

NHPCO Project ECHO 2023

Equity Where It Matters

Topic: Supporting Patients Experiencing Housing
Insecurity at the End of Life

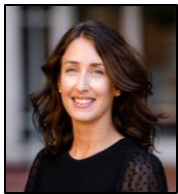
Date: 9/28/23

NHPCO Project ECHO Team



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Disclosures

Disclosure

The faculty and planners for this educational event have no relevant financial relationship(s) with ineligible companies to disclose.

Data Collection

In order to support the growth of the ECHO® movement, Project ECHO® collects participation data for each ECHO® program. Data allows Project ECHO® to measure, analyze, and report on the movement's reach. Data is used in reports, on maps and visualizations, for research, for communications and surveys, for data quality assurance activities, and for decision-making related to new initiatives.

Evaluation

You will be receiving an email with a link to complete a short survey about this session. Please complete the survey within 48 hours. We ask all participants to take the survey as it will help us to improve future sessions.

Ground Rules and Video Teleconferencing Etiquette

- This is an all share-all learn format; judging is not appropriate
- Respect one another – it is ok to disagree but please do so respectfully
- Participants – introduce yourself prior to speaking
- One person speaks at a time
- Disregard rank/status
- Remain on mute unless speaking and eliminate or reduce environmental distractions to improve sound/video quality
- Use video whenever possible; make eye contact with the camera when you are speaking
- **Do not disclose protected health information (PHI) or personally identifiable information (PII)**

Today's Agenda

- Introduction of Faculty – NHPCO Team
- Didactic Presentation – Faculty
- Case Study Presentation – Faculty
- Discussion – Session Participants, Faculty, and NHPCO Team
- Key Takeaways – Faculty and NHPCO Team
- Closing Remarks – NHPCO Team



Erin Collins, MN, RN, CHPN
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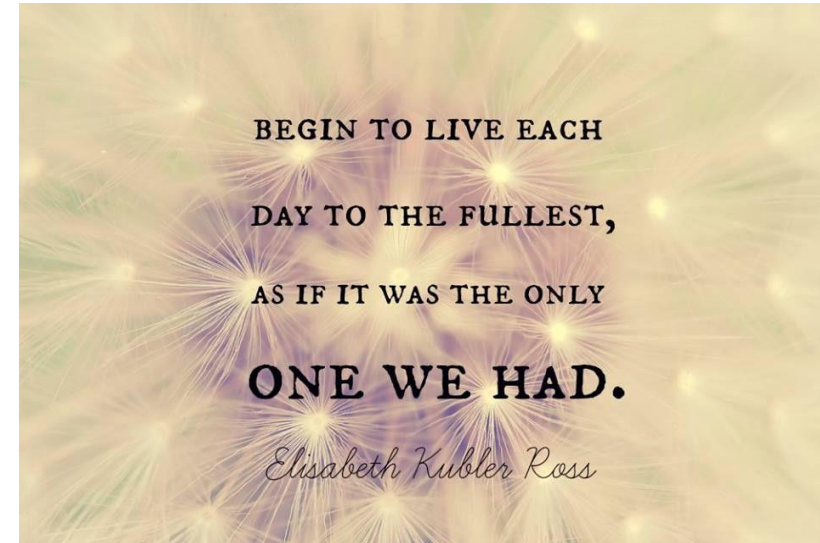
Sharon Harris, LVN, CHPLN, EOLD
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Session Faculty

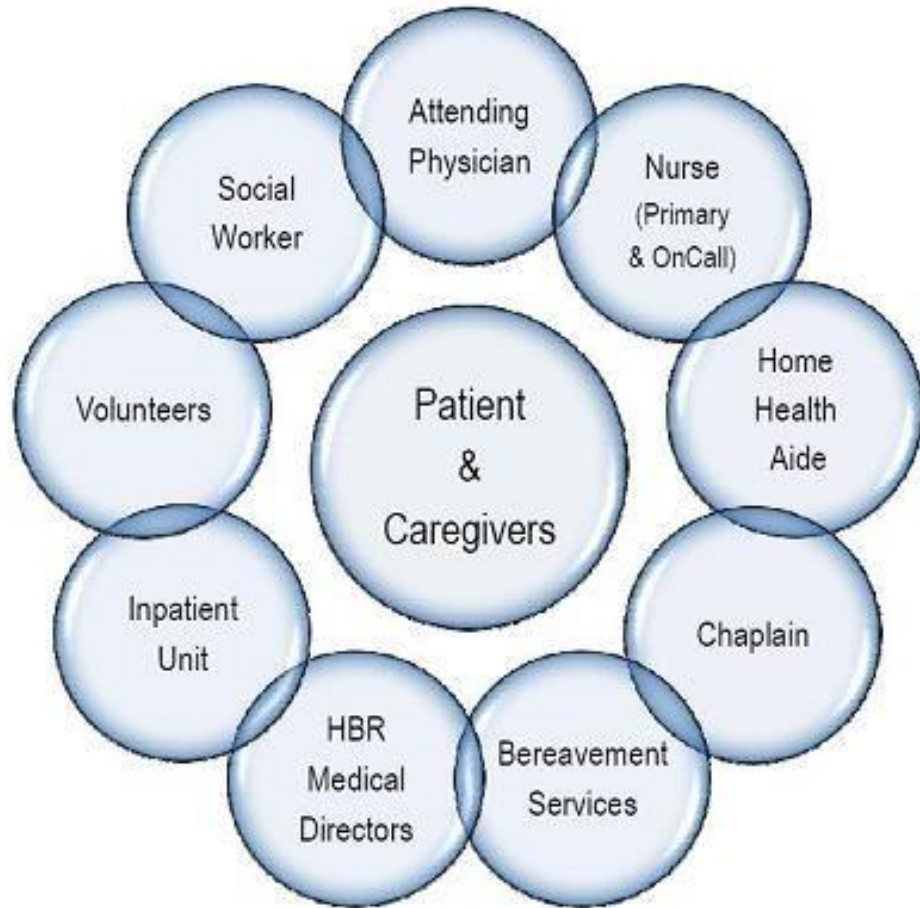
Didactic Presentation

End of Life Experience & Support

- Grief at end of life
- End of life goals and wishes
- Companionship for dying persons
- Hospice & Palliative Care Interprofessional teams



Interprofessional Teams



- Social Work
 - Dignity & Worth of person, advocacy, Right to Self-Determination, Code of Ethics
- Doula
 - Advocacy, service, comfort
- Chaplaincy
 - Spirituality, church and religious support, beliefs around poverty and charity

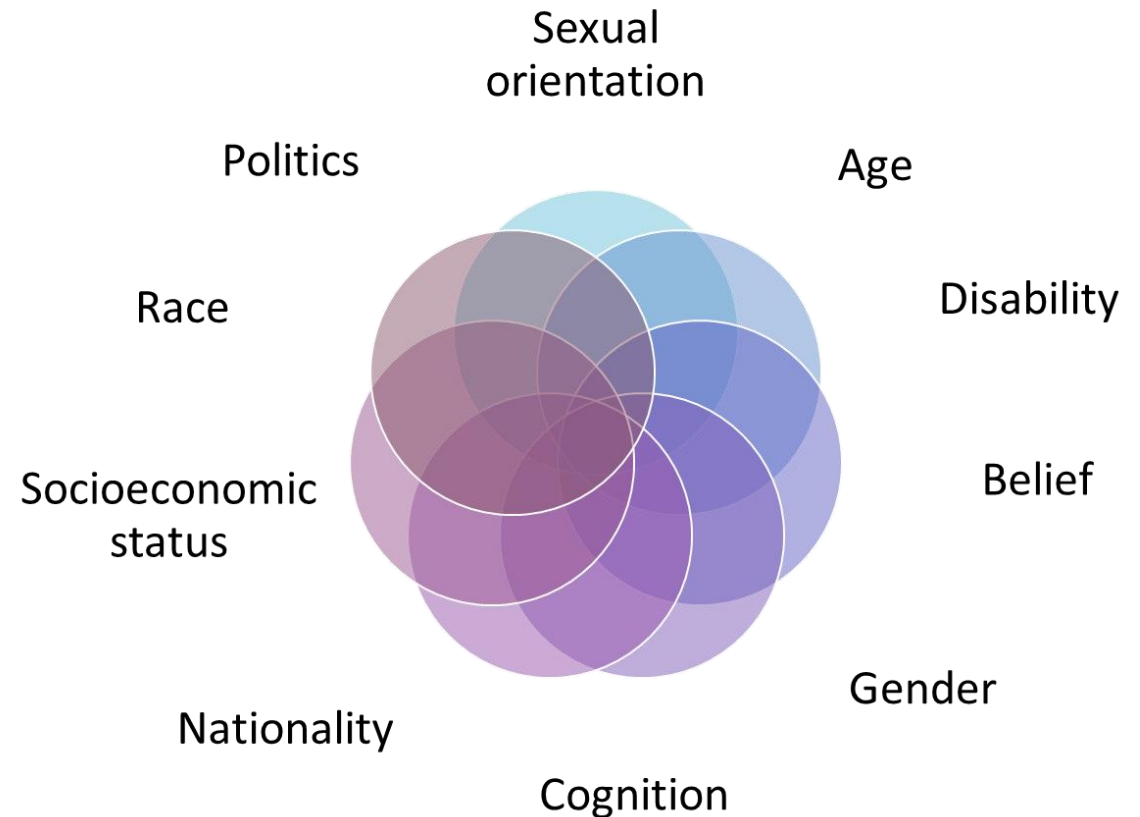
Intersectionality

Intersectionality Theory by Dr. Kimberle Crenshaw

Layers of privilege and oppression

What other layers might exist?

- Rurality?
- End of Life



End of Life Goals & Wishes



- People want to die at home, possibly with loved ones present
- Only 1/3rd of people who wish to pass at home actually do
Where do folks tend to pass instead?
- Reasons people may not pass at home
What supports are in place? Resources?
Waitlists.
- How might we bridge the gap?
 - Equity, access, and inclusion
- Cultural differences on acceptance of and access to hospice care

Additional housing barriers

- Financial crisis and stress
- Energy assistance, condition of the home
- Neighborhood safety, environmental safety
- Jail, homeless shelters, homeless
- Disability, limited respite/caregiving supports

Didactic Presentation Q&A

Case Study Presentation (BL's Story)

Situation



- BL is 79 and lives alone
- No identified caregiver
- No heat/air conditioning at home (it is July)
- Eligible for Medicaid Waiver, but there is a waitlist
- Increased falls
- No ramp, no accommodations in the home
- Waitlist for ramps, accommodations
- Lives in rural area
- No transportation
- Does not accept that she is dying. Very independent and spirited

Background

- Divorced at 34
- Jewish, not involved in community
- Estranged from only daughter
- One grandchild, only met once
- Uses walker, nearly wheelchair bound
- Refuses therapies
- Refused hospice until felt there was no other option
- History of mental health conditions, including OCD
- Few neighbors. Does not talk to them
- One good friend from high school, lives out of state, does call and write

Assessment

- End stage COPD, oxygen dependent
- What are current caregiver options?
- Refused an extended care facility and wants to die at home.
- No advance care planning in place
- No funeral arrangements made
- Many belongings and collections, bordering on hoarding
- Continued refusal of mental health support and medication
- Enjoys arts and crafts
- Struggling to pay bills at her home
- Home in need of repair
- Spiritual distress



Discussion and Recommendations

Discussion and Recommendations

- Recommend
 - Advocacy around Medicaid waiver waitlist
 - Current and political
 - Advocacy around waitlist for ramp & accommodations
 - Making sure social worker is involved
 - Bringing in Doula
 - Doula benefit patient, family, team
 - Advance care planning, safety plan, funeral planning
 - BL in control whenever possible
 - Offering options
 - Home repairs? Air conditioning? Lift Chair? (Dream Foundation)
 - End of life goals and wishes
 - Relationships?
 - Spirituality, Cultural Humility

Key Takeaways & Questions

1. Many low-income and unhoused/housing insecure individuals mistrust govt/social services- and also have mistrust of healthcare.
2. Thinking outside the box to build trust with community partners like end-of-life doulas or Community Health Workers can improve quality of life and continuity of care.
3. Housing is healthcare- this is a great place to start to improve a person's quality of life.

Action Steps

Consider political advocacy around Medicaid Waiver and expediting supports for dying persons.

Consider incorporation of end-of-life doulas into your programs to potentially bridge some caregiver gaps, provide respite, ease burden of care for hospice teams, and improve comfort and quality at end of life

References

Brazil, K., Bedard, M., & Wilson, K. (2002). Factors associated with home death for individuals who receive home support services: A retrospective cohort study. *BMC Palliative Care, 1*, 2–6.

Caswell, G., & O'Connor, M. (2015). Agency in the context of social death: Dying alone at home. *Contemporary Social Science, 10*(3), 249-261.

Chokshi D. (2018). Income, poverty, and health inequality. *JAMA, 319*(13):1312–1313.

Royal College of Nursing (2014). Only one third of dying people who wish to die at home actually do, survey finds. *Nursing Standard, 28*(46), 8-8.

Webb, W. A. (2015). When dying at home is not an option: exploration of hostel staff views on palliative care for homeless people. *International Journal of Palliative Nursing, 21*(5), 236-244.

Session Evaluation and Certificate of Completion

- Your feedback is valuable as we plan upcoming sessions!
- Project ECHO sessions are not accredited for continuing education, but we are able to offer a confirmation of completion for each session. To receive confirmation of completion, please complete the following [Project ECHO Session Evaluation and Knowledge Check](#) following each session.

NHPCO Health Equity Certificate

- Would you like to demonstrate your commitment to delivering culturally competent care across the continuum of serious illness in an equitable, inclusive, and person-centered manner?
 - NHPCO is pleased to offer a Health Equity Certificate for individuals who participate in at least 17 sessions in the *Equity Where It Matters* series
- Participants interested in earning the Health Equity Certificate must complete the [Project ECHO Session Evaluation and Knowledge Check](#) following each session.
- Effective July 20, the Session Evaluation and Knowledge Check can be completed using one link for each session.
- Session Evaluation and Knowledge Check links are unique for each Project ECHO session and do not expire. Links for each 2023 session can be found on the [NHPCO Project ECHO webpage](#).

Upcoming Sessions

Date: October 19, 2023

Topic: Culturally Responsive Trauma Informed Care

Date: November 2, 2023

Topic: Disrupting Ageism

Additional Information

NHPCO Project ECHO webpage:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/>

NHPCO Project ECHO session recordings and Key Takeaways:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/2023-project-echo-session-recordings/>

NHPCO Project ECHO Registration Link:

<https://nhpc.zoom.us/meeting/register/tZEsfu-trz4oGtQeKFw41UEIYNwjSli8QCBF>

For more information:

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