# Bereaved Next-of-Kin Narratives about Hospice Care in Assisted Living

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## Overview

- In this mixed-methods study, we interviewed bereaved next-of-kin of recently deceased residents of assisted living (AL) communities.
- We combined interviews with data from a nationally representative survey of AL administrators.
- Key motivations for enrolling in hospice in AL include meeting residents' higher care needs and preferences for dying in place.

## Aims

- Explore narratives about end-of-life (EoL) care according to bereaved next-of-kin of deceased residents from a diverse sample of AL communities.
- Stratify narratives based on AL retention policy at EoL and staffing, with a focus on narratives about hospice utilization and AL quality of care at EoL.

## Methods

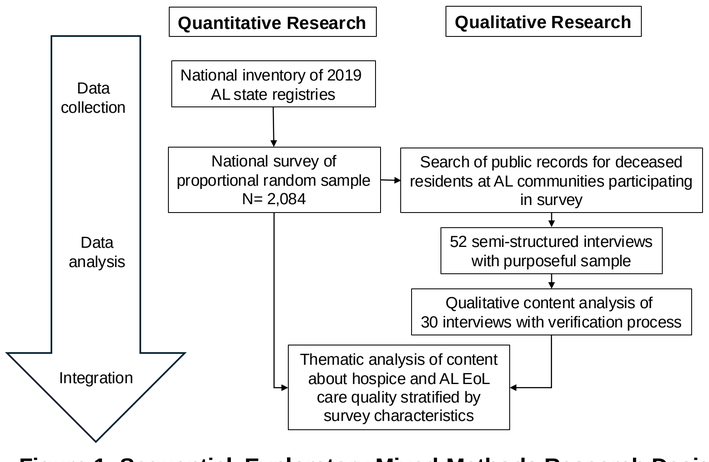


**Figure 1: Sequential, Exploratory Mixed-Methods Research Design**

## Results

"I said, 'what do you suggest,' because they were going to throw her out. And the only choice we would have would be to put her I guess, into a nursing home. And I didn't want to do that. I didn't want to move her, the people there were so nice. And so [AL] suggested maybe bringing in hospice, and I said 'okay.'"
- Next-of-kin of resident at AL with policy to retain dying residents on a case-by-case basis

"The only reason I brought hospice in was to try to take some of the pressure off the staff."
- Next-of-kin of a resident at AL with a policy to retain dying residents and no RNs/LPNs on staff

"I didn't feel that it was clear that if she didn't get [hospice], she couldn't stay there. I thought she'd be able to stay. I thought she'd be able to stay no matter what, and then finally, the nurse made it clear to me that with her twisted bowel, she would not be able to stay there."
- Next-of-kin of resident at AL with policy to retain dying residents

- Next-of-kin cited the desire for more staff attention and avoiding late transitions as key motivating factors for enrolling in hospice.
- Even in AL communities with policies to retain dying residents, net-of-kin reported receiving an ultimatum to enroll in hospice or move to a higher level of care (e.g. nursing home).
- Regardless of RN presence, hospice was elected to enhance staff access, particularly overnight.
- 96.2% of decedents in the qualitative sample resided in AL communities with policies to retain dying residents or evaluate them case-by-case.
  - The two decedents at ALs with a discharge policy were transferred before death.

**Table 1. National Distribution of EoL Retention Policies and RN Staffing**

| | | Any RN available at AL | | |
|---|---|---|---|---|
| | | Yes (%) | No (%) | Missing (%) |
| Policy at EoL | Retain | 688 (70.1) | 707 (69.0) | 13 (16.7) |
| | Case-by-case | 210 (21.4) | 218 (21.3) | 3 (3.8) |
| | Discharge or relocate | 64 (6.5) | 71 (6.9) | 1 (1.3) |
| | Missing | 19 (1.9) | 29 (2.8) | 61 (78.2) |
| | **Total** | **981** | **1025** | **78** |

## Conclusions

- Our study highlights hospice care's importance in allowing residents to die in place across AL communities with varying policies regarding end-of-life care and RN availability.
- AL community end-of-life retention policy and nursing staff availability did not align neatly with narratives about end-of-life care experiences, raising questions about the best policies to improve this care.

## References

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