End-of-life Discussion in Assisted Living Facilities
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Abstract
Discussion about end-of-life health care choices can contribute to honoring preferences or residents in assisted living facilities. Survey and focus group methodology were used to explore elder, family member, and staff perceptions about end-of-life discussion in assisted living facilities. Participant groups had different perspectives about what they viewed as important for end-of-life discussion.

Introduction
End-of-life (EOL) discussions in hospices, hospitals, and even long-term care may be too late to actively involve elders in making end-of-life decisions. As more assisted living facilities (ALFs) provide opportunities for residents to “age in place,” discussion in the assisted living setting about EOL treatment and care options will be needed in order to honor residents’ preferences when they are terminally ill. Knowing how to talk with patients and families about dying is challenging in a culture that tends to deny aging and the inevitability of death.

Method
Surveyed staff in 5 assisted living facilities on staff perceptions
Survey – modified Knowledge, Attitudinal, and Experiential Survey on Advance Directives
Focus groups with residents (3 groups), family members (2 groups, and ALF staff (2 groups)
ALF directors identified residents who had capacity for participation
Questions on conversations about end-of-life decision making and discussion
Focus groups audio taped and transcribed
Content analysis to identify themes

SURVEY RESULTS

Staff Survey (n = 32)

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<tr>
<th>Question</th>
<th>Mean</th>
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<tr>
<td>Advance directives are very important for all residents to have.</td>
<td>4.67</td>
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<td>It is important for all members of the healthcare team to uphold a resident’s wishes when they are in conflict with your own view.</td>
<td>4.59</td>
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<td>I am prepared to discuss end-of-life issues/AD with residents.</td>
<td>3.99</td>
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<td>I am usually able to answer residents’ or their families’ questions about advance directives.</td>
<td>3.66</td>
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<td>Residents have sufficient knowledge of their condition to make treatment and care decisions.</td>
<td>3.26</td>
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<td>If a resident does not have a record of an advance directive, it is the nurse’s responsibility to make the doctor aware of this.</td>
<td>3.18</td>
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<td>Sufficient time is spent with residents discussing advance directives.</td>
<td>3.06</td>
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Focus Group Themes

Residents (n = 16)
- End of life as a process
- Encounters with death and dying
- Prolonging life
- Conversations about end of life
- Making decisions
- Information needed

Family Members (n = 5)
- End of life as a process
- Care processes
- Conversations about end of life
- Making health care decisions
- Information needed (health status and care focus)

Staff Members (n = 11)
- Care coordination
- Staff roles in EOL care
- Working with family
- Conversations about end of life
- End-of-life educational needs

Discussion Points
- Although residents spoke about being ready to die, they believed that their family members were not willing to accept the residents’ readiness for death.
- Residents experienced minimal opportunities for discussing EOL health care choices. Few had discussed end-of-life treatment choices with physicians or ALF staff.
- Residents made many emphatic comments about not wanting to have life prolonged.
- Family members were much more concerned about care processes and expressed experiencing bewilderment about what to expect for prognosis and care options.
- Staff members may feel more secure with providing comfort care and are less confident about initiating end-of-life discussion.
- Residents wanted information about taking care of practical matters as well as learning about the effects of CPR and feeding tubes.
- Family members were most focused on needing information about care options as well as knowing what to expect regarding the decline of their elderly relative.
- Staff members identified a need for support groups for family members as well as education on how to support residents and families in the dying process.

Implications
The different perspectives of all involved in EOL situations should be considered when designing strategies for initiating EOL discussion in order to create a palliative care script that celebrates life but accepts a natural dying process through comfort and excellent holistic care.

Educational strategies for residents, family members, and staff will increase knowledge about what to expect at the end of life, available resources, and what can be done to support a peaceful death.

The culture of the organization must also change to embrace a palliative care philosophy.

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