

Envisioning the Future 2020 & BEYOND

**Death is not a Four-Letter Word:
Honoring Choice in Grief
in Long-term Care Communities**

Michelle Olson
PhD, LCAT, ATR-BC, ACC/MC

Pioneer Network

Thank YOU for being here!
A little about me &
what brought me here ...

Terms Used...

- **Residential care communities(RCHs)** instead of: *nursing home, skilled nursing facility, or long-term care facility*
- **Death care practices:** Practices and/or rituals staff employ *immediately after* a resident dies.
- **Person-centered/directed care:** Practices that support and respect an individual's daily choices, preferences and rights. These practices are driven by the elders & are part of the culture change movement (Devine, 2014).
- **Arts-informed inquiry:** A holistic form of arts-based research that is used to represent and respond to & understand a phenomenon and makes the findings more accessible to a wider range audience (Savin-Baden & Wimpenny, 2014).

Goals for this session.

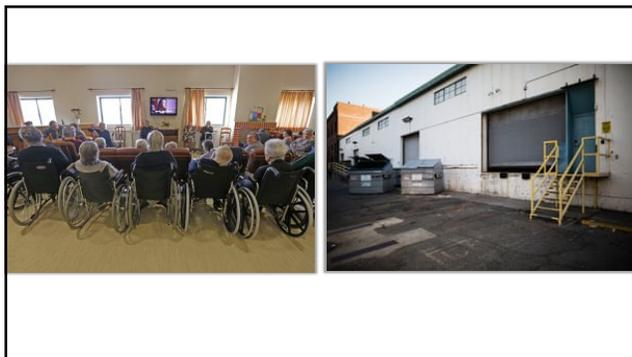
- Understand **death avoidance & disenfranchised grief**
- Learn how **person-centered care** and **ageism** relate to death in RCHs
- Explore how **death care practices** were **experienced & perceived by residents** in a research study
- Listen to **resident voices through art & poetry**
- Learn how and why **arts-based approaches** can enhance a research study
- Participate in a brief **mindful & creative experiential!**

Think about someone
you're close with...that you
see everyday.

This could be a friend
or a co-worker.

Envisioning the Future 2020 & BEYOND Pioneer Network









Contextual Factors & Disparity

Death is a natural occurrence in RCHs

Overt fear & avoidance of it

Envisioning the Future 2020 & BEYOND Pioneer Network

Background in Literature

No previous studies on this topic have directly related to **person-centered care** or have an **arts-based methodology**.

Literature on RCH *residents' perceptions of death of peers* is almost non-existent

Gaps in research date back to the 1980's, 1990's and 2000's

Staff recognize the losses that residents' face, however, they are often **unable to support these losses**.

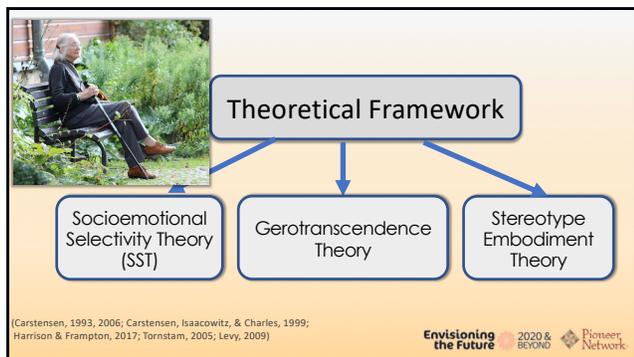
Findings of these older studies **continue to be relevant and largely unaddressed** today

Purpose of Study

To understand *how residents feel* about the death care practices within their RCH and their perceptions about their *own mortality* related to these death care practices.

Envisioning the Future 2020 & BEYOND Pioneer Network





- ### Sampling
- Purposive maximum variation sampling
 - 15 Participants from 4 RCH's (with hidden death care practices)
 - 6 Men, 9 Women
 - Ages 64-97
 - White, non-Hispanic
 - Catholic (11) Protestant (1) Jewish (2) No religious affiliation/theist (1)
 - Diverse SES and Education levels
 - 7 of 15 need ADL assistance

Research Questions

- 1) What are the **perceptions and experiences of resident deaths** related to the death care practices among residents living in RCHs?
- 2) Given the residents' perceptions and experiences of death care practices, what are residents' **perceptions of their own mortality**?
- 3) What imagery is evoked in residents' **creative expressions of resident death and their own mortality** related to the death care practices within their RCH?
- 4) How do residents' perceptions and experiences of the **death care practices within an RCH align with the person-centered care** recommended practices?

Methodology

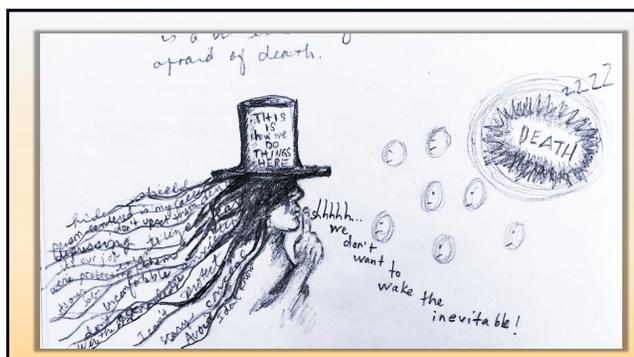
Multi-Case Study Approach

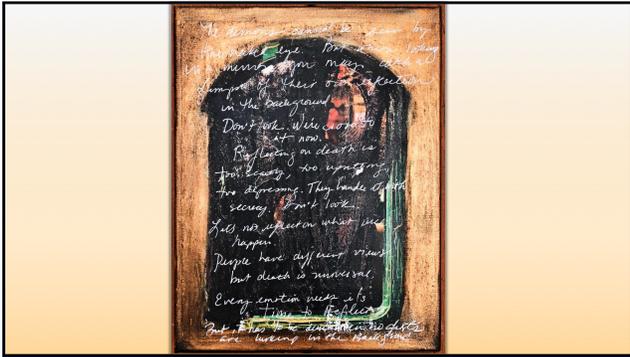
- Collection and analysis of data from and across **4 cases**
- **Focus Groups** conducted in all 4 cases (Lasting approx. 60 mins)

*Started every session with handshakes, deep breaths and served hot tea in china cups

Arts-Informed Approach

- **Found data Poetry** was derived from participants' words
- **Visual/creative expressions** were created in 2 of the 4 cases
- **Visual art and writing by artist-researcher** for reflexivity throughout research process







Found Data Poetry

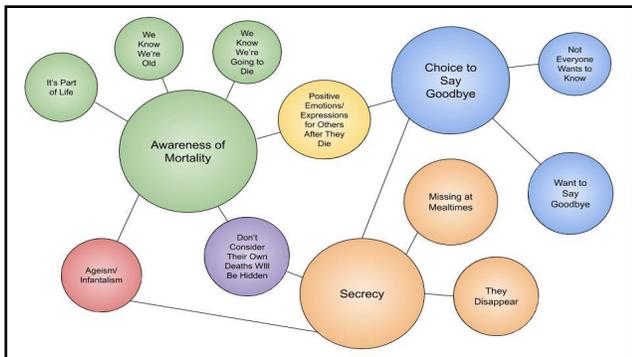


- This use of interpretive poetry **used the participants' own words** that were **selected from my perspective** as researcher.
- Used to **maximize trustworthiness**
- Can help **marginalized voices** such as RCH residents, to **be heard and articulated in a collective and meaningful way.** (Leavy, 2015)

Ensō Making

*...To be alive is a miracle
and when you breathe in
mindfully, you touch the
miracle of being alive.
~Thich Nhat Hanh*





➤ They Disappear

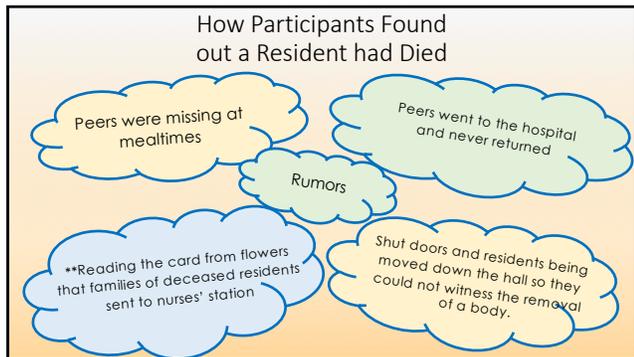
- Nobody knows about it.
- You just don't see a person
- It's an empty feeling.
- I don't see anything going on.
- Why is it a secret?
- We don't even know they're gone. They don't discuss it at all

Secrecy



➤ Missing at Mealtimes

- I ate with her three meals a day...
- At mealtime we sit across from one another...None of us in this place are by ourselves. We're friends.
- Sometimes the only way you know whether someone's passed away or not...is that they don't show up for meals
- You sit across from me for a year, 2 years, 3 years and then all of sudden...in the morning, you're not there.
- I ate with her everyday, no one told me. I had to ask.



Awareness of Mortality

It's Part of Life

- Nobody's gonna get out of it.
- It's going to happen, it's part of life.
- Coming and going...It's part of our lives.
- Death is universal—it's in every walk of life.
- It's a fact of life.
- We faced death in our lives, relatives, friends and family...

We Know We're Old

- We all know that we're old, some of us are older than others,
- We're older than the whole staff.
- We realize we're old, you know, we're anywhere from 75 on up...



We Know We're Going to Die

- You're in here one day, gone tomorrow.
- We're not going to live forever.
- You get used to the idea very quickly here.
- That's what people are here for, you know?

Choice to Say Good-Bye

➤ **Want to Say Good-Bye**

- We wanna say good-bye in our own way.
- I'm Catholic and I'd like to at least say a prayer or something, you know?
- At least tell me so I can say, 'rest in peace'...
- Tell us so we can know about it...give us the option!
- I would prefer seeing most of them...
- I would have liked to say good-bye to my friend, John...

➤ **Not Everyone Wants to Know**

- And maybe people, a lot of people can't face death
- Nancy would have never wanted to see or know anything...I don't want to see a dead person or people like that. They feel like that..
- Not everyone wants to know, ya know?
- Its different for most people...dealing with death is very different for people.
- I can handle it, but my roommate can't...she'd be crying all day.



Other Sub-Themes that Interconnected Between Themes & RQ's:

Positive Emotions & Expressions for Others After They Die

- This lady that died last week...was 102...she could tell such stories...she was so interesting...such a beloved person
- Ya know, all of a sudden, you can find something good in that person...

Don't Consider their Own Deaths Will be Hidden

- You don't worry about it, You'll be gone!
- I don't care what door they go out as long as we know about it...and we can see them before they go. I don't care if they go out the side door, the front door, whatever door.
- I never thought about it for myself here. Outside, I thought more than I do here.

Two Sides of Ageism in Hidden Death Care Practices

<p>Ageism/Infantilism: Perceived</p> <ul style="list-style-type: none"> • We're big people! We're not children. • We're not kids, we're older than the whole staff. • That's the way they want it here. • They're trying to protect their kids...We're not kids! 	<p>Internalized Ageism as Coping Mechanism:</p> <ul style="list-style-type: none"> • It's been this way since I'm here... • That's the way they want it here. • Sometimes you feel like if you walk over and ask them and you want to know, you'll rock the boat.
---	---



**Found Data
Poem:**

*Composite Voices
Across Cases*



Kintsugi Honoring Vase





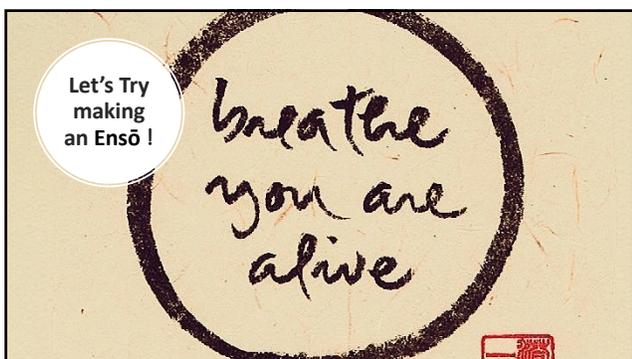






Implications for Practice & Policies

- Long-term healthcare professionals & CMS should understand that providing choice to say good-bye to deceased peers is *person-centered care* and it is *their right*.
- **Staff Education & support is imperative** to transform the medicalization of death care practices to more mindful holistic and compassionate approaches within these contexts where death is a common occurrence.
- Staff should pause & hold space for death and engage with residents in these meaningful conversations to help bring awareness to death avoidance, underlying death anxiety, ageist practices to reduce suffering.
- By creating an honoring ritual(s) at the time of death, staff can help residents (and themselves!) avoid feelings of disenfranchised grief (Doka, 2002) and to fully honor these relationships (Maitland, et al., 2012).





Remember...
LIVE LIFE
to the Fullest!
Thank you!

Michelle Olson
michelle@geropros.com
Connect with me: LinkedIn

Envisioning the Future 2020 & BEYOND Pioneer Network
