

Dementia Care and Quality of Life in Assisted Living and Nursing Homes: Perspectives of the Alzheimer's Association

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In funding the Collaborative Studies of Long-Term Care (CS-LTC) Dementia Care study that is the basis for most of the articles in this special issue of *The Gerontologist*, the Alzheimer's Association hoped to learn more about measuring quality of life in people with Alzheimer's disease and other dementias. The Association also hoped to learn about care practices and other factors associated with quality of life to support our efforts to develop guidelines for dementia care in assisted living and nursing homes. The study findings, as reported in this issue, exceeded our expectations. The inclusion of findings on the same topics from studies funded by the National Institute on Aging, Mather Institute on Aging, and others adds to the value of the special issue, making it a source of important new knowledge about Alzheimer's and dementia care.

The CS-LTC Dementia Care study involved several firsts for the Alzheimer's Association. In 2000, after the Association's Medical and Scientific Advisory Board decided to fund Dr. Sheryl Zimmerman's investigator-initiated proposal for a study of quality dementia care in assisted living, another Association division, the Program and Community Services Division, decided to add substantial funding to expand the scope of the study. This was the first time in the history of the Alzheimer's Association that a part of the organization other than the research grants program chose to fund a team of researchers.

In another first, we asked Dr. Zimmerman if her research team would be willing to accommodate a liaison panel, a group of Alzheimer's Association chapter staff and national board members that we thought would increase our understanding of the

study and its implications for policy and practice. The research team was willing and actually gave us much more than we requested. The liaison panel participated in three 2-day meetings with the research team and helped to identify areas of care for special attention in the study and the later analysis of its findings. Having the liaison panel required a commitment of time and resources from the panel members, the research team, and national Association staff. From our perspective, the time and resources were well spent.

Measuring quality of life in people with dementia is difficult and, in fact, is usually not done. The CS-LTC Dementia Care study tested many ways of measuring quality of life. Residents with dementia who were thought to be able to respond (those with Mini-Mental State Exam [MMSE] scores of 10 or higher) were asked about various aspects of their quality of life. Nursing home staff members and family members were interviewed, and several observational methods were used. The Association was particularly interested in Dementia Care Mapping (DCM) and provided additional funding to include DCM as one of the observational methods.

Findings from the CS-LTC Dementia Care study show that conclusions about residents' quality of life differ significantly, depending on who is asked and what instruments and procedures are used. The study by Edelman, Fulton, Kuhn, and Chang (2005, this issue) had similar findings, using many of the same instruments and procedures. These findings indicate that there is no single, quick, and easy way to measure quality of life in these residents, whether for research, staff training, quality improvement, or quality monitoring purposes. Both research teams conclude that different instruments and procedures are probably measuring different perspectives and realities and that a combination of approaches is needed to get a full picture of residents' quality of life.

The findings from these two studies and the comprehensive review of DCM by Brooker (2005, this issue) add greatly to current knowledge about

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measuring quality of life in people with dementia. More research is needed. In the meantime, it should be noted that people with quite advanced dementia were able to respond consistently to quality-of-life questions in both the CS-LTC Dementia Care and Edelman studies. We believe resident responses are very important and that resident interviews should be included in future research and quality-improvement initiatives.

For the CS-LTC Dementia Care study, the research team and liaison panel identified six areas of care for special attention: depression, behavioral symptoms, pain, food and fluid intake, activity involvement, and mobility. The way the research team looked at these areas of care—by measuring (a) the proportion of residents who had problems in each area, (b) whether and how these problems had been assessed by facility staff, (c) how the problems were treated, (d) how staff perceived the outcomes of treatment, and (e) how they perceived their own training, knowledge, and skills in each area—was particularly appropriate and valuable for generating practice and policy implications. The study findings helped inform the selection process of the care areas to focus on first in our *Campaign for Quality in Residential Care*. More importantly, the study served as the impetus for the Alzheimer's Association to lead the Campaign that involved key stakeholders, care experts, our chapter network, and consumers in the development of dementia care practice recommendations that will serve as the basis for advocacy efforts, staff training, and consumer education.

The Alzheimer's Association asked Dr. Zimmerman and her colleagues to expand the CS-LTC Dementia Care study to include nursing homes as well as assisted living facilities because we thought findings from the two settings would be quite different. In fact, the study found surprisingly few differences across settings in resident and staff characteristics and clinical outcomes of care. This finding is important for policy purposes, for example, for the development and revision of government regulations intended to ensure that assisted living facilities and nursing homes are capable of meeting their residents' service needs.

Despite the general finding of few differences between assisted living and nursing homes, two articles in this issue identify specific differences we think are important for anyone who is trying to choose the most appropriate residential care setting for a person with dementia. One article (Sloane, Zimmerman, Gruber-Baldini, et al., 2005, this issue) points out that hospitalization rates were higher for residents with mild dementia in assisted living versus nursing homes; the researchers suggest that assisted living facilities may have more difficulty than nursing homes taking care of a person with dementia who has substantial and/or unstable medical or nursing needs.

A second article (Port et al., 2005, this issue) points out that families of assisted living residents with

dementia had higher self-reported burden than families of nursing home residents with dementia. The researchers note that assisted living facilities generally offer greater independence but less physical care and protective oversight than nursing homes; they hypothesize that the higher burden may result from additional help provided by these families in order to obtain the benefits of greater independence for their relative with dementia. And further, that the additional help provided by families may account in part for the lack of significant differences in clinical outcomes for assisted living and nursing home residents.

Findings from an ethnographic study of decisions to retain or transfer residents with dementia in three assisted living facilities also show the importance of additional help provided by families (Mead, Eckert, Zimmerman, & Schumacher, 2005, this issue). Like the study by Sloane, Zimmerman, Gruber-Baldini, and colleagues (2005, this issue), this study found that discharges from assisted living facilities resulted more often from residents' non-dementia-related health crises than from any increased cognitive impairment, behavioral symptoms, or care needs. These findings help to explain the high proportion of assisted living residents who have severe cognitive and other impairments, despite facility retention and transfer policies that would seem to require that they be discharged.

The CS-LTC Dementia Care study resulted in a complex array of findings about associations between staff attitudes, staff training, care practices, and staff and resident perceptions of residents' quality of life. Some that seem important to us are:

1. The association between better resident perceptions about their own quality of life and greater staff involvement in care planning (Zimmerman, Sloane, et al., 2005, this issue);
2. The association between better nursing assistants' perceptions of residents' quality of life, the nursing assistants' positive attitudes about person-centered care, and their positive evaluations of the adequacy of their training about dementia care (Winzelberg, Williams, Preisser, Zimmerman, & Sloane, 2005, this issue); and
3. The association between staff members' confidence in their ability to provide good dementia care, positive attitudes about person-centered care, and higher self-reported job satisfaction (Zimmerman, Williams, et al., 2005, this issue).

As noted by the researchers, the cross-sectional nature of the data that underlie these and other findings from the CS-LTC Dementia Care study means that the direction of the associations is not certain, and some of the findings may be most useful for generating hypotheses for future research. The only longitudinal component of the study, which measured change in staff perceptions of residents' quality of life during a 6-month period, found less decline in quality of life for facilities that had more

staff training centered around the six areas of care and more frequent activities and staff encouragement of resident participation in activities (Zimmerman, Sloane, et al., 2005, this issue).

Many other findings from the research reported in this issue strike us as important for dementia care. These findings include:

1. The association between resident depression and behavioral symptoms, that depression was detected in only half the residents where it was present, and that nursing home residents were more likely to be treated by a mental health professional and reside in facilities that include mental health professionals in formal care planning (Gruber-Baldini et al., and Boustani et al., 2005, this issue);
2. The relatively modest level of agreement between residents and supervisors about whether the resident had pain, and the finding that one third of residents with pain were not receiving any treatment for it (Williams, Zimmerman, Sloane, & Reed, 2005, this issue);
3. The finding that residents who had meals in public dining areas (rather than in their own rooms) and residents who had meals in dining areas with more noninstitutional features were less likely to have low food and fluid intake (Reed, Zimmerman, Sloane, Williams, & Boustani, 2005, this issue);
4. The association between mobility limitations and low fluid intake (S. Williams et al., 2005, this issue);
5. The association between grooming and staff and residents' perception of the residents' quality of life (Zimmerman, Sloane, et al. 2005, this issue); and
6. The association between greater involvement of

families and greater resident participation in activities (Dobbs et al., 2005, this issue).

Other readers will certainly note other findings that strike them as important for care as well as research and policy.

We hope this issue of *The Gerontologist* will stimulate future research and public and private initiatives to improve quality of care. We are grateful to Dr. Zimmerman, Dr. Sloane, the research team for the CS-LTC Dementia Care study, and the other researchers who have contributed findings from their studies to this special issue. We also are grateful to our guest editor, Dr. Richard Schulz, for his time, diligence, and insight in bringing the special issue to fruition.

The Alzheimer's Association welcomes proposals for future studies on these topics. We hope other funders also will solicit and fund such proposals. More than half of all nursing home residents and substantial proportions of assisted living residents—a million people or more at any one time—have Alzheimer's disease or other dementias. Research to improve care and outcomes for residents with these conditions is clearly important.

The Alzheimer's Association will continue to advocate for improvements in care for assisted living and nursing home residents with dementia based on the best available evidence. We appreciate the many organizations and individuals that have worked with us thus far to produce and disseminate completed guidelines and training programs. We urge others to join our ongoing efforts to develop new guidelines, revise existing guidelines as new knowledge becomes available, and disseminate existing information and training to improve quality of care.