **Had a conversation with loved ones about EOL issues** 80%
- **Discussed the game or game questions with others** 70%
- **Re-read or reviewed on existing AD** 48%

---

Hello, Las Vegas, Nevada

Urban West

$n = 39$

Consent rate 92%

Hello, Broussard, Louisiana

Rural South

Consent rate 100%

$n = 43$
Concluding Remarks

- Attention must be paid to health disparities
- End-of-life tools are needed that are tailored for individual needs
- Start the conversation
- Spread Knowledge, Not COVID

Knowledge and Perception in the COVID-era

Survey with free text responses to assess:
- Knowledge
- Understanding of public health recommendations and intent to follow
- Perceptions and Concern re: COVID-19
- Information Sources
- Attitudes about re-opening

>8000 participants
5,948 fully complete surveys

Spread Knowledge, not COVID

covidsurvey.psu.edu

Available in 24 languages

For more information:
ivanscov@pennstatehealth.psu.edu or rilennon@pennstatehealth.psu.edu
Underserved Voices Need to be Heard and Represented!

Current Data: 9,210 participants
African Americans: 188 (2.3%)
Latinx: 247 (3.15%)
73 countries with 3 countries >100 respondents

Questions?

J. Randall Curtis, MD, MPH
Harborview Medical Center, University of Washington

Pastor Corey L. Kennard, MACM
Amplify Christian Church; Manager, Patient Experience, Ascension St. John Hospital, Detroit, MI

Lauren Jodi Van Scoy, MD
Penn State Milton S. Hershey Medical Center

Upcoming HFA Webinars

May 27: Therapeutic Response to Trauma and Loss in the COVID-19 Pandemic
Jenna Z. Marcus, MD
Therese A. Rando, PhD, BCETS, BCBT

June 16: The Evolving Role of the Trained Death Doula in End of Life Care
Alua Arthur

For more information, visit: hospicefoundation.org/Education/Upcoming-Programs
Online Bereavement Support Resource *Journeys* Newsletter is now available electronically

The June issue of Journeys is available as a PDF for unlimited use for $250 per issue. This online version makes it easy for you to forward these issues to your email distribution lists.

HFA's Complimentary COVID-19 Series Programs Available On Demand

https://hospicefoundation.org/Education/Free-COVID-19-Programs

HFA's 2020 *Living with Grief*® Program *Intimacy and Sexuality During Illness and Loss*

Live broadcast: September 24, 2020, 1:00pm to 3:00pm ET

Expert Panelists: Carla Arnold, PhD, FT, M.Ed., RSW, CCC; Alua Arthur, JD; John D. Cagle, PhD, MSW; Kenneth J. Doka, PhD, MDiv
This program is made possible by the John and Wauna Harman Foundation

Obtain Your CE Certificate

1. Go to educate.hospicefoundation.org
   If this is your first HFA certificate, click “Create a new account”
2. Enter the CE Code: 
3. Complete the exam
   You must pass at 80% or above and may retake the exam as many times as needed
4. Choose your board category and board
5. Complete the program evaluation
6. Print your certificate

CE Code expires May 20, 2021

Questions? Email HFA at onlineceu@hospicefoundation.org.