

BACKGROUND

Most individuals living with dementia in the US die in long-term care (LTC) facilities. Assisted living (AL) is a major provider of LTC for this population. Hospice services are widely used by these residents at the end of life (EOL), yet little is known about the quality of hospice care in AL. This study reports findings from bereavement interviews with informal caregivers (family or friend) of residents with advanced dementia.

METHODS

Parent study: This 5-year longitudinal study investigates informal caregivers involvement in EOL care of residents with advanced dementia in 50 diverse AL communities in the state of Georgia. Our goals are to:

- Improve understanding of the relationships among caregiver involvement, caregiver health, and the quality of life of AL residents with advanced dementia at the end of life; and
- Identify potential modifiable factors at the individual, AL, and wider community levels associated with adverse outcomes.

Current study sample and data set: We conducted qualitative interviews with 43 family caregivers of recently deceased AL residents. Ranging from 23 to 128 minutes (mean 36), interviews were digitally recorded, transcribed, and analyzed using thematic analysis. Interview guides consisted of open-ended questions and two measures to contextualize the qualitative data: the Satisfaction with Care at End of Life in Dementia (SWC-EOLD) scale and the Brief Grief Questionnaire (BGQ).

RESULTS

Table 1. Descriptive Characteristics of Bereaved Family Caregivers (n=43)			
	Mean/%	SD	Min/Max
Sociodemographic Characteristics			
Mean Age	63.6	10.8	27 – 84
Female	83.7%		
White	90.7%		
Hispanic/Latino	7.0%		
Some College or Higher	90.9%		
Married/Partnered	72.1%		
Relationship with Resident			
Daughter	67.4%		
Son	9.3%		
Spouse	9.3%		
Caregiver Health, Well-Being, and Caregiving Characteristics			
Self-Rated Health ¹	4.1	1.0	1 – 5
Zarit Burden Interview (ZBI-12) ²	16.6	8.8	0 – 36
No to Mild Burden (0-10)	30.2%		
Mild to Moderate Burden (10-20)	46.5%		
High Burden (>20)	32.6%		
Brief Grief Questionnaire ³	2.7	1.8	0 – 7
SWC-EOLD ⁴	32.1	6.9	13 – 40
Dementia Knowledge Scale ⁵ (mean % correct)	72.4	10.8	52 – 95

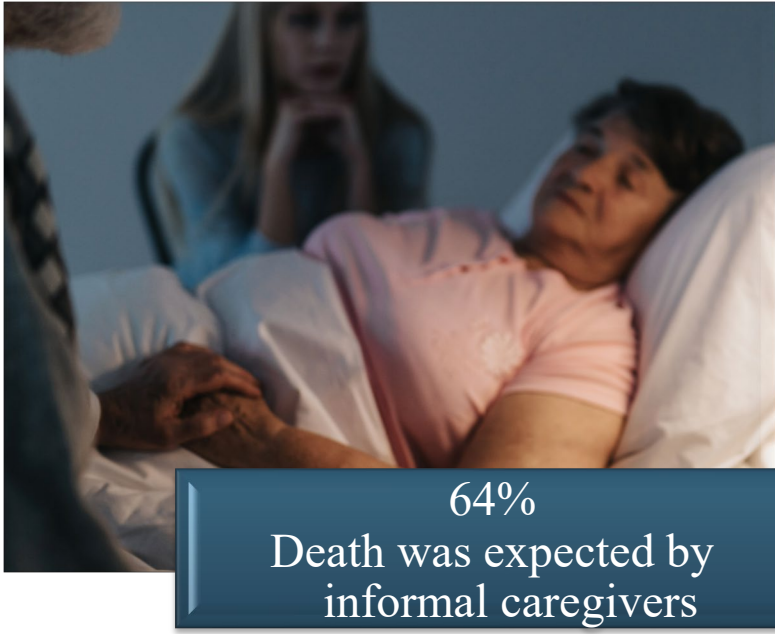
¹General Self-Reported Perceived Health (1-item); Higher scores reflect better self-rated health
²Zarit Burden Interview: Short (12-items); Total scores range from 0 to 48, with higher scores indicating greater perceived caregiving burden
³Brief Grief Questionnaire (BGQ) (5 items); Total scores range from 0 to10, with higher scores indicating greater levels of grief
⁴Satisfaction with Care at End of Life in Dementia (SWC-OLD) (10-items); Total scores range from 10 to 40, with higher scores indicating greater satisfaction with care at end of life
⁵Dementia Knowledge Assessment Tool (DKAT2) (21 items) scored out of a possible 100% with higher scores indicating greater levels of dementia knowledge

Table 2. Descriptive Characteristics of Deceased Residents (n=41) ¹			
	Mean/%	SD	Min/Max
Sociodemographic Characteristics			
Mean Age	83.6	8.7	66 – 104
Female	73.2%		
White	87.8%		
Hispanic/Latino	2.4%		
Some College or Higher	63.4%		
Married/Partnered	14.6%		
Dementia Diagnoses			
Alzheimer’s disease	31.7%		
Lewy Body dementia	2.4%		
Parkinson’s disease dementia	4.9%		
Vascular dementia	7.3%		
Frontotemporal dementia (FTD)	4.9%		
Early onset dementia	9.8%		
Other ²	12.2%		
Care Setting and Hospice Status			
Lived in Memory Care Unit	73.2%		
Under hospice care at Baseline	43.9%		
Under hospice care at Death	95.1%		

¹ The number of caregiver interviews (n=43) exceeds the number of deceased residents (n=41) because, for two residents, interviews were conducted with two caregivers rather than one
² Other types of dementia include senility, unspecified dementia, mixed Alzheimer’s disease, and vascular dementia
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RESULTS

Characteristics of the Death Experience



Qualitative Findings (Cross-Cutting Themes)

Communication Breakdowns and Fragmented Care Coordination

Lack of coordination between hospice providers and AL staff:

- Prior to [my mom] going on morphine. . . I did not feel like there was a lot of support. I think part of that was they (AL & hospice staff) were trying to be respectful and give us space. Part of it was that I did not know that [AL staff] were not allowed to administer Schedule II drugs. . . part of it was lack of communication between [AL staff] and hospice. [AL staff] didn't know if they were supposed to come in and help move [my mom]or take vital signs or stuff like that. The hospice nurse didn't know that [AL staff] couldn't administer Schedule II drugs, and [neither knew] . . . what was going on with each other.
27-year-old White daughter; 19 on SWC-EOLD

Families forced to coordinate care:

- AL [could] communicate better, and then hospice people [could] communicate better with the AL. The whole medication thing, that was all over the place. Improve the communication . . . don't expect the family member who is being traumatized anyway, that their parent is dying, and they don't really know what's going on, to have to deal with all that.
68-year-old White daughter; 38 on SWC-EOLD

Poor communication with families:

- I think [my sister-in-law] could have been more comfortable. Whatever was going on those four days before they called me, I don't think she was getting adequate end-of-life care. The call from the chaplain for this hospice [came] on the day she died, and then I said to him, ‘I didn’t know there was a chaplain.’ Then, I was told by the hospice nurse that I should have gotten a call from the head nurse who goes out to pronounce the body, and I said, ‘No. I didn’t.’ Well, [this head nurse] had the wrong phone number for me.
73-year-old White sister-in-law; 14 on SWC-EOLD

Conflicts Between Hospice Providers and AL Staff

- The hospice [nurse] had said something to the [AL staff], and she took it the wrong way. [The hospice nurse] was trying to let [the AL staff member] be aware of something. You know when somebody says something to try to give you correction, and then [that person] pops off because of the simple fact they don’t take criticism? That was exactly what happened. [The staff person] literally followed the hospice chick into [my mom’s] room. . . basically to confront the hospice nurse about something that was said. I was like, “Well, this isn’t the place. You shouldn’t be doing this in my mom’s room.”
*50-year-old White daughter
21 on SWC-EOLD*

Limited Care Continuity and Staffing Constraints

- They (hospice) had some challenges. The first one that I had, there were different people that would come every week, and it just wasn't a good experience for my mom. I just didn't feel like she was getting the care that she needed. Then the second group, they were good up until the last month, and that's when [Mom] had the ulcer on her back, and nobody told us about it. . . Then I got this other. So then there was another (third) hospice group that was referred to us by the nurse at [the assisted living].
*62-year-old White daughter
31 on SWC-EOLD*

Delayed Hospice Referrals

- At the time, I really didn’t know [someone with dementia] could be entered into hospice. It makes sense, but most people think that hospice is just for somebody at the end of life. I didn’t really have a clear view or information about hospice.
*70-year-old Black daughter
39 on SWC-EOLD*

Inadequate Symptom and Personal Care Management

- [When a person has fecal incontinence,] their bottom needs to be occasionally soaked in some warm water to get all that stuff out of there, because if they leave a little bit, it’s gonna burn your skin, and it’s gonna cause a bedsore. . . . They (hospice Certified Nursing Assistants (CNAs)) think ’cause you take a pan of water and clean him, you get it all, and then you’re gonna wonder why he has a bedsore. He had a bedsore twice. . . . They can move you. When they move you from side to side, they can wash that off.
*74-year-old Black ex-spouse
26 on SWC-EOLD*

Care Perceived as Lacking Dignity or Respect

- The only issue we had with hospice was their Certified Nursing Assistants (CNAs). There were several CNAs that were supposed to come 3 times a week and help shower [my father]. They provided him no dignity or respect. As soon as I found out about it, I would get rid of ’em. Even though he was 87 years old and even though he was slow in movement, his mind was still very active, and he felt like he was being treated like a two-year-old by those people. Not very caring. Not very understanding. Not respectful. They had to go. As soon as I would report the issue to the hospice nurse, they’d be gone.
*64-year-old White daughter
39 on SWC-EOLD*

When Hospice Works Well

- Hospice made all the difference in the world. They swooped in and they just took over all the medication, took over all the pain management, made sure that [Mom] got the perfect bed, the chair, everything she needed, [including] communication. I had a posse, from the pastor, to the social worker, to the nurse, to just—so many people that were in and out of [the assisted living community]. Of course, they took over bathing. The [AL community] does it twice a week. [Hospice] does it three times a week. I had this relief of knowing that Mom had more eyes on her. I can’t say enough positive things about the hospice organization.
*68-year-old White daughter
26 on SWC-EOLD*

CONCLUSION

Findings demonstrate significant gaps in hospice care for AL residents with advanced dementia, which negatively affect the EOL experiences of residents and caregivers. Results highlight critical areas for intervention, including, timelier hospice enrollment; improved interdisciplinary collaboration, care coordination, and continuity of care; more consistent clinical monitoring; enhanced pain and symptom control; and greater attention to dignity and respect at the end of life.