CoP/Training Call: End of Life Care and Culture

Guest Speakers:

Gloria Thomas-Anderson, LMSW
Thomas Harter, PhD

May 13, 2014
2:00 PM Eastern Time
Housekeeping

Call Norms:

• All lines will be muted during the call.

• We will begin Q & A after the training portion of today’s call.

• Please submit questions via the WebEx chat box or press 14 and the monitor will call on you.

• We are recording this call, and will post slides, recording, and transcript on [www.healthcarecommunities.org](http://www.healthcarecommunities.org) and [www.cmspulse.org](http://www.cmspulse.org).

• Evaluation: Please fill out our evaluation at the end of today’s call.
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<th>Topic</th>
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<td>Ava Richardson</td>
<td>Introduction</td>
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<tr>
<td>Thomas Harter, Ph.D.</td>
<td>The Importance of Planning for End-of-Life</td>
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<td>Gloria Thomas-Anderson, LMSW</td>
<td>End-of-Life Considerations Among African Americans</td>
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<td>Q/A</td>
<td>QIO Participants</td>
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<td>Ava Richardson</td>
<td>Announcements</td>
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Goals

- Understand the importance of planning for end-of-life care.
- Assess the cultural and subjective norms of end-of-life care among African Americans
- Explore the factors that impact disparities in end-of-life care.
Guest Speakers

Thomas D. Harter, Ph.D.
Associate Clinical Ethicist
Medical Research
Gundersen Medical Foundation
Advance Care Planning: the Gundersen Experience and Beyond

Thomas D. Harter, PhD
Associate Clinical Ethicist
Gundersen Health System
www.respectingchoices.org
What are the desired outcomes of Advance Care Planning (ACP)?

Ideally to “know” and to “honor” a patient’s informed plans, by...

1. Creating an effective planning process, including:
   a) selecting a well prepared health care agent or proxy when possible, and
   b) creating specific instructions that reflect informed decisions that are geared to the person’s state of health.

2. Having these plans available to the treating health professionals.

3. Assuring that plans are incorporated into medical decisions when needed.
Definition: Advance Directive (AD)

• A plan, made by a capable person or their surrogate, for future medical care regarding treatments or goals of care for a possible or probable event.

• This plan could be expressed:
  • Orally or in writing
  • If written, it could be in strict accord with specific state statutes or simply a documentation of the plan, e.g., a physician’s note OR BOTH.
Definition: Advance Care Planning (ACP)

A process of planning for future medical decisions. To be effective, this process includes...

- **Reflection** on beliefs, goals and values (including religious and cultural beliefs);
- **Understanding** of selected possible future situations and choices; and
- **Discussion** of these reflections and choices with those who might need to carry out the plan.
Relationship of ACP to ADs

ADs are only as good as the process of planning:

- If the person planning does not understand, reflect on, or discuss their choices/options adequately, the plan has a high probability of failure.
- ADs success is directly tied to the quality of the planning process or ACP.
What has been the standard approach in the US?

- Providing information to adults/patients about their legal rights to refuse tx and to have an advance directive (AD);
- Asking patients if they have an AD at admission;
- Encouraging the “filling out” of statutory AD documents;
- Asking simplistic questions like: *If your heart stops, should we do CPR?*
Evidence the Standard Approach to Advance Directives (AD) Consistently Fails to Improve Care

“Just completing a statutory AD does not work”

- The prevalence of ADs is low
  - prevalence is 20-30% in general population and less than 50% for end-stage illness

- ADs are most often unavailable at the place of treatment
  - Available to the physician only 25% of time

- ADs are most often not helpful to decision-making
  - Planning is too vague

- ADs are often not followed
  - not available, specific or understood or supported by loved ones


National information: Research in Action, AHRQ, Issue #12, March 2003
In order for ACP to be successful, 5 conditions must be met:

1. Plans must be created...need a high prevalence of planning.
2. Plans must be specific enough for the clinical situation.
3. Plans must be an accurate reflection of the patient preferences and be understandable to those making decisions.
4. Plans must be available to the decision-makers.
5. Plans must be incorporated into decisions when needed.

Key Elements in Designing an Effective ACP Program

#1 System Design
- AD document
- AD storage & retrieval
- ACP team & referral

#2 ACP Facilitation Skills Education
- ACP Team Education
- Other Stakeholders

#3 Community Engagement
- Materials that Engage
- Strategies to Engage
- Addressing Diversity

#4 Continuous Quality Improvement
- The Five Promises
- Implementation Project Plan

ACP Facilitation Skills Training...A Necessary Element for Success

• ACP is a process of communication...of understanding, reflection, and discussion
• Requires clinicians gain patient-centered communication skills and defined roles
• History of incomplete skills training for professionals
• Many clinicians remain uncomfortable, unprepared, and lack time and reimbursement
Facilitating an ACP conversation is best done in stages.

Attempting to plan for ALL possibilities in a single document is both impossible and unnecessary.
Stages of Advance Care Planning Over the Lifetime of Adults

**First Steps®**
Create POAHC and consider when a serious, permanent neurological injury would change goals of treatment

**Next Steps**
Determine what goals of treatment should be followed if complications result in “bad” outcomes

**Last Steps®**
Establish a specific plan of care expressed in medical orders using the POLST paradigm

Healthy adults or those with chronic illness who have not planned

Adults with progressive, life-limiting illness, suffering frequent complications

Adults whom it would not be a surprise if they died in the next 12 months
Benefits of ACP Facilitation

- Standardizes the process of planning so an effective, shared practice can be implemented across an organization or community.
- Improve the communication of care plans over time and setting.
- Better use of physician time: Includes physicians as a key component, but does not require physicians to spend great amounts of time helping the patient reflect.
- When physicians become part of the planning, their time investment can be significantly reduced.
- Creates a more patient and family center health system.
- Shifts the time spend in decision-making to an earlier time so the patient can participate. This avoids more costly decision processes when the patient may be critically ill.
- Makes it more probable that those close to the patient both know and support the plan created.
Is there evidence that such a system can be designed and be successful?
Prevalence, Availability, and Consistency of Advance Directives in La Crosse, County after the creation of an ACP system in ‘91-’93

<table>
<thead>
<tr>
<th></th>
<th>LADS I *</th>
<th>LADS II**</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Decedents with ADs (%)</strong></td>
<td>459 (85.0)</td>
<td>360 (90.0)</td>
<td>.023</td>
</tr>
<tr>
<td><strong>ADs found in the medical record where the person died (%)</strong></td>
<td>437 (95.2)</td>
<td>358 (99.4)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td><strong>Treatment decisions found consistent with instructions</strong></td>
<td>98%</td>
<td>99.5%</td>
<td>0.13</td>
</tr>
</tbody>
</table>


A Randomised, Controlled Trial Investigating the Impact of Advance Care Planning on End of Life Care in Elderly Patients

• Setting: Tertiary hospital in Melbourne, Australia
• Participants: Competent, English-speaking patients 80 or older admitted to internal medicine, cardiology, or pulmonary services.
• Excluded if they were expected to die or discharged within 24 hours, had an AD, or had no family
• The intervention group received ACP developed from the La Crosse model and the control patients received the local standard of care.

Detering KM, Hancock AD, Silvester W. A randomised controlled trial investigating the impact of advance care planning on end-of-life care in elderly patients. BMJ 2010;340:c1345doi:10.1136/bmj.c1345
Questionnaire on patient satisfaction administered at hospital discharge

(Values are percentages unless stated otherwise)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Intervention Group (N=133)</th>
<th>Control Group (N=139)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall level of satisfaction with hospital care</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Very satisfied</td>
<td>125 (93)</td>
<td>91 (65)</td>
<td></td>
</tr>
<tr>
<td>Satisfied</td>
<td>6 (5)</td>
<td>40 (29)</td>
<td></td>
</tr>
<tr>
<td>Not satisfied</td>
<td>2 (2)</td>
<td>8 (6)</td>
<td></td>
</tr>
</tbody>
</table>
## Australian Study Outcomes when Subjects Died

<table>
<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Control</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>n (%)</td>
<td>29 (19)</td>
<td>27 (17)</td>
<td>0.75</td>
</tr>
<tr>
<td>Age median, (IQR)</td>
<td>85 (84-89)</td>
<td>84 (81-87)</td>
<td>0.06</td>
</tr>
<tr>
<td>Sex, male n (%)</td>
<td>17 (59)</td>
<td>13 (48)</td>
<td>0.43</td>
</tr>
<tr>
<td>Patients completed ACP</td>
<td>25 (86)</td>
<td>0 (0)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Wishes known and followed</td>
<td>25 (86)</td>
<td>8 (30)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Wishes unknown</td>
<td>3 (10)</td>
<td>17 (63)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Effect on family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact of Event Score: median</td>
<td>5 (2-5.5)</td>
<td>15 (5-21)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Hospital Depression Scale</td>
<td>0 (0-1.5)</td>
<td>5 (0-9)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>
The Respecting Choices Model in more diverse populations

- This process of planning has been successfully used in multi-cultural places like:
  - Australia,
  - Singapore,
  - Vancouver, B.C.
  - Inter-City Hospital in Milwaukee,
  - Adolescent HIV infected population
  - Germany and
  - Hawaii.

- The full model has shown success in other outcomes in Australia.*

The Respecting Choices Model in Large Geographic areas in the USA

The model is being implemented in large metropolitan areas and geographic regions like the:

- Twin Cities where all major health systems have agreed to use standardized materials, documents, and training, under the leadership of the Metro Medical Society (Honoring Choices Minnesota);
- Throughout the state of Wisconsin sponsored by the Wisconsin Medical Society (Honoring Choice Wisconsin);
- In large health systems like Kaiser Permanente in Northern California;
Outcomes and Benefits of the Respecting Choices Systematic Approach
Respecting Choices ACP
Helping to Achieve the Triple Aim

- Better Patient Care
- Better Population Health
- Lower Per Capita Cost
How can Respecting Choices help improve care?

1. Improves patient care.

Effective advance care planning can better assure that patients receive medical management that matches their identified goals leading to

- the highest level of function possible,
- timely symptom management, and
- timely use of treatment along with both palliative and hospice care with no change in length of life.
How can Respecting Choices help improve care?

2. Improves population health:

- Patients and families are more satisfied with their care,
- it lowers moral distress, and
- leads to healthier bereavement after the death of the patient.
How can Respecting Choices help improve care?

3. Control the per capita cost of care.

Almost all Americans say they “don’t want to die hooked up to machines.” As people reach the point of advanced illness, they seek more support and less “curative” intervention. If we know when these choices occur and if we honor them, we will avoid the use of expensive resources patients don’t value and don’t benefit from.
## Cost of Care in the Last Two Years of Life*

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Hospital Days/Patient in Last 2 Years of Life</th>
<th>Total Cost of Care/Patient During Last 2 Years of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gundersen Lutheran</td>
<td>13.5</td>
<td>$18,359</td>
</tr>
<tr>
<td>Marshfield/St. Josephs</td>
<td>20.6</td>
<td>$23,249</td>
</tr>
<tr>
<td>University of Wisconsin</td>
<td>19.7</td>
<td>$28,827</td>
</tr>
<tr>
<td>Cleveland Clinic</td>
<td>23.9</td>
<td>$31,252</td>
</tr>
<tr>
<td>Mayo Clinic</td>
<td>21.3</td>
<td>$31,816</td>
</tr>
<tr>
<td>UCLA</td>
<td>31.3</td>
<td>$58,557</td>
</tr>
<tr>
<td>University of Miami Hospital &amp; Clinics</td>
<td>39.3</td>
<td>$63,821</td>
</tr>
<tr>
<td>New York University Medical Center</td>
<td>54.3</td>
<td>$65,660</td>
</tr>
</tbody>
</table>

* Based on 2007 Dartmouth Atlas Study Methodology. The Dartmouth Atlas methodology examines hospital inpatient care for the last two years of a Medicare patient’s life.
### Hospital Care Intensity Last Two Years of Life*

<table>
<thead>
<tr>
<th>Region/Hospital</th>
<th>Levels and Percentile</th>
<th>Overall Index</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>National Average</strong></td>
<td></td>
<td><strong>1.0</strong></td>
</tr>
<tr>
<td><strong>No Carolina Average</strong></td>
<td></td>
<td><strong>.80</strong></td>
</tr>
<tr>
<td><strong>Greensboro, NC</strong></td>
<td></td>
<td><strong>.91</strong></td>
</tr>
<tr>
<td><strong>Randolph Hospital</strong></td>
<td></td>
<td><strong>.78</strong></td>
</tr>
<tr>
<td><strong>90th Percentile</strong></td>
<td></td>
<td><strong>1.45</strong></td>
</tr>
<tr>
<td><strong>50th Percentile</strong></td>
<td></td>
<td><strong>.92</strong></td>
</tr>
<tr>
<td><strong>10th Percentile</strong></td>
<td></td>
<td><strong>.62</strong></td>
</tr>
<tr>
<td><strong>Wisconsin Average</strong></td>
<td></td>
<td><strong>.78</strong></td>
</tr>
<tr>
<td><strong>Gundersen Health La Crosse, WI</strong></td>
<td></td>
<td><strong>.40</strong></td>
</tr>
</tbody>
</table>

* Based on 2010 Dartmouth Atlas Study Methodology. The Dartmouth Atlas methodology examines hospital inpatient care for the last two years of a Medicare patient’s life.
Survival to Hospital Discharge after In-Hospital CPR, According to Year and Race

## CPR Attempts at GHS
### 20 year comparison

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</thead>
<tbody>
<tr>
<td># of CPR attempts</td>
<td>153</td>
<td>100</td>
<td>101</td>
<td></td>
</tr>
<tr>
<td>CPR attempts per 1000 admissions</td>
<td>5.8</td>
<td>4.6</td>
<td>2.8</td>
<td>P = 0.001</td>
</tr>
<tr>
<td>Alive at discharge after CPR attempt</td>
<td>12%</td>
<td>22%</td>
<td>33%</td>
<td>p = 0.002</td>
</tr>
</tbody>
</table>
Why is this ACP Program Unique?

• Comprehensive...works in
  – all health care settings
  – all aspects of care planning over a life time of a person/patient
  – community engagement

• Systematic
  – Defines role and responsibility of ACP team
  – Creates work flows and processes
  – Redesigns EMR to support ACP workflows and ACP facilitation

• Strongly grounded on Person and Family-centered shared decision-making process

• Clear successes in implementing in diverse populations

• Supported by strong research findings
Advance Care Planning: A Means to a Better End

“...one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes, and reasonably consistent with clinical, cultural, and ethical standards.”

Institute of Medicine’s definition of a “good death”
Resources

Websites
• http://www.gundersenhealth.org/respecting-choices
• http://www.honoringchoices.org/
• https://www.wisconsinmedicalsoociety.org/professional/hcw/
• http://iowacityhospice.org/honoring-your-wishes/

Articles
• http://www.innovations.ahrq.gov/content.aspx?id=2713 (AHRQ)
• http://www.bmj.com/cgi/content/full/340/mar23_1/c1345 (Detering)
• http://www.ncbi.nlm.nih.gov/pubmed/22233467 (LADS)
Guest Speakers

Gloria Thomas Anderson, LMSW
Educator, motivational speaker and author
Heart Tones
Disparities in End-of-Life Care:

Three Key Factors in African-American Healthcare Decision-making

by Gloria Thomas Anderson, LMSW
www.hearttones.com
Webinar Objectives:

- To examine the unique cultural, historical and spiritual values that may influence African-American decision-making.

- To identify prominent barriers to culturally appropriate healthcare provision.
3 Key Influences in African American End-of-Life Decision making

1) Historical
2) Spiritual/Cultural
3) Generational Values
Why The Historical Mistrust in Healthcare Research?

- Racial disparity in medicine
- The Tuskegee Syphilis study. (Chadwick, 1997)
- Less use of cardiac procedures, reduced access to renal transplants, and fewer surgeries for lung cancer (Peterson et al., 1997; Chen et al., 2001; Bach et al., 1999; Schulman et al., 1999; Ayanian et al., 1999)
Dr. Rodney Hood noted twice in history when health reform improved African American health outcomes:

Engrained Institutionalized Racism

1865-1872
1965-1975

The imbalance remains…
Cultural Influence of Spirituality and Religion

- West African background
- Slavery
- A Spiritual People
- The Church
Recurrent Themes in African American Spiritual Beliefs

- A source of comfort, coping and support
- An effective way to influence healing
- God is responsible for physical and spiritual healing
- The doctor is God’s instrument

(Johnson, Elbert-Avila & Tulsky, 2005)
Family centered approach ("village" concept)
High value on friends and non-family relationships
Sacrificing one’s own needs/family directed care
Focusing on “life” rather than “death”
Four Prominent Barriers That Can Hinder Culturally Responsive Care

1) Racial disparity in health care

2) Mistrust of doctors and proposed treatment options

3) Miscommunication

4) Cultural Competency “Miss-steps”
<table>
<thead>
<tr>
<th><strong>African-American Cultural Communication Style</strong></th>
<th><strong>Western-European Cultural Communication Style</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Collectivism</strong>—The belief that one’s identity is in large part a function of one’s membership and role in a group; interdependence and harmony of group members are valued.</td>
<td><strong>Individualism</strong>—The belief that the needs of the individual should be satisfied before those of the group; independence and self-reliance are valued.</td>
</tr>
</tbody>
</table>
Some Attitudes and Beliefs that Contribute to Healthcare Disparities & Service Delivery

- Biases
- Prejudice
- Stereotyping
- Discrimination
- Fear
- Ignorance
What’s Really Important at the End of Life?

- Building memories
- Being supported and surrounded by loved ones
- Leaving a legacy to be remembered by
References


Q&A

Press 14 to enter the queue to ask a question.
Announcements

- **Data Affinity Group: May 15, at 2:00pm ET**
  - Teleconference number 1-800-503-2899; Code: 8729608; Password: GETDATA

- **No Office Hours this month**

- **June CoP Call Tuesday June 10 at 2:00pm ET:**
  *Understanding Disparities Among Dual Eligibles with Mental Health Conditions*
Join the DNCC Community

To Join the DNCC Listserv:

• Log onto the SDPS system.
• Open Internet Explorer. Your default homepage should be qionet.sdps.org.
• At the top of the page, you should see a tab labeled “Listserve.” Click “Listserve.”
• Enter your user information at the top of the page and scroll down to “Disparities”. Join “Discussion” and “Notify”.
• Click “Subscribe”.

To Join DNCC Healthcare Communities:

• Log onto www.healthcarecommunities.org
• Sign in, or create an account.
• Scroll over the “Communities” tab, scroll down to “Available Communities” and select “QIO 10TH SOW”.
• Scroll down to DNCC and select “Join DNCC”.
SHARE YOUR SUCCESSES ON THE CMS PULSE WEBSITE!

Contact Ava Richardson
Phone: 410-872-9682
Email: richardsonav@dfmc.org
Thank you for participating in today’s webinar.

At the close of the presentation, you will automatically be directed to an evaluation screen.