

## Original Article

# Measuring End-of-Life Care and Outcomes in Residential Care/Assisted Living and Nursing Homes

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## Abstract

**Context.** The two primary residential options for older adults who require supportive care are nursing homes and residential care/assisted living. More than one-quarter of all deaths in the U.S. occur in these settings. Although the information available on end of life in long-term care has been growing, the comparative suitability of various measures to guide this work is unknown.

**Objectives.** To determine the optimal measures to assess end-of-life care and outcomes in nursing homes and residential care/assisted living.

**Methods.** A total of 264 family members of decedents from 118 settings were interviewed and provided data on 11 instruments that have been used in, but not necessarily developed for, long-term care populations; Overall, 20 scales and subscales/indices were evaluated. Measures were compared on their psychometric properties and the extent to which they discriminated among important resident, family, and setting characteristics.

**Results.** Prioritizing measures that distinguish the assessment of care from the assessment of dying, and secondarily that exhibit an acceptable factor structure, this study recommends two measures of care—the Family Perceptions of Physician—Family Caregiver Communication and the End of Life in Dementia (EOLD)-Satisfaction With Care—and two measures of outcomes—the EOLD-Symptom Management and the EOLD-Comfort Assessment in Dying. An additional measure to assess outcomes is the Mini-Suffering State Examination (MSSE). The care measures and the MSSE are especially valuable as they discriminate between decedents who were and were not transferred immediately before death, an important outcome, and whether the family expected the death, a useful target for intervention.

**Conclusion.** Despite these recommendations, measurement selection should be informed not only on the basis of psychometric properties but also by specific clinical and research needs. The data in this manuscript will help researchers, clinicians, and administrators understand the implications of choosing various measures for their work. *J Pain Symptom Manage* 2015;49:666–679. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

## Key Words

*Measurement, end of life, long-term care, residential care/assisted living, nursing home, death, dying*

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## Introduction

The number of deaths in long-term care settings has been rising, not only because of the increasing number of older adults but also because of the increasing

number of long-term care options. Today, 1.5 million older adults live in nursing homes, which evidence an annual mortality rate of 34% among residents in their first year after admission and 24% for residents with a length of stay beyond one year.<sup>1,2</sup> Another 733,300

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older adults live in residential care/assisted living communities (referred to as “assisted living” in this article).<sup>3</sup> These supportive environments provide room, board, assistance with activities of daily living, and 24 hour oversight, and exhibit annual resident mortality rates between 14% and 22%.<sup>4,5</sup> In total, although only 5% of the older adults reside in long-term care settings, more than one-quarter will die there.<sup>6,7</sup>

End-of-life care and dying differ in long-term care populations from other decedent populations in at least three important areas. First, 75% of long-term care decedents are cognitively impaired preceding death.<sup>8</sup> In fact, most (67%) older Americans whose underlying cause of death is attributable to dementia die in nursing homes.<sup>9</sup> Consequently, considerations as to what constitutes quality end-of-life care and a “good” dying experience in long-term care must take into account the cognitive status of the individual. Second, because people enter long-term care for a variety of reasons, they exhibit a range of chronic and acute illnesses; thus, the causes of death in this population are diverse. Depending on the setting, 14–31% of the residents die from heart disease, 14–18% from pneumonia, 6–13% from cancer, and 6–11% from Alzheimer disease.<sup>10</sup> Third, many of these individuals have been residing in the same setting in which they receive end-of-life care; therefore, what constitutes quality care and a good dying experience may well reflect components of the setting in which they lived, such as interpersonal care, the environment, and the role of family caregivers. Given these special considerations, what constitutes a “quality” dying experience may well be different in long-term care settings than it is for those dying at home or in acute care hospitals.

It is important to examine the quality of end-of-life care and the dying experience in long-term care settings because recent reports indicate numerous areas needing attention. For example, in their last month of life, 47–48% of long-term care decedents had pain and dyspnea, but staff and families rated the treatment they received as very effective for only one-half of these individuals.<sup>11</sup> Non-white residents were less likely to have completed a living will,<sup>12</sup> and although only a small proportion of decedents received resuscitation, 71% of those who did received it against their earlier health care decision.<sup>13</sup> In terms of communication with physicians, almost one-half of the families disagreed that they were kept informed (40%), received information about what to expect (50%), or understood the doctor (43%).<sup>14</sup>

Thus, in consideration of the number of individuals who are now dying and will die in long-term care settings in the future, the setting-specific nature of these

decedents and the care they receive, and ongoing concerns about care and outcomes, there is need for valid and reliable measures to assess end-of-life care and dying in long-term care. Although numerous publicly available measures have been used to assess care and dying in long-term care, not all of these measures were developed in these samples and, in fact, the development of only two measures has included significant representation of assisted living residents.<sup>8,14</sup> Furthermore, existing measures differ in their stated purpose, whether they have been used prospectively (pre-death) or retrospectively (post-death), whether the primary respondent is a patient, family member, professional caregiver, or other clinician, and the extent to which they assess care, outcomes, or both.<sup>15</sup> In sum, there is no detailed comparative psychometric information to guide the choice of measures to assess end-of-life care and outcomes in long-term care.

To determine the optimal measures to assess end-of-life care and outcomes in nursing homes and assisted living, this study evaluated 11 different instruments and their component scales/indices that have been used in, but not necessarily developed for, studies of care and dying in long-term care; overall, 20 scales and subscales/indices were evaluated. Measures were compared in terms of their psychometric properties as well as the extent to which they discriminated among important resident, family, and setting characteristics. Family members were selected as respondents, recognizing that most long-term care residents are unable to report at the end of life<sup>8</sup> and have an involved family member.<sup>16</sup> All measures were administered retrospectively so as to include respondents for whom the death was not expected.

## Methods

### *Nursing Home and Assisted Living Community Recruitment*

Long-term care communities were randomly selected from those participating in the Collaborative Studies of Long-term Care, a long-standing, multi-state, stratified random sample consortium of long-term care communities that is routinely refreshed.<sup>17</sup> To achieve diversity in the sample, nursing homes and assisted living communities were stratified by state (Florida, Maryland, North Carolina, and New Jersey), and assisted living communities were additionally stratified by size (<16 beds and  $\geq$ 16 beds, a cutpoint that has been shown to reflect setting differences).<sup>4,17</sup>

### *Decedent Identification and Family Recruitment*

Up to three eligible decedents per setting were identified via monthly telephone calls to a liaison in each community. Eligible decedents were those

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