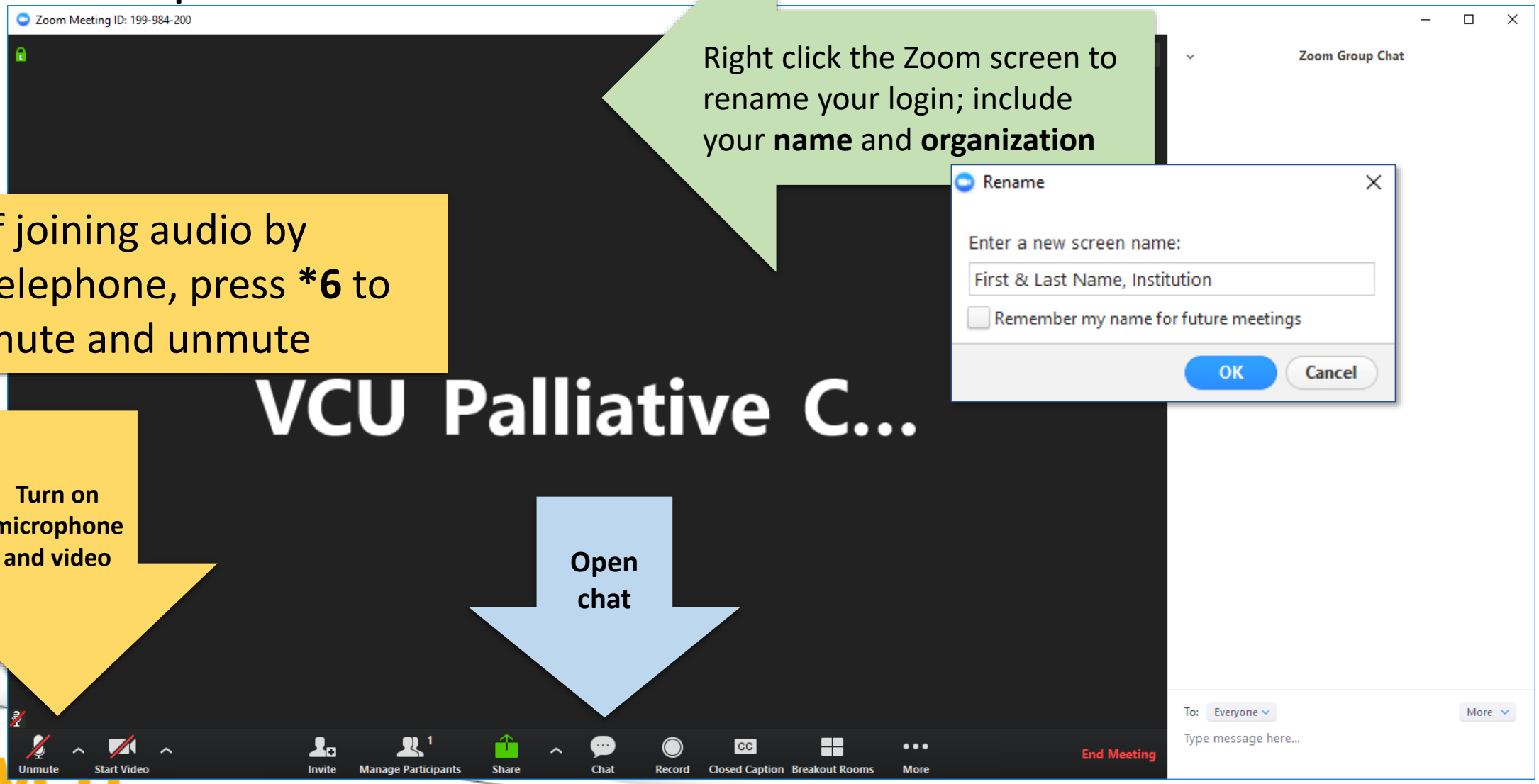
Creutzfeldt-Jakob Disease and Palliative Care
+ COVID-19 Update

Palliative Care Project ECHO
April 27, 2020

Setup



Right click the Zoom screen to rename your login; include your **name** and **organization**

If joining audio by telephone, press ***6** to mute and unmute

Turn on microphone and video

Open chat

JA Accreditation & Credit Designation Statements – LIVE Activities

VCU Health Continuing Education

In support of improving patient care, VCU Health is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME), the Accreditation Council for Pharmacy Education (ACPE), and the American Nurses Credentialing Center (ANCC), to provide continuing education for the healthcare team.

VCU Health designates this live activity for a maximum of **1.00 AMA PRA Category 1 Credits™**. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

1.00 ANCC contact hours

1.00 CE credits will be awarded for psychologists attending the entire program. Continuing Education (CE) credits for psychologists are provided through the co-sponsorship of the American Psychological Association (APA) Office of Continuing Education in Psychology (CEP). The APA CEP Office maintains responsibly for the content of the programs.

As a Jointly Accredited Organization, VCU Health is approved to offer social work continuing education by the Association of Social Work Boards (ASWB) Approved Continuing Education (ACE) program. Organizations, not individual courses, are approved under this program. State and provincial regulatory boards have the final authority to determine whether an individual course may be accepted for continuing education credit. VCU Health maintains responsibility for this course. **Social workers completing this course receive 1.00 continuing education credit**.

This activity was planned by and for the healthcare team, and learners will receive **1.00 Interprofessional Continuing Education (IPCE)** credit for learning and change.

Disclosures

In compliance with the Accreditation Council for Continuing Medical Education (ACCME) Standards for Commercial Support of CME, VCU Health Continuing Medical Education discloses all relevant relationships which program faculty and planners report having with “any entity producing, marketing, re-selling, or distributing health care goods or services consumed by, or used on, patients.” VCU Health Continuing Medical Education has procedures to resolve any apparent conflicts of interest.

The following Planning Committee and Presenting Faculty Members report having **no relevant financial relationships**:
Danielle Noreika, MD; Egidio Del Fabbro, MD; Diane Kane, LCSW; Tamara Orr, PhD, LCP, PMHNP-BC; Brian Cassel, PhD; Felicia Barner, RN; Candace Blades, JD, RN; Jason Callahan, MDiv

No commercial or in-kind support was provided for this activity

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

Case Presentation and Fast Fact #389

CREUTZFELDT-JAKOB DISEASE

EASTERN VIRGINIA MEDICAL SCHOOL

Jerry A. McQuain, MPT, DO

HOSPICE AND PALLIATIVE MEDICINE

CASE PRESENTATION

- 63 year-old female
- Past Medical History
  - None
- Past Surgical History
  - None
- Social History
  - Married 44 years, 3 children
  - Non-smoker, Non-drinker
  - Occasional marijuana
  - College graduate, Dental Assistant

CASE PRESENTATION

- Medications
  - None
- Physical Examination
  - Labile mood
  - Altered mentation
- Laboratory and Imaging Studies
  - UDS marijuana
  - Elevated ESR and anti-TPO
  - MRI: nonspecific gray matter disease

CASE PRESENTATION

- Diagnosis and Treatment
  - Major neurocognitive disorder
  - Olanzapine and mirtazapine

CASE PRESENTATION

- **1-month follow-up**
  - Inability to recognize children
  - Decreased verbal fluency
  - MMSE 7/30
  - Olanzapine, mirtazapine, risperidone
- **2-month follow-up**
  - Twitching / Jerking movements
  - Unable to follow 1-step command
  - Inappropriate laughing
  - R/O Hashimoto's thyroiditis
- **3-month follow-up**
  - Mutism
  - Myoclonus
  - B&B incontinence
  - Eating flowers and plant items
  - CSF: 14-3-3 and Tau proteins

CREUTZFELDT-JAKOB DISEASE

PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #389
PALLIATIVE CARE ISSUES IN CREUTZFELDT-JAKOB DISEASE

Jerry A McQuain DO, MPT; Marissa C Galicia-Castillo MD, FAAHPM; Deborah A Morris MD, FAAHPM

BACKGROUND

- Five human prion diseases
  - Kuru
  - Gerstmann-Staussler-Scheinker Syndrome
  - Fatal Familial Insomnia
  - Creutzfeldt-Jakob Disease (CJD)
  - Variant Creutzfeldt-Jakob Disease

CLINICAL PRESENTATION

- Incubation period
- Initial
  - **Walking, concentration, mood, sleep, diplopia, hallucinations**
- Rapidly progressive dementia - weeks to months
- Myoclonus

DIAGNOSIS

- Clinical suspicion
- Brain biopsy
- Constellation of criteria
  - Lumbar puncture
  - Clinical signs
  - Lack alternative diagnosis
  - Imaging

PROGNOSIS

- Uniformly fatal
- Hospice referral on diagnosis

NONPHARMACOLOGIC MANAGEMENT

- Interdisciplinary team
  - Grief
  - Compassionate Allowance
  - Education
- Music and Aromatherapy

PHARMACOLOGIC MANAGEMENT

- **Delirium and/or Agitation**
  - **Olanzapine**
  - **Risperidone**
  - **Quetiapine**
- **Myoclonus**
  - **Levetiracetam**
  - **Valproate**
  - **Clonazepam**

AFTER-DEATH CARE

- **Autopsy**
  - CJD Foundation covers cost
  - Does not delay funeral
- **Funeral arrangements**
  - Notify funeral home
  - Standard precautions plus
  - Avoid superficial contact with body at viewing
- **Cremation and burial**
  - No infection / environmental risk

RESOURCES

- CJD Foundation
- CJD Support Group Network
- CJD Support Network

QUESTIONS?

COVID-19 Update:
Telehealth & Palliative Medicine

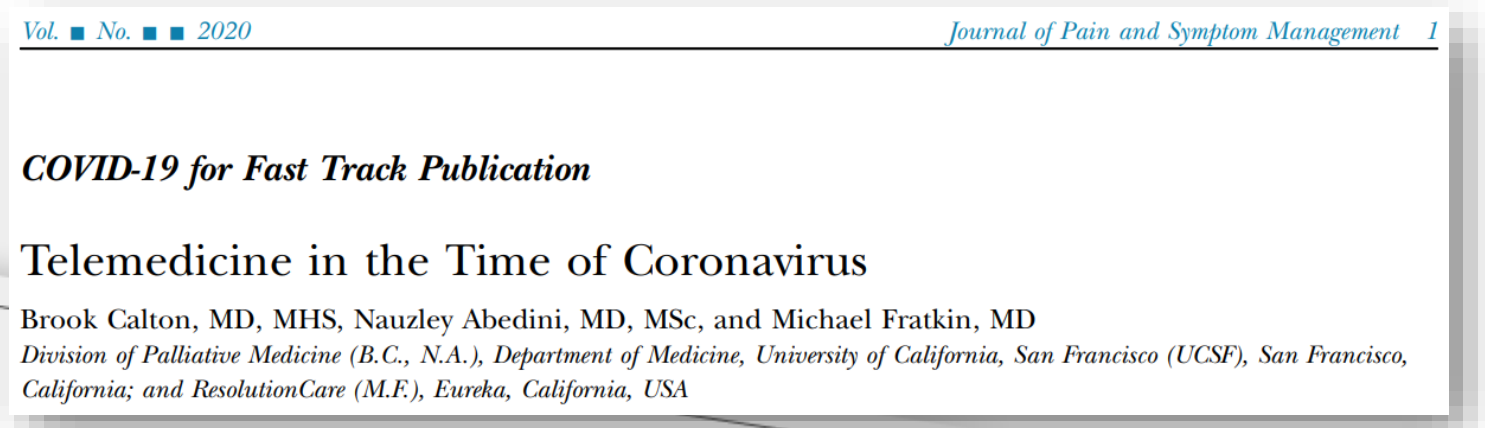
Outpatient Telehealth: Considerations

Regulatory

- Changes in enforcement of technology HIPAA compliance (check with hospital/local leadership to confirm)
- Reimbursement changes for telemedicine visits
  - Increasing viability of model

Practical

- Health system visitor restrictions forcing use of telehealth to engage with families and sometimes even with patients
- Infection control, conserving PPE, etc. by reducing number of in-person visits



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COVID-19 for Fast Track Publication

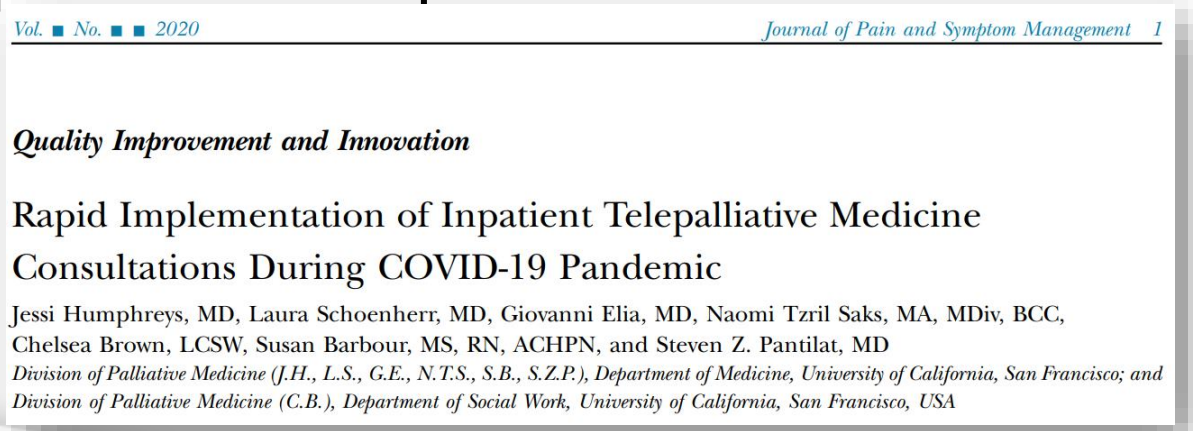
Telemedicine in the Time of Coronavirus

Brook Calton, MD, MHS, Nauzley Abedini, MD, MSc, and Michael Fratkin, MD
Division of Palliative Medicine (B.C., N.A.), Department of Medicine, University of California, San Francisco (UCSF), San Francisco, California; and ResolutionCare (M.F.), Eureka, California, USA

Inpatient Palliative Telehealth

"As we plan for decreased provider availability because of quarantine and redeployment and seek to reach increasingly isolated hospitalized patients in the face of coronavirus disease 2019, the need for telepalliative medicine in the inpatient setting is now clear."

- Limit PPE use & protect providers while providing continuity of care for patients in closed Covid-19 units
- Use technology provided in room or patient smart phone to connect
- Considerations: Pay careful attention to nonverbal cues on camera



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Quality Improvement and Innovation

Rapid Implementation of Inpatient Telepalliative Medicine Consultations During COVID-19 Pandemic

Jessi Humphreys, MD, Laura Schoenherr, MD, Giovanni Elia, MD, Naomi Tzril Saks, MA, MDiv, BCC, Chelsea Brown, LCSW, Susan Barbour, MS, RN, ACHPN, and Steven Z. Pantilat, MD

Division of Palliative Medicine (J.H., L.S., G.E., N.T.S., S.B., S.Z.P.), Department of Medicine, University of California, San Francisco; and Division of Palliative Medicine (C.B.), Department of Social Work, University of California, San Francisco, USA

CAPC resources available

capc Center to Advance Palliative Care

Telehealth and Palliative Care

Using telehealth offers many benefits to palliative care teams and their patients and families. There are 3 main "use cases" for telehealth: Provider-initiated visits; patient or caregiver call response; and provider-to-provider communications. This guide consolidates best practices on technology set-up, visit etiquette, and documentation/billing. For more detailed information, please see the individual resources on the CAPC website.

	Provider-initiated Visits	Patient/Caregiver Response	Provider-to-Provider Communications
Set-up and Process Basics	Invest in a high-quality webcam and microphone. Patients must be able to clearly hear you	Palliative care programs should have a 24/7 number to respond to patient calls. The call center should have procedures for routing the call to the appropriate clinician	Team members may collaborate on visits via telehealth
	Telehealth Platform during the COVID Emergency: CMS is authorizing the use of telephones with audio and visual capabilities, with HIPAA enforcement and penalties waived. Platforms can include: FaceTime, Skype, Updox, Zoom for Healthcare, Doxy.me, Google G Suite Hangouts. Advice is to use the platform that will be easiest for the patient/family, such as one that is already included in their smartphone.		
	Designate staff to help patients/families set up the platform, give consent, and prepare ahead of the first visit	Patients or caregivers are encouraged to call with questions, concerns, as well as to report urgent issues/change of condition	Palliative care clinicians can consult with treating colleagues via telehealth
	Prepare patients/families - make sure they have a place in the home ready, are comfortable communicating via the platform, have their questions answered, etc.	Clinicians can respond to patient/caregiver needs via telephone or can initiate a telehealth visit if they need to see the patient	Home health providers can also collaborate with the palliative care team via telehealth
	Train all members of the care team in how to use the technology, follow required etiquette, and document	Systems should be in place to notify the clinician when the patients are ready to see them; many technologies provide a virtual waiting room, but a phone call or text will work too	Communication protocols should be established within the team and with collaborating home heatlh agencies and other collaborators
	Ensure all staff can assist with technology questions and glitches during the actual visit. Provide a checklist to test capabilities	Designated staff (or the responding clinician) should be ready to help patient/family get on the platform	Team members, treating clinicians, and/or home-based staff should contact the program for help with issues and decision-making
	Schedule the visit, and send reminders with detailed instructions on how to access, and whom to call if there's a problem	Clinician should instruct where to place the device's camera to see the area of concern, such as a wound, when warranted	Tele-consult services, such as Project Echo, may work with palliative care teams to extend consultation capabilities into smaller hospitals or rural areas
	Check with your malpractice insurance carrier to make sure that services provided via telehealth are covered		

Project ECHO®
Virginia Commonwealth University

VCU

Additional considerations

- Access to technology: patients and families may not have hardware or skill set to use telehealth technology
- Video conferencing is preferable to telephone calls but may not be practical or available for al patients/families
- Disparities: make efforts not to exacerbate racial, socioeconomic, geographic disparities for populations lacking adequate internet access, devices, technological literacy
- Telehealth etiquette:
  - Look at the camera, pay attention to verbal and nonverbal cues
  - If possible, provide suggested scrips for communication to providers new to using telehealth

Hart, et al. Family-Centered Care During the COVID-19 Era
JPSM In press May 2020

Resources

- **Center to Advance Palliative Care (CAPC)** Toolkit COVID-19 Response Resources: Toolkit
- **VitalTalk** COVID-19 Communication Skills (Includes updated serious illness conversation guidance)
- **National Coalition for Hospice and Palliative Care** COVID-19 Resources page: https://www.nationalcoalitionhpc.org/covid19/
- **Respecting Choices** COVID-19 Resources https://respectingchoices.org/covid-19-resources/
- **Center to Transform Advanced Care** https://www.thectac.org/coronavirus/
- **National Hospice and Palliative Care Organization (NHPCO)** COVID-19 Information

Case

- 27 yom with rare GI cancer, metastatic
- Recent admission for fever during which also had increasing pain
- Pain improved on fentanyl IV while in the hospital
- Challenges additionally with PSBO vs ileus during inpatient stay

Case

- Recommended for metoclopramide and discharged with fentanyl patch and oxycodone which were effective for pain in the hospital
- In a prior life would have been seen by our nurse navigator in house, set up with an in person eval 1-2 weeks after discharge with potential for phone call in-between to check
- Currently we are encouraged to try not to see patients in person and nurse navigator has been encouraged to avoid inpatient spaces……how to ensure patients receive the care they need?

THANK YOU!

We hope to see you at our next ECHO