Correlates of Quality of Life for Individuals with Dementia Living at Home: The Role of Home Environment, Caregiver, and Patient-related Characteristics

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Objectives: *To examine prevalence of modifiable risk factors and their contribution to patient quality of life (QoL) as rated by dementia patients and family caregivers.* **Design:** *Cross-sectional.* **Setting:** *Home environment.* **Participants:** *88 patients and their caregivers.* **Measurements:** *Modifiable characteristics of home environments, patients, and caregivers were observed or obtained through interview. Demographics and ratings of patients' QoL were obtained from patients and caregivers.* **Results:** *Patients had mean Mini-mental Status Examination (MMSE) score = 17.7 ± 4.6, (range: 10−28) on an average 7.7 ± 2.4 neuropsychiatric behaviors, 6.0 ± 3.1 health conditions and moderate functional challenges; 70.7% (N = 58) had fall risk; 60.5% (N = 52) had sleep problems at least once weekly; and 42.5% (N = 37) had pain. An average of 8.1 ± 5.2 home hazards and 5.4 ± 4.1 adaptations were observed; 51.7% had unmet device/navigation needs. Patients' and caregivers' QoL ratings were unrelated to MMSE; and patients' self-rated QoL was higher than rated by caregivers. Number of health conditions and unmet device/navigation needs were inversely associated with patient self-rated QoL, and number of health conditions, frequency of behaviors, and level of negative communications were inversely associated with caregiver's assessment of patient QoL. Positive endorsement of caregiving was positively associated with caregiver's appraisal of patient QoL. Other factors were unrelated.* **Conclusions:** *Most patients lived at home with high fall risk, unmanaged behavioral symptoms, pain, sleep disturbances, environmental challenges, and multiple hazards. Except for health, factors associated with lower QoL differed for patients and caregivers. Results suggest need to improve QoL by addressing modifiable risk factors and tailoring interventions to patient and caregiver perspectives.* (Am J Geriatr Psychiatry 2013; ■:■−■)

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Over 5 million Americans have dementia, a progressive and irreversible neurodegenerative condition, with prevalence rates expected to reach over 16 million in the United States.[1,2] A pandemic, dementia is the greatest single contributor to the burden of disability and poor life quality in older people, and also negatively affecting over 15 million family members responsible for ongoing dementia care at home.[1–3]

As a cure is not available, maintaining and maximizing quality of life (QoL) is an important treatment goal in caring for people with dementia, and there is still much room for improvement.[4,5] Unclear is the best way to support QoL in patients at home where most will live throughout the disease course.[6] Specific treatment strategies have not been systematically developed and tested for this purpose. As an initial step towards advancing practical care strategies to support QoL, this study examines the prevalence of conditions that may compromise daily life at home and relationships between patient QoL ratings and cognitive functioning, and then identifies modifiable correlates of patient QoL as rated by patients with mild to moderate dementia and their family caregivers. Identifying risk conditions and independent modifiable factors contributing to QoL can lead to developing better tailored care interventions to support daily life for patients with dementia living at home.

A substantive research literature on QoL has considered the scalability of this construct in dementia,[7–9] whether scales are valid across disease stages,[10–12] and factors explaining patient—proxy discordance.[13] Studies consistently suggest that patient characteristics (higher cognitive status, functional capacity, pain management, and fewer behavioral problems) are associated with informal and formal caregivers' perceptions of higher patient QoL.[14,15] A common finding is that caregivers rate patients' QoL lower than they believe patients would rate themselves[16]; similarly, patients report higher QoL than staff or family.[17,18] Disparate proxy—patient ratings have been attributed to elevated caregiver burden and perceptions of patient suffering.[13,19] Of the few studies examining correlates of patient-rated QoL, most have been conducted outside of the United States.[20–23] Findings are inconsistent with some indicating lower QoL ratings with increased age and cognitive and functional declines and others not finding relationships. Limitations of QoL research include an almost exclusive focus on nursing home residents,[14,24,25] or end-stage disease patients,[26] and inclusion of a restricted range of potential contributing factors, highlighting that more research in this area, particularly for persons living at home with dementia, is necessary.[27]

A theoretical QoL framework relevant to dementia is Lawton's (1991) "good life" construct.[28] Consisting of four elements (psychological well-being, behavioral competence, objective environmental conditions, and perceived QoL), the framework emphasizes relationships between person-level (cognitive, functional competencies), and physical and social (caregiver) environmental attributes as QoL determinants. The framework suggests the need to consider intrapersonal, social-normative, and objective understandings of person—environment factors that may be associated with perceived QoL.

The present study focuses on an understudied group in QoL research, community-living patients in the United States with mild to moderate dementia. We examine prevalence of risk conditions and whether they uniquely contribute to patient QoL as perceived by patients and caregivers. Using objective assessments and caregiver and patient interviews, potential correlates of QoL were purposely selected from three domains (environment, patient, caregiver) consistent with Lawton's theoretical framework. Correlates selected also had to be amenable to intervention, clinically relevant, associated with well-being in other studies, or not previously considered. For example, no studies to our knowledge have examined home environmental factors in relationship to patient QoL although research with other clinical populations and Lawton's theoretical framework suggest a positive association.[29]

As this study was exploratory and descriptive of modifiable risk conditions and whether they uniquely contribute to QoL, formal hypotheses were not posited. Based on previous studies, however, we expected patients to report their QoL as higher than caregiver ratings, that correlates significantly associated with QoL would differ for patients and caregivers, and that each domain (home environment, patient, and caregiver) would independently contribute to QoL ratings.