

# Trajectories of Quality of Life in Older Persons with Advanced Illness

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**OBJECTIVES:** To examine subjective ratings of quality of life (QoL) in older adults with advanced illness.

**DESIGN:** Observational cohort study with interviews at least every 4 months for up to 2 years conducted between December 1999 and December 2002.

**SETTING:** Participants' homes.

**PARTICIPANTS:** One hundred eighty-five community-dwelling individuals aged 60 and older with advanced cancer, heart failure, or chronic obstructive pulmonary disease.

**MEASUREMENTS:** Participants were asked how they would rate their overall QoL.

**RESULTS:** Of participants who died, 46% reported good or best possible QoL at their final interview, 21% reported improvement in QoL from their penultimate to final interview, and 39% reported no change. Forty-nine percent of participants reported two or more changes in the direction of their QoL trajectories (e.g., QoL improved then declined). As measured over time in a multivariable longitudinal regression analysis, greater activity of daily living disability (adjusted odds ratio (AOR) = 0.85, 95% confidence interval (CI) = 0.75–0.95) and depressed mood (AOR = 0.42, 95% CI = 0.27–0.66) were associated with poorer QoL, whereas better self-rated health (AOR = 4.79, 95% CI = 2.99–7.69) and having grown closer to one's church (AOR = 1.99, 95% CI = 1.17–3.39) were associated with better QoL.

**CONCLUSION:** Although declining QoL is not an inevitable consequence of advancing illness, individuals' ratings of QoL are highly variable over time, suggesting that temporary factors may influence subjective QoL. Functional status, depression, and connection to one's religious com-

munity are shared determinants of QoL. *J Am Geriatr Soc* 58:837–843, 2010.

**Key words:** quality of life; longitudinal analysis; chronic disease

In older patients with advanced illness for whom little can be done to alter disease trajectories, maintaining quality of life (QoL) becomes an increasingly important goal of care. There has been little longitudinal study of QoL in older persons with advanced disease; evaluation of QoL is generally focused on health-related QoL (HRQoL). Measurement of HRQoL is based on an assessment of physical and mental health, including such factors as physical and emotional function, symptoms, and disease processes.<sup>1</sup> By definition, this conceptualization presumes that QoL worsens as health status declines.<sup>2,3</sup> However it has also been argued that HRQoL cannot be separated from the broader construct of global QoL.<sup>4</sup> Clinicians and patients have identified global QoL as a multidimensional construct comprising health-related and subjective components.<sup>5–8</sup> It has been proposed that, because global QoL is subjective, it is best captured with the use of a single question asking respondents to rate their overall QoL.<sup>9</sup> Although there is some evidence to support an association between health-status and global QoL,<sup>10</sup> it has also long been recognized that persons with substantial health problems or disability may report experiencing good QoL.<sup>3</sup> This finding suggests that QoL may not be directly associated with health status and, in turn, that decline in QoL may not be an inevitable consequence of disease progression. There have been few studies directly examining changes in subjective ratings of QoL over time in persons with serious illness, so the data on the extent to which health status influences subjective ratings of QoL is limited.

The purpose of this study was to provide a longitudinal examination of global QoL in older adults with advanced illness. Changes in QoL in the study cohort as a whole and

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Presented at the 2007 annual meeting of the American Geriatrics Society.

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DOI: 10.1111/j.1532-5415.2010.02817.x

in individual participants were examined. Factors associated with global QoL ratings were also evaluated to determine the relationship between QoL and health and psychosocial characteristics.

## METHODS

### Participants

Study participants were aged 60 and older; had a primary diagnosis of cancer, chronic pulmonary obstructive disease (COPD), or heart failure (HF); and were being cared for in subspecialty outpatient practices in greater New Haven or in one of three area hospitals: a university teaching hospital, a community hospital, and a Veterans Affairs hospital. The human investigations committee of each of the participating hospitals approved the study protocol. All patients provided written informed consent.

Trained research nurses screened sequential charts for the primary eligibility criterion, advanced illness, as defined according to the clinical criteria used by Connecticut Hospice<sup>11</sup> or those used in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment.<sup>12</sup> To improve prognostication with respect to advanced illness, the additional eligibility criterion of need for assistance with at least one instrumental activity of daily living (IADL)<sup>13</sup> was determined using telephone screening. Patients were excluded from the study if they had cognitive impairment, as measured using the Short Portable Mental Status Questionnaire and the Executive Interview, a test of executive functioning,<sup>14,15</sup> because the study relied on the accuracy of participant self-report, or if they were not full-time residents of Connecticut, because data collection was performed face to face. Screening and enrollment were stratified according to diagnosis to enroll approximately equal numbers of patients with cancer, HF, and COPD.

Of the 548 patients identified as eligible according to chart review, 30 had physicians who did not grant approval for further contact, 24 died before they were called, 18 declined the telephone screen, and six could not be reached for telephone screening. Of the 470 patients receiving the telephone screen, 108 were excluded because they required no assistance with IADLs, 77 because of cognitive impairment, and six because they were not full-time Connecticut residents. Of the 279 eligible participants, 51 refused participation, and two died before enrollment. The final sample consisted of 226 patients. Comparative analysis did not detect significant differences between participants and non-participants according to age or sex. Of eligible patients with HF, 8% refused participation, compared with 19% of patients with cancer and 25% of patients with COPD ( $P = .02$ ). Of the 226 participants, 26 (12%) died before completing a follow-up interview, eight (4%) withdrew after the initial interview, and seven (4%) were unable to complete full follow-up interviews. The 185 patients who underwent at least two interviews were included in the current study.

### Data Collection

Participants were interviewed in their homes at least every 4 months for 2 years or until they became too sick to participate or died. 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),<sup>16</sup> a prolonged hospitalization ( $\geq 7$  days), a hospitalization resulting in discharge to a nursing home or rehabilitation facility, or the introduction of hospice services. This interview schedule allowed respondent burden to be minimized while continuing to obtain interviews as participants' illnesses progressed. All variables were obtained using self-report.

Of the 185 participants, 83% participated in at least three interviews, 66% in at least four interviews, and 31% in seven or more interviews. In the 51% of patients who died, final interviews were performed a median of 87 days before 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.

Independent variables included measures of sociodemographic, health, and psychosocial status. Sociodemographic variables included age, education, sex, race or ethnicity, sufficiency of monthly income,<sup>17</sup> living arrangement, and marital status. Health status variables included self-rated health<sup>18</sup> (response choices: excellent, very good, or good vs fair or poor); extent of ADL disability<sup>16</sup> (range 0–14); self-rated life expectancy; pain and shortness of breath in the previous 24 hours (response choices: none vs mild, moderate, or severe). Psychosocial variables included depressed mood measured using the two-item Primary Care Evaluation of Mental Disorders instrument;<sup>19</sup> anxiety (question: "How would you describe your feelings of anxiety during the last 24 hours?" response choices: not anxious vs mildly, moderately, or very anxious); instrumental support (question: "Could you use more help with daily tasks than you receive?" response choices: none vs a little, some, or a lot); emotional support (question: "Could you use more emotional support than you receive?" response choices no vs a little, some, or a lot); number of close family or friend interactions (question: "How many close friends or relatives do you see at least once a month?" response examined in quartiles); primary caregiver (response choices: spouse, child, or other); and five questions related to spirituality or religiosity (degree of religiosity, extent to which religion was a source of strength and comfort, whether participants had, as a result of their illness grown closer to God, grown closer to church, or experienced spiritual growth).<sup>20</sup> Health and psychosocial variables were obtained at each interview.

### Data Analysis

The change in distribution of QoL ratings in the study cohort as a whole and in individual participants was examined. To evaluate the former, the frequency of QoL ratings was characterized at baseline and at the final interview, and the distribution of paired responses was compared using Bowker's test of symmetry. To evaluate the latter, QoL ratings were examined at each interview, and the frequency of four different trajectories of individuals' responses was characterized. These trajectories were defined as improving (QoL rating in at least one interview was higher than that at

the previous interview and 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 declined further or remained the same at each of the subsequent interviews); no change (QoL ratings at each time point were the same); variable (two or more changes in the direction of the trajectory over time; i.e., QoL improved then worsened or vice versa).

To evaluate QoL at the end of life, two QoL outcomes according to whether the patient lived or died were examined in bivariate analysis using the chi-square statistic. The first outcome was the QoL rating at the patient's final interview. For this analysis, QoL responses were dichotomized as best possible or good versus fair, poor, or worst possible.<sup>2,10</sup> The second outcome was change in QoL from the penultimate to last interviews as described by three trajectories: improved, worsened, or no change.

Generalized linear mixed effects models were used to examine associations between health and psychosocial factors and QoL, as assessed at each interview. Variables associated with QoL over time in bivariate analysis with  $P < .10$  were entered into a multivariable model. Time was included in the model regardless of significance. The correlation between variables measuring similar constructs was examined. When the correlation was greater than 0.3, the single variable that demonstrated the strongest association in bivariate analysis was entered into the model. All significance tests were two-sided and were regarded as statistically significant if they yielded a  $P$ -value  $< .05$ .

All statistical analysis was performed using SAS Version 9.2 (SAS Institute, Cary, NC).

## RESULTS

### Study Population

Table 1 describes the 185 participants at the start of the study. In the previous year, 45% had been hospitalized two or more times, and 34% had been admitted to an intensive care unit. Only 39% rated their health as excellent, very good, or good. In contrast to their poor health ratings, 65% of patients reported their QoL to be best possible or good. During the 2-year follow-up period, 95 participants (51%) died.

### Description of QoL Trajectories

As shown in Figure 1A, at both the baseline and final interviews, a larger proportion of participants reported best possible or good than worst possible, poor, or fair QoL. Participants' responses were not significantly different at the final interview from the baseline interview, although fewer participants rated their QoL as best possible or good at the final interview than at the baseline interview, and more participants rated their QoL as fair, poor, or worst possible.

In contrast to the small change in ratings in the cohort overall from initial to final interview, there was great variability in ratings by individuals over time. Although 22% of participants had an unchanging trajectory, 16% reported improving, and 13% reported worsening trajectories. Forty-nine percent of participants had variable trajectories. Figure 2 shows randomly selected examples of individual

**Table 1. Characteristics of Participants at Baseline (N = 185)**

Characteristic	Value
Diagnosis, n (%)	
Cancer	54 (29)
Chronic obstructive pulmonary disease	74 (40)
Heart failure	57 (31)
Age, mean $\pm$ standard deviation	73 $\pm$ 7
$\geq$ High school education, n (%)	120 (65)
White, n (%)	168 (91)
Female, n (%)	85 (46)
Married, n (%)	104 (56)
Self-rated health excellent, very good, good, n (%)	72 (39)
Depressed, n (%)	89 (48)
Pain, n (%)	89 (48)
Self-rated life expectancy, n (%)	
<2 years	22 (12)
$\geq$ 2 years	87 (47)
Uncertain	76 (41)
$\geq$ 2 hospitalizations in the previous year, n (%)	83 (45)
Disability in $\geq$ 1 activities of daily living, n (%)	63 (34)
Intensive care unit admission in previous year, n (%)	63 (34)
Quality of life best possible or good, n (%)	120 (65)

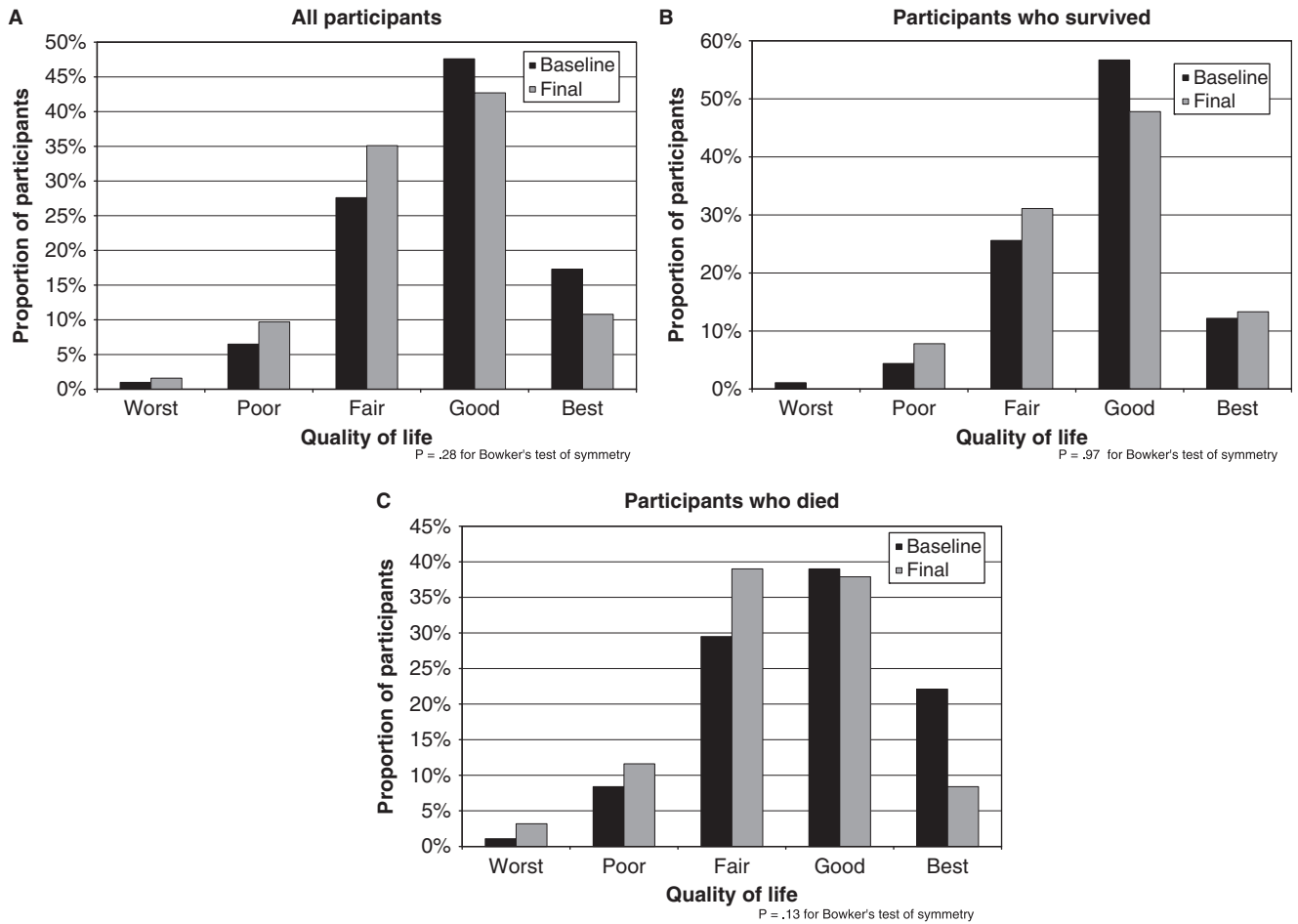
variable QoL trajectories. The variability in QoL ratings by individuals over time did not reflect small changes in response from among a narrow range of ratings; instead ratings spanned the full range of response categories and could change by several categories from one interview to the next. Of the 91 participants with variable trajectories, 34 (37%) had a change of at least two categories from one interview to the next, and 48 (53%) had a difference of at least two categories between their lowest and highest QoL ratings.

### Characterization of QoL at the End of Life

The shift from better to worse QoL ratings from baseline to final interview was more pronounced in participants who died than in those who survived (Figure 1B and C). Although a larger proportion of the participants who died than of those who survived rated their QoL as fair, poor, or worst possible in their final interview (Table 2), 46% of those who died reported a best possible or good QoL. Twice as many participants (40%) who died reported a decline in their QoL from next to last to last interview as those who survived (21%), although approximately equal proportions of those who survived (19%) and died (21%) reported improved QoL.

### Factors Associated with QoL

In bivariate analysis, participants with greater ADL disability, pain, depressed mood, anxiety, and self-rated life expectancy of less than 2 years were significantly more likely to report lower QoL (Table 3). Participants reporting excellent, very good, or good self-rated health; sufficient instrumental support; greater number of close family and friend interactions; and having grown closer to their church

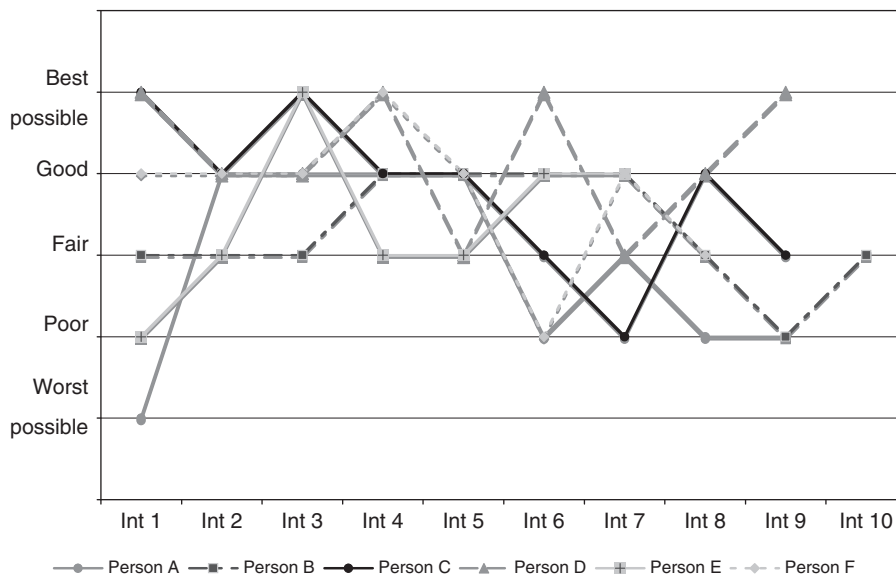


**Figure 1.** Distribution of quality-of-life ratings at baseline interview (black bars) and final interview (gray bars). (A) All participants. (B) Participants who survived. (C) Participants who died.

were significantly more likely to have better QoL. One additional measure of social support, sufficient emotional support, was significantly associated with better QoL but was also correlated with the presence of sufficient instru-

mental support. Three additional measures of greater religiosity—degree of religiosity, religion as a source of strength and comfort, and having grown spiritually—were significantly associated with better QoL but were also

Examples of Individual QoL Trajectories over Time



**Figure 2.** Examples of individual quality-of-life trajectories over time.

**Table 2. Final Quality of Life (QoL) of Participants Who Survived to the End of the Study and Who Died During 2-Year Follow-Up Period**

QoL Rating	n (%)		P-Value
	Survived (n = 90)	Died (n = 95)	
Rating at final interview best possible or good	55 (61)	44 (46)	.04
Change in rating from penultimate to final interview			
Improved	17 (19)	20 (21)	.008
Worsened	19 (21)	38 (40)	
No change	54 (60)	37 (39)	

correlated with having grown closer to church. Time was not associated with QoL ratings. Additional variables not associated with QoL in bivariate analysis included demographics (age, race, sex, education, sufficiency of monthly income, living arrangement, marital status), diagnosis, and relationship to primary caregiver.

In multivariable analysis, four variables remained statistically significant. Depressed mood was strongly associated with lower QoL ratings (adjusted odds ratio = 0.42, 95% confidence interval = 0.27–0.66) (Table 3). Greater ADL disability was also significantly associated with lower QoL ratings, whereas better self-rated health and feeling closer to one’s religious community were significantly associated with higher QoL ratings. To examine whether self-rated health, a construct that encompasses a range of more-specific measures of health,<sup>21</sup> was accounting for the relationship between the social support and symptom variables and QoL, the multivariable model was rerun without self-rated health. None of the social support or physical symptom variables was significantly associated with QoL when self-rated health was excluded from the model, although the relationship between sufficiency of instrumental support and QoL became stronger and approached significance (Table 3).

**DISCUSSION**

This study of community-dwelling older persons with advanced illness used a subjective, global measure—“How would you rate your overall quality of life?”—to explore the longitudinal ratings of QoL and to evaluate factors associated with QoL over a 2-year period. Participant ratings illustrate that decline in QoL is not an inevitable consequence of advancing illness. 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. Although the final QoL ratings of participants who died during follow-up were lower than those who survived to the end of the study, a substantial proportion of participants who died had preserved QoL. Greater ADL disability and depressed mood were associated with poorer QoL, whereas better self-rated health and having grown closer to one’s church were associated with better QoL.

Several prior studies have assessed subjective ratings of QoL in small selected cohorts of persons with advanced illness. Previous cross-sectional studies, conducted in patients receiving hospice services<sup>22</sup> and in patients with advanced cancer,<sup>23</sup> have demonstrated preserved QoL despite impaired function and bothersome symptoms. Previous longitudinal studies, examining mean QoL ratings in study populations of patients in hospice<sup>24</sup> and patients with amyotrophic lateral sclerosis,<sup>25</sup> have found relatively stable QoL ratings over time. The current study expands similar findings to a larger cohort of persons with a variety of advanced chronic illnesses studied over a longer period of time. The preservation of QoL despite advancing illness lends further empirical support for the phenomenon of response shift, or a change in individuals’ internal values, standards, or conceptualizations of QoL as health declines.<sup>26</sup>

By examining QoL trajectories in individual participants, the current study also demonstrates that small changes in QoL ratings on the population level mask highly variable individual QoL ratings over time. A similar pattern of individual variability in will to live has been described in

**Table 3. Factors Associated with Best Possible or Good Quality of Life Ratings (N = 185)**

Factor	Odds Ratio (95% Confidence Interval)		
	Bivariate	Multivariable	Multivariable Excluding Self-Rated Health*
Self-rated health excellent, very good, or good	6.07 (3.89–9.46)	4.79 (2.99–7.69)	—
Greater activity of daily living disability	0.73 (0.65–0.82)	0.85 (0.75–0.95)	0.79 (0.70–0.89)
Depression	0.27 (0.18–0.40)	0.42 (0.27–0.66)	0.38 (0.24–0.58)
Grown closer to church as a result of illness	2.45 (1.49–4.03)	1.99 (1.17–3.39)	2.09 (1.23–3.55)
Has sufficient instrumental support	2.21 (1.39–3.52)	1.32 (0.80–2.18)	1.63 (.99–2.67)
Number of family and close friend interactions	1.29 (1.06–1.56)	1.14 (0.92–1.41)	1.10 (.89–1.36)
Moderate to severe pain	0.56 (0.38–0.82)	0.77 (0.51–1.17)	0.76 (0.51–1.14)
Moderate to severe anxiety	0.62 (0.43–0.91)	0.95 (0.62–1.44)	0.92 (0.61–1.39)
Moderate to severe shortness of breath	0.68 (0.44–1.07)	1.14 (0.71–1.85)	1.05 (0.65–1.69)
Self-rated life expectancy < 2 yrs	0.56 (0.33–0.97)	0.83 (0.47–1.47)	0.77 (0.43–1.35)
Time	0.98 (0.96–1.01)	0.99 (0.97–1.02)	1.00 (0.98–1.03)

\* See text for further explanation.

older, terminally ill patients with cancer in a palliative care setting.<sup>27</sup> This variability suggests that temporary factors may influence subjective determinations of QoL. Although temporary, these factors may play an important role in individuals' valuations of their QoL, as elucidated in a prior study that asked persons with cancer to indicate the most important influences on their QoL over the previous 2 days. These influences included good and bad news and weather, enjoying family and friends, and surprises. In addition, the influence of more-traditional domains, such as symptoms and function, were described in terms of change (e.g., pain or mobility being better or worse).<sup>4</sup> Changes in affect and symptoms from the previous day have similarly been shown to influence self-rated health, the single factor most strongly associated with QoL in the present study.<sup>21</sup> Taken together, these findings suggest that subjective QoL is an intrinsically unstable construct, affected by how the person is feeling and what they are experiencing now in relationship to how they felt and what they experienced in the recent past.

In addition to self-rated health, depression, functional status, and religiosity, measured in terms of closeness to one's church, were associated with QoL in a multivariable model. These factors are amenable to intervention, and these associations highlight the importance of maximizing function,<sup>28</sup> addressing spiritual concerns,<sup>29</sup> and treating depression<sup>30</sup> in persons with advanced illness, even as they experience individual influences on their QoL.

The conceptualization of QoL as generally preserved despite worsening health but also variable in older persons with advanced illness has several implications for the care of these persons. First, preservation of QoL accounts in part for the persistence of preferences to receive invasive therapies with a risk of adverse outcomes in the face of advancing illness.<sup>31</sup> The ability to adapt to worsening health status and recalibrate conceptions of QoL may in part be responsible for the difficulty many patients have in coming to terms with a shift in treatment goals away from life extension and toward comfort or other outcomes that are commonly referred to as focusing on "QoL."<sup>32</sup> The variability in QoL ratings may also be responsible for inconsistencies in preferences. The same temporary factors associated with assessments of QoL may be associated with variability in patients' willingness to undergo burdensome or risky therapies.<sup>33</sup> Second, although understanding QoL as a highly personal and mutable construct supports the use of subjective global measures to assess QoL, it also raises questions about the utility of such measures as targets for intervention. To the extent that factors that are intrinsically unstable or cannot be externally influenced influence QoL, it is an outcome that may not reflect the effects of interventions aimed at improving health or psychosocial status. Moreover, high QoL ratings in the face of symptom burden or psychosocial concerns demonstrate that patients can adapt to factors that are amenable to intervention<sup>22</sup> and that patients with high QoL ratings may nonetheless have unmet health-related and psychosocial needs. Despite the limitations of global QoL measures, inquiries by clinicians about patients' global QoL, if accompanied by questions designed to understand the factors affecting an individual's assessment, may help to strengthen the clinician-patient relationship and help clinicians to understand patient preferences and decision making.

The study results are limited by a lack of ethnic and racial variability, which may affect their generalizability. Because of the relatively long time between final interviews and death in participants who died, there may have been further changes in QoL that were not captured in the study. Because the study examined QoL in patients with advanced illness, missing data are unavoidable. The largest cause of missing data in the study was mortality. It is unclear whether these data are missing in the sense that this term is frequently used, because these data, along with the data from participants who became cognitively impaired or more severely ill, are not recoverable.<sup>34</sup> There were also missing data from participants who dropped out of the study for other reasons or who failed to consent to a second year of participation, and therefore, it is unknown whether these missing data introduce bias into the results. QoL was examined in the analytic portion of this study as dichotomous variables because of the limitations in alternative approaches. The response categories could not appropriately be considered as ordinal, given the potential for uneven intervals between them. Although the cut point used to create the two levels of QoL is a plausible one, distinguishing between QoL rated as good or better versus less than good, and has been used previously, it was nonetheless a somewhat arbitrary decision, and the results may have been different if a different cut-point had been chosen.

As demonstrated that decline in QoL was not an inevitable consequence of advancing illness, this study also illustrated the highly variable nature of subjectively assessed QoL. Although a subjective measure may provide the most accurate assessment of self-perceived QoL, a more-directed survey of modifiable factors might prove more helpful to clinicians wishing to identify potential points of intervention for persons with advanced disease.

## ACKNOWLEDGMENTS

**Conflict of Interest:** The editor in chief has reviewed the conflict of interest checklist provided by the authors and has determined that the authors have no financial or any other kind of personal conflicts with this paper.

Dr. Fried is supported by Grant K24 AGAG028443 from the National Institute on Aging (NIA).

This study is supported by the Summer Training in Aging Research Topics—Mental Health (a program of the National Institute of Mental Health), P30 AG21342 from the Claude D. Pepper Older Americans Independence Center at Yale University, and R01 AG19769 from the NIA.

**Author Contributions:** Study concept and design: RS, PK, TRF. Acquisition of subjects and data: JOL, TRF. Analysis and interpretation of data: RS, PK, PHVN, JOL, TRF. Preparation of manuscript: RS, TRF. Editing of manuscript: PK, PHVN, JOL.

**Sponsor's Role:** The sponsors had no role in the design, methods, subject recruitment, data collection, or analysis and preparation of the paper.

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