Published in final edited form as:

J Am Med Dir Assoc. 2016 January 1; 17(1): 44–52. doi:10.1016/j.jamda.2015.07.019.

Factors Associated with Changes in Perceived Quality of Life among Elderly Recipients of Long Term Services and Supports

Mary D. Naylor^a, Karen B. Hirschman^a, Alexandra L. Hanlon^a, Katherine M. Abbott^a, Kathryn H. Bowles^a, Janice Foust^b, Shivani Shah^b, and Cynthia Zubritsky^c

^aNewCourtland Center for Transitions and Health; University of Pennsylvania School of Nursing, 418 Curie Blvd, Claire M. Fagin Hall, Philadelphia, PA 19104

^bCenter for Home Care Policy & Research, Visiting Nurse Service of New York, 5 Penn Plaza, 12th floor New York, NY

^cUniversity of Pennsylvania School of Medicine, Department of Psychiatry, 3535 Market St., Philadelphia, PA

Introduction

In the U.S., more than six 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 (e.g., bathing, dressing, cooking, etc.) and can be provided in a variety of settings (e.g., 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 Medicine⁶ and other leading clinical scholars⁷⁻¹² as an important outcome for the growing

Corresponding Author: Mary D. Naylor, PhD, RN - Marian S. Ware Professor of Gerontology; Director, NewCourtland Center for Transitions and Health; University of Pennsylvania School of Nursing, 418 Curie Blvd, Claire M. Fagin Hall RM341, Philadelphia, PA 19104; naylor@nursing.upenn.edu; Tel: (215) 898-6088; Fax: (215) 573-4225.

Co-authors:

Karen B. Hirschman, PhD, MSW - *Research Associate Professor*; University of Pennsylvania School of Nursing, 3615 Chestnut Street, Philadelphia, PA 19104; hirschk@nursing.upenn.edu; Tel: 215-573-3755; Fax: (215) 573-4225

Alexandra L. Hanlon, PhD - *Research Professor*; University of Pennsylvania School of Nursing, 418 Curie Blvd., Philadelphia, PA 19104-6096

Katherine M. Abbott, PhD - *Assistant Professor*; Department of Sociology and Gerontology, Miami University, Oxford, OH 45056

Kathryn H. Bowles, PhD, RN, FAAN - van Ameringen Chair in Nursing Excellence, Professor of Nursing; University of Pennsylvania School of Nursing, 418 Curie Blvd., Philadelphia, PA 19104-6096

Janice B. Foust, PhD, RN - *Assistant Professor*; College of Nursing and Health Sciences, University of Massachusetts - Boston, 100 Morrissey Blvd., Boston, MA 02125-3393

Shivani Shah, MPH - *Research Analyst II*; Center for Home Care Policy & Research, Visiting Nurse Service of New York, 5 Penn Plaza, 12th floor, New York, NY 10001

Cynthia D. Zubritsky, PhD - Director of Integrated Primary Care and Behavioral Health Initiatives for the Center for Mental Health Policy and Services Research; University of Pennsylvania School of Medicine, Department of Psychiatry, 3535 Market St., Philadelphia, PA 19104

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

LTSS population. The emphasis on HRQoL is important because the construct underscores this population's perspectives about their well-being, which is affected both by changes in their health¹²⁻¹⁴ 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

While 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 proxies¹⁸⁻²², limits its use to advance care processes and outcomes. The few reported longitudinal studies have focused on a single context (e.g., nursing homes) as the unit of analysis^{16,23}, focused on a limited set of HRQoL domains²⁴ 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 paper, 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 two 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 paper¹⁷, was an adaptation of the Wilson & 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 (e.g., emotional status, cognitive function, behaviors, and environmental characteristics) identified from a systematic literature review and other QoL 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 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), assisted living facilities (ALFs), or nursing homes (NHs).

Participating Sites and Sample

A convenience sample of 59 sites derived from 11 LTSS organizations in three states on the east coast of the U.S. (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 (e.g., diagnosis of paranoia), or a terminal prognosis.

Recruitment

Two recruitment approaches were implemented. In two states (PA and NJ), a volunteer staff member at each site pre-screened 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 Screener³² (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, a RA explained the study and obtained assent or consent.

Human Subjects

The study was approved by the University of Pennsylvania's (Penn), 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 Mini Mental State Examination (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 (indicating no cognitive impairment to very mild cognitive impairment). Those whose MMSE scores ranged from 12-22 (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 & Cleary HRQoL conceptual framework¹⁷, 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 bachelors' prepared RAs with specialized preparation in enrollment and data collection processes provided by the study team. Consented older adults received nine face-to-face interviews at three month intervals through two years following enrollment. Whenever possible, the same RA conducted these interviews. Among older adults whose negative changes in health status precluded in-person interviews (e.g., 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 (e.g., nurse assistants, home health aides, family members). Selected health resource use data were abstracted by RAs from enrollees' medical records quarterly. Additionally, quarterly surveys were completed by leaders at participating LTSS to identify major organizational changes that might influence older adults' health and quality of life. All data are stored on a secure server at the University of Pennsylvania, School of Nursing.

Measures

Individual LTSS recipient characteristics (e.g., race, ethnicity, gender, age, education, and marital status) were collected from enrollees at baseline. The primary outcome variable was elicited from all enrollees at baseline and at each follow up data collection point using the question: "How would you rate your overall quality of life at the present time?" Options represented a five point Likert scale included: poor, fair, good, very good, and excellent.³⁴⁻³⁶ Earlier studies have demonstrated that the single item, which asks respondents to rate overall quality of life using a five point Likert scale ranging from poor (1) to excellent (5), is a reliable and valid measure of adults' well-being.³⁴⁻³⁶

Several repeated measure predictor variables that align with the HRQoL conceptual framework¹⁷ were gathered at baseline and then quarterly through two years using a set of valid and reliable instruments (See Table 1). The instruments selected to assess the primary outcome and each of the aforementioned domains were chosen based on the literature that suggested ample evidence for use with individuals with mild to moderate cognitive impairment (e.g., quality of life item³⁷, Symptom Bother Scale³⁸; Geriatric Depression Scale Short Form³⁹⁻⁴¹; and Medical Outcomes Short Form 12 item [SF-12]⁴²). The following is a brief description of these measures and the instruments used to generate data on these metrics.

Symptom status was assessed using the Symptom Bother Scale.⁴³ This instrument measures the presence and severity of 13 physical symptoms typically associated with aging or

chronic illness (i.e., aching, pain, stiffness, fatigue). Enrollees rated the degree to which they were bothered by each symptom on a one to three scale, with higher scores indicating more symptomatology. Symptom bother has been positively associated with ADL deficits and depression, and negatively associated with subjective health, providing support for the validity of the scale.^{44,45} Cronbach's alphas were 0.78 to 0.85. A summary score of the total number of bothersome symptoms was generated for modeling.

Functional Status. Cognitive function was assessed using the Mini Mental State Examination [MMSE].³¹ This widely used assessment tool measures orientation to time and place, recall ability, short-term memory and arithmetic ability in elderly patients. This instrument consists of 11 questions, divided into two sections. The first section requires verbal responses to questions related to orientation, memory and attention, the second section requires reading and writing and assesses the individual's ability to name, follow verbal and written commands, write a sentence, and copy a polygon. The MMSE total score ranges from 0 to 30 and reflects the number of correct responses with common cut points for cognitively intact >23, mildly impaired 23-20, and moderately impaired 19-12. Cutoff scores will be adjusted for educational level using the guidelines proposed by Uhlmann and Larson.⁴⁶ The MMSE has well-established reliability and validity (test-retest .82-.98; inter-rater .88; internal consistency 0.96) criterion-related validity (confusion) Spearman's rho, 0.76; discriminant validity (depression), $r=0.38$; concurrent validity (confusion), $r=0.80$).⁴⁷

Physical function was measured using the Katz Basic Activities of Daily Living [BADL]⁴⁸ tool which assesses individuals' abilities to perform activities such as bathing, dressing, toileting, transferring, continence, and feeding. Scores range from 0-6 with higher scores indicating better function. Inter-rater reliability of 0.95 and correct classification of 96% of people has been reported using the instrument.⁴⁹ Importantly, among cognitively impaired enrollees, caregivers (e.g., certified nurse assistant, home health aides, or family caregivers) who assisted this group of older adults with day-to-day activities provided information on BADLs; no other data were elicited from caregivers.

General Health Perception. The Medical Outcomes Survey Short Form Physical Composite Score [SF-12 PCS] was used to assess enrollees' ratings of their health based on eight domains: physical functioning, role limitations (physical and emotional), social functioning, pain, mental health, physical health, and vitality.^{50,51} SF-12 PCS scores were weighted and summed so that general population scores have a mean of 50 and a standard deviation of 10.⁵⁰ Higher SF-12 scores reflect better overall physical health.

Emotional Status. Two tools were used to assess emotional status of enrollees: the Geriatric Depression Scale – Short Form [GDS-SF] and the SF-12 Mental Composite Score [SF-12 MCS]. The GDS-SF³⁹ was used to assess the presence and severity of depression. This instrument has demonstrated validity and reliability for measuring depression among both institutionalized⁵² and older adults with dementia.^{40,53} All items answered are in a “yes” or “no” format for ease of comprehension by older adults with cognitive impairment.³⁹⁻⁴¹ The following psychometric indices have been reported: sensitivity 0.84-0.89; specificity, 0.73-0.95; discriminant validity with a clinical diagnosis of depression, 0.84.⁵⁴ The SF-12

MC;S⁵⁰, similar to the SF-12 PCS, is a weighted summary score of a patient's self-reported overall mental health. Higher scores indicate better overall mental health.

Social Support. The Medical Outcomes Survey-Social Support [MOS-SS]⁵⁵ was used to assess the availability of four types of support: emotional or informational, tangible, affection, and positive social interaction. Each item is rated on a five-point Likert scale from none of the time to all of the time. Subscales are generated using combinations of items with higher subscale score suggesting increased social support. Internal consistency for the MOS-SS measures are consistently high ($\alpha > 0.90$).^{55,56}

In addition to data generated from in-person interviews, selected health resource data were abstracted by RAs from enrollees' medical records. Specifically, the number of hospitalizations between each interview time point (every three months through last interview at 24 months) and total days in hospice care were documented.

Analyses

Guided by a comprehensive conceptual model, a single quality of life rating elicited from enrolled older adults at all data collection points formed the basis for the use of longitudinal mixed effects modeling to examine the relationship between quality of life and each of the multiple HRQoL domains. Distribution of the quality of life measure follows a unimodal symmetric distribution and satisfies the assumptions for mixed effects modeling. Mixed effects modeling takes advantage of all available data (up to the point of loss to death or withdrawal) and also can address missing data.⁵⁷⁻⁵⁹ Because the level of missingness was not excessive due to either death (21%) or withdraw (7%) and patterns of missingness were not detected, the mixed effects modeling relied on all available data. Sensitivity analyses were conducted that included only those patients remaining alive throughout the study period. Findings remained the same as that observed for the entire sample and, thus, the results of the full dataset are presented here.

Both random slopes and intercepts were modeled to represent the participant level deviation from the average, or fixed-effect, slope over time and intercept, respectively. Restricted maximum likelihood estimation was used, along with a compound symmetry covariance structure. The outcome was analyzed as repeated observations (quarterly assessments over two years), with mean-centered baseline outcome scores as a covariate. Potential fixed-effects (e.g., age, sex) were identified using simple main effects and two-way interaction-with-time models on the basis of an inclusion criterion, $p \leq 0.20$.^{60,61} An initial multivariable mixed effects model was constructed using the aforementioned two-way interaction-with-time covariates, along with the corresponding main effects. Using this full model, interactions were sequentially eliminated on the basis of least significance until only interaction effects demonstrating $p \leq 0.20$ remained.^{60,61} Covariates which were not included in the aforementioned final interaction model but demonstrated $p \leq 0.20$ in simple main effects models were then added to the final multivariable interaction model and assessed sequentially as described above. The final multivariable model included covariates and interaction terms demonstrating significance only at the $p \leq 0.05$ level. Because of confounding between LTSS options (H&CBS, ALF and NH) and race and ethnicity, neither of these latter variables was included in the multivariable modeling process.

Results

Sample Recruitment and Retention

Between March 2007 and July 2010, 470 older adults, evenly divided among three common LTSS provider types (158 in NHs; 156 in ALFs; and 156 in H&CBS), were enrolled. Of 1311 older adults screened, 37% did not meet eligibility criteria, largely due to severe cognitive impairment and/or prior LTSS experience. Of the 831 eligible referrals, 37% refused to participate, primarily reporting lack of interest or time as major reasons for refusals. An additional 6% did not have a legally authorized representative and, thus, could not be enrolled. Five individuals in NY were dropped because the site project coordinator could not confirm the reliability of data entered for these enrollees (see Figure 1). Thus, a total of 470 older adults were enrolled in this study. By the completion of the two year follow-up, 21% had died and 7% withdrew. Thus, the sample at the completion of data collection had decreased from 470 to 337. In addition to attrition, a range of issues including deteriorating health and acute hospitalizations resulted in missing interviews ranging from 6%-16% at each of the data collection points throughout the study period. When interviews were not possible, data from chart reviews continued to be collected.

Sample Characteristics at Baseline

A detailed description of the socio-demographic and clinical characteristics of the 470 enrollees at baseline in this study is presented in Table 2. Enrollees were a mean of 81 years of age (range: 60-98); the majority were female (71%) and widowed (52%). Twenty percent were Hispanic; 16% of interviews were conducted in Spanish. Fifty-one percent were Caucasian. Thirty-four percent were African American; 12% reported more than one race. Approximately two-thirds of the sample (64%) completed high school (12 years of education or higher).

Data abstracted from health records revealed that enrollees had a mean of nine documented chronic health conditions. On average, this sample reported independence in four of six BADLs; in contrast, 20% reporting being dependent on four or more BADLs. Approximately 60% of enrollees were cognitively intact at enrollment (assessed via MMSE). Of the remaining 40%, 24% had MMSE scores suggesting mild cognitive impairment while 16% had scores suggesting moderate cognitive impairment. Forty-three percent scored ≤ 5 on the Geriatric Depression Scale-Short Form (GDS-SF; range: 0-15) at baseline which is suggestive of depression and average emotional well-being score was lower than average (SF-12 Mental Composite Score=37.3), when compared to the norm for this scale (norm=50; range: 0-100). Eleven percent scored >10 on the GDS-SF, suggesting severe depression.³⁹ On average, LTSS enrollees reported 6 bothersome physical symptoms, with 34% reporting >8 bothersome symptoms.

On average, LTSS enrollees reported lower general physical health (SF-12 Physical Composite Score), when compared to the norm for this scale (norm=50; range: 0-100). The majority of enrollees indicated that they had social support (emotional/informational, tangible, affection and positive social interaction) available most or all of the time. Sixty-three percent of LTSS enrollees rated their quality of life as excellent, very good or good,

while 34 percent provided fair or poor ratings; two percent did not provide baseline data on this measure.

Characteristics, including HRQoL Domains, Associated with Single Item Quality of Life Ratings over Time

Using separate bivariate mixed effects models, selected HRQoL domains and enrollee characteristics were associated with quality of life ratings on the basis of $p < 0.20$. Bivariate mixed effects models of several individual characteristics at baseline: (i.e., age, education and mean number of chronic conditions) were associated with quality of life ratings (see Table 3). HRQoL domains associated with quality of life included symptom status, functional status (physical and cognitive), perceived general health, emotional status, and social support (all, $p < 0.001$). Selected health resource use factors (hospitalizations, $p = 0.06$ and use of hospice services, $p = 0.12$) were included in the multivariate model building. Additionally, time ($p = 0.18$) and the interaction of time and cognitive status ($p = 0.003$) were significantly associated with quality of life ratings.

Based on the results of the bivariate analysis, a final multivariable mixed effects model was developed to determine which enrollee characteristics and HRQoL domains were associated with quality of life from the time of enrollment through two years. Only variables significant at $p < 0.05$ were kept in the final model. Due to confounding with LTSS options (H&CBS, ALF or NH), neither race nor ethnicity were included in the final model.

Major Findings

Holding all other variables constant, multiple HRQoL domains were found to be strongly associated with quality of life in this study sample (see Table 4). On average, quality of life ratings were higher among those with: higher general physical function (SF12-PCS) ($p < 0.001$) and emotional well-being (SF12-MCS) ($p < 0.001$) ratings, fewer depressive symptoms (GDS-SF) ($p < 0.001$), and greater emotional or informational social support ($p = 0.004$). Notably, average quality of life ratings were higher among those with increased deficits in basic activities of daily living (BADLs, $p = 0.02$).

Quality of life ratings were highest among enrollees who at baseline were receiving LTSS from ALFs ($p < 0.001$), followed by NHs ($p = 0.12$), when compared to H&CBS (mean scores: 3.4 vs 2.96 vs 2.66, respectively). Overall, major directional changes uncovered using the final multivariable mixed effects model reveal that quality of life ratings decreased over time ($p < 0.001$). Finally, average quality of life ratings tended to decrease over time (*interaction term*) among enrollees with greater cognitive impairment (lower MMSE scores), whereas these same scores tended to increase over time among enrollees with less cognitive impairment (higher MMSE scores, $p < 0.001$).

Discussion

This study offers a unique longitudinal perspective on key dimensions of HRQoL for 470 English and Spanish-speaking older adults who, at the time of enrollment, were new recipients of LTSS. Over a two year period, mean ratings of overall quality of life among this sample declined. The importance of examining changes in this population overall and

not just by type of LTSS organization is reinforced by the fact that 13% of the sample transferred from one type of LTSS setting to another during the 24 month follow up, with the most common transition from ALF or H&CBS to NH, which is consistent with other research findings.⁶²⁻⁶⁵

Given a common baseline of multiple chronic conditions complicated by a range of physical, emotional and/or cognitive deficits requiring LTSS and the anticipated progression of these deficits over time, the observed negative directional change in quality of life is not unexpected.⁶⁶⁻⁶⁸ However, it is important to note that such a trajectory is not necessarily the norm. For example, baseline data for this sample reveal that older adults residing in ALFs had fewer functional deficits at enrollment and, overall, reported a higher quality of life compared to enrollees receiving LTSS from H&CBS or in NHs. One possible explanation is that the LTSS provided to ALF enrollees at critical points earlier in their chronic illness and disability trajectories promoted improvements in key domains such as physical, emotional or cognitive function. Alternatively, LTSS interventions may have delayed progression of such deficits. Perhaps the transition to ALFs helped foster social connections and minimize the effects of isolation. The association between enrollees' roles in decision making regarding LTSS options and quality of life also is important to examine. Further exploration of the influence of these and other factors on the trajectories of changes in HRQoL both overall and among specific subgroups is needed.

In this study, the inclusion of older adults with all but severe levels of cognitive impairment provided a unique opportunity to explore the perspectives of this vulnerable subgroup. Overall, findings reinforce those of other scholars who found increased cognitive deficits have a negative impact on quality of life¹⁵ over time.²⁵ Findings from other studies revealed that cognitively impaired older adults residing in NHs or ALFs who received care in specific units designed for this population or from specially trained staff reported higher ratings of quality of life than the sample in this study.^{15,69,70} Once again, most of these studies were cross-sectional and did not include the diverse sub-groups represented in this study. Longitudinal changes in quality of life and the relationships to the quality of services provided need further examination. It is important to note that among LTSS enrollees with fewer cognitive deficits, quality of life increased over time. Perhaps this subgroup is better able to adapt to new environments (ALF, NH) or receiving LTSS at home and, thus, their quality of life improves over time. Overall, these findings reinforce the importance of efforts by LTSS providers to promote cognitive health, especially among LTSS recipients with cognitive deficits.

In general, study results have strengthened appreciation of the potential impact of selected HRQoL domains on quality of life. Specifically, findings reinforce the work of other scholars⁷¹⁻⁷³ relative to the importance of the emotional and social support in relationship to quality of life. Increased depressive symptoms appear to have a negative impact on quality of life. Findings also reveal that enhanced emotional or informational social support may be important in promoting an enhanced sense of well-being. Other scholars have reported that the nature of relationships between caregivers and care recipients is likely a significant determinant of quality of life.⁷⁴ Knowledge of emotional and social support factors that both enhance and hinder quality of life has care delivery implications for LTSS providers. Efforts

to mitigate depressive symptoms, for example, should be accompanied by strategies to promote social networking or informed decision-making to optimize this outcome. Additionally, promoting networking could further increase access to social supports among this population of LTSS recipients.

Study findings raise questions regarding the relationship between LTSS options and quality of life that need further exploration. While the majority of older adults in the U.S. may prefer to remain in their homes⁷⁵, increased understanding of the impact of this choice for those coping with deficits that require LTSS is needed. In this study, enrollees receiving H&CBS reported, on average, a significantly lower quality of life than enrollees in ALFs. Overall, the sociodemographic and clinical profile of the H&CBS group is much more similar to those enrolled from NHs than those enrolled from ALFs, suggesting a higher level of physical, cognitive and emotional deficits at the time this subgroup began to receive LTSS. In addition to the possibility that earlier intervention may play a role, the possibility also exists that the intensity of services available via H&CBS may not be adequate to address this group's complex care needs. There also is growing concern that the decline in social networks is greater among vulnerable older adults served by H&CBS relative to those served in facilities such as ALFs and NHs.

Contrary to the study hypothesis suggested by other scholars^{15,76}, quality of life in this sample was higher among those with higher dependency in activities of daily living. This finding may serve as a reminder that older adults have the capacity to adapt to major functional deficits over time, ultimately placing greater emphasis on having a sense of meaning and purpose in life in perceptions of quality of life. Additionally, LTSS may provide greater access to interventions designed to improve or delay progression of deficits. Since BADLs are a common focus of all LTSS providers, findings also may suggest the value of targeted, evidence-based interventions, designed to promote mobility or enable feeding, bathing and toileting. Perhaps the combination of focused LTSS interventions and the social contact provided by care team members in their delivery contributed to this unanticipated directional change. These findings require further exploration.

Overall, findings suggest that a complex, interconnected set of factors is associated with quality of life among older adults receiving LTSS. To address the complex needs and goals of this growing group of care recipients, substantive changes in care processes and outcomes may be necessary. The development, endorsement and use of alternative, evidence-based measures of care quality such as those suggested by study findings (e.g., placing equal attention on care processes that promote health while addressing deficits) and outcomes (e.g., considering the interaction of the most relevant domains such as emotional status and quality of life) are needed.⁷⁷ Fostering environments where services are guided by the multidimensional nature of factors that influence quality of life are needed.⁷⁸ Ultimately, agreement on a new vision that places a premium on the centrality of quality of life as the most relevant construct to guide measurement and improvement of LTSS performance is necessary.

Limitations

Since this study relied on data from a convenience sample of LTSS enrollees from three states on the east coast of the U.S, findings are not representative of entire population served by LTSS. Additionally, the diversity of enrollees from which the sample was drawn presented multiple methodological challenges. For example, due to confounding, race and ethnicity could not be included in the final model. The vast majority of LTSS recipients who identified themselves as Hispanic were recipients of H&CBS. To address this limitation, a sensitivity analysis of the final model excluding all LTSS recipients that self-identified as Hispanic revealed no changes in directional findings. Findings reported in this paper relied on average ratings; subgroup analyses are needed to examine trajectories of changes in HRQoL among diverse subgroups both within and across the LTSS provider options and explore the individual and environmental factors contributing to these differences. About 15% of the sample were assessed as having cognitive deficits in the moderate range (MMSE = 12-19), which could raise questions about the reliability of their self-reported data including the primary outcome. However, several standardized quality of life measures with an item similar to the one used in this study and designed for older adults with dementia have been validated among elders with MMSE scores as low as 10.^{27,79} Finally, the study design does not permit the identification of causal linkages.

Conclusion

Despite limitations, findings from this robust set of longitudinal data elicited directly from the voices of a diverse group of older adults advance knowledge regarding what is arguably the most important outcome of elderly LTSS recipients, quality of life. Understanding the associations between multiple HRQoL domains and quality of life over time represents a critical step in the journey to enhance the care processes and outcomes of vulnerable older adults who are served by a range of LTSS providers.

Acknowledgments

This work was supported by the National Institute for Aging and National Institutes for Nursing Research at the National Institutes of Health (R01AG025524) and the Marian S. Ware Alzheimer Program, University of Pennsylvania. The authors wish to thank the older adults participating in this study as well as the administrators and staff from the LTSS facilities who provided guidance throughout the study period.

REFERENCES

1. Kaye HS, Harrington C, LaPlante MP. Long-term care: who gets it, who provides it, who pays, and how much? *Health Affairs (Millwood)*. 2010; 29(1):11–21.
2. AHRQ. The Characteristics of Long-Term Care Users. AHRQ Research Report. Rockville, MD: Jan. 2001 AHRQ Publication No. 00-00492001AHRQ Publication No. 00-0049
3. Friedland, R.; Summer, L. Demography is not destiny, revisited. *The Commonwealth Fund*; Mar. 2005 Commonwealth Fund Pub. #789
4. Naylor MD, Kurtzman ET, Miller EA, Nadash P, Fitzgerald P. An Assessment of State-Led Reform of Long Term Service and Supports. *Journal of Health Politics, Policy and Law*. 2015; 40(3):531–574.
5. Reinhard SC, Kassner E, Houser A. How the Affordable Care Act can help move States toward a high-performing system of long-term services and supports. *Health affairs*. 2011; 30(3):447–453. [PubMed: 21383363]

6. IOM. Committee on Improving Quality in Long-Term Care, Improving the quality of long-term care. National Academy Press; Washington, DC: 2001.
7. Ware JE. Methodology in behavioral and psychosocial cancer research. Conceptualizing disease impact and treatment outcomes. *Cancer*. 1984; 53(10 Suppl):2316–2326. [PubMed: 6367942]
8. Ware JE. The status of health assessment 1994. *Annu Rev Public Health*. 1995; 16:327–354. [PubMed: 7639876]
9. Aaronson NK, da Silva FC. Prospects for the future: quality of life evaluation in prostatic cancer protocols. *Prog Clin Biol Res*. 1987; 243B:501–512. [PubMed: 3659048]
10. Fitzpatrick R, Fletcher A, Gore S, Jones D, Spiegelhalter D, Cox D. Quality of life measures in health care. I: Applications and issues in assessment. *Bmj*. 1992; 305(6861):1074–1077. [PubMed: 1467690]
11. Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *Jama*. 1995; 273(1):59–65. [PubMed: 7996652]
12. Kane RA, Kling KC, Bershadsky B, et al. Quality of life measures for nursing home residents. *J Gerontol A Biol Sci Med Sci*. 2003; 58(3):240–248. [PubMed: 12634291]
13. Gold, M.; Siegel, J.; Russell, L.; Weinstein, M., editors. Cost-Effectiveness in Health and Medicine. Oxford University Press; New York: 1996.
14. Guyatt GH, Eagle DJ, Sackett B, et al. Measuring quality of life in the frail elderly. *J Clin Epidemiol*. 1993; 46(12):1433–1444. [PubMed: 8263570]
15. Shippee, TP.; Henning-Smith, C.; Kane, R.; Lewis, T. Resident- and Facility-Level Predictors of Quality of Life in Long-Term Care. *The Gerontologist*. 2013. doi: 10.1093/geront/gnt148<http://gerontologist.oxfordjournals.org/content/early/2013/12/17/geront.gnt148.abstract>
16. Shippee, TP.; Hong, H.; Henning-Smith, C.; Kane, RL. Longitudinal Changes in Nursing Home Resident-Reported Quality of Life: The Role of Facility Characteristics. *Research on Aging*. 2014. doi:10.1177/0164027514545975<http://roa.sagepub.com/content/early/2014/08/12/0164027514545975.abstract>
17. Zubritsky C, Abbott KM, Hirschman KB, Bowles KH, Foust JB, Naylor MD. Health-related Quality of Life: Expanding a Conceptual Framework to Include Older Adults Who Receive Long-term Services and Supports. *Gerontologist*. 2013; 53(2):205–210. [PubMed: 22859435]
18. Berlowitz DR, Du W, Kazis L, Lewis S. Health-related quality of life of nursing home residents: differences in patient and provider perceptions. *J Am Geriatr Soc*. 1995; 43(7):799–802. [PubMed: 7602036]
19. Hays RD, Siu AL, Keeler E, et al. Long-term care residents' preferences for health states on the quality of well-being scale. *Med Decis Making*. 1996; 16(3):254–261. [PubMed: 8818124]
20. Samus QM, Mayer L, Baker A, et al. Characteristics and outcomes for assisted living residents with dementia: Comparing dementia-specific care units with non-dementia-specific care units. *Journal of the American Geriatrics Society*. 2008; 56(7):1361–1363. [PubMed: 18774972]
21. Kanwar A, Singh M, Lennon R, Ghanta K, McNallan SM, Roger VL. Frailty and Health-Related Quality of Life Among Residents of Long-Term Care Facilities. *Journal of Aging and Health*. 2013; 25(5):792–802. [PubMed: 23801154]
22. Kane RL, Kane RA, Bershadsky B, et al. Proxy sources for information on nursing home residents' quality of life. *J Gerontol B Psychol Sci Soc Sci*. 2005; 60(6):S318–S325. [PubMed: 16260714]
23. Kane RA, Lum TY, Cutler LJ, Degenholtz HB, Yu TC. Resident outcomes in small-house nursing homes: a longitudinal evaluation of the initial green house program. *J Am Geriatr Soc*. 2007; 55(6):832–839. [PubMed: 17537082]
24. Degenholtz HB, Rosen J, Castle N, Mittal V, Liu D. The Association Between Changes in Health Status and Nursing Home Resident Quality of Life. *The Gerontologist*. 2008; 48(5):584–592. [PubMed: 18981275]
25. Abrahamson K, Clark D, Perkins A, Arling G. Does Cognitive Impairment Influence Quality of Life Among Nursing Home Residents? *The Gerontologist*. 2012; 52(5):632–640. [PubMed: 22230491]
26. Selwood A, Thorgrimsen L, Orrell M. Quality of life in dementia—a one-year follow-up study. *Int J Geriatr Psychiatry*. 2005; 20(3):232–237. [PubMed: 15717339]

27. Brod M, Stewart AL, Sands L, Walton P. Conceptualization and measurement of quality of life in dementia: the dementia quality of life instrument (DQoL). *Gerontologist*. 1999; 39(1):25–35. [PubMed: 10028768]
28. Patrick DL. Finding health-related quality of life outcomes sensitive to health-care organization and delivery. *Med Care*. 1997; 35(11 Suppl):NS49–57. [PubMed: 9366879]
29. U.S. Department of Health and Human Services. Healthy People 2020. U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion; Washington, DC: 2010.
30. Folstein, MF.; Folstein, SE.; Fanjiang, G. Mini-Mental State Examination Clinical Guide. Psychological Assessment Resources, Inc.; Lutz, FL: 2001.
31. Folstein MF, Folstein SE, McHugh PR. “Mini-mental state”. A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*. 1975; 12(3):189–198. [PubMed: 1202204]
32. Callahan CM, Unverzagt FW, Hui SL, Perkins AJ, Hendrie HC. Six-item screener to identify cognitive impairment among potential subjects for clinical research. *Medical care*. 2002; 40(9): 771–781. [PubMed: 12218768]
33. Crum RM, Anthony JC, Bassett SS, Folstein MF. POpulation-based norms for the mini-mental state examination by age and educational level. *JAMA*. 1993; 269(18):2386–2391. [PubMed: 8479064]
34. Yohannes AM, Dodd M, Morris J, Webb K. Reliability and validity of a single item measure of quality of life scale for adult patients with cystic fibrosis. *Health and quality of life outcomes*. 2011; 9:105. [PubMed: 22117573]
35. Zimmerman M, Ruggero CJ, Chelminski W, et al. Developing brief scales for use in clinical practice: The reliability and validity of single-item self-report measures of depression symptom severity, psychosocial impairment due to depression, and quality of life. *J Clin Psychiat*. 2006; 67(10):1536–1541.
36. Sloan JA, Zhao X, Novotny PJ, et al. Relationship Between Deficits in Overall Quality of Life and Non–Small-Cell Lung Cancer Survival. *Journal of Clinical Oncology*. 2012; 30(13):1498–1504. [PubMed: 22454418]
37. Godin J, Keefe J, Kelloway EK, Hirdes J. Nursing home resident quality of life: testing for measurement equivalence across resident, family, and staff perspectives. *Qual Life Res*. 2015:1–10.
38. Naylor MD, Hirschman KB, Bowles KH, Bixby MB, Konick-McMahan J, Stephens C. Care coordination for cognitively impaired older adults and their caregivers. *Home Health Care Serv Q*. 2007; 26(4):57–78. [PubMed: 18032200]
39. Yesavage J, Brink T, TL R, et al. Development and validation of a geriatric depression screening scale: a preliminary report. *Journal of Psychiatric Research*. 1983; 17(1):37–49. [PubMed: 7183759]
40. Katz, I.; Parmalee, P. Assessment of depression in patients with dementia. In: Lawton, M.; Holmes, D.; Ory, M., editors. *Measurement in elderly chronic care populations*. Springer; New York, NY: 1997. p. 90–103.
41. Conradsson M, Rosendahl E, Littbrand H, Gustafson Y, Olofsson B, Lövheim H. Usefulness of the Geriatric Depression Scale 15-item version among very old people with and without cognitive impairment. *Aging & Mental Health*. 2013; 17(5):638–645. [PubMed: 23339600]
42. Gharacholou SM, Reid KJ, Arnold SV, et al. Cognitive Impairment and Outcomes in Older Adult Survivors of Acute Myocardial Infarction: Findings from the TRIUMPH Registry. *American heart journal*. 2011; 162(5):860–869. e861. [PubMed: 22093202]
43. Heidrich SM, D’Amico D. Physical and mental health relationships in the very old. *J Community Health Nurs*. 1993; 10(1):11–21. [PubMed: 8496721]
44. Heidrich SM, Ryff CD. Physical and mental health in later life: the self-system as mediator. *Psychol Aging*. 1993; 8(3):327–338. [PubMed: 8216953]
45. Heidrich S. The self, health, and depression in elderly women. *West J Nurs Res*. 1994; 16(5):544–555. [PubMed: 7992492]
46. Uhlmann RF, Larson EB. Effect of education on the mini-mental state examination as a screening test for dementia. *J Am Geriatr Soc*. 1991; 39(9):876–880. [PubMed: 1885862]

47. Anthony JC, LeResche L, Niaz U, von Korff MR, Folstein MF. Limits of the 'Mini-Mental State' as a screening test for dementia and delirium among hospital patients. *Psychol Med.* 1982; 12(2): 397–408. [PubMed: 7100362]
48. Katz S, Akpom CA. Index of ADL. *Med Care.* 1976; 14(5 Suppl):116–118. [PubMed: 132585]
49. Edwards MM. The reliability and validity of self-report activities of daily living scales. *Canadian Journal of Occupational Therapy.* 1990; 57(5):273–278.
50. Ware, J.; Kosinski, M.; Turner-Bowker, D.; Gandek, B. How to Score Version 2 of the SF-12 Health Survey. QualityMetric Incorporated; Lincoln, RI: 2002.
51. Ware J Jr, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Med Care.* 1996; 34(3):220–233. [PubMed: 8628042]
52. Burke WJ, Nitcher RL, Roccaforte WH, Wengel SP. A prospective evaluation of the Geriatric Depression Scale in an outpatient geriatric assessment center. *J Am Geriatr Soc.* 1992; 40(12): 1227–1230. [PubMed: 1447439]
53. Yesavage, JA.; Brink, TL.; Rose, TL.; Adey, M. The Geriatric Depression rating scale: Comparison with other self-report and psychiatric rating scales. In: Crook, T.; Ferris, S.; Barton, R., editors. *Assessment in geriatric psychopharmacology.* Mark Powley; Madison, CT: 1983.
54. Yesavage JA, Brink TL, Rose TL, et al. Development and validation of a geriatric depression screening scale: a preliminary report. *J Psychiatr Res.* 1982; 17(1):37–49. [PubMed: 7183759]
55. Sherbourne CD, Stewart AL. The MOS social support survey. *Soc Sci Med.* 1991; 32(6):705–714. [PubMed: 2035047]
56. Gómez-Campelo P, Pérez-Moreno E, de Burgos-Lunar C, Bragado-Álvarez C, Jiménez-García R, Salinero-Fort M. Psychometric properties of the eight-item modified Medical Outcomes Study Social Support Survey based on Spanish outpatients. *Qual Life Res.* 2014; 23(7):2073–2078. [PubMed: 24563111]
57. Diggle, P.J.; Heagerty, P.; Liang, K-Y.; Zeger, S.L. *Analysis of Longitudinal Data.* Oxford University Press; 2002.
58. Laird NM, Ware JH. Random-effects models for longitudinal data. *Biometrics.* 1982; 38(4):963–974. [PubMed: 7168798]
59. Zeger SL, Liang KY. Longitudinal data analysis for discrete and continuous outcomes. *Biometrics.* 1986; 42(1):121–130. [PubMed: 3719049]
60. Maldonado G, Greenland S. Simulation Study of Confounder-Selection Strategies. *Am J Epidemiol.* 1993; 138(11):923–936. [PubMed: 8256780]
61. Vittinghoff, E.; Glidden, D.; Shiboski, S.; McCulloch, C. *Regression Methods in Biostatistics: Linear, Logistic, Survival, and Repeated Measures Models.* Springer; New York, NY: 2005.
62. Friedman SM, Steinwachs DM, Rathouz PJ, Burton LC, Mukamel DB. Characteristics Predicting Nursing Home Admission in the Program of All-Inclusive Care for Elderly People. *The Gerontologist.* 2005; 45(2):157–166. [PubMed: 15799980]
63. Kenny AM, Bellantonio S, Fortinsky RH, et al. Factors Associated With Skilled Nursing Facility Transfers in Dementia-specific Assisted Living. *Alzheimer Disease & Associated Disorders.* 2008; 22(3):255–260. [PubMed: 18580590]
64. Rosenberg PB, Mielke MM, Samus QM, et al. Transition to Nursing Home From Assisted Living Is not Associated With Dementia or Dementia-Related Problem Behaviors. *Journal of the American Medical Directors Association.* 2006; 7(2):73–78. [PubMed: 16461247]
65. Young Y. Factors Associated With Permanent Transition From Independent Living to Nursing Home in a Continuing Care Retirement Community. *Journal of the American Medical Directors Association.* 2009; 10(7):491–497. [PubMed: 19716066]
66. Helvik AS, Engedal K, Benth JS, Selbaek G. A 52 month follow-up of functional decline in nursing home residents - degree of dementia contributes. *Bmc Geriatr.* 2014;14. [PubMed: 24484314]
67. McConnell ES, Branch LG, Sloane RJ, Pieper CF. Natural history of change in physical function among long-stay nursing home residents. *Nurs Res.* 2003; 52(2):119–126. [PubMed: 12657987]

68. McConnell ES, Pieper CF, Sloane RJ, Branch LG. Effects of Cognitive Performance on Change in Physical Function in Long-Stay Nursing Home Residents. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*. 2002; 57(12):M778–M784.
69. Shippee TP, Henning-Smith C, Rhee TG, Held RN, Kane RL. Racial Differences in Minnesota Nursing Home Residents' Quality of Life: The Importance of Looking Beyond Individual Predictors. *Journal of Aging and Health*. 2015
70. Zimmerman S, Sloane PD, Williams CS, et al. Dementia care and quality of life in assisted living and nursing homes. *Gerontologist*. 2005; 45(Spec No 1(1)):133–146. [PubMed: 16230760]
71. Cummings SM. Predictors of Psychological Well-being among Assisted-Living Residents. *Health & Social Work*. 2002; 27(4):293–302. [PubMed: 12494721]
72. Gitlin LN, Hodgson N, Piersol CV, Hess E, Hauck WW. Correlates of Quality of Life for Individuals with Dementia Living at Home: The Role of Home Environment, Caregiver, and Patient-related Characteristics. *The American Journal of Geriatric Psychiatry*. 2014; 22(6):587–597. [PubMed: 23890928]
73. Meeks S, Van Haitsma K, Kostiwa I, Murrell SA. Positivity and Well-being Among Community-Residing Elders and Nursing Home Residents: What Is the Optimal Affect Balance? *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. 2012; 67(4):460–467.
74. Wilson CB, Davies S, Nolan M. Developing personal relationships in care homes: realising the contributions of staff, residents and family members. *Ageing & Society*. 2009; 29(07):1041–1063.
75. Morley JE. Aging in Place. *Journal of the American Medical Directors Association*. 2012; 13(6): 489–492. [PubMed: 22682696]
76. Sloane PD, Zimmerman S, Williams CS, Reed PS, Gill KS, Preisser JS. Evaluating the Quality of Life of Long-Term Care Residents With Dementia. *The Gerontologist*. 2005; 45(suppl 1):37–49. [PubMed: 16230748]
77. Dewar B, Nolan M. Caring about caring: Developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies*. 2013; 50(9):1247–1258. [PubMed: 23427893]
78. Xu D, Kane RL, Shamlivan TA. Effect of nursing home characteristics on residents' quality of life: a systematic review. *Archives of gerontology and geriatrics*. 2013; 57(2):127–142. [PubMed: 23623273]
79. Logsdon RG, Gibbons LE, McCurry SM, Teri L. Assessing quality of life in older adults with cognitive impairment. *Psychosom Med*. 2002; 64(3):510–519. [PubMed: 12021425]

Figure 1.
Number of LTSS recipients who were screened, enrolled and completed study.

Table 1

Measurement Domains¹⁷ and Data Collection Instruments

Measurement Domains ¹⁷	Data Collection Instruments	Instrument Description
Health Related Quality of Life		
Quality of Life (outcome variable)	Single item overall quality of life rating ³⁴⁻³⁶	Five point Likert scale (1-5) with higher score suggesting higher overall quality of life.
Symptom Status	Symptom Bothers Scale ⁴³	13 items summed to create a total number of symptoms.
Functional Status	Mini Mental State Examination [MMSE] ³¹ *Katz Basic Activities of Daily Living [BADL] ⁴⁸	MMSE: range 0-30; Lower score suggests greater cognitive impairment. BADL: range 0-6; Lower score suggests increased functional deficits.
General Health Perception	Medical Outcomes Survey Short Form [SF-12 v2] ⁵⁰ - Physical Composite Score [SF-12 PCS]	Composite score that ranges from 0-100; Higher score suggests better overall physical health perception.
Emotional Status	Geriatric Depression Scale [GDS] ³⁹ Medical Outcomes Survey Short Form [SF-12 v2] ⁵⁰ - Mental Composite Score [SF-12 MCS]	Range: 0-15; Higher score suggests increased depressive symptoms present. Composite score that ranges from 0-100; Higher score suggests better overall emotional well-being
Social Support	Medical Outcomes Survey-Social Support Survey [Social Support] ⁵⁵ - Emotional or Informational - Tangible - Affection - Positive Social Interaction	Five point Likert scale rating (1-5). Higher subscale score suggests increased feelings of each of these dimensions of social support.
Characteristics		
Individual	Date of birth, gender, marital status, race, education, income	Collected at baseline only.
Environment	Context of LTSS (i.e., H&CBS, ALF or NH)	
Resource Use	Total number of hospitalizations and hospice days	

* Asked of formal (e.g., certified nurse assistant, home health aides) or informal (e.g., family) caregivers for enrollees with MMSE<24. H&CBS=Home and community based services; ALF=Assisted living facilities; NH=nursing homes.

Table 2
Sociodemographic and Clinical Characteristics of Older Adults Receiving Long Term Services and Supports, N=470

Variable	N (%) or mean±SD (range)
Characteristics of the Individual	
Gender: Female	334 (71.06)
Marital Status	
Married	93 (19.78)
Widowed	243 (51.70)
Separated or Divorced	82 (17.45)
Single (never married)	51 (10.85)
Unknown/Not reported	1 (0.21)
Race	
White	239 (50.85)
African American	162 (34.47)
More than one race	57 (12.13)
Other (Asian/ Native Hawaiian or Pacific Islander/ American Indian or Alaskan Native)	9 (1.91)
Not Reported	3 (0.64)
Ethnicity, <i>Hispanic</i>	93 (19.79)
Age (<i>years</i>)	80.88±8.71 (60-98)
Education (<i>years</i>)	11.89±4.42 (0-26)
Missing	1 (0.21)
Number of Chronic Conditions ⁺	8.63±3.94 (1-27)
0-4	70 (14.89)
5 to 8	182 (38.72)
>8	218 (46.38)
Health Related Quality of Life Domains	
Symptom Status	
Number of Symptoms	6.1±3.2 (0-13)
0 to 3	104 (22.13)
4 to 8	234 (49.79)
> 8	158 (33.62)
Missing	18 (3.83)
Functional Status	
Cognitive - Mini Mental State Examination (MMSE)	23.96 ±4.29 (12-30)
No or little cognitive impairment	278 (59.15)
Mild cognitive impairment	115 (24.47)
Moderate cognitive impairment	73 (15.53)

Variable	N (%) or mean±SD (range)
Missing or unable to complete	4 (0.85)
Basic Activities of Daily Living	4.3 ±1.9 (0-6)
Number with no functional deficits	25 (5.32)
Number with 1-3 functional deficits	108 (22.98)
Number with 4 or more functional deficits	92 (19.57)
Missing or unable to complete	17 (3.62)
General Health Perception	
SF-12 Physical Composite Score	49.01±10.52 (13.89-76.18)
Missing or unable to complete	17 (3.62)
Emotional Status	
Depressive Symptoms (GDS-SF)	4.55 ±3.39 (0-15)
0-4 normal	269 (57.23)
5-10 suggestive of mild to moderate depression	173 (36.81)
10 suggestive of severe depression	53 (11.28)
Emotional Well-being (SF-12 Mental Composite Score)	37.27±10.95 (12.60-61.31)
Missing or unable to complete	17 (3.62)
Medical Outcomes Survey - Social Support	
Emotional or Informational	2.72 ±1.02 (0-4)
Tangible	2.97 ±0.95 (0-4)
Affection	2.79 ±1.18 (0-4)
Positive Social Interaction	2.46 ±1.14 (0-4)
Overall Quality of Life *	2.97±1.07 (1-5)
Excellent	40 (8.51)
Very Good	101 (21.49)
Good	157 (33.40)
Fair	127 (27.02)
Poor	35 (7.45)
Missing	10 (2.13)
Characteristics of the Environment	
Assisted Living	156 (33.19)
Nursing Home	158 (33.62)
Home and Community Based	156 (33.19)
Resource Use Prior to LTSS	
One or more hospitalizations in last 3 months	101 (21.49)
Missing or unable to complete	2 (<1.0)

SD=standard deviation;

⁺ Number of chronic conditions was limited by the clinical documentation system used by one of the H&CBS. An additional review of records and outreach to primary care physicians was conducted to confirm accuracy of number of chronic conditions (80% response rate). Percent may not add to 100 due to rounding.

* Overall quality of life median=3.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 3
Bivariate Mixed Effects Models Predicting Quality of Life over Time for Older Adults Receiving LTSS

Main Effects for Dependent Variable (Domain)	PE	SE	95% CI	p-value
Characteristics of the Individual				
Gender (Female)	0.042	0.082	-0.120 - 0.203	0.613
Age (years)	0.012	0.004	0.004 - 0.021	0.004
Education (years)	0.051	0.008	0.036 - 0.067	<0.001
Number of Comorbid Conditions	0.017	0.010	-0.002 - 0.035	0.083
Symptom Status				
Number of Symptoms	-0.070	0.007	-0.084 - -0.055	<0.001
Functional Status				
Cognitive - Mini Mental State Examination (MMSE)	0.018	0.005	0.009 - 0.027	<0.001
Basic Activities of Daily Living	0.053	0.011	0.030 - 0.075	<0.001
General Health Perception				
SF-12 Physical Composite Score	0.023	0.002	0.019 - 0.027	<0.001
Emotional Status				
Depressive Symptoms (GDS-SF)	-0.129	0.006	-0.142 - -0.117	<0.001
Emotional Well-being (SF-12 Mental Composite Score)	0.023	0.002	0.020 - 0.026	<0.001
Social Support				
Emotional or Informational	0.170	0.021	0.128 - 0.211	<0.001
Tangible	0.169	0.023	0.123 - 0.215	<0.001
Affection	0.128	0.019	0.091 - 0.165	<0.001
Positive Social Interaction	0.149	0.019	0.112 - 0.186	<0.001
Characteristics of Environment				
Assisted Living	0.641	0.085	0.475 - 0.808	<0.001
Nursing Home	0.197	0.086	0.029 - 0.365	0.022
Home and Community Based	Reference			

Main Effects for Dependent Variable (Domain)	PE	SE	95% CI	p-value
Resource Use				
Number of rehospitalizations	-0.057	0.030	-0.116 - 0.003	0.063
Not enrolled in Hospice	0.271	0.168	-0.081 - 0.622	0.124
Time (Months)	-0.003	0.002	-0.006 - 0.001	0.179
Time Interactions with Dependent Variable (Domain)				
Characteristics of the Individual				
Time × Gender (Female)	-0.001	0.004	-0.010 - 0.007	0.753
Time × Age (years)	0.000	0.000	-0.001 - 0.000	0.210
Time × Education (years)	0.000	0.000	-0.001 - 0.001	0.497
Time × Number of Comorbid Conditions	0.000	0.001	-0.001 - 0.001	0.661
Symptom Status				
Time × Number of Symptoms	0.000	0.001	-0.001 - 0.001	0.770
Functional Status				
Time × Cognitive impairment (MMSE)	0.001	0.000	0.000 - 0.002	0.003
Time × Basic Activities of Daily Living	0.001	0.001	-0.001 - 0.003	0.328
General Health Perception				
Time × SF-12 Physical Composite Score	0.000	0.000	0.000 - 0.000	0.685
Emotional Status				
Time × Depressive Symptoms (GDS-SF)	0.000	0.001	-0.001 - 0.001	0.768
Time × Emotional Well-Being (SF-12 Mental Composite Score)	0.000	0.000	0.000 - 0.000	0.909
Social Support				
Time × Emotional or Informational	-0.001	0.002	-0.005 - 0.003	0.570
Time × Tangible	0.001	0.002	-0.004 - 0.005	0.704
Time × Affection	0.002	0.002	-0.002 - 0.005	0.341
Time × Positive Social Interaction	0.000	0.002	-0.004 - 0.003	0.824
Characteristics of Environment				

Main Effects for Dependent Variable (Domain)	PE	SE	95% CI	p-value
Time × Assisted Living Facilities	0.000	0.004	−0.009 - 0.008	0.934
Time × Nursing Home	0.001	0.005	−0.009 - 0.010	0.853
Time × Home and Community Based Services	Reference			
Resource Use				
Time × Number of Rehospitalizations	0.002	0.004	−0.006 - 0.009	0.655
Time × Not enrolled in Hospice	0.002	0.024	−0.046 - 0.049	0.951

Time = 3 month intervals through 24 months. PE = Parameter Estimate; SE = Standard Error; CI=Confidence Interval. GDS-SF = Geriatric Depression Scale – Short Form. SF-12 =Medical Outcomes Short Form 12-item.

Table 4
Multivariable Mixed Effects Models Predicting Quality of Life over Time for Older Adults Receiving Long Term Services and Supports

Variable	PE	SE	95% CI	p-value
Functional Status				
Cognitive – Mini Mental State Examination (MMSE)	0.002	0.007	-0.011 - 0.015	0.771
Basic Activities of Daily Living	-0.027	0.012	-0.050 - -0.004	0.023
General Health Perception				
SF-12 Physical Composite Score	0.024	0.002	0.020 - 0.028	<0.001
Emotional Status				
Depressive Symptoms (GDS-SF)	-0.071	0.008	-0.087 - 0.056	<0.001
Emotional Well-being (SF-12 Mental Composite Score)	0.020	0.002	0.016 - 0.024	<0.001
Social Support				
Emotional or informational	0.061	0.021	0.019 - 0.102	0.004
LTSS Context				
Assisted Living Facilities	0.307	0.067	0.177 - 0.438	<0.001
Nursing Home	0.106	0.069	-0.029 - 0.241	0.122
Home and Community Based Services	Reference			
Time (3 months)	-0.038	0.010	-0.058 - -0.017	<0.001
Time interaction				
Time × MMSE	0.002	<0.001	0.001 - 0.002	<0.001

Time = 3 month intervals through 24 months. PE = Parameter Estimate; SE = Standard Error; CI=Confidence interval. GDS-SF = Geriatric Depression Scale – Short Form. SF-12 = Medical Outcomes Short Form 12-item.