

8-17-2009

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**Longitudinal Evaluation of Quality of Life in Older Persons
With Advanced Illness**

A Thesis Submitted to the
Yale University School of Medicine
in Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

by
Rachel Solomon
2009

Longitudinal Evaluation of Quality of Life in Older Persons with Advanced Illness

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Background

Efforts to understand and evaluate quality of life (QoL) among persons with chronic disease have resulted in the development of indices that measure QoL according to the severity of disease, symptoms, and functional impairments. By definition, inclusion of these domains presumes that QoL declines as illness progresses. However, this assumption may not reflect the subjective experience of QoL in older persons with advanced illness. There has been little empiric longitudinal study of QoL in this population.

Methods

At interviews performed at least every four months for up to two years (more frequently for individuals with significant changes in their health status), 185 community-dwelling individuals ≥ 60 years of age with advanced cancer, heart failure, or chronic obstructive pulmonary disease were asked "How would you rate your overall quality of life?" Response choices included: worst possible, poor, fair, good, and best possible.

Results

We identified four different QoL trajectories which we defined as: *improving* (QoL rating in at least one interview was higher than that at the previous interview and either improved or remained the same at each of the subsequent interviews); *worsening* (QoL rating in at least one interview was lower than that at the previous interview and either declined further or remained the same at each of the subsequent interviews); *no change* (QoL ratings at each time point were the same); and *variable* (there were two or more changes in the direction of the trajectory over time; e.g. QoL improved then worsened or vice versa). Nearly one-half (49%), of participants reported variable QoL trajectories. Among participants who died during the study, 46% reported good or best possible quality of life at the last interview and 21% reported improvement in QoL from the second-to-last to final interview.

Functional status, symptoms, self-rated health, social support, and religious identity were associated with QoL in bivariate analysis; in multivariable analysis, greater activities of daily living disability and depressed mood were significantly associated with a lower QoL, while higher self-rated health and feeling closer to one's religious community were significantly correlated with higher QoL ratings.

Conclusions

Declining QoL is not an inevitable consequence of advancing illness, but rather appears to be highly variable over time. Although QoL may decline with objective measures of worsening illness, a sense of closeness to a religious community and higher subjective ratings of health appear to preserve QoL despite worsening illness.

Acknowledgements

The years teach much which the days never knew. ~Ralph Waldo Emerson

I dedicate this thesis to my beloved elders – Nana, Aunt Anna, Uncle Johnny, Aunt Zosia, and Michaela Scotto – for painting into my awareness the pains and joys of aging. In particular, to the memory of my grandmother, Stephanie Bissonnette, whose life was my beginning. And, to Mickey for inspiring in me the courage to start fresh, for seeing my truth before I knew it, and for continuing to try new things even as you approach a full century of living.

I am tremendously grateful to the mentors who helped me to shape this project. Thank you, to Paul Kirwin, for enduring guidance, enthusiasm, and encouragement throughout. And to Terri Fried who offered tireless support as I struggled to find clarity in our data and the words to describe our findings: your generosity with your time and your example as role model and mentor through these four years have made formative contributions to my medical education and development.

Thank you also to Peter van Ness and John O’Leary for making our questions priorities and for creating the complicated statistical models that allowed us to find answers.

Finally, to my family, for your patience and support through all of the wanderings that eventually led me back home.

Funding for this research was provided by Summer Training in Aging Research Topics – Mental Health (START-MH, a program of the NIMH), the NIA, and the VA HSR&D.

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Introduction

Worldwide, in both developed and developing countries, increasing life expectancies and declining fertility rates are resulting in rapid growth of the population of people aged 65 and above.¹ Indeed, by 2030, the global population of older adults is expected to increase from 420 million in 2000 to 973 million.² The same trend holds true in the United States where the number of individuals aged 65 and older is projected to double such that, by the year 2030, an estimated 71 million older adults will account for approximately 20% of the U.S. population.³ The medical interventions and prevention efforts that have contributed to increasing life expectancies have also prompted a transition in leading causes of death from acute illness and infectious disease to chronic, non-communicable diseases. As compared to younger population sub-groups, older adults are disproportionately affected by chronic illnesses. In the United States, for example, 80% of older adults are living with at least one chronic condition and 50% have at least two.² In specific, cancer, diabetes, and diseases of the heart and circulatory system now represent some of the main causes of mortality, morbidity, and disability in old age.³⁻⁵

Quality of life (QoL) is emerging as a key endpoint in assessing both the effectiveness of interventions and the maintenance of good health in the elderly.^{4,6,7} A multidimensional and highly subjective construct, QoL has been characterized by the World Health Organization (1993) as:

...the individual's perception of their position in life in the context of the culture and value systems in which they live and in relationship to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a

*complex way by a person's physical health, psychological state, level of independence and their relationships to salient features of their environment.*⁷

Interest in QoL as a valuable treatment outcome is reflected in a growing body of literature; and is corroborated by descriptions of QoL as an indicator of overall patient well-being, a predictor of patient outcomes, and a barometer in evaluating the effectiveness of therapeutic interventions.⁸ It has also been suggested that impaired QoL may result in patient non-adherence to treatment.^{4,9}

Both aging and chronic illness may be expected to present multiple, often repeated, challenges to QoL. Changes in domains such as physical health, psychological well-being, and the social support networks of individuals may result in declines in functionality, independence, social interaction, and community involvement.^{4,6,7,10} In addition, older people, especially women, are frequently charged with increased caregiving responsibilities at home which may both engender physical strain and cause individuals to become more distant from their social networks.⁴ As any of these challenges experienced independently might be expected to negatively impact QoL, multiple, overlapping insults – as are likely to be experienced in the setting of aging compounded by chronic illness – might also be expected to effect declines in QoL. Further, in older patients with advanced illness for whom little can be done to alter disease trajectories, maintaining QoL becomes an increasingly important goal of care.^{4,7,}
¹⁰ Yet, little is known about the experience of QoL in this population.

Quality of Life: Conceptualization and Measurement in the Literature

In the setting of increasingly effective medical interventions that more reliably allow for the postponement of death, traditional measures of treatment outcomes such as mortality or technical success have been complemented by a growing interest in assessing the quality of lives preserved despite chronic disability.^{4, 7} Indeed, over the past three decades, there has been a proliferation of work evaluating QoL as a key outcome. Indeed, according to Hickey, a literature search for ‘Quality of Life’ on MEDLINE yielded no publications relating to QoL in 1973, one publication in 1974, and almost 1600 publications in 2004.⁴ But even as interest in QoL has burgeoned, efforts to define and operationalize the construct remain an active source of controversy.^{4, 6, 7, 11} Gill and Feinstein (1994), in their appraisal of QoL measurements in the literature, found that QoL was defined in only 11 of the 75 articles they reviewed.⁸ Others have found the term ‘quality of life’ to be used interchangeably with such terms as health-status, functional status, subjective well-being, life satisfaction, and functional disability.⁴

More recently, consensus has developed around QoL as a multidimensional and highly subjective construct.^{4, 6-8, 10-12} As stated by Kutner, “QoL consists of physical, emotional, social, cognitive, and spiritual components and appears to be a function of the gap between an individuals’ hopes and expectations and their actual experience.”¹⁰

Further efforts to standardize definitions have resulted in differentiation between QoL, as defined by the WHO (see above), and a more narrowly defined health-related quality of life (HR-QoL). Whereas the WHO characterization of QoL accounts for the influences

of cultural context, value systems, psychological state, and environment as well as physical health and function, Patrick and Erickson have limited the definition of HR-QoL to “*the value assigned to the duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy.*”⁴ Notably, however, the standardized measures of QoL that have grown out of these distinct definitions have been roundly criticized by researchers who hold that patients do not distinguish between health-related and non-health-related aspects of their lives when asked to evaluate their QoL.^{8, 11}

More significantly, it has been argued that standardized scales narrow the definition of QoL by depersonalizing a construct that is largely reflective of individual exposures and experiences.^{4, 6, 7, 11} Proponents of this critique argue that predefining components of QoL and assigning them equivalent value assumes that individuals are referencing a shared set of factors when asked to qualify their QoL. Standardized scales, they argue, impose an external frame of reference on individuals who may ascribe little meaning to the designated domains or who may assign varying degrees of priority to the elements selected.^{4, 6} As O’Boyle notes, QoL is akin to ‘happiness’ inasmuch as we all recognize the term but understand it slightly differently.⁴ In keeping with the logic put forth by these arguments, QoL should be treated as a completely personal construct that can only be defined by the patient.^{7, 8, 11}

This line of thinking is bolstered by a lack of data identifying constituent elements of QoL and the suggestion that related factors, if there are universals, may be different

among people in different phases of life.^{4,6,7,11} Although there is a growing literature exploring QoL in the elderly, much of the research to-date has employed measures developed for use in younger populations which fail to include QoL-related concerns specific to older individuals.^{4,7} While there is little agreement as yet regarding how best to assess QoL in the elderly, findings that expectations and priorities change with advancing age suggest that applying standardized definitions of QoL to this subpopulation may fail to elucidate QoL as it is experienced by older individuals.^{4,6,11}

Physical Function and QoL: The Adaptation Hypothesis

Of particular interest as relates to QoL in the elderly and disabled is the question of the relationship of QoL to physical function. While QoL is generally agreed to be a multidimensional construct comprising both health-related and subjective components.^{4,6-8,10-12} measures of QoL in the health literature have tended to reference domains that can be objectively measured such as physical function, symptoms, and disease processes.^{4,7,12,13} By definition this conceptualization presumes that QoL worsens as health-status declines. Although there is some evidence to support a correlation between health-status and QoL,^{11,14,15} a growing body of literature demonstrates that patients adapt psychologically to the declines in function that occur as a result of illness or aging.^{7,10,12,13,16,17} Two phenomena have been identified to characterize this process. The first, dubbed the “disability paradox,” describes the preservation of QoL noted in populations of terminally ill, disabled, and elderly adults despite declines in physical health.^{4,10} The “response shift” hypothesis addresses this phenomenon by suggesting that people

recalibrate as health declines and that subjective response to the global question “How is your QoL?” may change as people adapt to their altered physical capacity.¹²

Findings compatible with adaptation suggest that QoL may not be directly correlated with health-status and, in turn, that decline in QoL may not be an inevitable consequence of disease progression.

Resilience

Another process that may contribute to preservation of QoL despite challenges to physical function is resilience. As with QoL, consensus regarding a definition of resilience has been difficult to achieve. However, it is now broadly understood to be a process of positive adaptation involving both internal traits (such as hardiness and high self-efficacy) and external factors (such as social support)^{18, 19} that fosters “the capacity to remain well, recover, or even thrive in the face of adversity.”¹⁹ More simply, resilience is described as the ability to “bounce back” from highly stressful or traumatic situations.^{16, 19, 20} Although some researchers suggest that resilience, reflective of personality, is likely to remain stable across the lifespan,^{18, 21} others note a lack of longitudinal studies and suggest that, as in the case of QoL, the operational definition may be different at different stages of development.²² Further, it has been suggested that aging, by virtue of survivorship, may be associated with increased resilience.²¹ Because survivorship often selects for adaptational competence, older adults may tend to be a more resilient socio-demographic sub-population, and, therefore, better equipped to adapt to the challenges of illness and disability experienced later in life.

While the relationship between resilience and QoL is not yet well understood, Lawford (2001) has proposed that resilience may be a central concept in a theoretical model of QoL.¹⁸ Resilience and QoL, she notes, are similar constructs in that both are multidimensional, latent (they are subjective experiences that cannot be directly observed or measured), and demonstrate high internal variability (i.e. people may be compromised in one domain but not in others). She suggests that the preservation of QoL in subsets of populations facing common challenges (e.g. terminal illness, the loss of a loved one) may, therefore, be attributable to factors responsible for promoting resilience. In other words, the same “protective factors” that promote resilience – for example, high self-esteem, internal locus of control, strong role models – may both inform and, in turn, “protect” self-assessment of QoL. Resilient individuals, by virtue of enhanced adapting and coping skills, may be better insulated against declines in QoL.

While data supporting this relationship is scarce, a positive correlation between QoL and resilience in the elderly is suggested by research that shows the two constructs to have similar associations. For example, Montross et al found that both QoL (measured using the MOS-SF-36) and resilience (measured using the CD-RISC) were preserved among community-dwelling older adults who subjectively identified themselves as “aging successfully” despite having common chronic physical illnesses and disabilities.²³ Additionally, the three factors found by Hardy et al to be associated with resilience in non-disabled, community-dwelling elders – freedom from functional disability, few depressive symptoms, and high self-rated health – are among those demonstrated to be associated with QoL.^{6, 16, 19, 24-28}

In summary, resilience, like “response shift,” may act to preserve QoL in older individuals challenged by declining function; and may thereby protect against decline in QoL as an inevitable consequence of disease progression.

Measuring QoL in the Elderly and Terminally Ill

Although standardized instruments are intended to more reliably and comprehensively measure QoL,^{4,7} many existing scales may, as the adaptation and resilience literature suggests, underestimate QoL in older, terminally ill, or disabled individuals by assigning value to physical function and by failing to include – or allow for prioritization of – areas of greater concern to the individuals assessed.^{4,7} Subjective, global measures have been proposed as an alternative to standardized scales in assessing QoL.⁸ Whereas standardized scales define QoL in terms of pre-specified domains, a global question, such as “How would you rate your overall quality of life?” recognizes QoL to be a highly personal construct and allows patients to reference their internal definitions of QoL.^{6,8,11}

Studies employing subjective measures to evaluate QoL in older adults support the contention that standardized scales may not be accurately assessing QoL in this subpopulation. Indeed, in a prior study, Covinsky et al. found discordance between self-assessed global quality of life and objectively measured health-status in a significant proportion of older patients surveyed. These results imply that, for individual patients, assumptions about overall QoL should not be tied to objective health-status markers alone.¹¹ Likewise, Bowling has determined that older adults asked to subjectively self-

assess QoL appear to be referencing such factors as social comparisons and expectations, personality and psychological characteristics, and social capital – domains frequently unaccounted for by standardized measures.⁶

The concerns of terminally ill patients asked to self-assess QoL may be similarly mischaracterized by standardized scales. In an older, terminally ill population receiving Hospice care, Kutner et al found that subjective QoL was preserved despite compromised functional status and troublesome symptoms.¹⁰ A semi-structured questionnaire consisting of pre-defined domains as well as a global QoL question was administered to patients. Notably, participant ratings of the physical function domains were lower than their ratings of the psychosocial and spiritual aspects, suggesting that participants may have differentially prioritized these factors when self-assessing their global QoL. A majority of the participants also endorsed strong spiritual connections, a strong sense of hope (as reflected in sustained beliefs regarding the value of life and the potential of each day), and a positive outlook on life, suggesting that factors not typically measured by standardized QoL scales may have contributed to their conceptualizations of QoL.¹⁰

In keeping with the adaptation and resilience literature, these studies suggest that the subjective approach to measurement of QoL offers important benefits in our cohort of older adults with advancing illness in whom physical function is likely to be compromised. In addition to more accurately capturing self-perceived QoL, use of a subjective measure allows for the examination of associations between patients' ratings of their QoL and specific domains of health and psychosocial status: an effort which may, in turn, reveal a broader range of factors related to QoL.

Statement of Purpose

The purpose of this study was to provide a longitudinal exploration of the subjective ratings of QoL among older adults with advanced illness. Specifically, the aims of the study were as follows:

1. To determine whether and how QoL changes over time in older persons with advanced chronic illness.
2. To examine the premise of the inevitability of decline in QoL with progression of illness by describing QoL at the end of life.
3. To identify factors associated with QoL in older adults with advanced chronic illness.

Methods

Overview

I devised the aims of this secondary data analysis. However, prior to my involvement, the dataset was collected for the Longitudinal Examination of Attitudes and Preferences (LEAP) study.

Participants

The following text describes the LEAP recruitment and enrollment process. Patients with advanced illness were identified by reviewing the charts of all persons 60 years of age or older who had received a primary diagnosis of cancer, heart failure (HF), or chronic obstructive pulmonary disease (COPD) and who were being cared for in either subspecialty outpatient practices in greater New Haven or in one of three area hospitals: a university teaching hospital, a community hospital, and a Veteran's Administration hospital. Screening and enrollment were stratified according to the diagnosis in order to enroll approximately equal numbers of patients with cancer, HF, and COPD. The human investigations committee of each of the participating hospitals approved the study protocol. All patients provided written informed consent.

Sequential charts were screened for the primary eligibility criterion, advanced illness, as defined according to either the clinical criteria used by Connecticut Hospice²⁹ or those used in the Study to Understand Prognoses and Preferences for Outcomes and Risks of

Treatment (SUPPORT).³⁰ In order to improve prognostication with respect to advanced illness, an additional eligibility criterion, need for assistance with at least 1 instrumental activity of daily living (IADL) (e.g. driving, preparing meals, doing housework, shopping, managing finances, managing medication, and using the telephone) was determined by telephone screening.^{31, 32} Patients were excluded from the study if they had cognitive impairment as measured by the Short Portable Mental Status Questionnaire and a test of executive function,³³ or if they were not full-time residents of Connecticut.

Of the 548 patients identified as eligible by chart review, 30 had physicians who did not provide permission for participation, 6 could not be reached, 24 died before they were called, and 18 declined participation. Of the 470 patients screened, 108 were excluded because they required no assistance with IADLs, 77 because of cognitive impairment, and 6 because they were not full-time Connecticut residents. Of the 279 eligible participants, 2 died before enrollment and 51 refused participation. The final sample consisted of 226 patients. Non-participants did not differ significantly from participants according to age or sex. Of eligible patients with HF, 8% refused participation as compared with 19% of patients with cancer and 25% of patients with COPD ($p = 0.02$). Of the 226 participants, 8 (4%) withdrew after the initial interview, 26 (12%) died before completing a follow-up interview, and 7 (4%) were unable to complete full follow-up interviews. Ninety eight (79%) of the surviving 124 participants consented to a second year of participation.

Only the 185 patients who underwent at least 2 interviews were included in the current study.

Data Collection

LEAP participants were interviewed in their homes at least every four months for two years or until they either became too sick to participate or died. All variables were obtained by self-report. If a participant experienced a decline in health status, as determined during a monthly telephone call, the next interview was scheduled immediately. Decline in health status was defined as a new disability in a basic activity of daily living (ADL) (e.g. ambulating, transferring, dressing, eating, drinking, personal hygiene, or taking medication), a prolonged hospitalization (≥ 7 days), a hospitalization resulting in discharge to a nursing home or rehabilitation facility, or the introduction of hospice services. This interview schedule allowed us to minimize respondent burden while continuing to obtain interviews as participants' illnesses progressed.

Of the 185 participants, 83% participated in at least 3 interviews, 66% in at least 4 interviews and 31% participated in 7 or more interviews. In the 51% of patients who died, final interviews were performed a median of 87 days prior to death (interquartile range 42, 112).

The outcome measure, assessed at each interview, was a global QoL question: "How would you rate your overall quality of life?" Response choices included *best possible*, *good*, *fair*, *poor*, or *worst possible*. In bivariate and multivariable analysis, QoL,

responses were dichotomized as *best possible/good* versus *fair/poor/worst possible* as has been done in prior studies.^{5, 11}

Given the exploratory nature of this study, we chose to evaluate a broad range of independent variables including measures of sociodemographic, health, and psychosocial status in order to identify factors that might be associated with QoL. Sociodemographic variables included age, education, sex, race/ethnicity, sufficiency of monthly income, living arrangement, and marital status.³⁴ Health status variables included self-rated health (response choices: *excellent, very good, or good* vs. *fair or poor*); number of ADL and IADL disabilities (range 0-7; scored on a 3-point scale where 0 = no help, 1 = needs help, 2 = unable to do);³⁵ self-rated life-expectancy (question: “If you had to take a guess, how long do you think you have to live?”); pain, shortness of breath, and physical discomfort in the past 24 hours (response choices: *none* vs. *mild, moderate, or severe*);^{36, 37} and death during follow-up. Symptoms selected reflect high prevalence in our cohort and likelihood of progression with time. Psychosocial variables included depressed mood measured using the 2-item PRIME-MD (Primary Care Evaluation of Mental Disorders) instrument;³⁸ anxiety (question: “How would you describe your feelings of anxiety during the last 24 hours?” with response choices: *not anxious* vs. *mildly, moderately, or very anxious*); instrumental support (question: “Could you use more help with daily tasks than you receive?” with response choices: *none* vs. *a little, some, or a lot*); emotional support (two questions: “Can you count on anyone to provide you with emotional support?” with response choices *yes* vs. *no*; and “Could you use more emotional support than you receive?” with response choices *no* vs. *a little, some, or a*

lot); close family / friend interactions (question: “How many close friends or relatives do you see at least once a month?”); primary caregiver (response choices: *spouse*, *child*, or *other*); and degree of religiosity / spirituality (five questions assessing degree of religiosity, religion as a source of strength and comfort, closeness to God, closeness to church, and spiritual growth). Health and psychosocial variables were obtained by LEAP investigators at each interview.

Data Analysis

Aim 1: To determine whether and how QoL changes over time in older persons with advanced chronic illness. For specific aim one, longitudinal evaluation of changes in QoL, we analyzed both population and participant-specific data. To evaluate change in QoL over time in the population as a whole, we characterized the frequency of QoL ratings at baseline and at the final interview.

To evaluate change in QoL over time among individual participants, we examined QoL ratings at each interview and characterized the frequency of four different trajectories of individuals’ responses. We defined these trajectories as: *improving* (QoL rating in at least one interview was higher than that at the previous interview and either improved or remained the same at each of the subsequent interviews); *worsening* (QoL rating in at least one interview was lower than that at the previous interview and either declined further or remained the same at each of the subsequent interviews); *no change* (QoL ratings at each time point were the same); *variable* (there were two or more changes in the direction of the trajectory over time; e.g. QoL improved then worsened or vice versa).

Aim 2: To examine the premise of the inevitability of decline in QoL with progression of illness by describing QoL at the end of life. For specific aim two, evaluation of QoL at the end of life, we examined two QoL outcomes according to whether the patient lived or died in bivariate analysis using the chi-square statistic. The first outcome was the QoL rating at the patient's final interview; the second was the change in QoL from the penultimate to last interviews as described by three trajectories: improved, worsened, or no change.

Aim 3: To identify factors associated with QoL in older adults with advanced chronic illness. For specific aim three, examination of the associations between health and psychosocial factors and QoL as assessed at each interview we used generalized linear mixed effect models. Variables associated with QoL in bivariate analysis with $p < 0.10$ were entered in stepwise fashion into a multivariable model. Time was included in the model regardless of significance. The correlation among variables measuring similar constructs was examined. When the correlation was >0.04 , the single variable that demonstrated the strongest association in bivariate analysis was entered into the model.

All statistical analysis was performed using SAS Version 9.1 (SAS Institute, Cary, NC).

Results

Study Population

Table 1 provides a description of the 185 participants who underwent at least two interviews. At baseline, 65% of patients reported a QoL of *best possible* or *good*; and 39% rated their health as *excellent, very good,*

Table 1. Characteristics of 185 Participants at Baseline

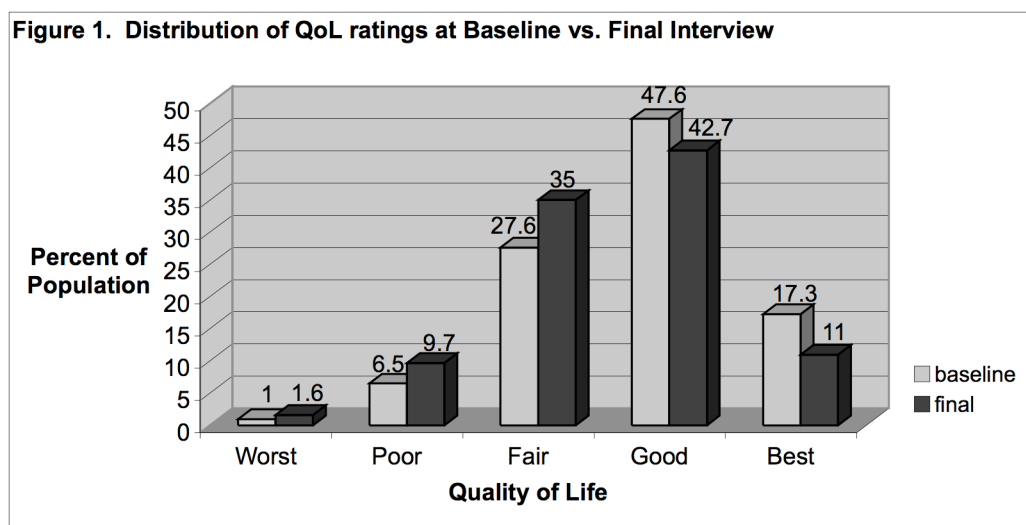
Characteristic	Value (percent)
Diagnosis	
Cancer	29
Chronic Obstructive Pulmonary Disease	40
Congestive Heart Failure	31
Age, mean \pm SD, years	73 \pm 7
Education, \geq High School	65
White race	91
Female sex	46
Married	56
Self-rated quality of life: best possible or good	64
Self-rated health: excellent, very good, or good	39
Depressed	48
Pain	48
Self-rated life expectancy	
< 2 years	12
\geq 2 years	47
Uncertain	41
\geq 2 hospitalizations in the past year	45
\geq 1 ADL disability	34
Intensive Care Unit admission in the past year	34

or *good*. In the past year, 45% had been hospitalized \geq 2 times and 34% had been admitted to an Intensive Care Unit. Only 12% estimated that they had less than 2 years to live.

Description of QoL Trajectories

As shown in **Figure 1**, among the entire cohort there was only a small shift in the distribution of QoL ratings from baseline to the final interviews. As compared to baseline, fewer participants rated their QoL as *best possible* or *good* at the final interview, and more participants rated their QoL as *fair, poor, or worst possible*. However, at both

the baseline and final interviews, a larger proportion of participants reported a *best possible* or *good* QoL than selected *worst*, *poor*, or *fair*.



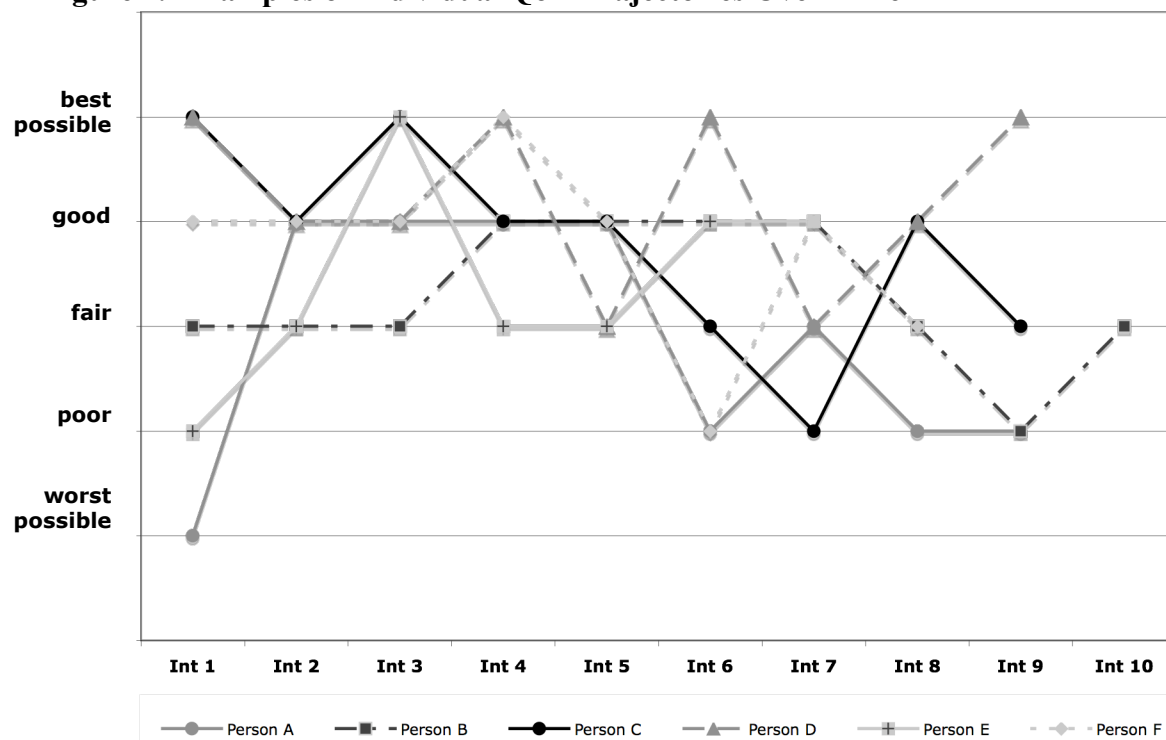
The prevalence of individual trajectories of QoL over time (improving, worsening, no change, and variable) are presented in **Table 2**. Despite the small change in ratings in the cohort overall from initial to final interview, there was great variability in ratings by individuals over time. While 22% of participants described *unchanging*, 16% reported *improving*, and 13% reported *worsening* QoL trajectories, the most frequently described trajectory as reported by close to one-half (49%) of participants was *variable*. **Figure 2** shows examples of individual participant QoL trajectories. Notably, the variability

Table 2. QoL Trajectories Measured by the Global Question Over All Interviews

Trajectory	Frequency	Percent
No Change	41	22
Worsening	24	13
Improving	29	16
Variable	91	49

in QoL that participants reported over time was not confined to a small range of closely related responses, but spanned the full range of QoL described by the response choices.

Figure 2. Examples of Individual QoL Trajectories Over Time



Characterization of QoL at the End of Life

Although a larger proportion of the participants who died, as compared to those who survived, rated their QoL as *fair/poor/worst possible* in their final interview (**Table 3**), almost one-half (46%) of those who died reported a *best possible* or *good* QoL. A larger proportion of those who died experienced a decline in their QoL from next to last to last interview; however, equal proportions of those who survived and who died reported an improved QoL (**Table 3**).

Table 3: Characterization of QoL at End of Life

	Survived (n=90)	Died (n=95)	p-value
	n (%)		
Rating at final interview			
Best possible / good	55 (61%)	44 (46%)	0.04
Change from penultimate to final interview			
Improved	17 (19%)	20 (21%)	0.008
Worsened	19 (21%)	38 (40%)	
No change	54 (60%)	37 (39%)	

Bivariate and Multivariable Correlates of Ratings of QoL

Bivariate and multivariable analyses of sociodemographic, health status, and psychosocial variables with QoL ratings revealed that there were few factors significantly associated with QoL (**Table 4**). In bivariate analysis, participants who died and participants with poorer functional status, depressed mood, pain, self-rated life expectancy of less than 2 years, anxiety, and shortness of breath were significantly more likely to report lower QoL. Participants reporting excellent, very good or good self-rated health, a sense of having grown closer to their religious community, and sufficient instrumental support were significantly more likely to have higher QoL. Time was not associated with QoL ratings. Additional variables revealing no association with QoL in bivariate analysis included demographics (age, race, gender, education, sufficiency of monthly income, living arrangement, marital status), diagnosis, IADL's, physical discomfort, emotional support, number of social interactions, and relationship to primary caregiver.

In multivariable analysis, only four variables remained significant. Greater ADL disability and depressed mood were significantly associated with a lower QoL while higher self-rated health and feeling closer to one's religious community were significantly associated with a higher QoL.

Table 4. Factors Associated with Global QoL in Bivariate & Multivariable Analysis

	Best Possible / Good QoL	
	Unadjusted OR	Adjusted OR
Greater ADL dependence	0.73 (0.65, 0.73)	0.84 (0.74, 0.94)
Depression	0.27 (0.18, 0.40)	0.39 (0.26, 0.59)
Self-rated health: Exc. / Very Good / Good	6.25 (3.85, 9.09)	4.89 (3.07, 7.79)
Grown closer to church	2.45 (1.49, 4.03)	2.21 (1.31, 3.71)
Has sufficient Instrumental Support	2.21 (1.39, 3.52)	--
Pain	0.56 (0.38, 0.82)	--
Self-rated life expectancy <2 yrs	0.56 (0.33, 0.97)	--
Died	0.62 (0.37, 1.05)	--
Anxiety	0.62 (0.43, 0.91)	--
Shortness of breath	0.68 (0.44, 1.07)	--
Time	0.98 (0.96, 1.01)	0.99 (0.97, 1.02)

Shading denotes factors that retained significance in multivariable analysis.

Discussion

Summary and implications

In this study we used a subjective, global measure – “How would you rate your overall quality of life?” – to explore the longitudinal experience of QoL among severely ill older adults; and to evaluate factors associated with QoL in this population. Our results illustrate that decline in QoL is not an inevitable consequence of advancing illness in the elderly. Whereas QoL ratings in the population overall showed only a small shift toward worsening ratings from the beginning to the end of the study period, individual QoL trajectories were highly variable; and strictly worsening trajectories were described by only a small fraction of the population. Further, QoL ratings at participants’ final interviews show that QoL was preserved both in the population as a whole and at the end of life.

Although we looked at a broad range of sociodemographic, health status, and psychosocial variables, only four factors were associated with QoL in multi-variable regression analysis. Greater ADL disability and depressed mood were significantly associated with a lower QoL while higher self-rated health and feeling closer to one’s religious community were significantly associated with a higher QoL. Notably, in support of our findings of preservation of QoL, time, a proxy for progression of disease, was not associated with QoL.

Surprisingly, we found no correlations between QoL and any of our sociodemographic variables or social or emotional support. Although instrumental support was associated with QoL in bivariate analysis, this association was not maintained in multivariable analysis. One possible explanation for this is that the effects of instrumental support were captured by self-rated health or religious participation. The absence of associations between QoL and the demographic factors age and gender is consistent with previous research in the elderly and chronically ill.^{6, 10} However, our data fail to corroborate previously identified correlations between QoL and such factors as social relationships, personal social capital (perceived social network structure and social and emotional support), social activities, and social comparisons and expectations (e.g. of financial, living, and health circumstances).^{6, 9, 16} While the effects of these psychosocial and socioeconomic factors may also be confounded with self-rated health and/or religious participation, their failure to retain significance in this population of chronically ill elderly is a significant departure from both our expectations and previous findings and, therefore, warrants further investigation.

Preservation of QoL in the majority of participants in a population challenged by both illness and aging is consistent with a growing body of literature that describes psychological adaptation to decline in function. While an association between QoL and certain dimensions of worsening health status, as seen in prior investigations,^{6, 11, 16} has been replicated in our study, no correlation between time – suggesting progression of disease – and QoL was identified. Our other marker for disease progression, death, showed a modest association with QoL in bivariate analysis but fell out of the

multivariable model suggesting confounding with physical function (as captured by level of ADL dependence). The weakness of the association between death and QoL is further supported by the high proportion of those who died during the study who endorsed good or improving QoL ratings at the end of life. Our findings related to the associations of time and death to QoL suggest that participants are in some way adjusting for the multifactorial health-status decompensations that are likely to accompany progression of illness or end of life. This “disability paradox,” the preservation of QoL despite declines in physical health, has been previously observed in populations of terminally ill, disabled, and elderly individuals.^{4, 7, 10, 12, 16}

As QoL can be understood to reflect the gap between an individual’s hopes or expectations and reality as it is experienced, “response shift” theory addresses the disability paradox by suggesting that people adapt to changing clinical situations by bringing their expectations more closely in line with their realities. According to this model, maintenance of high self-perceived QoL is accomplished by adjusting internal values, standards, or conceptualizations of QoL to accommodate changes in health status.¹² Similarly, The Berlin Aging Study describes a process of adaptation to aging characterized by *selection* (or paring down) of goals or domains of function, *compensation* for losses, and *optimization* of existing resources and abilities such that self-perceived QoL remains high.^{4, 16} Given that our participants were both elderly and chronically ill and therefore highly susceptible to changes in health status, preserved QoL in this population supports the process of psychological adaptation described in these

studies and suggests that individuals were referencing and/or prioritizing alternate domains when asked to assess their QoL.

But the variability in QoL ratings along with the paucity of factors associated with QoL in our study underscore how little we understand about the domains individuals reference when self-assessing QoL. If QoL was influenced by consistent, identifiable domains, we would have expected to see more correlations with the independent variables we explored and greater stability within the trajectories. Instead, we mapped fluctuating trajectories with little relation to our independent variables. Chochinov et al (1999) describe a similar pattern of instability in will to live among older, terminally ill cancer patients in a palliative care setting.¹⁷ Like QoL in our study, will to live appeared stable within the population. However, individual patient's scores showed significant fluctuation even within a 12-hour period, the shortest interval examined. Further, factors influencing will to live in the study population changed as patients grew closer to death. QoL may be a similarly dynamic construct. Individuals' conceptualizations of QoL – and, by extension, the factors that people reference when asked to self-assess QoL – may change with time and / or circumstance. Further, QoL may be impacted by transient experiences – like the birth of a grandchild or a visit from a friend – that temporarily inform an individual's perceived QoL by altering mood or outlook. This dynamic model of QoL is consistent with “response shift” adaptation strategies in that it suggests that people are continuously re-defining and re-prioritizing the areas they reference in self-assessing QoL. However, it also suggests that QoL may be governed by factors that are difficult to reliably measure or quantify.

Understanding QoL as an unstable construct implies that a broader, more subjective QoL measure is necessary to accurately assess self-perceived QoL in this population. If, as our findings suggest, self-perceived QoL is a highly personal and mutable construct, an effective measure would need to capture the vast, temporally sensitive, and highly individualized array of considerations that might constitute QoL for a person at any given time. Standardized QoL measures that comprise a set of largely objective, pre-defined domains do not allow for this level of individuation and are, thereby, limited in their ability to accurately capture self-perceived QoL. Subjective measures, which by definition elicit individualized responses, offer enhanced accuracy and appear, therefore, to be preferable for use in our population.

But, while strictly subjective measures may more accurately capture self-perceived QoL, the instability of QoL suggested by our findings of variability and limited associations calls into question the usefulness and reliability of subjective measures in guiding clinical interventions and decision-making. In short, although the global measure (by allowing for more highly personalized conceptualizations of QoL) transcends the conceptual limitations of objective scales, it appears to be similarly limited in its clinical value.

Three arguments support this contention. First, the subjective measure describes a highly unstable construct that is seemingly unalterable by way of discrete interventions. One of our goals, in seeking to better understand self-perceived QoL in the severely ill elderly, was to identify means of maintaining or improving QoL in individuals for whom cure is no longer likely. Although we identified several factors associated with QoL, these associations alone do not explain the degree of variability observed within the

trajectories. Indeed, our study describes self-perceived QoL as a dynamic construct, which, by definition, offers little potential for remediation. Even if clinicians attend to all of the potentially remediable variables known to be related to QoL, we are unlikely to alter self-perceived QoL in a lasting or meaningful way. If QoL improves following an intervention we do not know whether to attribute that improvement to the intervention, to psychological adaptation, or to other exposures or experiences related to that individual's natural course of being.

Second, the instability of self-perceived QoL describes a construct that is likely transient in nature. If the variability of the trajectories is attributable to transient exposures and experiences, then measured QoL, while providing important insights into a patient's well-being in a given moment, cannot be relied upon as an effective long-term index. For example, using a global QoL measure to guide treatment recommendations in a patient with terminal disease and low self-perceived QoL could be misguided given that the patient's QoL the following week might appear much improved.

Finally, in addition to describing a relatively unalterable and transient construct, the purely subjective measure of QoL is limited in its ability to predict or link to other outcomes. Whereas more objective standardized measures of QoL tend to elicit information about multiple life areas, a global measure neither identifies factors perceived to be impacting QoL; nor does it guide the clinician in evaluating – and potentially identifying – domains of concern to the patient that might be more amenable to intervention. As a growing body of work demonstrates disagreement between patients

and their proxies regarding QoL and other health-status outcomes,^{4, 7, 39} clinicians cannot assume that factors they perceive to be concerning for a patient are, in fact, problematic for that individual. These findings underscore a limitation common to both objective and subjective measures of QoL: neither comprehensively elicits information that is necessarily relevant to the maintenance or improvement of QoL. In the case of the global subjective, this shortcoming is due to a failure to evaluate for life areas that patients feel to be related to their QoL. A clinician who elicits a poor QoL rating from a patient using a global measure is afforded only that knowledge; little is garnered as regards the direction, or potential re-direction, of care. Similarly, however, a clinician who relies on a more objective standardized measure elicits information about a variety of areas of potential interest to the clinician, but may be surveying domains of little concern to the patient and missing those of greater relevance. For example, a patient who endorses a high symptom burden may neither be distressed by her symptoms nor feel that they have a negative impact on her QoL. Thus, while we entered into this investigation believing that a subjective measure might be a more accurate and, therefore, more favorable means of assessing QoL, it appears that neither purely subjective nor highly objective standardized scales provide an effective clinical assessment of QoL.

Given that accurate assessment of QoL remains critical, the shortcomings of a subjective measure of QoL in identifying potential points of intervention might be remediated with supplemental questions or guidelines. QoL, regardless of conceptualization, retains intrinsic value both as a desirable outcome and a comprehensive marker of individual well-being. Thus, while a global question is useful in accurately assessing current QoL, a

more directed evaluation would be a constructive adjunct, ensuring that clinicians familiarize themselves with patients' concerns and take time to explore with patients a variety of life areas in which they might be able to offer support. In a paper evaluating quality of life while dying in terminally ill older men, Vig (2003) suggests that in order to assist patients in meeting their goals and maximizing their QoL clinicians should be encouraged to have a dialogue with their patients in which they ask three questions: What is most important in your current life? Do you have specific concerns about the future? And, what would you consider a good death?⁹

Similarly, the SEIQoL (Schedule For Evaluation Of Individual Quality of Life) is a semi-standardized scale for the measurement of QoL based around three questions that allow for the individuation of conceptualization and maintenance of QoL: what areas of life are important to the respondent, how are they currently doing in each of these areas, and what is the relative importance of each of these areas to them.¹³ Though it has been noted to be "too complex for routine use,"⁷ the SEIQoL has been used successfully in the palliative care setting as well as in the elderly; and a shorter variant, the SEIQoL-DW, is being explored as a more user-friendly alternative.^{7, 13}

While Vig's guidelines and the SEIQoL provide examples of more comprehensive applications of a subjective measure, further exploration of the role of QoL assessment in the care of the chronically ill elderly is required to better describe appropriate clinical measurement of QoL in this population.

Notably, our finding that some people describe more predictable trajectories further supports this recommendation. While the relative stability described by members of our cohort endorsing *worsening*, *improving*, and *unchanged* trajectories may be attributable to chance and might have been diminished with more measurements, it may also signify that these individuals maintain more fixed associations and/or are less vulnerable to transient effectors. Further, there may be more of a role for aspects of personality such as optimism / pessimism or internal locus of control in these individuals. Like participants who endorsed *variable* trajectories, individuals endorsing *improving* or *unchanged* trajectories seem to be adapting to health-status decline in that they were able to maintain their QoL ratings despite progression of disease over time. This may indicate stronger buffering associations in these sub-groups (e.g. stronger connections to religious communities, increased resilience) or less experience of or susceptibility to such negative effectors as depression and functional decline. In individuals who endorsed *worsening* trajectories, however, fixed associations may have made them less adaptable to health-status decline. These individuals may have less robust buffering relationships and / or be more susceptible to negatively correlated domains. Repeated administration of a single global question over time may play an important role in identification of individuals endorsing more apparently ‘stable’ trajectories; and who may, by virtue of this increased ‘stability’ describe more consistently associated factors which may, in turn, be amenable to intervention. This type of assessment would be particularly beneficial in the detection of individuals in steady decline who might be more responsive to QoL enhancing efforts.

Even as our data echo questions about the conceptualization of QoL, our results suggest several QoL-related factors that should be explored as important points of prevention and intervention. First, of the factors we found to be negatively associated with QoL, depression represents an important point of clinical intervention for improvement of QoL. While both major depression and its more prevalent subsyndromal counterparts have been found to be strong predictors for impaired QoL in the elderly and terminally ill,^{25, 40, 41} depression in these populations often goes undiagnosed and untreated.^{40, 42} The known prevalence of depression in these populations – estimated at 5-15% of older adults^{25, 43} and up to 77% of patients with advanced illness⁴⁰ – suggests that this is a widespread problem that could easily be addressed in a setting of heightened sensitivity and regular depression screens. Further, evidence supporting the effectiveness of treatment of depression in the elderly, those with co-morbid illnesses, and the terminally ill,⁴¹⁻⁴³ recommends clear clinical interventions that would mediate both the effects of depression and, in turn, impaired QoL.

Less clear, is the significance of feeling closer to one's religious community in its association with QoL. If this variable reflects one's sense of spirituality, then its association with QoL could be interpreted as an affirmation of Kutner's contention that the QoL construct is intrinsically inclusive of a spiritual domain. This model would suggest that people in whom the spiritual domain is well-developed or maintained experience more robust QoL by virtue of the fact that (at least) one constituent element of their conceptualization of QoL remains consistently intact.

Interestingly, however, of the religious variables that we measured, closeness to G-d, spiritual growth, and religion as a source of strength and comfort had less bearing on QoL than feeling a part of a religious community. In light of the fact that social, emotional, and instrumental supports failed to retain significance in our model, closeness to one's religious community appears to be a marker for something we don't yet fully understand. Data supporting the role of religion in promoting better health outcomes and improved QoL,^{44,45} describe mechanisms including improved social supports, psychological health, and coping skills.^{45,46} Seemingly more relevant to our finding, however, is Koenig's finding that medically ill older adults who were able to provide spiritual support or comfort to others were less likely to be depressed and more likely to experience higher QoL.⁴⁴ This data is supported by a study in which elderly adults who assisted others in informal ways demonstrated greater feelings of personal control and, in turn, lower levels of depression.⁴⁷ While being closer to one's church could certainly create opportunities for the chronically ill elderly to provide support to others, further study is needed to examine both the significance of religious community and the role of giving back in the preservation of QoL.

Notably, however, if the link between feeling close to a religious community and QoL is providing support to others, then the religion variable may be confounding for resilience. In the resilience literature, extending support to others and religious involvement have both been found to be related to one another and to promote resilience.²⁰ By extension, closeness to religious community and the opportunities that this closeness may provide for individuals to "give back," may point to resilience in our participants. The notion that

resilience may contribute to preservation of QoL in our population is further supported by two findings. First, three of the four factors we found to be associated with self-perceived QoL – preservation of function, having few depressive symptoms, and high self-rated health – were found by Hardy et al to be associated with resilience in community-dwelling older persons.¹⁹ Association of high self-rated health with both preserved QoL and resilience further supports Bowling's finding that internal traits (personality or psychological predispositions such as optimism-pessimism) may play a role in the self-assessment of QoL.⁶ Second, as noted by Foster, the elderly, by virtue of having survived into old age, may demonstrate increased resilience as a population.²¹ Indeed our cohort, with a mean age of 73, is notable, at baseline, for displaying high self-rated health (39%) and high self-rated life-expectancy (47%) despite having at least one ADL deficiency (34%) and multiple hospitalizations (45%) and/or an ICU admission (34%) in the past year. The potential contributions of resilience to the preservation of QoL in our population, suggest that increased knowledge about factors that promote resilience may help us to better understand self-perceived QoL.¹⁸

The final QoL-related factor revealed by our study that requires mention as a potential point of intervention is physical function. Although a significant proportion of our participants reported preservation of QoL despite declines in health status, functional status maintained a relationship to QoL. This is a long-known, and much studied association,^{6, 11, 28} and one which, like depression, could be aptly addressed with heightened sensitivity and simple interventions at multiple points of contact within the healthcare system. Especially in older adults, among whom functional limitations are

common even outside of illness,²⁸ improved efforts can be made toward fall prevention, physical rehabilitation, and treatment of such mobility limiting conditions as urinary incontinence and osteoarthritic pain.²⁸ Further, in individuals in whom functional decline is unavoidable, counseling regarding disease progression and projected physical limitations may help patients to adjust their expectations so as to facilitate psychological adaptation. Whether via prescriptive or verbal interventions, addressing limitations to functionality in a preventative or timely manner could act to mitigate avoidable impairments to QoL.

Limitations

Although the LEAP (Longitudinal Examination of Attitudes and Preferences) dataset from which our data was drawn was extremely comprehensive in the scope of sociodemographic, health status, and psychosocial information collected, the LEAP study was not designed to assess factors associated with QoL. Our study must therefore be treated as a preliminary review. Our findings are also limited by a lack of ethnic and racial variability. While the proportion of non-white participants in our study is consistent with Connecticut demographics, this overall disparity may limit generalizability to the broader population. Finally, our study involved individuals with only three types of advanced chronic illness. Results may differ for individuals with other chronic conditions such as renal failure or dementia.

Conclusion

In summary, decline in QoL was not an inevitable consequence of advancing illness in this population of severely ill older adults. Further, QoL was found to be highly variable with few associated factors suggesting that it is a dynamic construct. While a subjective measure is likely the most accurate depiction of self-perceived QoL, a more directed survey may prove more helpful to clinicians wishing to identify potential points of intervention. In particular, clinicians should attend to depression and functionality, and assess whether patients are involved in religious communities. Given the exploratory nature of this study, further research is required to more clearly elucidate the nature of our findings.

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