VCU Palliative Care ECHO*

February 24, 2020

Communication in Serious Illness, Part I

*ECHO: Extension of Community Healthcare Outcomes

Continuing Medical Education

February 24, 2020 | 12:00 PM | teleECHO Conference

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Disclosures

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Danielle Noreika, MD **Candace Blades, JD, RN** **Emily Rivet, MD, MBA**

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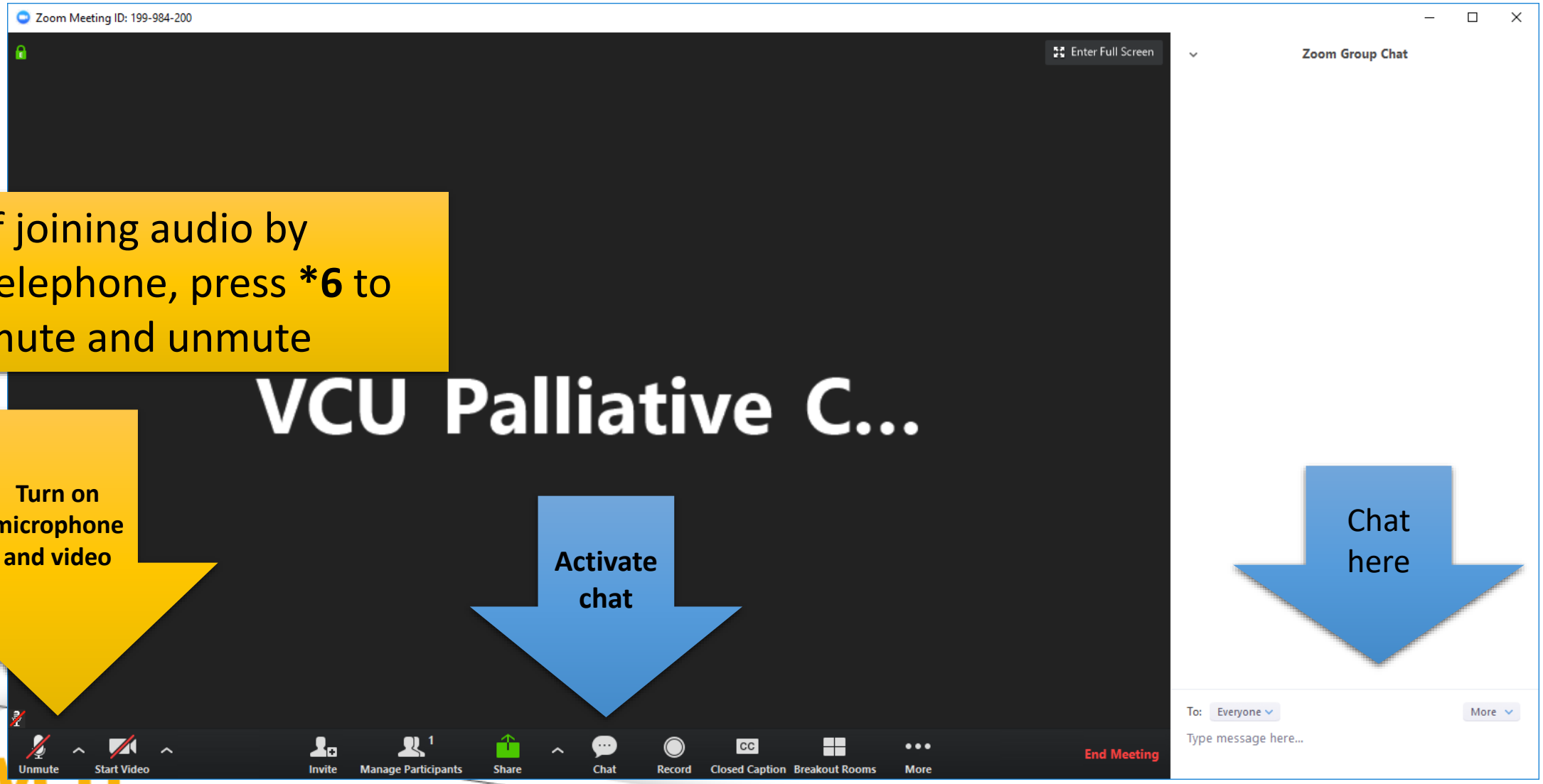

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Chat here

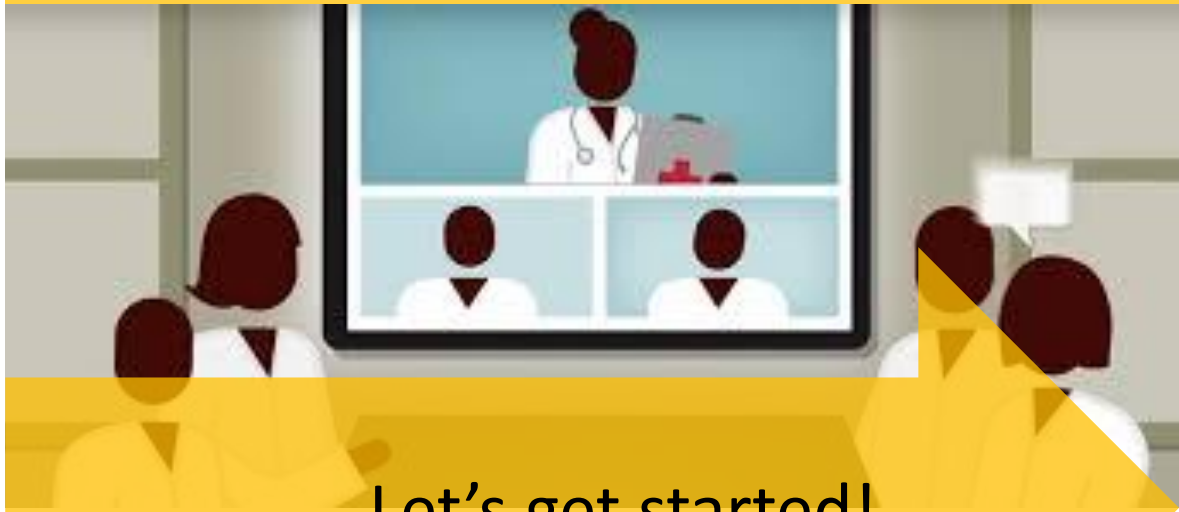
What to Expect

I. Didactic Presentation
   - Questions and discussion

II. Case Discussion
   - Case Presentation
   - Clarifying questions from spokes, then hub
   - Recommendations from spokes, then hub
   - Summary (hub)

III. Closing and Questions

- Monthly tele-ECHO sessions (1 hour)
- Didactic presentations developed by inter-professional experts in palliative care
- Website: www.vcuhealth.org/pcecho
- Email: pcecho@vcuhealth.org



Let's get started!

Our ECHO Team: Planning Committee

Clinical Leadership	**Egidio Del Fabbro, MD** VCU Palliative Care Chair and Program Director **Danielle Noreika, MD, FACP, FAAHPM** Medical Director/Fellowship Director VCU Palliative Care
Clinical Experts	Candace Blades, JD, RN – Advance Care Planning Coordinator Brian Cassel, PhD – Palliative Care Outcomes Research Jason Callahan, MDiv – Palliative Care Specialty Certified Felicia Hope Coley, RN – Nurse Navigator Diane Kane, LCSW – Palliative Care Specialty Certified Tamara Orr, PhD, LCP – Clinical Psychologist
Support Staff	
Program Managers	Teri Dulong-Rae & Bhakti Dave, MPH
Telemedicine Practice Administrator	David Collins, MHA
IT Support	Frank Green

Introductions

ECHO: Communication in Serious Illness Part 1

February 24, 2020

Communication

Painting a *Rational* Picture During Highly Emotional End of Life Discussions: A Qualitative Study of Internal Medicine Trainees and Faculty. El-Rouby et al. *J Gen Int Med.* 2020.

However, based on certain physicians' accounts, the distinction between a patient's or family's *lack of understanding* and *lack of acceptance* of a clinical situation could be hazy. Some physicians questioned the patient and family's ability to understand when overwhelmed by grief.

I don't know how you would understand something if you cannot accept it anyways. My read of the situation was that it was all grief. (R3)

It is part of their grief response, and they are not in a place where they are willing to accept the course of illness. And I know that generally what happens is that after repeated hospital admissions, they will most of the time come to a place where they understand. (AP5)

Many participants also reported negative emotions such as frustration or anxiety when being obliged to provide treatments perceived as futile and causing suffering.

I think that it can be frustrating when you end up with a decision that you think is not in the best interest of the patient for sure. (R4)

By focusing their efforts on reaching a shared understanding of the clinical situation and of a rationale for decision-making, our participants self-delineated the boundaries of their professional responsibilities regarding end-of-life care (i.e., help patients and relatives to understand, not to accept or make the "right" decisions). When a patient or family's end-of-life decision did not align with a physician's views of a clinical situation, these boundaries mitigated physician's negative reactions to the decision. However, it did not always shield decisions.

[…} my focus is always on trying to explain things as clearly as I can and to provide as much support as I can for that family because it's obviously a really difficult conversation. (R5)

However, only two participants mentioned explicitly that emotional support was an integral aspect of end-of-life discussions.

They are human beings and they are going through a very tough time. […] Dealing with situations of live and death are very emotionally challenging. But I always say to the families, I am not here for the patient only, we are here for you as well, tell us how we can help you. (AP2)

So, you know, I mostly sat with him for support. And he was very sad. And his son came in, and that's when I left. I just didn't want him to sit there by himself. And mostly, we talked about the stuff that they [he and his wife, the patient] did together and his kids and his grandkids. (F2)

Participants also reported making conscious efforts to minimize patients' and family's negative reactions and, at times, felt responsible for these emotions:

My gut reaction is always to give a silver lining because I don't want people to feel bad. (R7)

People do not want a physician who is defensive, people want empathy, and they want someone at their side […]. And I have to reflect back to them what they are saying in different words so that they can understand that I'm hearing their concerns without sounding judgemental or defensive. (AP1)

Review Article

PALLIATIVE MEDICINE

Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence

Rebecca J Anderson[1], Steven Bloch[2], Megan Armstrong[1], Patrick C Stone[1] and Joseph TS Low[1]

Palliative Medicine
2019, Vol. 33(8) 926–941

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Themes

1) Highlighting deterioration
2) Patient/family involvement in decision making
3) Post decision interactional work (“non-abandonment”)
4) Tailoring
5) Honesty and clarity
6) Communication strategies vary
7) Different IDT members have different roles

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ARTICLE IN PRESS

ORIGINAL REPORTS

Palliative Care and Communication Training in Neurosurgery Residency: Results of a Trainee Survey

Stephen P. Miranda, MD,[,†] Kristen G. Schaefer, MD,[‡,§,||] G. Edward Vates, MD, PhD,[¶] William B. Gormley, MD, MPH, MBA,[||,#] and Mary K. Buss, MD, MPH[||,**]*

[*]Department of Neurosurgery, Hospital of the University of Pennsylvania, Philadelphia, Pennsylvania; [†]Leonard Davis Institute of Health Economics, University of Pennsylvania, Philadelphia, Pennsylvania; [‡]Division of Palliative Medicine, Brigham and Women's Hospital, Boston, Massachusetts; [§]Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, Boston, Massachusetts; [||]Harvard Medical School, Boston, Massachusetts; [¶]Department of Neurosurgery, University of Rochester Medical Center, Rochester, New York; [#]Depart-

Explicit teaching to Neurosurgery Residents

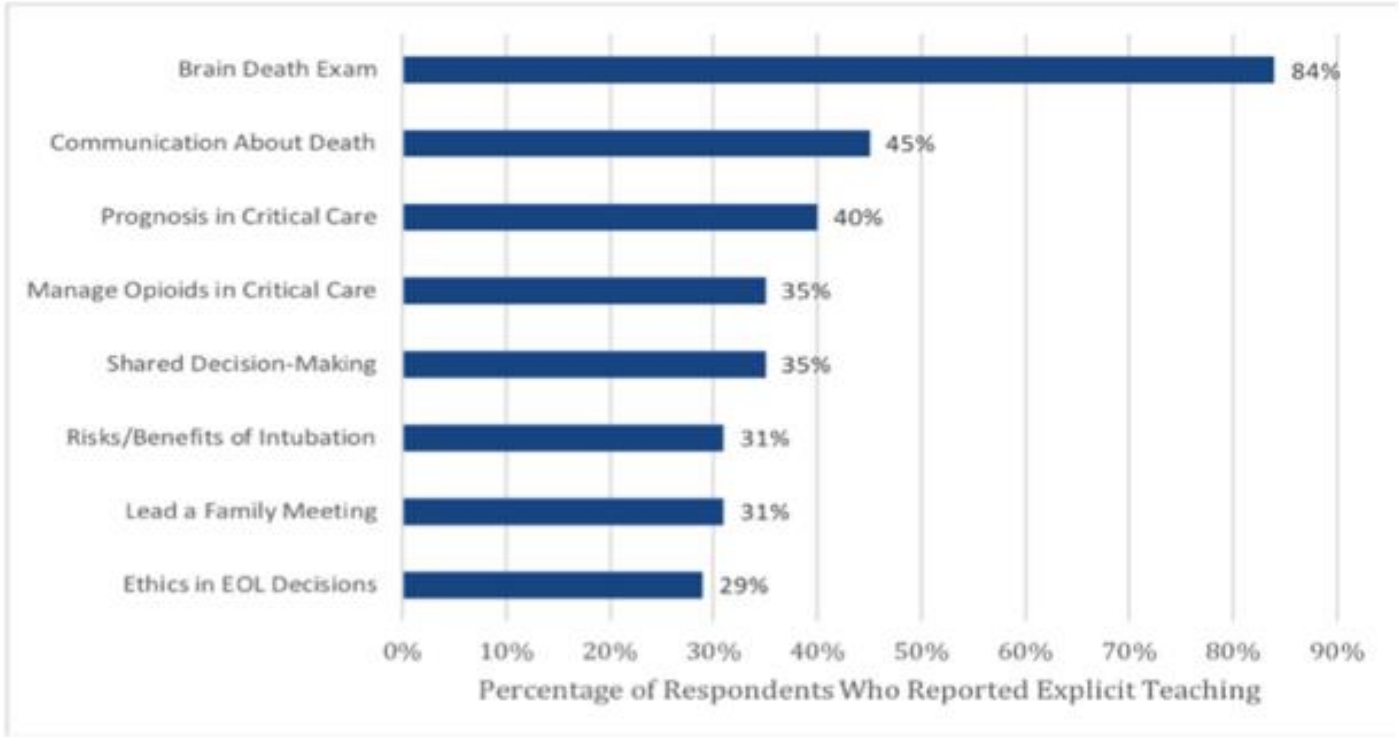


FIGURE. 1. Clinical training in palliative care and serious illness communication competencies.
Residents were asked to answer the following question: "In your residency, have you been *explicitly taught* the following things (as opposed to learning on your own)?" The percentage that answered "yes" for each of the following competencies is displayed here: perform a brain death exam, communicate to a surrogate or family member that a patient is dying, formulate prognoses in neurocritical care, manage opioid medications in critically ill patients, engage in shared decision-making, explain the risks and benefits of intubation and mechanical ventilation, lead a family meeting, and utilize ethical frameworks in end-of-life care.

Teaching methods: Craniotomy vs WLST

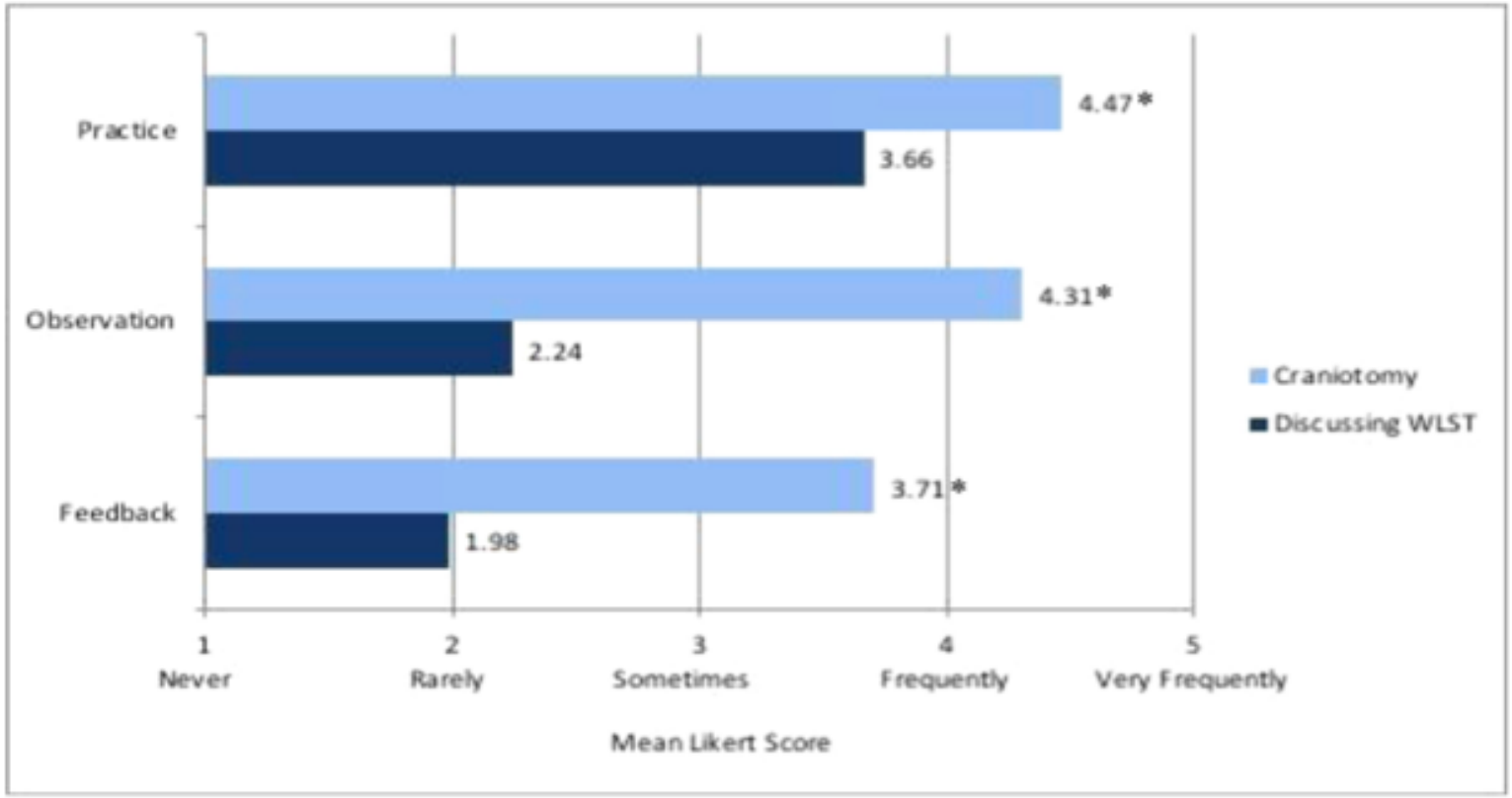
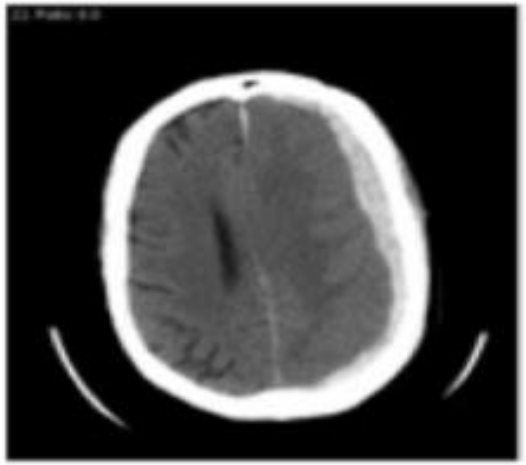


FIGURE. 2. Comparing resident education in palliative care vs. neurosurgical procedures.
Residents were asked, on average, how often they performed or participated in craniotomies, and how often they led discussions about withdrawing or withholding life-sustaining treatment (WLST) with a patient or family in the ICU. Residents were also asked how often they performed these tasks while being observed by an attending, and how often they received feedback on their technique. Residents answered on a Likert scale from 1 to 5 as follows: (1) Never, (2) Rarely (a few times per year), (3) Sometimes (monthly), (4) Frequently (almost every week), (5) Very Frequently (a few times per week). Comparative results (mean Likert score) are displayed here.
*All p values < 0.01.

Reconciling what we're communicating



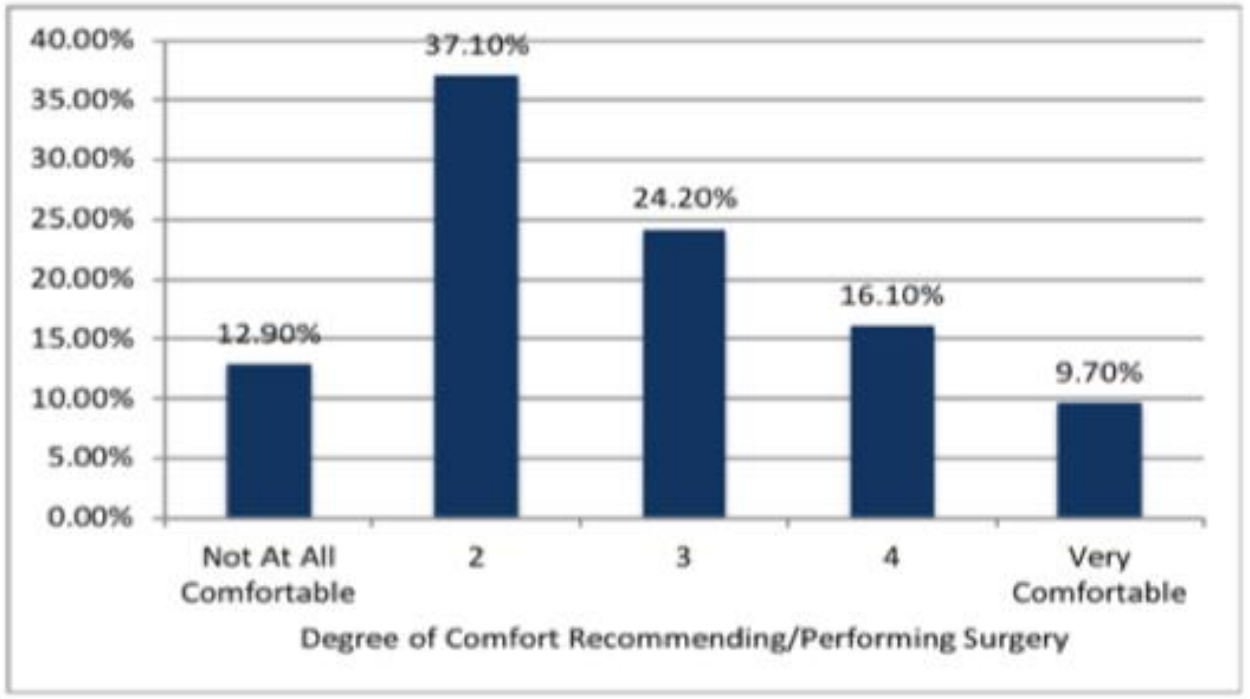


FIGURE 3. Clinical vignette.

We all have participated in the emergent care of a patient and questioned whether a neurosurgical intervention would markedly change the outcome, in terms of survival, function, or quality of life.

The following scenario is drawn from experience with such clinical dilemmas: "A frail man with mild dementia in his late 80s, was found down in his nursing home, and now presents obtunded with right-sided hemiparesis. Imaging revealed an acute subdural hematoma with midline shift (see below). He was taking lifelong anticoagulation medication for recurrent deep venous thrombosis. On examination, his GCS was 4 with pupillary changes."

Residents were asked to recall a patient they cared for who resembled the one in the vignette above.

Regardless of whether a decision for surgery was made in their case, residents were asked how comfortable they personally would have felt recommending and/or performing surgery on their patient, on a Likert scale from 1–5. Results are displayed in the figure above, from "Not At All Comfortable" to "Very Comfortable." 50% expressed some degree of discomfort.

Research

Original Investigation

Effect of Palliative Care-Led Meetings for Families of Patients With Chronic Critical Illness
A Randomized Clinical Trial

Shannon S. Carson, MD; Christopher E. Cox, MD, MPH; Sylvan Wallenstein, PhD; Laura C. Hanson, MD, MPH; Marion Danis, MD; James A Tulsky, MD; Emily Chai, MD; Judith E. Nelson, MD, JD

IMPORTANCE Family caregivers of patients with chronic critical illness experience significant psychological distress.

OBJECTIVE To determine whether family informational and emotional support meetings led by palliative care clinicians improve family anxiety and depression.

DESIGN, SETTING, AND PARTICIPANTS A multicenter randomized clinical trial conducted from October 2010 through November 2014 in 4 medical intensive care units (ICUs). Adult

Editorial page 35

Supplemental content at jama.com

CME Quiz at jamanetworkcme.com and CME Questions page 95

A Word of Caution

eAppendix 2. Guideline materials for SIT Meetings

Guideline materials for SIT clinicians to supplement education and training sessions at the start of the study, with periodic reinforcement based on feedback of fidelity to template items.

Main objectives of SIT Meetings

- Determine the family's understanding of the patient's illness, prognosis and treatments
- Enhance the family's understanding of chronic critical illness
- Discuss potential burdens and benefits of continuing intensive care treatment
- Explore relevant values of the patient and family
- Elicit treatment preferences that the patient may have expressed
- Align family expectations with clinicians ' expectations
- Integrate information previously received from multiple caregivers
- Discuss expected care needs for the longer term, in light of the patient's cognitive and functional status and level of dependence on medical and nursing interventions
- Contribute other information and support as needed by the family for establishing goals of care with the ICU physician

Carson et al, JAMA. 2016;316(1):51-62. doi:10.1001/jama.2016.8474

From: **Barriers to Goals of Care Discussions With Seriously Ill Hospitalized Patients and Their Families: A Multicenter Survey of Clinicians**

JAMA Intern Med. 2015;175(4):549-556. doi:10.1001/jamainternmed.2014.7732

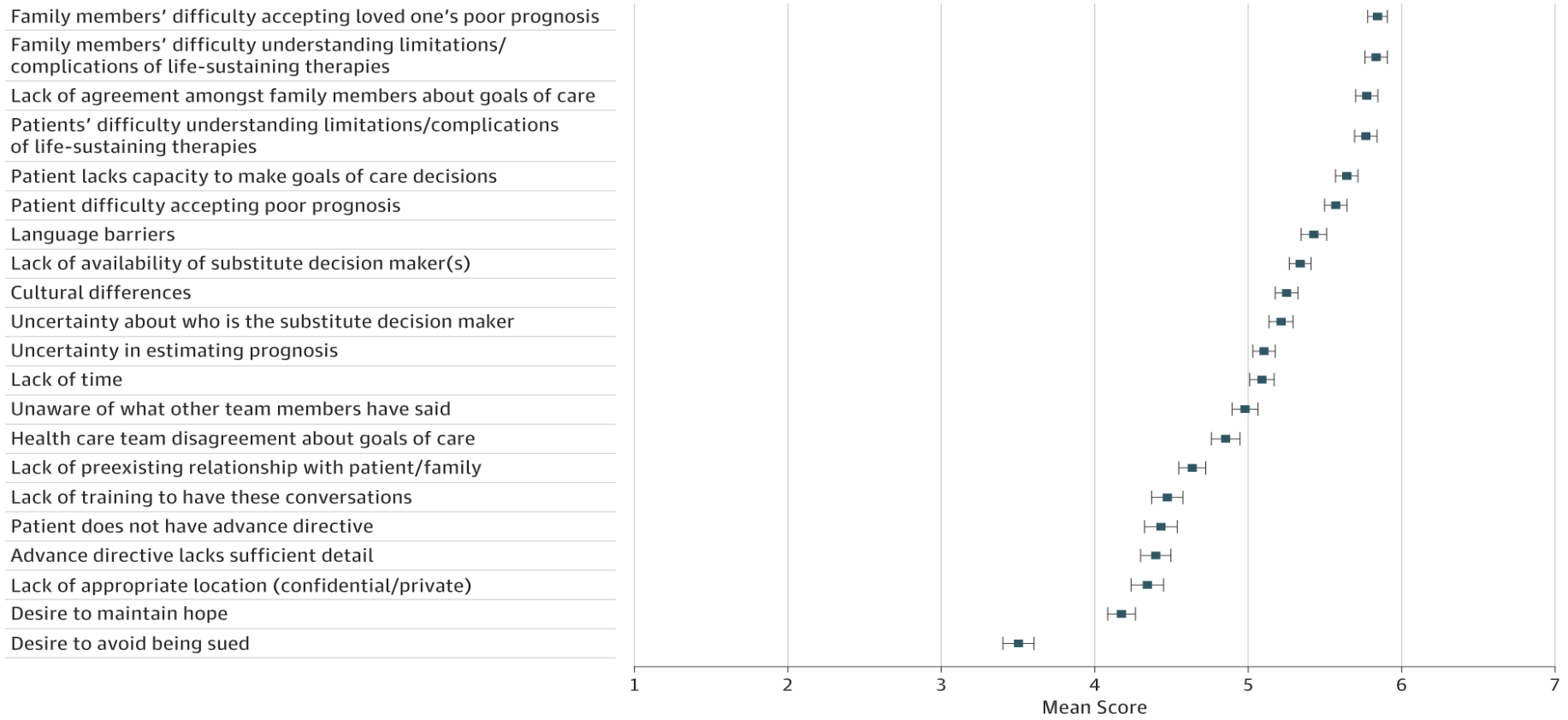


Figure Legend:
Importance of Barriers to Goals of Care Discussions as Perceived by Clinicians on Medical Teaching UnitsSymbols and error bars denote the point estimates and 95% CIs of the mean importance score for a given barrier. Questionnaire items were rated on a scale from 1 to 7, with 1 indicating "extremely unimportant" and 7 indicating "extremely important."

Reasons Physicians Provide Futile Treatment at end of life: a qualitative study. *J Med Ethics 2016.*

Table 1 Reasons doctors said contributed to the provision of futile treatment

Reason	Number of doctors citing reason	Proportion of total sample (n=96) (%)	Number of doctors citing a main reason*	Proportion of those citing a main reason* (n=80) (%)
Doctor-related factors	92	96	44	55
Trained to treat	81	84	31	39
Inexperience with death and dying	42	44	3	4
Don't want to give up hope	38	40	4	5
Aversion to death	37	39	4	5
Worries about legal risk	29	30	6	8
Poor communication	28	29	14	18
Doing everything possible	23	24	3	4
Emotional attachment to patients	19	20	0	0
Personality, personal experiences or religion	12	13	0	0
Patient-related factors	87	91	51	64
Family or patient request	63	66	33	41
Prognostic uncertainty	47	49	17	21
Lack of information about patient wishes	36	38	7	9
Hospital-related factors	65	68	12	15
Specialisation	27	28	5	6
Medical hierarchy	26	27	1	1
Hospitals designed to provide acute care so it does	25	26	4	5
Hard to stop once started	22	23	0	0

Communication makes a difference

Substantial evidence links conversations about patients' values and goals to:

- improved quality of life
- better patient and family coping
- enhanced goal-consistent care
- more, earlier hospice care
- fewer hospitalizations at the end of life

Mack JCO 2010; Wright JAMA 2008; Chiarchiaro AATS 2015; Detering BMJ 2010; Zhang Annals 2009

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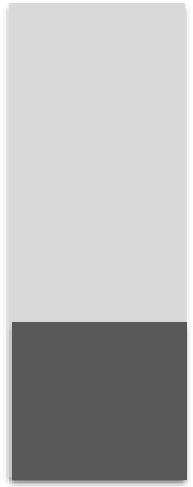
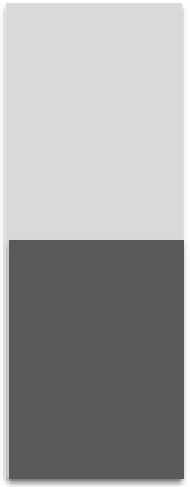
Patients assume clinicians have been trained, but…



only

29%

had formal training



and

46%

were ‘unsure’ of what to say

National survey of primary care and specialist physicians. Cambia Health Foundation; California Healthcare Foundation; John A. Hartford Foundation. 2016.

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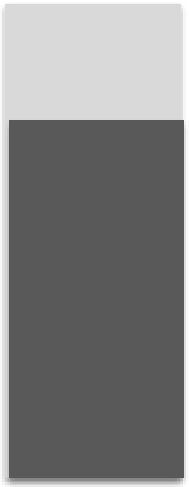
Even though clinicians agree that these conversations matter…



71%

<u>don’t</u> have a system in place to routinely ask about goals

National survey of primary care and specialist physicians. Cambia Health Foundation; California Healthcare Foundation; John A. Hartford Foundation. 2016.

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1. I provide the following instructions in the event my attending physician determines that my death is imminent (very close) and medical treatment will not help me recover:

[CHECK ONLY 1 BOX IN THIS PART 1.]

☐ I do not want any treatments to prolong my life. This includes tube feeding, IV fluids, cardiopulmonary resuscitation (CPR), ventilator/respirator (breathing machine), kidney dialysis or antibiotics. I understand that I still will receive treatment to relieve pain and make me comfortable. (OR)

☐ I want all treatments to prolong my life as long as possible within the limits of generally accepted health care standards. I understand that I will receive treatment to relieve pain and make me comfortable. (OR)

☐ *[YOU MAY WRITE HERE YOUR OWN INSTRUCTIONS ABOUT YOUR CARE WHEN YOU ARE DYING, INCLUDING SPECIFIC INSTRUCTIONS ABOUT TREATMENTS THAT YOU DO WANT, IF MEDICALLY APPROPRIATE, OR DON'T WANT. IT IS IMPORTANT THAT YOUR INSTRUCTIONS HERE DO NOT CONFLICT WITH OTHER INSTRUCTIONS YOU HAVE GIVEN IN THIS ADVANCE DIRECTIVE.]:*

What Matters Most in Life: Quality of life differs for each person. What is important to you?

AT THE END OF LIFE, some people are willing to live through a lot for a chance of living longer. Other people know that certain things would be very hard on their quality of life.

At the end of life, which of these things would be very hard on your quality of life?

Check the things below that would make you want to focus on comfort rather than trying to live as long as possible.

- ☐ Being in a coma and not able to wake up or talk to my family and friends
- ☐ Not being able to live without being hooked up to machines
- ☐ Not being able to think for myself, such as dementia
- ☐ Not being able to feed, bathe, or take care of myself
- ☐ Not being able to live on my own
- ☐ Having constant, severe pain or discomfort
- ☐ Something else _____

☐ **OR**, I am willing to live through all of these things for a chance of living longer.

Communication Challenges

- Time
- Patient/Family psychosocial dynamics
- System issues
- Lack of training
- Lack of support
- Uncertainty in prognosis
- Lack of cohesion amongst various medical team members
- Concrete yet flexible communication structure
- Documentation/legal paperwork that corresponds to communication

How will we overcome all of this? Until next time ;)

Questions and Discussion

Case Presentation

Candace Blades, JD, RN

QUESTION:
How can we ensure that interventions we are offering are congruent with patient goals, values and preferences?

- *Treatment options (goals of care)*
- *Communication*
- *Advance Care Planning*

Case history

- 74 yo AAF w/ pmhx of hypothyroidism, GOUT, a-fib on apixaban, CHFpEF, DMII (last A1C 6.5 in Nov 2019), CKD III (creatinine 1.4) and severe iron deficiency anemia requiring daily iron pills and iron infusions and morbid obesity.
- She states she does not know why she is seeing the surgeons as she states she got a colonoscopy and CT scans but was not told what they found.
- She is wheelchair bound due to her weight and fatigue.
- Her colonoscopy noted a large fungating sigmoid mass that is biopsy proven adenocarcinoma with MLH1 mutation.
- She has a family hx of gastric cancer (mom) and lung cancer (brother).

Patient has Advance Directive

We were contacted by the surgeon due to concerns about a lack of advance care planning documents, particularly a Healthcare Power of Attorney, and met with the patient at the time of her pre-op appointment.

She understood that she had "stomach cancer" that had not spread and that surgery was planned.

In the course of the Serious Illness conversation, she stated that she "wanted to feel better" and enjoys playing Bingo, cards and checkers with friends at the assisted living facility where she lives. We discussed the fact that the surgery may help her feel better, but because of her co-morbidities, could also leave her unable to do the things she enjoys.

We also reviewed an Advance Directive that she had executed the day before with the assistance of a social worker at her facility. She was not sure what the purpose of the document was. We planned to meet with her niece who was driving in from North Carolina the next day.

After the conversation with the patient and her niece, the plan was to have further discussion with the surgeon about expected outcomes of the surgery to be sure that they were in alignment with the patient's goals (she was willing to undergo surgery if she would "feel better" after and be able to resume her normal activities). We discussed the need for her to name a successor agent and agreed that the living will provisions of the advance directive prepared the day before were not congruent with her goals, values and preferences.

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Pro tip: Add this number to your contacts!

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Text course code to (804) 625-4041

Course Code:

17205-17203

Deadline is 7 days from today

You will receive a confirmation text that your attendance has been recorded

Complete Evaluation & Claim Credit

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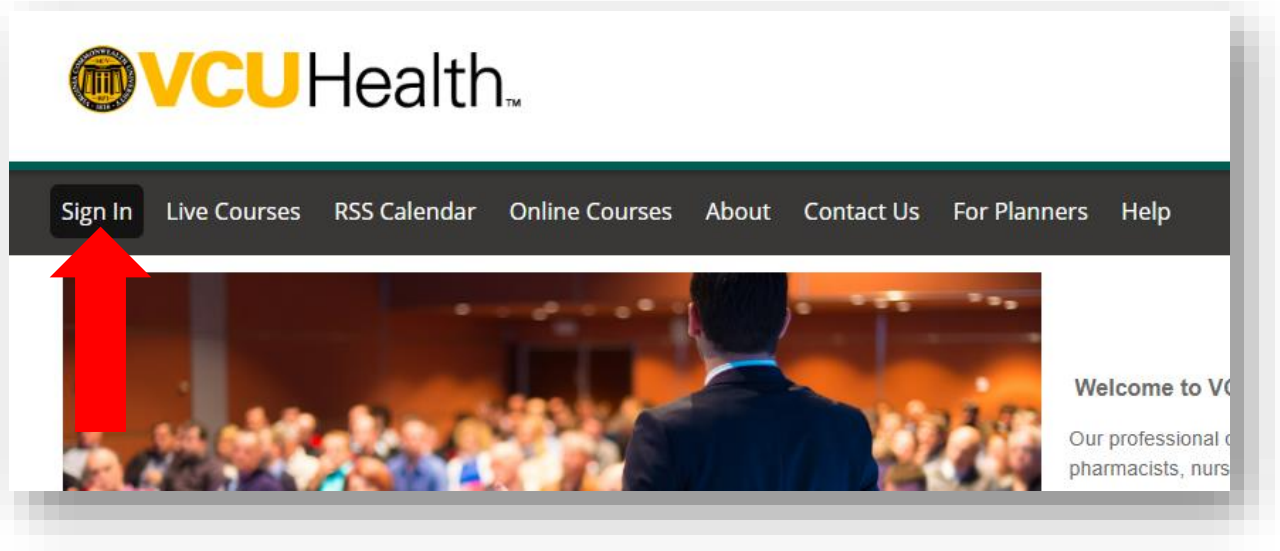
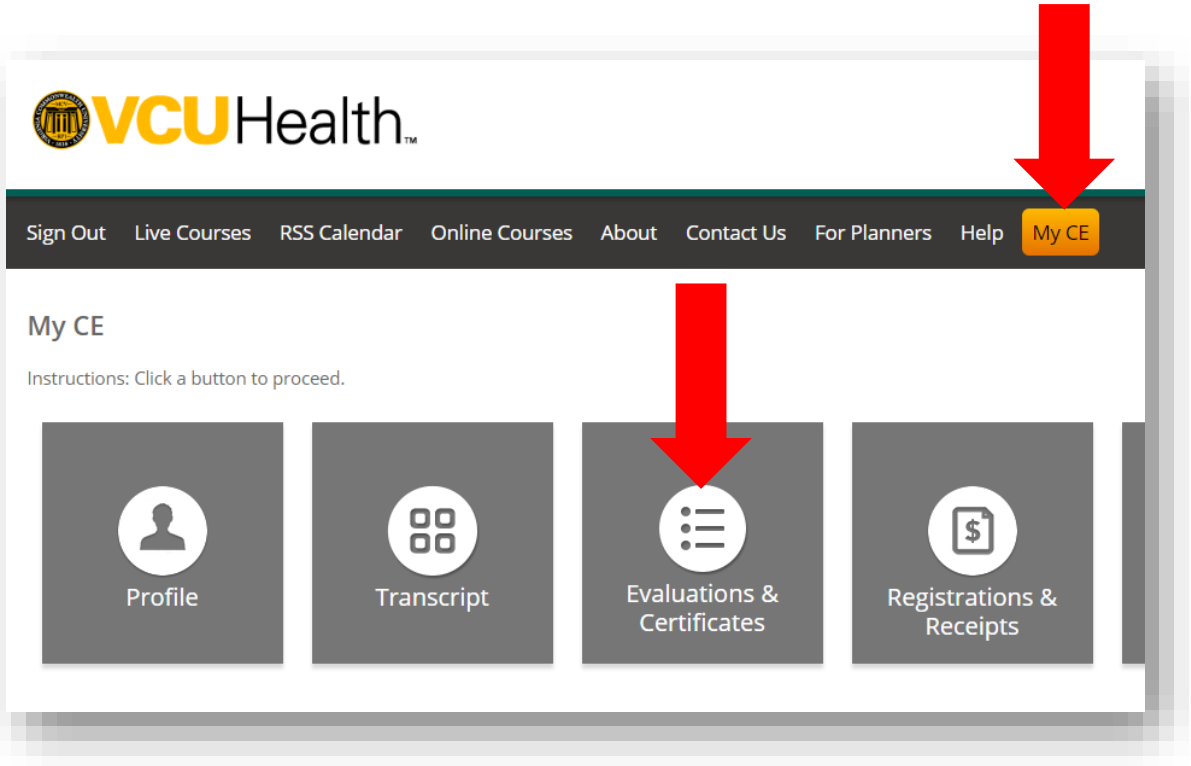


Complete Evaluation & Claim Credit

- Click **MY CE**
- Click on **Evaluations & Certificates** to view evaluations that need to be completed for sessions you have attended. This also allows you to view/print/email certificates



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VCU Health Palliative Care ECHO

Our VCU Health Palliative Care ECHO program partners with community practices caring for patients with serious illness and applies our interdisciplinary care team - a mix of physicians, nurses, social workers, psychologists, chaplains and more - to provide pati care support and education throughout Virginia.

We have a l standing palliative care program with an inpatient unit, consult service and supportive care clinic to provide serious illn are. Many communities in Virginia do not have access to palliative care and we're here to help.

- View Palliative Care ECHO sessions (CME/CEU available).
- Submit a case study (registered participants only).
- Subscribe to our mailing list to receive announcements and invitations to ECHO sessions.

Contact us for more information or help with any questions about our program.

About Palliative Care

THANK YOU!

We hope to see you at our next ECHO