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Geoffrey Tremont, PhD, is Director of Neuropsychology, Rhode Island Hospital, and Assistant Professor of Psychiatry, The Warren Alpert Medical School of Brown University.

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#### CORRESPONDENCE

Geoffrey Tremont, PhD  
Rhode Island Hospital  
593 Eddy Street  
Providence, RI 02903  
Phone: (401) 444-4500  
e-mail: gtremont@lifespan.org

## Family and Professional Caregiving of Individuals with Dementia in Long-term Care

Jennifer Duncan Davis, PhD, and Alicia J. Curtin, PhD, GNP-BC

More than 5 million people in the United States suffer from Alzheimer's disease or related dementias; the majority are over 65. In Rhode Island, more than 24,000 individuals are currently diagnosed with dementia.<sup>1</sup> Although family members initially care for most patients at home, many patients eventually require **long-term care (LTC)**. In Rhode Island, 45.4% of the approximately 8,000 residents in LTC have a diagnosis of dementia.

This review describes the health effects on both family and professional caregivers in the LTC setting, including some empirically supported interventions for family and professional caregivers.

### FAMILY CAREGIVER ROLE AFTER PLACEMENT

After relatives enter LTC, many caregivers will perform similar tasks as they did when their relative lived at home; this may include basic activities, like eating and dressing, although nursing home staff will be providing care round-the-clock. The majority of families continue to manage finances, complete errands, and provide transportation to appointments. While family members can play an essential role in caregiving, and regular visitation has been associated with increased staff

satisfaction,<sup>2</sup> it is important to balance the care provided by the family and that provided by the nursing home staff, to minimize stress for both parties.

### FAMILY CAREGIVER BURDEN FOLLOWING PLACEMENT

Many caregivers experience an initial sense of relief following placement, but longitudinal studies suggest that many caregivers experience new stresses and challenges as they cope with placement.<sup>3</sup> This can lead to persistent emotional burden and depressive symptoms in the caregivers, in part because they must re-adjust their expectations about care and collaborate with staff. On average, dementia caregivers will have provided home care for five years prior to placement, and at the time of placement may view themselves as experts in their family member's care. Consequently, successful renegotiation of their role following placement is vital to healthy adaptation.<sup>4</sup> In fact, the quality of the family-staff relationship is associated with important caregiver mental health outcomes, including depression<sup>5</sup> and burnout.<sup>6</sup>

In addition to role adjustment, dementia caregivers report guilt about the decision to place, perceived failure

as a caregiver, concern about worsening cognitive and behavioral problems in their family member, financial challenges, and family conflict about the family member's care.<sup>7</sup> Post-placement stress appears particularly heightened for spouses, caregivers who visit more frequently, and caregivers who are less satisfied with the help they receive from others.<sup>8</sup> Similarly, older caregiver age, poor physical health, and low income are significant predictors of caregiver depression following placement, regardless of whether the individual has a diagnosis of dementia; burden is even greater if the person has cognitive impairment.<sup>9</sup> As would be expected, pre-placement levels of depression and burden appear to be risk factors for poor adjustment as caregivers may have limited coping resources at that time to adjust to placement and may be particularly vulnerable to the new stressors.<sup>10</sup>

### INTERVENTION PROGRAMS: CAREGIVERS

Most nursing homes in Rhode Island have support programs for the residents, but only a small minority offer support groups for family members.<sup>11</sup> Similar trends exist nation wide.<sup>1</sup> Though caregiving support groups may be of value, there

are no empirically validated intervention programs available for caregivers at risk for depression. Receiving counseling prior to placement may serve as a buffer, because caregivers who received counseling showed fewer depressive symptoms and lower levels of burden following placement compared to those who received no intervention.<sup>12</sup> One in-nursing-home intervention, the Family Intervention Education Program, has shown positive outcomes in patient mood and behavior and caregiver communication with the patient.<sup>13</sup> In addition, our group at Rhode Island Hospital developed a psychosocial intervention delivered entirely by telephone, **Family Intervention: Telephone Tracking – Nursing Home (FITT-NH)** to facilitate dementia caregiver adjustment early in the placement process. Caregivers who received FITT-NH showed a significant reduction in feelings of guilt related to placement and reported more positive perceptions of interactions with staff compared to a non-contact control group.<sup>14</sup>

### **PROFESSIONAL CAREGIVING IN LONG-TERM CARE SETTINGS**

In the LTC setting, **certified nursing assistants (CNAs)** provide most of the daily care. Turnover rates among CNAs are the highest, compared with **registered nurses (RNs)** and **licensed practical nurses (LPNs)**. This turnover impairs quality of care. Although caregiver burden has been studied extensively in family caregivers, there are limited studies exploring caregiver burden and distress among professional staff in LTC settings.

Professional caregivers spend approximately 40% of their time managing disruptive behaviors while providing complex physical care to residents with dementia.<sup>15</sup> Residents with more behavioral symptoms create more distress for nursing staff. However, when compared to family caregivers, the overall stress level of professional staff is lower.<sup>16</sup> Meeting the expectations of residents' family members often leads to role conflict and ambiguity. Often administrative support is limited regarding how best to develop and maintain trusting relationships and open communication.<sup>5</sup>

The concept of burnout has been used to describe a syndrome of emotional exhaustion, depersonalization

and reduced personal accomplishment occurring in persons who provide direct patient care.<sup>17</sup> Evers, Tomic and Brouwers<sup>18</sup> demonstrated that residents' aggressive behavior and the number of hours worked weekly were positively correlated with emotional exhaustion among staff in long term care. In Abrahamson's et al research,<sup>5</sup> nursing home staff's burnout and low job satisfaction were related to conflict with family members. Often nursing home staff experienced conflict when they attempted to meet the expectations of family members within a system that often values efficiency, uniformity, and cost containment.

Parsons et al<sup>19</sup> conducted a statewide survey examining turnover and job satisfaction among 550 CNAs. The CNA turnover was linked to job satisfaction: 40% of the respondents were either neutral or dissatisfied with their position. Respondents were most satisfied with their closeness to residents and their effect on residents' care, and dissatisfied with limited decision-making, pay and employee benefits. The CNAs identified their relationship with the residents and co-workers as the most important work issues. Even residents' physical assaults or disruptive behavior were not seen negatively.

### **INTERVENTIONS PROGRAMS: STAFF**

Many programs have been developed to retain LTC staff and decrease the level of stress in caring for residents with dementia. Specialized care units, self-managed and CNA-empowered work teams, peer support, interventions to increase self-efficacy, and treatment of behavioral symptoms have been piloted in the LTC setting, as well as strategies to promote continuity of care, institute merit raises, and reduce inefficiencies.

Yeatts & Cready<sup>20</sup> studied the effects of CNA-empowered work teams on resident care and level of stress among staff. Small groups of three to eight CNAs met weekly, discussed work procedures, and participated in decision-making in resident care. When compared to nursing homes with traditional management approaches, the nursing homes implementing CNA-empowered work teams resulted in better resident care, enhanced CNA performance, improved CNA

cooperation with nursing and decreased CNA turnover.

Peer mentoring is also aimed at improving the quality of care and increasing retention rates of staff. Two programs, "Growing Strong Roots," for new CNAs who are mentored by experienced CNAs, and "Peer Mentoring for Long Term Care Charge Nurses," for nurses managing LTC units, improved the retention of new and the turnover of professional staff.<sup>21</sup>

### **COMBINED INTERVENTION PROGRAMS: CAREGIVERS AND STAFF**

Since the collaboration between staff and family is critical to positive outcomes for the resident, interventions that target the family-staff relationship may be the most effective. Pillemer and colleagues<sup>22</sup> attempted to increase cooperation and communication among nursing home family caregivers and staff through "Partners in Caregiving." Participants were taught communication and conflict resolution techniques. The intervention was associated with improved attitudes toward each other and no increase in staff-family conflicts. In addition, participants showed a reduction in depressive symptoms, but not burden, compared to a control condition. This approach was modified for and evaluated in dementia special care units.<sup>23</sup> Results of a randomized trial showed significant improvements in family caregivers' communication with staff and increased care involvement in spouse caregivers. Staff reported reduced conflict with families and reduced depression and staff behavior towards family was improved. Staff burnout increased in the control group. Similarly, Maas and colleagues<sup>24</sup> showed that a family-staff written negotiation of the extent and nature of family involvement in care (Family Involvement in Care Intervention) improved both caregiver and staff attitudes toward caregiving, though minimal effects were identified for perceived conflicts between family members and staff. Technology-based, education programs have also been used with nursing home caregivers. A Web-based system of interactive training and interactive communication with the facilities was associated with increased knowledge of dementia care, though a small sample size and lack of a control group limit the interpretation of these findings.<sup>25</sup>

## CONCLUSIONS AND FUTURE DIRECTIONS

Many family members experience persistent caregiver burden following relatives' placement due to multiple factors, including guilt related to placement, role adjustment, expectations of care, and communication with LTC staff. Similarly, the staff faces burnout linked to low pay, minimal benefits, the challenges of managing residents' behavior symptoms, and the complexities of interacting with families. Taken together, the burden and burnout experienced by both family and staff impair care. Currently, the only empirical support for intervention programs are results of small pilot studies. These programs offer promise for psychosocial treatment; the most effective approach may be to develop interventions that address communication between staff and family caregivers.

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Jennifer Duncan Davis, PhD, is Clinical Neuropsychologist, Rhode Island Hospital, and Assistant Professor (Clinical), Department of Psychiatry and Human Behavior, The Warren Alpert Medical School of Brown University.

Alicia J. Curtin, PhD, GNP-BC, is Associate Professor, College of Nursing, University of Rhode Island, and Clinical Assistant Professor, Department of Family Medicine, The Warren Alpert Medical School of Brown University.

## Disclosure of Financial Interests

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## CORRESPONDENCE

Jennifer Davis, PhD  
Rhode Island Hospital  
596 Eddy Street  
Providence, RI 02903  
Phone: (401) 444-4500  
e-mail: jdavis3@lifespan.org

