

**CAG  
2021**

**Hindsight 20/20:**  
*Looking Back for a Vision  
Forward in Gerontology*

OCTOBER 20-23  
VIRTUAL CONFERENCE

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## ***"I want to make sure my last requests are taken seriously": The challenges of advance care planning engagement in long term care***

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# Background



ACP encourages reflection and communication about future care preferences

ACP is Person Centered & Core to Palliative Approach

ACP promising for supporting living & dying in LTC

# ACP Challenging in LTC

## Stigma

- How to bring up death when trying to support life?

## Staffing

- Limited time
- 70-90% non-regulated staff

## Prioritization of physical tasks over emotional bonds

- Little space for emotional discussions

# Purpose

Resident and Family Perspectives on

when, how, and with whom ACP discussions should be introduced

conditions that challenge and support ACP Communication



# Methods

Interpretative  
Descriptive  
Approach

7 Focus Groups  
In 4 LTC homes

35 residents  
16 families

# Residents Participants Families

- Mean age 74 (57-92)
  - 57% women
  - 85.7% **had not** talked to staff about EOL Care
- Mean age 66 (25-83)
  - 85.5% women
  - 25% adult children; 25% spouses; 25% siblings; 25% other
  - 64% **had** talked to staff about EOL

# EOL Conversations Critical but Rare

- *gives you options you never thought of (Alice FFG)*
- *Ensures there are no misunderstanding (Steven, RFG)*
- Staff must initiate because:
- 'You don't really know what you would say to staff' (Shannon, FFG)





## Relational Connections More Important than Staff Rank

*I: What staff would you have that discussion [about ACP] with?*

*Ben: Those who care.*

*Eliot: Those who care and want to try to help.*

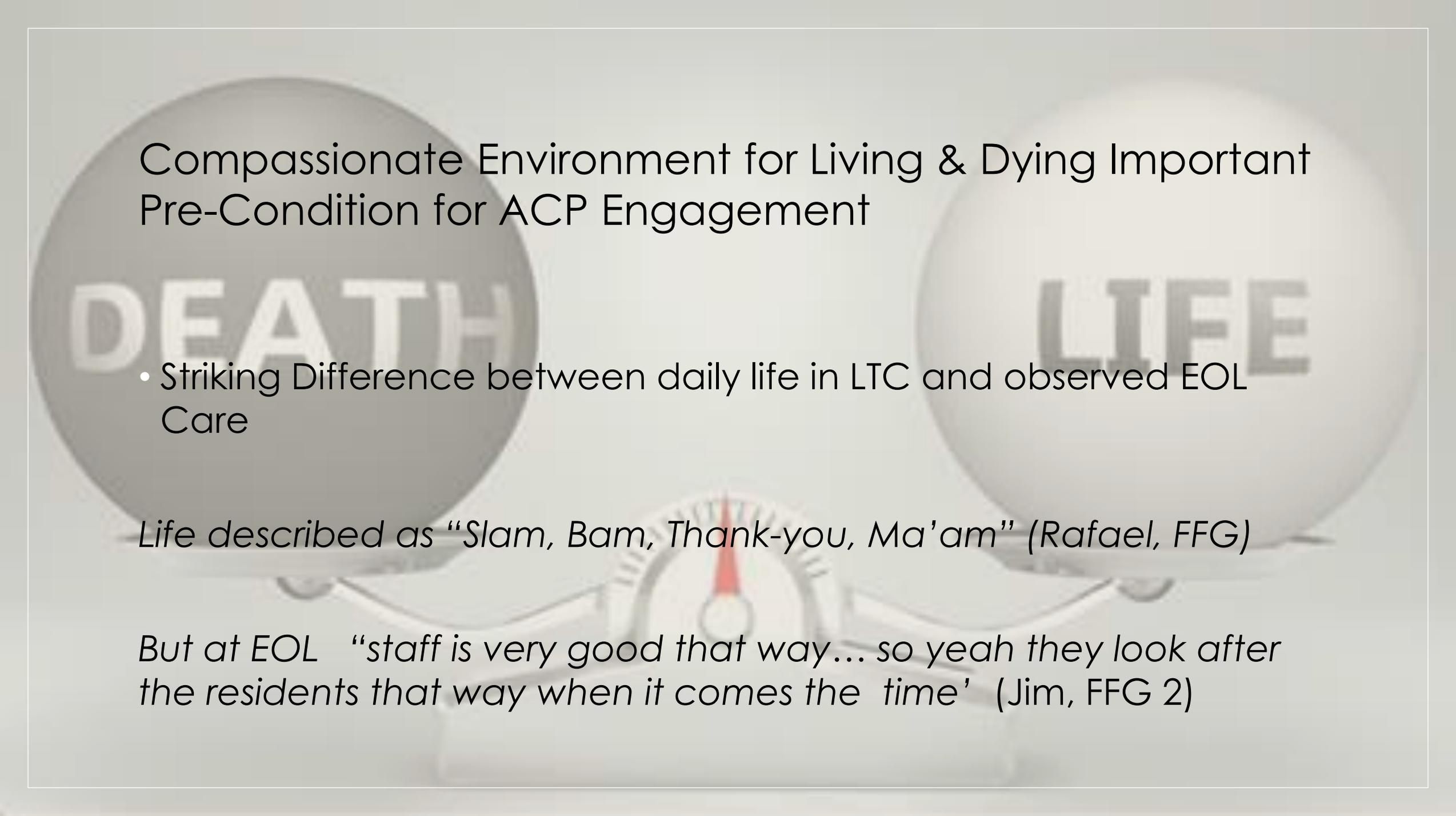
*Lillian: Not the ones who are here because it's a job. (RFG 4).*

# Key Findings: Time and Opportunities for Meaningful Connections Limited



*I had a very brief five-minute meeting in the hall at the nursing station, where they told me that 'well you know she's palliative and we're going to keep her comfortable and pain free'. That was it. [but] I would like to sit down with staff and talk about different options available... Just so they could tell me their thoughts and I could either you know agree or disagree.*

*(Shannon, FFG 2).*



## Compassionate Environment for Living & Dying Important Pre-Condition for ACP Engagement

- Striking Difference between daily life in LTC and observed EOL Care

*Life described as “Slam, Bam, Thank-you, Ma’am” (Rafael, FFG)*

*But at EOL “staff is very good that way... so yeah they look after the residents that way when it comes the time’ (Jim, FFG 2)*



# Discussion and Implications

Clarify and Create a Role for All Staff in ACP

“Grief Literary”- death and dying is everyone’s responsibility

# Discussion and Implications

- ❑ 'readiness' often described in ACP as an individual issues
- ❑ 'readiness' or lack thereof may be systemically driven

Are You  
Ready?

# Discussion and Implications

- Team huddles could compliment ACP initiatives
- Encourage teams to collectively work together
- Staffing levels need to be adequate for all staff to participate



# A Few Concluding Statements

COVID responses in LTC highlighted medicalized task-based nature of our health system

- Better to risk dying alone than to risk dying

Compassionate Care must be viewed as a priority in LTC

- Lack of compassion inhibits ACP
- Compromises quality of life/care



# THANK YOU

Sussman et al (In Press). "Slam, Bam, Thank-you, Ma'am": The Challenges of Advance Care Planning Engagement in LTC. *Canadian Journal on Aging*