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Original Study

Development and Psychometric Properties of the Family Distress in Advanced Dementia Scale

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ABSTRACT

Objective: The majority of scales to measure family member distress in dementia are designed for community settings and do not capture the unique burdens of the nursing home (NH) environment. We report the psychometric properties of a new Family Distress in Advanced Dementia Scale for use in the NH setting.

Design, Setting, Participants: Cross-sectional questionnaire of 130 family member health care proxies of NH residents with advanced dementia in 31 Boston-area NHs.

Methods: Thirty-one initial items were evaluated, measuring the frequency over the past 3 months of sources of distress. Exploratory factor analysis identified domains of distress; Cronbach's alpha was computed for each domain. Associations between the domains and other measures were evaluated using Pearson correlation coefficients, including measures of depression (PHQ-9), satisfaction with care (Satisfaction with Care at the End-of-Life in Dementia [SWC-EOLD]), and caregiver burden (Zarit Burden Interview short version).

Results: Factor analysis suggested 3 domains: emotional distress (9 items), dementia preparedness (5 items), and NH relations (7 items). Cronbach's alpha coefficients were 0.82, 0.75, and 0.83 respectively. The PHQ-9 correlated most strongly with the emotional distress factor ($r = 0.34$), the SWC-EOWD correlated most strongly with the NH relations factor ($r = 0.35$), as did the Zarit Burden Scale ($r = 0.50$).

Conclusions: The Family Distress in Advanced Dementia Scale encompasses 3 domains of distress. This scale represents a much needed tool to assess distress among family members of NH residents with advanced dementia and provides a metric to evaluate interventions in the population.

Family members provide the majority of care for persons with dementia.[1] A substantial body of research from community settings has demonstrated that family members of patients with dementia are at increased risk of mood disorders, physical ailments, reduced employment, as well as increased healthcare utilization and mortality.[2–8] It is now also recognized that although many such family members experience relief upon institutionalization of their loved one, a substantial proportion remain at elevated risk of adverse outcomes because of the unique stresses of the nursing home (NH) environment.[9] Given that up to 90% of patients with dementia will be cared for in a NH,[10] and as many as 70% of Americans with dementia will die in this setting,[11] there is need for measures that capture the distress and burden of families of patients with dementia in this setting.[12]

Caregiver burden is a multidimensional concept, defined as "the physical, psychological or emotional, social, and financial problems that can be experienced by family members."[13] Several measures of dementia caregiver burden exist.[14–18] However, the vast majority of these are designed for use in community settings and focus on burdens specific to that environment. For example, representative items address the physical toll of performing daily patient care such as bathing, or of interrupted caregiver sleep because of needing to

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supervise the patient at night. Other items address social concerns such as needing to rely on others for assistance with caregiving tasks or the stress related to restricted social life because of caring for the patient in the home. As such, existing measures do not adequately assess the unique burdens of family members whose loved ones reside in the NH, which are distinct from the daily stressors associated with caring for a person with dementia in the home. There have been few new caregiver scales for this population, although there has been a recent addition to the literature of a scale developed to measure burden among family members of NH patients with dementia conducted in Japan.[19] However, this may not reflect the experiences of families or NH residents in the United States.

There are several potential sources of distress that are unique to families of NH residents with advanced dementia, including communication with NH staff, perceived need for vigilance to ensure adequate care, guilt over NH placement, quality of NH care, financial concerns, and the burdens of visitation and surrogate medical-decision making.[9,20–22] Existing scales do not adequately address these concerns. For these reasons, we sought to build on the available literature to develop a concise and easy to administer instrument that captures the unique distress of families of NH residents with advanced dementia, with the goal of identifying family members who might benefit from additional education or support.

Methods

Participants

Participants were family member health care proxies (HCPs) of NH residents with advanced dementia, recruited from 31 NHs in the Boston area. As a first step in recruitment, trained research assistants contacted NHs in order to identify potentially eligible residents with advanced dementia based on the following criteria: (1) has dementia (any type) based on chart review; (2) Global Deterioration Scale[23] stage of 7 based on nurse interview, (cannot recognize family, minimal verbal communication, total functional dependence, incontinence of urine and stool, inability to ambulate independently); and (3) an English speaking HCP who was a family member of the resident (legal guardians and other nonrelatives were excluded). As a second step in recruitment, HCPs of these residents were contacted by telephone to explain the study, solicit their participation, and obtain informed consent. All HCP responses were obtained during a telephone interview conducted by a trained research assistant. The Institutional Review Board at Hebrew SeniorLife approved the conduct of this study.

Scale Items

Areas of family member distress were identified a priori based on review of the literature,[14–17,24,25] and a prior qualitative study of HCPs of NH residents with advanced dementia,[22] which identified particular areas of distress in this population, including inadequate resident personal care, need for family member vigilance, difficulty with communication with NH physicians, and challenges of surrogate decision making.

After consideration of the literature, 4 initial domains were identified: (1) disease-specific issues related to the patient having advanced dementia; (2) family member mental health; (3) responsibilities of surrogate decision-making; and (4) NH quality of care. Preliminary items were created to reflect each domain and were reviewed by all authors to evaluate content validity and to refine wording. A total of 31 preliminary items were retained to reflect the domains. The advanced dementia domain (items 1–6, Table 1) contained items relating to knowledge of what to expect in advanced

Table 1
Mean Values and SDs of Frequency Responses to Initial Scale Items

Item	Mean	SD
1. I have felt that I don't know what to expect in my loved one's illness	1.9	1.3
2. I have felt that I don't know how to communicate with my loved one	2.8	1.7
3. I have felt isolated from my loved one	2.6	1.7
4. I have been concerned about what to expect when my loved one is close to death	2.0	1.4
5. I have felt my loved one is less of the person he or she used to be	3.8	1.6
6. I have felt worried that my loved one will die alone*	1.9	1.4
7. I have felt scared or helpless because of my loved one's illness	2.4	1.5
8. I have felt that my loved one has endured enough suffering*	3.2	1.6
9. I have felt anxious about my loved one's illness	2.4	1.4
10. I have felt a sense of longing for my loved one as they used to be	3.4	1.5
11. I have felt depressed or sad because of my loved one's illness	2.7	1.4
12. I have felt emotionally drained because of my loved one's illness	2.3	1.4
13. I have felt a sense of disbelief over my loved one's illness*	1.5	1.0
14. I have wanted to have more information about the course of dementia	1.8	1.2
15. I have wanted to be more involved in medical decisions for my loved one*	1.5	1.1
16. I have felt unsure about the course of my loved one's illness	2.0	1.4
17. I have not felt supported by nursing home staff in making medical decisions	1.3	0.8
18. I have not understood the medical decisions regarding my loved one	1.2	0.6
19. I have felt unsure about what my loved one would want in terms of medical care*	1.3	0.8
20. I have felt conflict with other family members about medical decisions for my loved one*	1.2	0.8
21. I have felt that the staff at the nursing home have not communicated with me about medical decisions for my loved one	1.2	0.7
22. I have felt a sense of guilt over having my loved one in the nursing home*	2.0	1.5
23. I have had difficulties communicating with staff at the nursing home	1.3	0.7
24. I have had difficult relationships with staff at the nursing home	1.1	0.3
25. I have felt the need to watch over the care my loved one is getting at the nursing home*	1.9	1.3
26. I have not been able to visit the nursing home as much as I would like*	2.6	1.5
27. I have felt that my loved one is not getting good medical care at the nursing home	1.2	0.7
28. I have felt that my loved one is not treated with respect at the nursing home	1.2	0.5
29. I have felt that my loved one has not been clean or well-groomed at the nursing home	1.4	0.8
30. I have felt that I have not been made to feel welcome at the nursing home	1.1	0.3
31. I have had concerns about not being able to pay for nursing home care for my loved one*	1.3	0.9

SD, standard deviation.

*Item not included in final scale.