



“I still think about them...”


Professionalism & Emotional Connection in End-of-Life Care

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AGENDA



- INTRODUCTION
 - DIRECT CARE STAFF
 - A SHORT CASE STUDY
 - REVIEW OF RESEARCH LITERATURE
 - USING REFLECTIVE PRACTICES
 - RECOMMENDATIONS FOR PRACTICE
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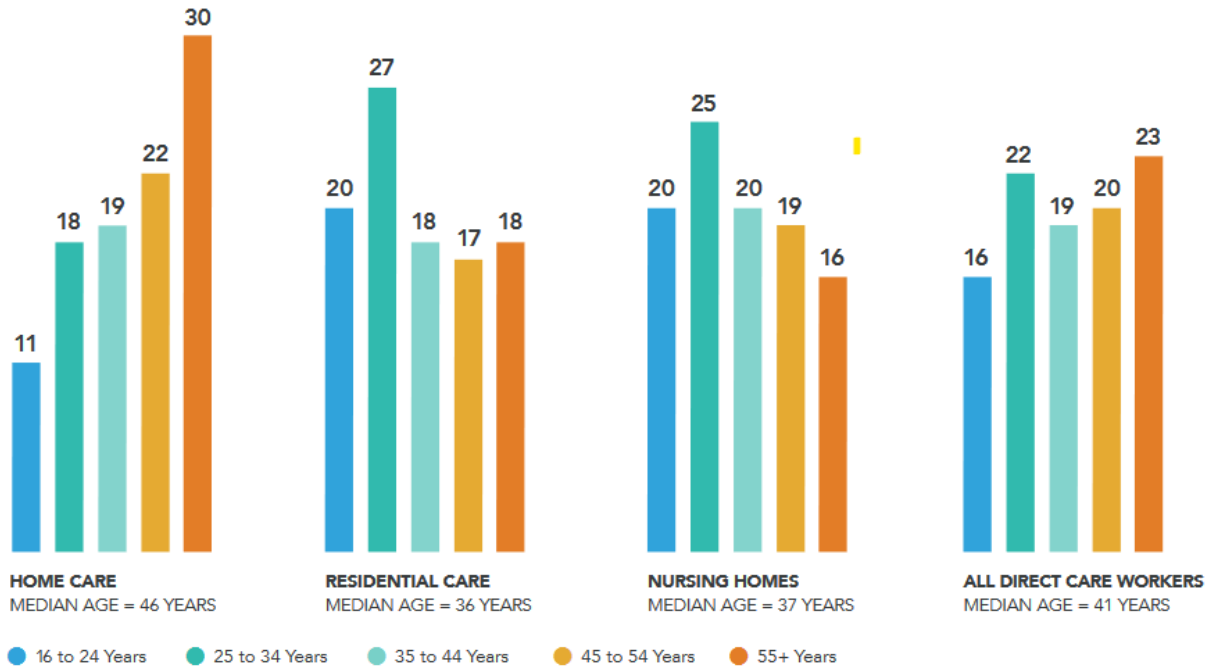
Learning Objectives

- Participants will be able to identify common grief reactions experienced by direct care staff after a resident dies.
- Participants will be able to explain how communal rituals can aid grieving process.
- Participants will be able to describe best practices in handling a resident's death in LTC

About Me



Direct care staff in LTC



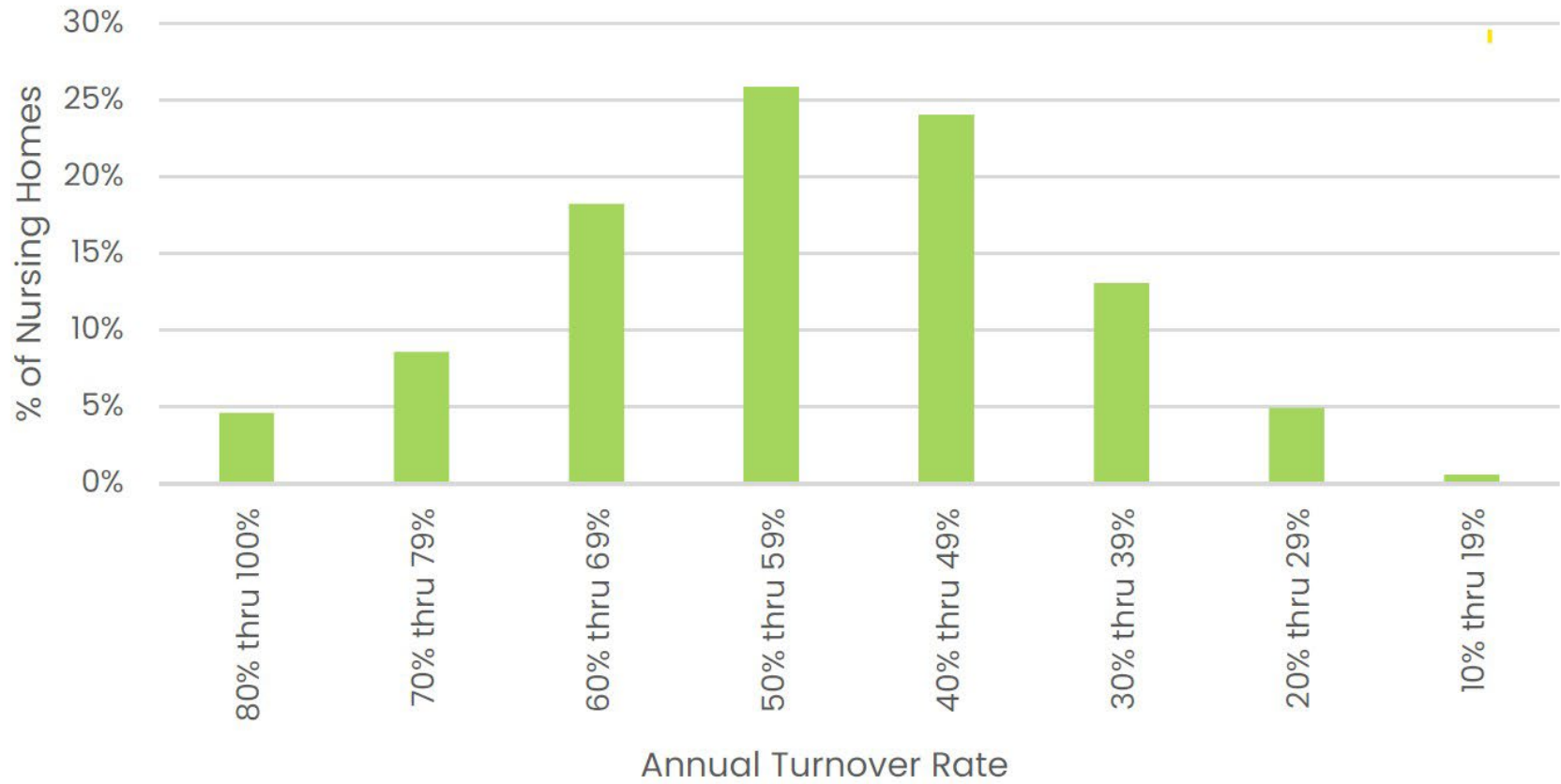
Source: Ruggles, Steven, Sarah Flood, Ronald Goeken, Josiah Grover, Erin Meyer, Jose Pacas and Matthew Sobek. 2019. *IPUMS USA: Version 9.0*. Minneapolis, MN: IPUMS, University of Minnesota. <https://doi.org/10.18128/D010.V9.0>; analysis by PHI (July 8, 2019).

Who are they?

- High school students
- Nursing students
- “Career” CNAs
- Recent immigrants
- HCPs outside the US

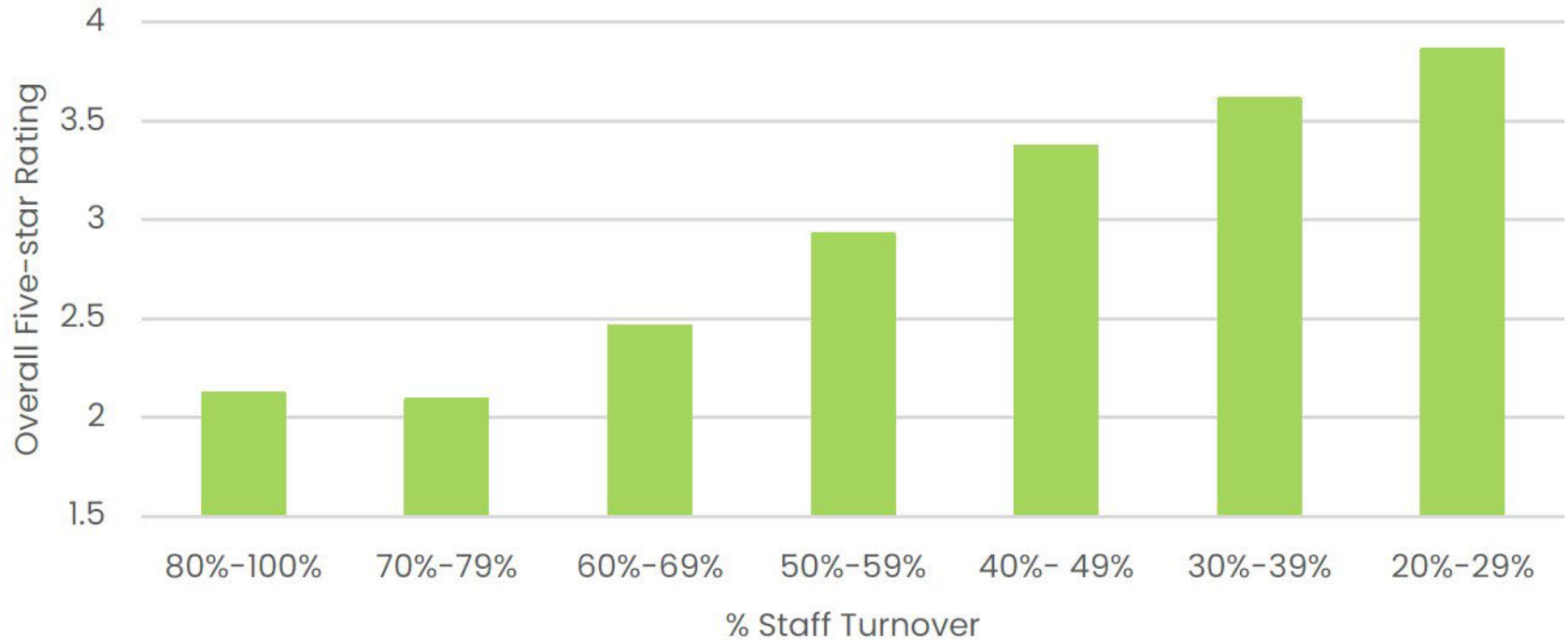
Direct care staff in LTC

Over 1/2 of Homes Replace 50% of Staff or More Per Year



Direct care staff in LTC

As Staff Turnover Decreases Overall Five-Star Ratings Increase



“For healthcare professionals, long-term NH care involves repeated emotional experiences of establishing contact, bonding, and caring, while also dealing with separation and grief.”

ADLAND, LAVIK & RAMVI (2021)

What happens when a resident dies?



Flurry of activity, noise,

Removal of the body

Removal of possessions, clothing

Reluctance to communicate the death

Informal “gossip” among staff



Maylene

A Brief Case Study:

- Process
- Effects on Residents
- Effects on Staf

Grief in NH residents

- Intrusive memories about the loss
- Avoidance and emotional numbing;
- Increased physiological arousal – irritation, anger, interrupted sleep patterns
- Inability to shift focus
- Inability to find joy in life
- Consistency in mood –the feelings are always present.
- Early intervention may interrupt the grieving process.
- Residents who experience complicated grief may benefit from grief counseling.
- Monitor health effects i.e., not eating, disrupted sleeping patterns, unusual weight loss.
- Recognize social isolation.

Helping Patients Cope with Grief, Commentary by Stephen T. Dudley, DVM, MD University of Washington School of Medicine, Seattle, Washington,
<https://www.aafp.org/pubs/afp/issues/2019/0701/p54.html>

Supporting Residents During Grief & Loss



Name: “You feel overwhelmed”



Understand: “There is so much going on, how can I help you?”



Respect: “I’m really impressed with how well you are handling everything.”



Support: “I’ll be here with you all shift.”



Explore: “What is the hardest part?”

Myths about NH staff



- Resident death is “part of the job”
- Professional boundaries prevent staff from experiencing grief
- NH staff grief is sign of enmeshment or countertransference
- Staff should appear “strong” in front of residents by not talking about the deceased.

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In reality, NH staff...

- Form strong relationships with residents over time
- Take pride in their ability to work with difficult residents
- Reminisce about former residents
- After death, continue to associate the room to the former resident
- Feel slighted if they are not informed
- Fear they have failed as professionals

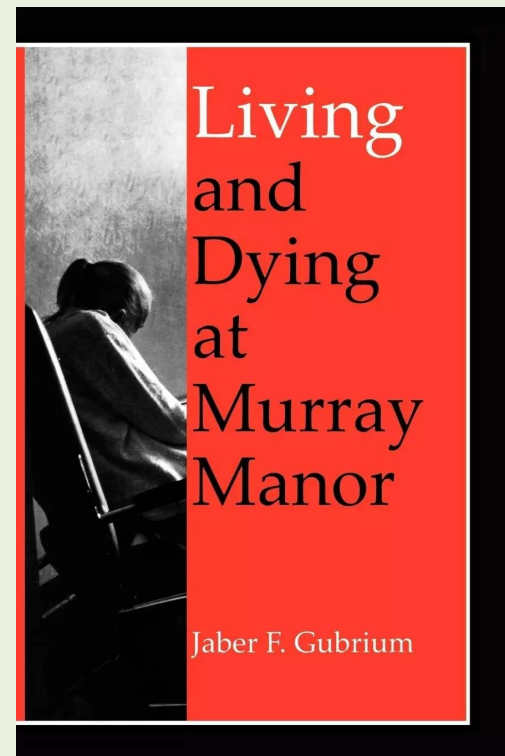
Review of research literature

Backstage vs frontstage

- Mixed communication/euphemisms
- Effect of hospice involvement
- Misconceptions about HIPAA

Superstitions/ spirituality

- Opening the window
- “they always die in 3s”
- “they’re in a better place”



Review of research literature, cont'd

Direct care staff's response to resident death depends on:

- How quickly they are notified
- How they are notified – by text? by charge nurse? by peers?
- How the body is removed
- How quickly the bed is replaced
- Whether they can talk to family members
- Whether they had opportunity to say good-bye

Review of research literature, cont'd

Direct care staff perceive conflict between distanced professionalism and the emotional relationships they develop with residents

Suppressing these feelings puts staff at risk of moral distress, compassion fatigue & burnout

Staff grief was more intense when staff-patient relationships were close, care was provided for longer, and staff felt emotionally unprepared for the death

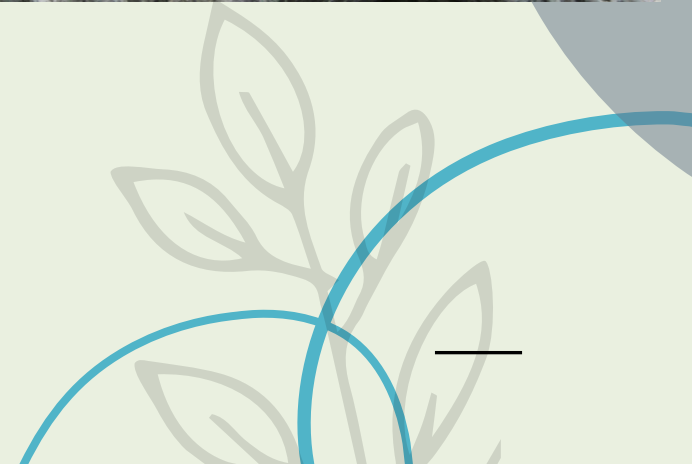
Staff felt sorrow for residents dying alone, without family, and worked to provide emotional support and comfort, particularly for residents with dementia.

“Long-term care administrators view death as something that might upset residents,” said Dr. Toni Miles, a professor of epidemiology and biostatistics at the University of Georgia. “So, when someone passes away, doors are closed and the body is wheeled discretely out the back on a gurney. It’s like that person never existed.”

Graham, J. (2018, september 4). Creating rituals to honor the dead at long-term care facilities. *KFF Health News*. <https://kffhealthnews.org/news/creating-rituals-to-honor-the-dead-at-long-term-care-facilities>

Recommendations for Practice

- Acknowledge staff expertise with residents and special relationships
- Encourage nursing management to talk with CNAs and nurses after a resident death
- Consider a notification process for staff to include part-time and PRN workers
- Be aware of potential for grief among surviving residents after a death
- Consider incorporating memorial rituals for facility and/or team





A balloon release concludes the annual bereavement ceremony at Gray Health & Rehabilitation in Gray, Ga. (Grant Blankenship for KHN)



References

- Adland, A. K., Gripsrud, B. H., Lavik, M. H., & Ramvi, E. (2022). "They stay with you": nursing home staff's emotional experiences of being in a close relationship with a resident in long-term care who died. *Journal of holistic nursing*, 40(2), 108–122. <https://doi.org/10.1177/08980101211017766>
- Barooah, A., Boerner, K., Van riesenbeck, I., & Burack, O. (2015). Nursing home practices following resident death: The experience of certified nursing assistants. *Geriatric Nursing*, 36(2), 120–125. <https://doi.org/10.1016/j.Gerinurse.2014.11.005>
- Graham, J. (2018, september 4). Creating rituals to honor the dead at long-term care facilities. *KFF Health News*. <https://kffhealthnews.org/news/creating-rituals-to-honor-the-dead-at-long-term-care-facilities>
- Gubrium, J. (1997). *Living and dying at Murray Manor*. University of Virginia Press.
- The National Consumer Voice for Quality Long-Term Care. (2022). *High staff turnover: A job quality crisis in nursing homes*.
- Oliver, D. P., Porock, D., & Oliver, D. B. (2006). Managing the secrets of dying backstage: The voices of nursing home staff. *OMEGA - Journal of Death and Dying*, 53(3), 193–207. <https://doi.org/10.2190/3p8g-5jad-j2nf-bkgk>
- Maitland, J., Brazil, K., & James-abra, B. (2012). "They don't just disappear": Acknowledging death in the long-term care setting. *Palliative & Supportive Care*, 10(4), 241–247. <https://doi.org/10.1017/s1478951511000964>
- Nasu, K., Konno, R., & Fukahori, H. (2020). End-of-life nursing care practice in long-term care settings for older adults: A qualitative systematic review. *International journal of Nursing Practice*, 26(2), e12771. <https://doi.org/10.1111/ijn.12771>
- Padilla, D. (2023, December 13). *Supporting healing from grief and loss in nursing facilities* [online]. Center of Excellence for Behavioral Health in Nursing Facilities.
- Scales, K. (2020). *It's time to care: A detailed profile of America's direct care workforce*. Phi. <https://www.Phinational.org/resource/its-time-to-care-a-detailed-profile-of-americas-direct-care-workforce/>
- Waldrop, D. P., & Nyquist, K. (2011). The transition from routine care to end-of-life care in a nursing home: Exploring staff perspectives. *Journal of the American Medical Directors Association*, 12(2), 114–120. <https://doi.org/10.1016/j.Jamda.2010.04.002>