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Original Study

Factors Associated With Changes in Perceived Quality of Life Among Elderly Recipients of Long-Term Services and Supports

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A B S T R A C T

Objectives: Advance knowledge about changes in multiple dimensions of health related quality of life (HRQoL) among older adults receiving long-term services and supports (LTSS) over time and across settings.
Design: A prospective, observational, longitudinal cohort design.
Setting: Nursing homes (NHs), assisted living facilities (ALFs), community.
Participants: A total of 470 older adults who were first-time recipients of LTSS.
Measurement: Single-item quality-of-life measure assessed every 3 months over 2 years. HRQoL domains of emotional status, functional status, and social support were measured using standardized instruments.
Results: Multivariable mixed effects model with time varying covariates revealed that quality-of-life ratings decreased over time ($P < .001$). Quality-of-life ratings were higher among enrollees with fewer depressive symptoms ($P < .001$), higher general physical function ($P < .001$), enhanced emotional well-being ($P < .001$), and greater social support ($P = .004$). Ratings also were higher among those with increased deficits in activities of daily living ($P = .02$). Ratings were highest among enrollees who received LTSS from ALFs, followed by NHs, then home and community-based services (H&CBS), but only findings between ALFs and H&CBS were statistically significant ($P < .001$). Finally, ratings tended to decrease over time among enrollees with greater cognitive impairment and increase over time among enrollees with less cognitive impairment ($P < .001$).
Conclusions: Findings advance knowledge regarding what is arguably the most important outcome of elderly LTSS recipients: quality of life. Understanding associations between multiple HRQoL domains and quality of life over time and directly from LTSS recipients represents a critical step in enhancing care processes and outcomes of this vulnerable population.

In the United States, more than 6 million older adults receive long-term services and supports (LTSS) in their homes, assisted living facilities (ALFs), and nursing homes (NHs)[1]; this number is expected to double by 2030.[2,3] LTSS is defined as assistance and support with basic and instrumental activities of daily living (eg, bathing, dressing, cooking) and can be provided in a variety of settings (eg, home, NHs, ALFs).[4,5] Currently, LTSS are characterized as a rapidly growing, fragmented and costly "system" with substantial and persistent concerns about quality.[6]

Health-related quality of life (HRQoL) has been identified by a committee of the Institute of Medicine[6] and other leading clinical scholars[7–12] as an important outcome for the growing LTSS population. The emphasis on HRQoL is important because the construct underscores this population's perspectives about their well-being, which is affected both

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by changes in their health[12–14] and the quality of the LTSS they receive.[12,13,15,16] HRQoL is now recognized as a complex construct, encompassing multiple domains, including biological and physiological factors, symptom status, physical and cognitive functional status, general health perceptions, emotional status, social support, and overall quality of life.[17]

Although HRQoL is gaining traction as a construct that should supplement or, in some situations, replace traditional measures used to assess LTSS for this population, common methodological issues, the absence of conceptual frameworks and reliance on data from one measure, typically assessed from one LTSS organizational type using a single data collection point or proxies,[18–22] limits its use to advance care processes and outcomes. The few reported longitudinal studies have focused on a single context (eg, NHs) as the unit of analysis,[16,23] focused on a limited set of HRQoL domains[24] or were limited to a specific subgroup, commonly older adults with dementia.[16,25,26]

The paucity of rigorous data on the natural history of changes in multiple domains of HRQoL among elderly LTSS recipients and the possible contributions of diverse LTSS care experiences over time by these same individuals have important implications for current and future LTSS consumers, the LTSS "system" and society. This study was designed to address important gaps in knowledge regarding longitudinal changes in multiple HRQoL dimensions among older adults who receive care from multiple LTSS providers.

The primary aims of this study were to advance knowledge about changes in multiple dimensions of health and quality of life among older adults receiving LTSS over time and across settings (Aim 1); examine relationships between and among HRQoL domains (Aim 2); and explore the influence of selected contextual factors on different trajectories (Aim 3). In this article, associations between changes in key dimensions of health and perceived quality of life (hereafter referred to as "quality of life") of older adults receiving LTSS over a 2-year period (Aim 1) are reported. Among older adults who were new recipients of LTSS at the time of enrollment, the major hypotheses were that (1) overall quality of life would decrease over time and (2) the subgroup of LTSS recipients with higher physical, cognitive, or emotional function and increased social support at baseline would report higher quality of life over time.

Methods

Design

The framework that guided this study, reported in an earlier article,[17] was an adaptation of the Wilson and Cleary HRQoL conceptual model.[11] Briefly, this model describes relationships between and among multiple HRQoL domains, including biological and physiological factors, symptom status, physical functional status, general health perceptions, social support, and overall quality of life.[11] This model was augmented to include additional domains (eg, emotional status, cognitive function, behaviors, and environmental characteristics) identified from a systematic literature review and other quality-of-life conceptual models[27,28] and considered by clinical experts as relevant to elderly recipients of LTSS.[7,9,11,12,29] The adapted model informed study hypotheses and guided study design and methods.

A prospective, observational, cohort design was used to assess changes in each of the aforementioned domains among a sample of older adults who were first-time recipients of LTSS and, at the time of enrollment, receiving services from one of the following common providers: home and community-based services (H&CBS), ALFs, or NHs.

Participating Sites and Sample

A convenience sample of 59 sites derived from 11 LTSS organizations in 3 states on the east coast of the United States (PA, NJ, NY) agreed to participate in this study. Older adults were eligible to participate if they were age 60 years or older, new LTSS recipients (enrolled within 60 days of start of LTSS), able to communicate in English or Spanish, and had a score of 12 or greater on the Mini Mental State Examination (MMSE).[30,31] Older adults were considered ineligible if, at baseline, they had documented severe cognitive impairment (MMSE <12), impaired reality (eg, diagnosis of paranoia), or a terminal prognosis.

Recruitment

Two recruitment approaches were implemented. In 2 states (PA and NJ), a volunteer staff member at each site prescreened older adults and introduced the study to all potentially eligible older adults. This group also received a brochure in English or Spanish that explained the purpose of the study and eligibility criteria. Contact information on those who agreed to be approached was sent by the staff member via secure messaging to the study's project manager. Interested older adults were then visited by a research assistant (RA) who explained the study and obtained assent or consent. In the third state (NY), potentially eligible older adults were identified via an electronic database search and initially contacted by a staff member via phone. After explaining the study, and conducting the Six-Item Screener[32] (SIS) to assess older adults' orientation and recall, eligible participants were scheduled for in-home interviews; the SIS has been validated for telephone use. This procedure was used because, unlike potentially eligible enrollees who are clustered in ALFs or NHs, older adults receiving H&CBS reside in communities spread across a wide geographic area. During subsequent home visits to those who passed the cognitive screen, an RA explained the study and obtained assent or consent.

Human Subjects

The study was approved by the University of Pennsylvania's, the Philadelphia Veterans Medical Center's, and the Visiting Nurse Service of New York's Institutional Review Boards (IRBs). All IRBs approved the use of the MMSE, adjusted for age and education,[30,33] to assess older adults' capacity to provide informed consent. Eligible older adults provided written informed consent using a conservative MMSE cut point of 23 or higher (indicating no cognitive impairment to very mild cognitive impairment). Those whose MMSE scores ranged from 12 to 22 (indicating mild to moderate impairment) provided assent; written informed consent for this latter group was obtained from their legally authorized representatives. The consent form was reviewed in detail and the opportunity to ask questions was provided to all potential enrollees and their legally authorized representatives (if needed). At each follow-up visit, the RA reviewed the purpose of the longitudinal interview study and reiterated the voluntary nature of research, allowing for questions to be asked and seeking continued agreement to be interviewed.

Data

Guided by the adapted Wilson and Cleary HRQoL conceptual framework,[17] a comprehensive assessment tool was developed, refined following pilot testing, and then used to elicit information on all selected HRQoL domains. Data were elicited primarily via in-person interviews with older adults conducted quarterly by bachelor's prepared RAs with specialized preparation in enrollment and data collection processes provided by the study team. Consented older adults received 9 face-to-face interviews at 3-month intervals through 2 years following enrollment. Whenever possible, the same RA conducted these interviews. Among older adults whose negative changes in health status precluded in-person interviews (eg, stroke, decline in cognitive status), selected data about the older adult, specifically performance on basic activities of daily living (BADLs), were obtained via brief interviews conducted with caregivers (eg, nurse assistants,