

Introduction: Dementia Care and Quality of Life in Assisted Living and Nursing Homes

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It is well recognized that the number of older adults who suffer from dementia has been increasing and will continue to do so over the coming years. In fact, nothing short of a three-fold rise in the number of people with Alzheimer's disease is expected to occur between 2000 and 2050, and those with moderate or severe disease may number as many as 6.5 million midway through the century (Sloane et al., 2002). As the severity of dementia increases, families face challenging caregiving demands, and many find residential long-term care to be the best option for ongoing oversight. Historically, nursing homes have been the primary setting for the institutional care of older adults. During the last decade, however, their prominence in providing care for individuals who do not need medical services has been challenged by the growth of residential care/assisted living (RC/AL)—facilities or discrete portions of facilities that are licensed by the states at a nonnursing home level of care, and provide room, board, 24-hour oversight, and assistance with activities of daily living. Recent estimates indicate that 23% to 42% of RC/AL residents have moderate or severe dementia, as do more than 50% of nursing home residents (Zimmerman et al., 2003). The number of RC/AL and nursing home beds exceeds 800,000 and 1.8 million, respectively (Institute on Medicine, 2001), suggesting that well more than 1 million individuals with dementia already reside in these settings.

The matter of "quality" of life for individuals with dementia has been increasingly recognized during the last decade, and countless textbooks and manuals have been written to provide guidance on enhancing quality of life (see, for example, Fazio, Seman, & Stansell, 1999; Kovach, 1996; Volicer &

Bloom-Charette, 1999). Efforts to define and measure this multidimensional component have progressed as well, and there now exist numerous valid and reliable instruments to do so (see, for example, Albert & Logsdon, 2000). What has been absent from the field is the study of quality of life for individuals with dementia in long-term care settings—both nursing homes and RC/AL facilities. Without this information, it has not been possible to evaluate components of care that relate to better quality of life. In this context, the work conducted by the Collaborative Studies of Long-Term Care (CS-LTC) constitutes a significant contribution to what is known about quality of life and its correlates in long-term care. Another contribution of the work conducted by the CS-LTC is its basis in community-based participatory research, which maximizes its utility for practice and policy. As detailed in the following "Perspectives of the Alzheimer's Association," the Association is using this information as the basis for its evidence-based consumer education, advocacy, and staff training efforts. Thus, the work presented in this issue is a necessary step toward the improvement of care and the quality of life for persons with dementia.

The Collaborative Studies of Long-Term Care

The CS-LTC, initiated in 1997, is a series of multistate projects that have studied almost 5,000 residents in more than 350 RC/AL facilities and nursing homes, with the goal of better understanding issues related to quality of life and quality of care. The CS-LTC was initiated in response to the proliferation of RC/AL facilities, to address the paucity of information regarding the needs of their residents and the care that they receive, especially in light of the great diversity among these facilities. A detailed overview of the structure and process of RC/AL, obtained through the CS-LTC, is available elsewhere (Zimmerman et al., 2003; Zimmerman, Sloane, & Eckert, 2001).

The Dementia Care study reported in this issue is one of the CS-LTC projects, which collected data

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from 421 residents in 45 facilities across Florida, Maryland, New Jersey, and North Carolina between 2001 and 2003. These four states were selected because they exhibit differences in the structure and financing of RC/AL and nursing home care. A multilevel sampling frame was used to select facilities and residents for participation. Within each state, a region of contiguous counties was identified that represent the state, and a sampling frame was constructed consisting of all nursing homes and licensed facilities within each region. RC/AL facilities were stratified into three types to assure inclusion of the broad range of options: (a) facilities with < 16 beds; (b) facilities with \geq 16 beds of the “new-model” type that offer add-on services, cater to a more impaired population, and/or provide nursing care; and (c) “traditional” facilities with \geq 16 beds, not meeting new-model criteria. Sampling all three types of facilities assured broad representation of facilities and variability in resident case-mix, policy, and care provision.

The Dementia Care project was based on a purposive stratified sample of 45 facilities, 33 of which were already participating in the CS-LTC and were known to have variability in some components of dementia care (e.g., acceptance of behavioral symptoms). The Alzheimer’s Association identified an additional 12 facilities that incorporated features of particular interest (e.g., did or did not have responsive owners, a special care unit, individualized care, daily programming, staff training, and/or select environmental features). Within facilities, the primary criteria for selecting resident study participants were being aged 65 or older and having a diagnosis of dementia; for purposes of efficiency, facilities with fewer than 2 eligible residents (in facilities with fewer than 16 beds) or 13 eligible residents (in all other facilities) were excluded from the study. Eligible facilities were enrolled in a manner that maintained stratification of facility type across states. Twenty-two facilities (33%) refused to participate, but they did not differ from participating facilities with respect to type, size, or location. The final sample included 14 facilities (31%) with fewer than 16 beds, 11 (24%) traditional facilities, 10 (22%) new-model facilities, and 10 (22%) nursing homes. Twelve facilities were from North Carolina, and all other states had 11 facilities.

Residents were randomly selected in each facility from among those 65 years of age or older who had a diagnosis of dementia, excluding those who had a primary diagnosis of Huntington’s disease, alcohol-related dementia, schizophrenia, manic-depressive disorder, or mental retardation. To maintain representation across facility type, a maximum of 4 residents per smaller facility and 19 per larger facility was established. A total of 575 eligible residents or their families were approached for consent. Of these, 421 (73%) agreed to participate, 66 (11%) refused, and 88 (15%) were unable to provide consent and had family who were unreachable.

Data collection from residents and staff was conducted on-site, and family members were contacted by telephone. Interviews were conducted with each resident; his or her family member; the direct care provider who provided the most hands-on care and knew the most about the resident’s care, health, mood, and daily activities; the supervisor (the staff member above the direct care provider level who knew the most about the resident); and the facility administrator (to obtain facility-level data). Additionally, data collectors observed residents during one meal, and during the course of a single day at 5-min intervals during three 1-hr observation periods; also, the physical environment of each facility was observed.

The design of the Dementia Care project allowed a comparatively modest number of residents and facilities to be sampled; consequently, the study’s power to detect some associations is limited. However, the sample included facilities with large proportions of residents with dementia (the average reported percent of residents with a diagnosis of dementia was 55% to 57%) and a relatively high proportion of facilities with Alzheimer’s special care units (54%). Thus, while findings related to the prevalence of resident and facility characteristics are not meant to be generalizable to all facilities or nursing homes, the study may well represent dementia care as it is currently being practiced. Further, although the number of facilities and residents sampled was necessarily limited, the patterns of associations found in this study are not expected to differ dramatically in other facilities.

Organization of the Special Issue

This special issue includes 16 manuscripts, grouped within four headings. Not all are derived from the CS-LTC Dementia Care study. The first four manuscripts address conceptualization, measurement, and correlates of resident quality of life, and include articles focusing on a single quality-of-life measure (Brooker; Samus et al.) and comparing multiple measures (Edelman, Fulton, Kuhn, & Chang; Sloane, Zimmerman, Williams, et al.). They discuss the different perspectives of what components constitute aggregate quality of life and the measures and methods of data collection that arose from these concepts. Because of these differences, correlations between measures are moderate at best, suggesting that multiple indicators are needed to adequately reflect the richness of life.

The next six articles are brief reports from the CS-LTC Dementia Care study, focusing on discrete domains of quality of life. Recognizing that aggregate measures of quality of life do not easily translate to practice recommendations, a liaison panel convened by the Alzheimer’s Association suggested focused attention to six critical areas—depression, behavioral symptoms, mobility, pain, food and fluid intake, and activity involvement—each of which is

the topic of a brief report. All reports are constructed with a similar format, addressing the prevalence of problems within the domain, methods for assessing and treating residents in the domain, and staff training in the domain. Associations between domain attributes and resident and facility characteristics also are reported. The findings clearly demonstrate room for improved outcomes in these critical areas: between 50% and 60% of residents with dementia display behavioral symptoms and low food and fluid intake, 20% to 25% exhibit depression or pain, and 14% have high mobility limitations. Staff assessment and perception of impairment is highest for behavior, but lowest for fluid intake, and perceived success of treatment is highest for pain management. Between 50% and 75% of administrators report training the majority of their staff in all domains of care, and more than 75% of staff feel adequately trained to assess and treat each domain. Based in part on the findings of these studies, the Association has focused its first set of practice recommendations on pain, food and fluid intake, and activity involvement, and recommendations in other areas are forthcoming (Alzheimer's Association, 2005).

The next four articles are special topics related to quality of life and quality of care. The first three use data from the CS-LTC Dementia Care study, addressing two important contributors to quality of life in RC/AL facilities and nursing homes: families and staff. The first discusses how families fill care provision gaps, concluding that they tailor their involvement in accordance with the needs of the resident and the setting (Port et al.). The second two (Zimmerman, Williams, et al.; Winzelberg, Williams, Preisser, Zimmerman, & Sloane) address staff attitudes, stress, and satisfaction, with findings indicating that person-centered attitudes and more staff training relate to higher quality-of-life ratings and worker satisfaction. The fourth is an ethnographic study, examining issues that relate to transitions into, out of, and within RC/AL, for residents with dementia (Mead, Eckert, Zimmerman, & Schumacher).

Two additional studies specifically address the relationship of care to quality of life and resident outcomes. The first is based on a larger CS-LTC study of 1,252 participants, and compares outcomes for residents with dementia in RC/AL facilities and nursing homes, examining mortality, hospitalization, morbidity, and change in functional status over one year. With the exception of residents with major medical needs, outcomes did not differ significantly

across the two types of settings (Sloane, Zimmerman, Gruber-Baldini, et al.). The second article is a comprehensive examination of structural and process elements of care in the CS-LTC Dementia Care study and how they relate to 11 measures of quality of life, including change in quality of life over 6 months. Findings from this study have important implications for staffing and facility policies and practices, including staff attitudes and training (Zimmerman, Sloane, Williams, et al.).

Research in quality-of-life assessment and care in RC/AL and nursing homes is in its infancy. Sample size limitations in the work presented in this issue restrict the ability to conduct complex model testing, and the cross-sectional nature of much of the data limits the ability to draw causal inferences. Ideally, larger and longitudinal studies will be conducted across the range of long-term care settings such as those included in this issue, using admissions cohorts and monitoring quality of life and determining the components of care that relate to quality of life from the moment their influence begins. As will become clear through the information presented in the articles to follow, such an undertaking will require multiple measures; further, it should be conducted in close collaboration with community partners who can advise on the practicalities of care provision and help assure that resulting information can be used to improve practice and policy. Given the increasing numbers of individuals with dementia who reside in assisted living and nursing homes, the importance of this effort cannot be overstated.

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