Factors Supporting Quality of Life Over Time for Individuals With Amyotrophic Lateral Sclerosis: The Role of Positive Self-Perception and Religiosity

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ABSTRACT

Background: *Amyotrophic lateral sclerosis (ALS) is a progressive neuromuscular disease with no known cure. Maintaining quality of life (QOL) as the disease progresses is an important treatment goal.* ***Purpose:*** *The purpose of this study is to identify factors that support QOL as ALS progresses.* ***Methods:*** *Changes in QOL were monitored in 162 individuals with ALS at 3- to 4-month intervals. Forty-nine of the participants survived in the study for over 1 year and were included in a longitudinal comparison. The 49 long-term participants were younger and stronger at Time 1 than were the participants who died before reaching the 1-year point. The McGill Quality of Life Scale demonstrated a high and stable QOL despite physical deterioration.* ***Results:*** *Patients maintained a positive self-perception of their health despite the physical deterioration. Over time, self-perception of health and religiosity were shown to be significantly correlated with QOL.* ***Conclusions:*** *Results support the need for better instrumentation to enable future studies to more precisely measure multiple dimensions of ALS-related QOL, to identify reference points for self-ratings of both health and QOL, and to capture the religious and spiritual mechanisms related to QOL as individuals face the end of life.*

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INTRODUCTION

Quality of Life

Consistent with the biopsychosocial model of health (1–3), quality of life (QOL) is best viewed as an individual integration of physical aspects such as symptoms of illness or wellness, psychological aspects such as emotional responses and beliefs, and social aspects such as interpersonal relationships and social support. Recently, there has been more interest in understanding mind–body relations in general, and this interest has been extended to treatment outcome questions.

Religiosity

The construct of religiosity. Religiosity is distinguished from spirituality in that religiosity refers to a search for the divine through beliefs and practices associated with an organized faith group, and spirituality refers to a search for the sacred or divine through any type of life experience (4). Similarly, Pargament (5) defined religion as the junction of the sacred and the significant. By that definition, religion was seen as a way for people to hold on to things they care about. Religious practices were viewed as the process by which people searched for significance in life events.

Religious participation and health. There has been ample research suggesting that religious participation is positively associated with decreased mortality rates in patients with a wide variety of illnesses (6–10). In their meta-analytic review of 42 studies, McCollough, Hoyt, Larson, Koenig, and Thoresen (11) found that the relationship was quite robust. Previous research (12) suggested that the diagnosis of a terminal illness may lead to individuals seeking comfort from religions and spiritual connections. Additional work (13) suggested that approaching mortality impacted faith development so that people moved from a more external behavior-focused practice (such as church attendance) to a more internal belief-focused practice (such as self-perceptions of faith-related comfort) over time. Amyotrophic lateral sclerosis (ALS) is a terminal disease that lends itself well to studying developmental processes associated with the end of life because it has a relatively long trajectory (usually 2–5 years) and the patient's cognitive function generally remains intact.

Amyotrophic Lateral Sclerosis

ALS is a terminal degenerative neuromuscular disease of unknown etiology. Modern pharmacological therapies prolong life by only 2 to 3 months on average, and there are no treatments yet capable of reversing or stopping progression of the illness (14,15).

Patients with ALS experience a progressive loss of motor neurons, leading to progressive weakness affecting voluntary muscles. The illness may begin as arm or leg weakness, or it

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may present with slurring of speech, difficulty swallowing, or shortness of breath. Eventually, most patients experience all of these symptoms. The 5-year survival rate has been reported to average 25%, and the 10-year survival rate is approximately 10% (16).

ALS and QOL. Previously, we reported that although individuals with ALS showed a steady decline in physical function, QOL remained high (17–19). Those results could be a reflection of adaptation to ALS and a change in the relative importance of various dimensions in one's life. It is not unreasonable to assume that although changes in physical function, as early markers of ALS, would present a powerful challenge to maintaining a quality lifestyle initially, people may find over time that other things, such as a connection with the divine, are really more important than their ability to walk or run. Changing priorities and expectations for one's life would therefore be a reflection of successful adaptation to chronic illness and may play an important role in acceptance of the inevitable decline until death that people with ALS face. Alternatively, negative self-perceptions may lead to a self-fulfilling prophecy and contribute to premature disengagement and diminished QOL.

The purpose of this longitudinal study was to learn whether there was a change in the relation of various indicators with QOL as ALS progressed. This article expands on data reported at earlier points in the study (17–19) by reporting the complete data set and comparing the long-time survivors with those lost to the study due to death or other reasons.

Hypothesis 1—Religiosity scores will change although QOL remains stable as ALS progresses. Consistent with previous work (13) with HIV+ individuals, we anticipate the life-threatening experience of progressing ALS will be a faith development experience. We anticipate an increase in private religiosity scores over time as one's mortality becomes more salient.

Hypothesis 2—QOL maintains a positive relation with self-rated health over time. As ALS progresses, people may adjust their reference points for evaluating their health. When evaluating their present health state, people with progressing ALS may begin to compare their function with that of other ALS patients who have progressed further into the degenerative course of the illness, or with the future deterioration they expect for themselves. Therefore, QOL will become positively related to self-perceived health as an individual progresses through the disease trajectory.

Hypothesis 3—Religiosity and subjective evaluation of health are independent through the course of ALS. There are no data pointing to a link between how one evaluates one's health and one's religious experience. Although religiosity was previously shown (19) to become related to QOL over the course of the illness, changes in expectations used to subjectively evaluate health status are expected to keep the two constructs relatively uncorrelated. Therefore, our final hypothesis is the null hypothesis, that subjective evaluation of health and religiosity are independent through the course of ALS.

METHOD

Participants

One hundred sixty-two individuals (72 women and 90 men) being treated for ALS at the M.S. Hershey Medical Center ALS Clinic participated in the study. The medical center serves the population living in central Pennsylvania primarily representing a mixture of rural and suburban settings, with several smaller cities such as Harrisburg and Lancaster included in the service area as well. The population served by this clinic is predominately White, as was the sample.

Materials

QOL was measured by the McGill Quality of Life (MQOL) instrument (20,21). This is a 16-item scale by which people evaluate their lives over the past 2 days on five subscales using a 10-point semantic-differential format: Physical Symptoms (3 items), Physical Well-Being (1 item), Psychological (4 items), Existential (6 items), and Social Support (2 items). The mean of the five scale means is the total QOL score (range = 1–10).

Religiosity was assessed by the Idler Index of Religiosity (22). This is a four-item index, with two items assessing public religiosity (frequency of church attendance and number of church members known personally) and two items measuring private religiosity (how religious they perceived themselves to be and the amount of strength and comfort obtained from religious practices). The scores are summed to produce public, private, and total religiosity scores (ranges of 2–10, 2–7, and 4–17, respectively).

Self-perceived health was measured with a visual analog scale, Single Item Self-Rated Health (SISRH) (23); on this scale, people were asked to mark the state of their health today. The scale was vertical and anchored by 100 at the top and 0 on the bottom, marked in 10-point increments, with slash marks indicative of individual units between each 10-point increment.

Muscle strength was assessed by the physician during the physical examination on four muscle groups bilaterally and was graded using the Medical Research Council (MRC) scale ranging from 0 (*weakest*) to 5 (*strongest*) (24). A composite MRC score was then obtained by summing up these values and dividing by 8. In addition, the physician completed the ALS Functional Rating Scale (ALSFRS) (25,26) as part of his evaluation. The ALSFRS is a 40-point scale consisting of 10 items ranging from 0 (*worst function*) to 40 (*best function*) that evaluate areas of function such as speech, arm use, walking, and breathing.

As an additional measure of physical function, we employed a 19-item questionnaire that has been extracted from the Sickness Impact Profile (27) in the national ALS Patient Care Database. This scale has been shown to correlate well with physical function, albeit by patient report (17,27,28). The scores range from 0 to 100.

Finally, during the 1st year of the study we added a measure of spirituality to determine whether religiosity was different from spirituality in terms of QOL. The 10-item Spiritual Well-Being Scale (29) was used. It is a 6-point Likert-type scale with scores ranging from 1 to 6. Due to the late inclusion of this measure, only 83 of the participants had that indicator at Time 1, and only 11 participants had it at all five data points. Therefore, the analysis of that measure should be considered as exploratory.

For all measures, the higher the number the more positive the evaluation of that dimension.

Procedure

Patients were seen approximately every 3 to 4 months at the ALS clinic. All individuals with definite or probable ALS using El Escorial Criteria (30) and who were intellectually capable of providing informed consent were offered the opportunity to participate in the study. During the study enrollment period, 240 patients who met the El Escorial Criteria were seen at the clinic; of those, 162 (67.5%) were judged to be intellectually capable to consent (no apparent dementia or psychosis) and agreed to participate. Data were collected individually at each clinic visit. With the exception of the two physician assessments, data were collected by an individual independent of the clinic staff—a licensed psychologist or student under supervision. The study was approved by the Institutional Review Boards of the Pennsylvania State University and its College of Medicine.

RESULTS

Sample Representativeness

Due to the nature of the illness, not all patients entered into the study survived to provide a full year's data. Table 1 shows the comparison of the long-term participants ($n = 49$) in the study with those lost due to death ($n = 53$) or other reasons ($n = 32$), as well as those who had been entered into the study less than 1 year when the study concluded ($n = 28$). Significant differences between groups were found for age at entry into the study, $F(3, 158) = 5.001$, $p < .002$; age at onset of ALS, $F(3, 158) = 6.233$, $p < .001$; and ALSFRS, $F(3, 158) = 5.291$, $p < .002$. The 53 individuals who died prior to completion of 1 year in the study were significantly older and had significantly lower ALSFRS scores at Time 1 than did the long-term participants, as indicated by an analysis of variance (ANOVA). Table 2 compares the initial self-reported ratings of health, QOL, and religiosity scores. Consistent with results found on the age and functional status, an ANOVA indicated that those who died prior to completing 1 year in the study reported lower self-perception of health at Time 1 than did the long-term survivors, $F(3, 158) = 4.758$, $p < .003$.

Hypotheses Tests

Hypothesis 1—Religiosity scores will change although QOL remains stable as ALS progresses. Repeated measures ANOVAs produced no significant changes in QOL; in public, private, or total religiosity scores; or in spiritual well-being (Table 3). It should be noted that the Spiritual Well-Being measure was added late in the study, and there were only 11 participants who had that measure at each point in time. Therefore, the analysis of the Spiritual Well-Being measure was conducted with very low power and should be considered exploratory.

Hypothesis 2—QOL maintains a positive relation with self-rated health over time. Pearson correlation coefficients measuring the relations between the MQOL total score for each of the five assessments show a steady pattern of positive correlations, ranging from .41 to .60 ($p < .01$) (Table 4).

Hypothesis 3—Religiosity and subjective evaluation of health are independent through the course of ALS. Pearson correlation coefficients for self-rated health and religiosity scores showed modest correlations at Times 3 and 4, but returned to nonsignificant relations at Time 5 (rs = .22, .22, .16, respectively, with total, public, and private religiosity at Time 5).

TABLE 1

Mean and Standard Deviation Characteristics of Long-Term Participants Compared With All Other Participants in Study at Time 1

	Participants							
	Long-Term Participants[a]		*New Participants*[b]		*Died Prior to Time 5*[c]		*Lost to Study*[d]	
Indicator	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Demographics								
Age in years[e]	57.77	13.03_{a}	62.82	$11.01_{a,b}$	67.36	11.78_{b}	61.31	$14.06_{a,b}$
ALS specific								
Age of onset in years[e]	54.90	13.20_{a}	60.50	$11.10_{a,b}$	65.53	11.78_{b}	58.47	$14.20_{a,b}$
Duration in months	34.86	27.21	28.89	25.65	21.51	16.14	35.00	39.12
Muscle strength	3.70	1.07	3.68	1.04	3.43	1.12	3.92	0.93
Functional rating[e]	27.88	6.29_{a}	27.79	$6.71_{a,b}$	23.68	6.61_{b}	28.34	$6.39_{a,b}$
SIP/ALS–19	79.76	20.15	71.99	21.06	66.43	19.04	77.96	21.03

Note. Means with the same subscript are not significantly different at $p < .05$ in post hoc tests using Bonferonni correction for multiple comparisons. SIP/ALS–19 = 19 items from the Sickness Impact Profile (SIP) (28) used to compile an amyotrophic lateral sclerosis (ALS) specific measure of health status.

[a]Female $n = 20$, male $n = 29$. [b]Female $n = 10$, male $n = 18$. [c]Female $n = 26$, male $n = 27$. [d]Female and male $n = 16$. [e]Group means differ significantly, $p < .01$, by one-way analysis of variance.

TABLE 2

Mean and Standard Deviation Quality of Life and Religiosity Scores for All Participants at Time 1

	Participants							
	Long-Term Participants[a]		*New Participants*[b]		*Died Prior to Time 5*[c]		*Lost to Study*[d]	
Indicator	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Quality of Life								
Health Rating[e]	75.49	17.06_{a}	73.21	$22.37_{a,b}$	62.51	18.62_{b}	72.56	$17.17_{a,b}$
McGill Total QOL	7.63	1.19	7.89	1.24	7.18	1.23	7.35	1.37
McGill subscales								
Physical	5.97	2.77	7.50	2.51	5.99	2.74	6.53	2.48
Well-Being	7.12	1.95	7.32	2.25	6.77	2.16	7.19	1.69
Psychological	7.69	1.93	7.71	2.25	6.71	2.40	6.95	2.19
Existential	7.89	1.34	7.84	1.87	7.50	1.42	7.51	1.61
Support	9.06	1.06	9.04	1.39	8.92	1.52	8.51	1.55
Idler Religiosity								
Public	7.10	2.44	6.42	2.69	6.30	2.58	6.65	2.44
Private	6.31	0.89	5.81	1.49	5.92	1.24	5.81	1.19
Total	13.41	3.06	12.30	3.93	12.23	3.31	12.45	3.23
Spiritual Well-Being	5.67	0.36	4.48	1.37	4.62	1.17	4.92	1.12

Note. Sample sizes for Spiritual Well-Being vary: 11 at Time 1, 15 at Time 2, 17 at Time 3, 25 at Time 4, and 35 at Time 5. Due to the smaller number of subjects and later inclusion in the study, this analysis should be considered exploratory. Means with the same subscript are not significantly different at $p < .01$ in post hoc tests using Bonferonni correction for multiple comparisons.

[a]*n* = 49. [b]*n* = 28. [c]*n* = 53. [d]*n* = 32. [e]Group means differ significantly, $p < .01$, by analysis of covariance controlling for age of onset.

TABLE 3

Changes in Mean and Standard Deviation for Quality of Life and Religiosity Indicators Over Five Assessments

	Time									
	1 (Intake)		*2 (3–4 Months)*		*3 (6–8 Months)*		*4 (9–12 Months)*		*5 (12–16 Months)*	
Indicator	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Quality of Life										
Health Rating	75.49	17.06	72.30	16.44	69.71	17.21	71.35	22.05	71.16	19.32
McGill subscales										
Total	7.23	1.19	7.67	1.29	7.55	1.46	7.57	1.30	7.51	1.41
Physical	5.97	2.87	6.48	2.57	6.53	2.89	6.69	2.77	6.96	2.29
Well-Being	7.12	1.95	7.59	1.72	7.22	2.06	7.37	1.72	6.96	1.87
Psychological	7.69	1.93	7.81	1.98	7.72	1.94	7.47	2.41	7.36	2.52
Existential	7.89	1.34	7.82	1.44	7.83	1.51	7.68	1.68	7.51	1.74
Support	9.07	1.06	8.64	1.44	8.53	1.64	8.73	1.30	8.74	1.64
Idler Religiosity										
Total	13.41	3.06	13.08	2.93	13.04	3.18	13.41	2.73	13.04	3.03
Public	7.10	2.44	6.97	2.31	6.78	2.51	7.12	2.14	6.78	2.47
Private	6.31	0.89	6.10	0.90	6.24	0.97	6.29	0.89	6.27	0.91
Spiritual Well-Being	5.67	0.36	5.43	0.43	5.24	0.86	5.28	0.50	5.43	0.61

Note. No significant differences in any indicator within participants across time. Sample sizes for Spiritual Well-Being vary: 11 at Time 1, 15 at Time 2, 17 at Time 3, 25 at Time 4, and 35 at Time 5. Due to the small number at all five times (*n* = 11), comparisons over time for this measure had very low power and therefore should be considered exploratory.

TABLE 4
Correlations of Total McGill Quality of Life Score With Quality of Life and Religiosity Indicators

Indicator	*Time* *1 (Intake)*	*2 (3–4 Months)*	*3 (6–8 Months)*	*4 (9–12 Months)*	*5 (12–16 Months)*
Quality of Life					
Health Rating	.41**	.47**	.48**	.52**	.60**
McGill subscales					
Physical	.71**	.68**	.65**	.63**	.47**
Well-Being	.58**	.78**	.73**	.74**	.73**
Psychological	.69**	.66**	.78**	.74**	.80**
Existential	.72**	.82**	.78**	.63**	.84**
Support	.36*	.62**	.63**	.43**	.72**
Idler Religiosity					
Total	.15	.28	.37**	.33*	.46**
Public	.14	.19	.27	.28*	.39**
Private	.13	.42**	.49**	.34*	.50**
Spiritual Well-Being	.08	.08	.17	–.12	.54**

Note. Sample size for Spiritual Well-Being varied over time: 11 at Time 1, 15 at Time 2, 17 at Time 3, 26 at Time 4, and 35 at Time 5.
**p* < .05. ***p* < .01.

TABLE 5
Hierarchical Regression Analysis for Factors Contributing to Quality of Life Over Time

Variable	R^2	*p*	β	*SEB*	*Beta*
Time 1					
Step 1	.17	.003			
Self-perceived health			2.872E–02	.01	.41
Step 2	.17	.013			
Self-perceived health			2.083E–02	.01	.40
Private religiosity			6.871E–02	.18	.05
Time 2					
Step 1	.22	.001			
Self-perceived health			3.685E–02	.01	.47
Step 2	.31	.001			
Self-perceived health			3.104E–02	.01	.40
Private religiosity			.44	.18	.31
Time 3					
Step 1	.23	.001			
Self-perceived health			4.054E–02	.01	.48
Step 2	.33	.001			
Self-perceived health			2.793E–02	.01	.33
Private religiosity			.52	.20	.35
Time 4					
Step 1	.27	.001			
Self-perceived health			3.058E–02	.01	.52
Step 2	.31	.001			
Self-perceived health			2.702E–02	.01	.46
Private religiosity			.31	.19	.21
Time 5					
Step 1	.37	.001			
Self-perceived health			4.403E–02	.01	.60
Step 2	.53	.001			
Self-perceived health			3.946E–02	.01	.54
Private religiosity			.64	.16	.41

Note. *N* = 48.

Hierarchical Regression Analyses

Self-perceived health had the most consistent relation with QOL over time. In addition, religiosity showed a trend to increase its relation with QOL over time (Table 4), although the sample size precludes testing the significance of the changes. To examine the contribution of those two variables over time, we conducted hierarchical regression analyses at each data point. The total MQOL score was the outcome QOL variable. At Step 1, self-perceived health measured by the SISRH score, was entered. Following that, we entered the Idler Private Religiosity score at Step 2 as the indicator of religiosity because that aspect of religiosity can more likely be maintained or strengthened as mobility decreases. As Table 5 shows, the combination of those two variables increased their association with QOL from approximately 17% of the variance at Time 1 to 53% at Time 5, primarily due to the contribution of self-perceived health. There was a trend for the change in R^2 owing to the addition of religiosity to increase over time as well. The change in R^2 was not significant at Times 1 and 4, but more substantial at Time 2, $F(1, 45) = 5.81, p < .02$; Time 3, $F(1, 46) = 6.34, p < .01$; and Time 5, $F(1, 46) = 16.33, p < .001$.

DISCUSSION

Sample Representativeness

The 49 individuals who remained in the study were younger and less impaired at the onset of the study than were those who died during the data collection, but the long-term survivors did not differ from other patient groups on any indicators at Time 1. This suggests that the individuals who survived the full year in the study are fairly representative of all but the oldest and weakest ALS patients seen at this clinic.

Hypothesis Tests

Unlike research with HIV+ individuals (13), but consistent with an earlier report of the trend with ALS patients over 6 months (17), we found no changes in the mean scores over 1 year. However, we did find that the relation of religious practices and QOL changed as ALS progressed. There was a consistent pattern for religiosity practices to become strongly related to QOL through the course of the study. Because we included spirituality later in the study, we were unable to make scientifically meaningful comparisons of spiritual well-being over time. However, a sense of spiritual well-being through the life–death trajectory is potentially clinically significant and merits consideration in future studies.

Our expectation that self-perceived health would show a positive relation with QOL was also supported. Although not as healthy as they were before the onset of ALS, the long-term participants rated themselves as in relatively good health. We suspect this may be due to their comparing their health with that of other ALS patients who had already died. The relatively positive self-perceived health was, in turn, related to a positive overall evaluation of QOL.

At 6 and 9 months, self-perceived health was correlated somewhat with religiosity scores, but this was not the case at the 1-year point. This pattern is difficult to interpret. This may represent spurious results, and the finding should be replicated with an independent sample before we draw conclusions regarding the relation of religiosity and self-rated health.

The final analyses were conducted to examine how the combination of self-rated health and religiosity contributed to QOL over time. Self-perceived health had a consistent relation with QOL over time. Although not initially related to QOL, private religiosity (depth of faith and strength or comfort found in religion) showed a trend to increase its role in QOL over time. By the 1-year point, the combined effects of self-perceived health and private religiosity accounted for 53% of the variance in QOL. It is likely that social relations associated with public religiosity provides an additional supportive factor.

These results also point to the need for further research. Although the MQOL performed much as expected, there is room for improvement in capturing the life experiences of individuals with ALS. Due to the unique characteristics of this illness, with a wide range of symptom patterns, there is a need for an ALS-specific QOL instrument. The reference points for ALS patients' self-evaluation remains unclear. The data suggest that not only is the ability to maintain a positive self-perception of one's overall health supportive, but also the search for significance in life events is supportive of QOL. Religiosity appears to be an important aspect of these people's lives; therefore, perhaps some faith-based intervention may be beneficial in supporting people with ALS. Unfortunately, these data do not adequately distinguish the faith, social, and existential components of the experiences of ALS patients, and they warrant further work to understand the role of these factors in the lives of individuals with ALS and other life-threatening illnesses. Further, there is a difference between QOL and quality of death. The transition from quality of living to quality of dying needs to be studied because it is possible that the needs of individuals at various points on the life–death trajectory are different and, therefore, would require different interventions to support peace and dignity throughout the process.

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