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RESOURCES AND WELL-BEING IN AMYOTROPHIC LATERAL SCLEROSIS PATIENTS AND CAREGIVERS: A LONGITUDINAL, DYADIC ANALYSIS

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Abstract

Socioemotional selectivity theory predicts that as the end of life approaches, resources that provide immediate, hedonic reward become more important and resources that provide delayed rewards become less important. The present study tested the theory in the context of marital dyads in which one partner had been diagnosed with amyotrophic lateral sclerosis (ALS), a terminal disease. ALS patients (N = 102) and their spouses (N = 100) reported their loneliness, financial worry, and psychological health every 3 months for up to 18 months. In multilevel dyadic models, patients and spouses had similar levels of financial worry and loneliness, but spouses' psychological health was more affected than patients' by financial worry. In actor-partner models, patients' and spouses' loneliness was associated with the other's psychological health. Finally, patient psychological health predicted mortality risk. In conclusion, the present study provides good support for the predictions of socioemotional selectivity theory in a strong test of the theory.

Resources and Well-being in Amyotrophic Lateral Sclerosis Patients and Caregivers: A Longitudinal, Dyadic Analysis

As people age and their time remaining in life decreases, their motivations and values shift toward close social relationships and positive emotional experience and away from relationships and resources that are more closely aligned with status and knowledge (Carstensen, Isaacowitz, & Charles, 1999; Fung & Carstensen, 2004; Riediger, Schmiedek, Wagner, & Linderberger, 2009). Socioemotional selectivity theory predicts that such shifts are adaptive insofar as they maximize resources that can be realized immediately (i.e., happiness and social connection) over resources that are more important for future use or take time to develop. The present study examines concern about social and financial resources as predictors of psychological well-being and patient survival among amyotrophic lateral sclerosis (ALS) patients and their spousal caregivers.

ALS causes progressive deterioration of upper and lower motor neurons, ultimately resulting in complete paralysis, respiratory weakness, and either death or continuous mechanical ventilation. The disease is almost twice as common in men as in women and is associated with older age, with peak incidence around age 70. ALS is considered a terminal disease, with five-year survival of 25% and ten-year survival of 10% (Shaw, 2000). Therefore, a diagnosis of ALS is very likely to decrease the amount of time remaining in life.

Like advancing age, a potentially terminal illness may refocus motivations and values. In a comparison (made before highly active antiretroviral therapy) of gay men who were HIV seronegative, HIV seropositive but asymptomatic, or HIV

seropositive and symptomatic, symptomatic men assigned the most weight to the potential for positive interaction with social partners and the least weight to potential for "getting to know" novel social partners. HIV seronegative and asymptomatic men had the opposite pattern. Asymptomatic men also attached less weight to novel social partners than did seronegative men (Carstensen & Fredrickson, 1998). Notably, the three groups had similar chronological age. These results suggest that terminal illness and the progression of such illness orient goals and values toward positive social interactions and positive affect in the present.

Dyads in which one partner has been diagnosed with ALS provide a valuable context in which to study socioemotional shifts and their emotional and health consequences. Socioemotional selectivity theory predicts that, following from the effects of ALS on time remaining in life, patients' goals and values should be aligned with close social resources to a greater degree than spouses'. Spouses' goals and values should be aligned with resources important for the future (such as finances) to a greater degree than patients'. Furthermore, the importance of goals and values should determine their influence on psychological health (Emmons, 1986; King, Richards, & Stemmerich, 1998; McGregor & Little, 1998; Segerstrom, Jones, Scott, & Crofford, 2016). Because close social resources are more important to patients, concerns in that domain should affect them to a greater degree than spouses, and vice versa.

The dyadic context provides for a strong test of these predictions. There are dyadic similarities in psychological well-being in ALS patients and caregivers (Garcia et al., in press). Indeed, some aspects of quality of life are more affected by

ALS disease progression for caregivers than for patients (Roach et al., 2009). Both members of the dyad are confronting challenges associated with ALS, but only patients are confronting the possibility of their own premature mortality. Therefore, comparing dyad members allows for isolation of the effect of ALS on time remaining in life from other aspects of the disease that affect both members of the dyad, such as general awareness of mortality and changes in life circumstances.

Dyadic longitudinal models consider couples as an "interdependent relational system" coping with disease over time (Lo et al., 2013). Laurenceau and Bolger (2012, 2013) have proposed two models for accounting for dyadic similarity and difference in longitudinal data. Multilevel analysis for distinguishable dyads (Laurenceau & Bolger, 2013) structures the model such that estimates of intercepts, time slopes, and effects of explanatory variables are generated for each member of the dyad separately. Of course, this can also be accomplished by fitting separate models for each member of the dyad, but dyadic multilevel analysis is preferable because the covariance between dyad members in these estimates is part of the model estimation. Therefore, in using such models, the degree to which married couples are similar to each other becomes explicit.

Another approach is actor-partner multilevel analysis (Laurenceau & Bolger, 2012). Like dyadic multilevel analysis, these models estimate within-dyad covariances. However, they also include the influence of one partner's explanatory variable on the other partner's outcome (actor-partner effects). For example, because social concerns are hypothesized to affect patients to a greater degree than spouses, actor-partner models can test whether patients' social concern affects their

psychological health *and* whether their spouses' social concern also affects patients' psychological health (cf., Kouros, Papp, & Cummings, 2008; Zhou et al., 2011).

The present study investigated the relationships between social and financial concerns and psychological health among patients and caregivers in the Seattle ALS Patient Profile Project (McDonald et al., 1994). In this multi-site study, patients and caregivers were interviewed in their homes multiple times over approximately 18 months, allowing for examination of both stable individual differences and change over time in concerns about resources and psychological health. Social concerns were operationalized as loneliness. Loneliness is distinct from social isolation *per se* in that it reflects a discrepancy between personal goals or expectations for social connection and experienced social connection (Rook, 1984). Perceived deficits in close relationships (e.g., close friends in adolescence or family members in older age) affect loneliness to a greater degree than perceived deficits in causal relationships (Routasalo, Savikko, Tilvis, Strandberg, & Pitkälä, 2006; Russell, Cutrona, McRae, & Gomez, 2012). Therefore, loneliness reflects concern about the type and quality of social relationships that socioemotional selectivity theory predicts become more important as the end of life approaches. Financial concerns were operationalized as worry about having enough money to meet financial needs. The following hypotheses were tested:

1. Accounting for dyadic similarity, patients should have higher social concern, and spouses, higher financial concern. This prediction follows from the relative importance of social and financial resources among patients and spouses.

2. Accounting for dyadic similarity, patients' psychological health should be more affected by social concerns, and spouses', by financial concerns. This prediction arises because resources and goals that are important to or valued by the individual have greater impact on psychological health than those that are less important or valued.

Additional exploratory analyses used actor-partner models to test whether spouses' social and financial concerns affected patient psychological health and vice versa.

Finally, a composite of many psychological variables including depression, hopelessness, and perceived stress (but not including loneliness or financial worry) predicted patient survival at a 3.5-year follow-up in the Seattle ALS Patient Profile Project (OR = 2.24 for lowest or worst tertile vs. highest or best tertile; McDonald et al., 1994). Therefore, the final hypothesis tested whether concerns and psychological health were related to patient survival through a 20-year follow-up:

3. More social concern and poorer psychological health, but not more financial concern, should predict patient survival.

Additional exploratory analyses tested whether spouses' social and financial concerns and psychological health affected patient survival.

Method

Participants

Participants were 102 patients with ALS and 100 spousal caregivers from the Seattle ALS Patient Profile Project. The analytic sample was a subset of the total sample (N = 143 patients and 123 caregivers). There were 103 spouse-patient dyads in the study (20 patients had no caregiver in the study; 20 had another family

member or paid caregiver in the study). One patient and two spouses were not included in analyses because they were missing all financial worry or loneliness data. Demographic characteristics of the final analytic sample are shown in Table 1.

Inclusion criteria (as reported by McDonald et al., 1994) were neurologist-confirmed diagnosis of ALS and ability to communicate in English. Exclusion criteria were dementia diagnosis and "known" alcoholism.

Table 1. Demographic characteristics of patients and spouses at baseline

		Patient Mean (SD) or % (n/102)	Spouse Mean (SD) or % (n/100)
Age (years)		60.3 (11.7)	57.9 (12.5)
Gender	Male	73.5 (75)	26.0 (26)
	Female	26.5 (27)	74.0 (74)
Race	White/Caucasian	96.1 (98)	96.0 (96)
	Black/African-American	2.0 (2)	2.0 (2)
	Asian-American	1.0 (1)	1.0 (1)
	Native American	1.0 (1)	1.0 (1)
Highest Education	Grade 1-6	0.0 (0)	1.0 (1)
	Grade 7-9	5.9 (6)	9.0 (9)
	Grade 10-12	34.3 (35)	37.0 (37)
	GED	4.9 (5)	3.0 (3)
	Some college	25.5 (26)	29.0 (29)
	College graduate	12.8 (13)	7.0 (7)
	Some post-graduate	5.9 (6)	7.0 (7)
	Master's degree	5.9 (6)	4.0 (4)
	Doctoral degree	4.9 (5)	3.0 (3)
ALSS	Total score	24.5 (8.4)	
Respiratory support	On (any duration)	11.8 (12)	
	Not on	79.4 (81)	
	Started during study	8.8 (9)	

Note. ALSS = ALS Severity Scale. An ALSS score of 24.5 is considered "moderate" disease.

Procedure

Patients were recruited from ALS clinics and support groups at 3 sites (Seattle, WA; San Francisco, CA; and Philadelphia, PA). They were interviewed every 3 months in their homes for up to 18 months, responding to a number of standard questionnaires as well as study-specific questions. The University of Washington Human Subjects Committee provided approval for the study, and all participants provided informed consent. Data were collected between March, 1987 and August, 1989.

There were 925 person-interviews available for analysis (481 for patients and 444 for spouses). Missing data were due to patient death before the end of the study (171 and 166 person-interviews for patients and spouses, respectively), withdrawal from the study (43 and 77 person-interviews), or unexplained missing data (19 and 13 person-interviews).

Measures

The study included a large number of idiosyncratic questions as well as standard scales. Although a broad measure of resources would be desirable (e.g., the Conservation of Resources Evaluation; Hobfoll & Lilly, 1993), such a measure was not available in the dataset. Therefore, relevant measures were selected that (1) were asked of both patients and spouses in the same way at every interview, (2) had reasonable distributions (i.e., no ceiling or floor effect), and (3) had sufficient variability between and within people to test relationships with psychological health at both levels. The following measures met those criteria as well as being substantively parallel in that they represent concern about the resource domain.

Financial worry. Financial worry was measured with a single item asked of both patients and spouses about how much worry he or she was currently experiencing over having enough money to meet financial needs. They responded on a scale of 1 = no worry to 10 = extremely worried. The intraclass correlation (ICC) for patients was .67 and for spouses was .66, indicating that about two-thirds of the variance in financial worry was stable (between people) and one-third was changing (within people).

Loneliness. Loneliness was measured with the 4-item survey version of the UCLA Loneliness Scale (Russell, Peplau, & Cutrona, 1980). Items refer to feeling "in tune" with others, feeling understood, and having enough companionship. This version had adequate internal consistency in the validation sample (α = .75). The ICC for patients was .48 and for spouses was .56, indicating about half of the variance in loneliness was stable (between people) and half was changing (within people).

Psychological health. Psychological health was operationalized as a composite of scores on the Beck Depression Inventory, the Beck Hopelessness Scale, and the Perceived Stress Scale (Beck, Steer, & Carbin, 1988; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961; Beck, Weissman, Lester, & Trexler, 1974; Cohen, Kamarck, & Mermelstein, 1983). Collectively, these scales include items reflecting psychological health in both the affective domain (e.g., sadness, anger, anxiety) and the cognitive domain (e.g., expectancies, control). All scales had adequate reliability and validity in validation samples. ICCs for the individual scales in patients ranged from .58 - .78 and in spouses, from .63 - .78. Therefore, most of the variance in

psychological health was due to stable individual differences, with about a quarter of the variance due to within-person changes over time. Correlations among the 3 scales between and within people indicated that they were sufficiently related to each other to create a psychological health composite. For patients, between-person correlations among the scales were .53 - .63 and within-person correlations were .43 - .46; for spouses, between-person correlations were .49 - .69 and within-person correlations were .14 - .45. The composite was created by converting each scale score to percent of maximum possible (Cohen, Cohen, Aiken, & West, 1999) and taking the mean of the three scales. Therefore, the composite has a minimum of 0 and a maximum of 100. The composite was reasonably normally distributed (skewness = 0.48). Percent of maximum possible is preferred to other methods of standardization (e.g., Z scores) in longitudinal data because it maintains the distributions of and absolute differences in the variables both between and within individuals (Moeller, 2015).

Disease severity. The ALS Severity Scale (ALSS; Hillel, Miller, Yorkston, McDonald, & Konikow, 1989) total score was used to index disease severity. The score is a sum of functions in speech, swallowing, upper extremities, and lower extremities and has a maximum score of 40. Higher scores reflect better function. Scores above 28 are considered mild disease severity; 17-28, moderate; and lower than 17, severe.

Survival. Dates of death were obtained during the study and at 3 follow-ups in 1990, 1994, and 2008. Dates of first use of ventilation were recorded during the study and at the 3 follow-ups. In addition, during the study, the number of hours

that the patient used ventilation was also recorded. The category "20-24 hours" was considered continuous ventilation. Twelve patients were on continuous ventilation at the first interview and were excluded from survival analyses. One patient began continuous ventilation during the study. Of the patients who began any ventilation during the follow-up, 3 patients who survived more than a few months after beginning ventilation were considered to have been on continuous ventilation. Survival time was operationally defined as months from diagnosis to death or continuous ventilation.

Data analysis

Data were primarily analyzed in multi-level models with couples at Level 2 and time (interview) at Level 1. Two models were fitted: a dyadic analysis that tested the hypotheses separately but simultaneously for patients and spouses (using SAS [9.3] PROC MIXED with restricted maximum likelihood estimation; Laurenceau & Bolger, 2013) and an actor-partner analysis that tested the hypotheses including partner effects (using Mplus [7] twolevel with full information maximum likelihood estimation; Laurenceau & Bolger, 2012). These analyses use all available observations without listwise deletion.

Dyadic analysis. Before proceeding to dyadic analysis, possible covariance structures of psychological health over time were compared. First-order autoregressive, compound symmetric, and Toeplitz structures with and without heterogeneous variances were fitted separately for patients and spouses. Only the heterogeneous Toeplitz was a satisfactory fit to the data for patients (by Aikake's information criterion and likelihood ratio test); none of the structures were a

satisfactory fit for spouses; and the heterogeneous Toeplitz was not a satisfactory fit for patients and spouses together. Therefore, an unstructured covariance matrix for time was specified.

The dyadic analysis uses dummy codes for patient (1/0) and spouse (1/0) to select subsets of the data for patient and spouse effects. In the simplest model with no predictors, for dyads *j* over times *i*, patients *p* and spouses *s* have paired equations:

$$PH_{ijP} = B_{0jP} + e_{ijP}$$

$$PH_{ijS} = B_{0jS} + e_{ijS}$$

$$B_{0jP} = \gamma_{01P} + U_{0jP}$$

$$B_{0jS} = \gamma_{01S} + U_{0jS}$$

γ_{11P} is the fixed intercept for patients (with U_{1jP} allowing for individual differences in individual intercepts, i.e., a random effect). γ_{11S} is the fixed intercept for spouses. Importantly, the random effects for patient and spouse intercepts generate a covariance matrix that includes the patient and spouse variances as well as their covariance:

$$\text{Cov(U)} = \begin{bmatrix} \sigma 2P & \sigma PS \\ \sigma SP & \sigma 2S \end{bmatrix}$$

This model can be expanded to include effects of both (continuous) time and explanatory variables. The explanatory variables included financial worry and loneliness, centered within cluster. That is, each person had a Level 2, between-person variable that was his or her mean across all interviews (superscript B in the equations below) and represent the effects of individual differences and Level 1, within-person variables that were the deviations from that mean at each interview

(superscript W in the equations below) and represent changes over time. The Level 2 variable was grand mean centered. The time variable was centered around the fourth interview (of 7). The model was as follows:

$$PH_{ijP} = B_{0jP} + B_{1jP}(time_{ijP}) + B_{2jP}(X1^{W}_{ijP}) + B_{3jP}(X2^{W}_{ijP}) + e_{ijP}$$

$$PH_{ijS} = B_{0jS} + B_{1jS}(time_{ijS}) + B_{2jS}(X1^{W}_{ijS}) + B_{3jS}(X2^{W}_{ijS}) + e_{ijS}$$

$$B_{0jP} = \gamma_{01P} + \gamma_{02P}(X1^{B}_{jP}) + \gamma_{03P}(X2^{B}_{jP}) + U_{0jP}$$

$$B_{0jS} = \gamma_{01S} + \gamma_{02S}(X1^{B}_{jS}) + \gamma_{03S}(X2^{B}_{jS}) + U_{0jS}$$

Finally, by the likelihood ratio test with mixture degrees of freedom, there were not significant random effects of linear time (note that categorical time was used in the estimation of the covariance matrix and continuous time was used as an explanatory variable). Patients had a random loneliness slope (X^{W} for patient loneliness; p = .0056), which was included in the final model. Spouses' random loneliness slope (p = .046) was not included although it was also statistically significant, because its inclusion along with the patient random slope caused estimation and convergence problems with the model. SAS (as well as other software) syntax for this type of model is provided by Laurenceau and Bolger (2013). Because SAS does not adjust the AIC for number of fixed effects, the AIC for each model was adjusted by adding double the number of fixed effects in the model.

Note that by dropping one dummy code, the remaining dummy code represents the difference between patients and spouses. In the simple example above, this model becomes:

$$PH_{ij} = B_{0j} + e_{ij}$$

$$B_{0j} = \gamma_{00} + \gamma_{01}(patient_{j}) + U_{0j}$$

γ_{01} is thus recognizable as the unique effect of being a patient (with spouse as reference). This same approach can be used to test for the difference between patients and spouses in the effects of explanatory variables.

Sensitivity analysis expanded this model to include gender and study site as covariates. Because socioemotional selectivity theory has also been tested with regard to effects of both chronological age and disease severity, exploratory analyses included these variables in the model as main effects and interactions with explanatory variables. They are represented as M in the equations below:

$$PH_{ijP} = B_{0jP} + B_{1jP}(time_{ijP}) + B_{2jP}(X1^{W}_{ijP}) + B_{3jP}(X2^{W}_{ijP}) + e_{ijP}$$

$$PH_{ijS} = B_{0jS} + B_{1jS}(time_{ijS}) + B_{2jS}(X1^{W}_{ijS}) + B_{3jS}(X2^{W}_{ijS}) + e_{ijS}$$

$$B_{0jP} = \gamma_{01P} + \gamma_{02P}(X1^{B}_{jP}) + \gamma_{03P}(X2^{B}_{jP}) + \gamma_{04P}(X1^{B}_{jP}*M_{jP}) + \gamma_{05P}(X2^{B}_{jP}*M_{jP}) + \gamma_{06P}(M_{jP}) + U_{0jP}$$

$$B_{0jS} = \gamma_{01S} + \gamma_{02S}(X1^{B}_{jS}) + \gamma_{03S}(X2^{B}_{jS}) + \gamma_{04P}(X1^{B}_{jS}*M_{jS}) + \gamma_{05P}(X2^{B}_{jS}*M_{jS}) + \gamma_{06S}(M_{jS}) + U_{0jS}$$

$$B_{2jP} = \gamma_{21P} + \gamma_{22P}(M_{jP})$$

$$B_{2jS} = \gamma_{21S} + \gamma_{22S}(M_{jS})$$

$$B_{3jP} = \gamma_{31P} + \gamma_{32P}(M_{jP})$$

$$B_{3jS} = \gamma_{31S} + \gamma_{32S}(M_{jS})$$

For significant interactions, simple slopes were estimated and tested by recentering the involved variables around the target values (Aiken & West, 1991).

Actor-partner analysis. The analyses above included only "actor" effects (e.g., the relationship between patient financial worry and patient psychological health). Actor-partner analyses built on those results by including "partner" effects, where patient financial worry or loneliness (at both levels) were added as predictors of

spouse psychological health and spouse financial worry or loneliness (at both levels) were added as predictors of patient psychological health. To simplify these models, effects of financial worry and loneliness were tested in separate models. Finally, by the likelihood ratio test with mixture degrees of freedom, patients as actors (p = .009) and spouses as partners (p = .0059) had random loneliness slopes, which were included in the final model. Mplus syntax for this type of model is provided by Laurenceau and Bolger (2012).

Survival analysis. Cox proportional hazards regression (SAS [9.3] PROC PHREG) was used to predict survival in the 90 patients not on continuous ventilation at baseline. For the remainder of the patients, survival was defined as time from diagnosis to death or continuous ventilation. Explanatory variables were the Level 2, between-person variables for financial worry, loneliness, and psychological health for patients and spouses. The proportional hazards assumption was met for these variables by the supremum test. Further models added demographic and disease covariates (age, gender, symptom onset location [bulbar, limb, or other], disease duration at study entry, and disease severity at study entry). Note that data were collected prior to the 1996 approval of the only current life-prolonging drug for ALS (Riluzole).

Results

Correlative and descriptive results

Table 2 shows the correlations among mean (across interviews) loneliness, financial worry, and psychological health for patients (below diagonal) and spouses (above diagonal) as well as the correlations with age, gender, and mean disease

severity. There were statistically significant correlations between higher loneliness and worse psychological health for patients and spouses and between more financial worry and worse psychological health for spouses. Higher ALSS scores (indicating less severe disease) were also associated with less financial worry and better psychological health among spouses.

Table 2. Correlations among Level 2 (mean) variables among patients (N = 102; below diagonal) and spouses (N = 100; above diagonal)

	Loneli-ness	Financial worry	Psycho-logical health	Age	Gender	ALSS
Loneliness	-	.09	.46**	.05	-.16	-.10
Financial worry	.08	-	.37*	-.06	.10	-.20*
Psychological health	.45**	.07	-	.15	.08	-.20*
Age	-.11	-.07	.24*	-	-.19	.09
Gender (1 = female)	-.10	.00	.09	.00	-	.13
ALSS	-.06	-.08	-.18	.05	-.11	-

* $p < .05$

** $p \leq .0001$

Note. Higher scores on psychological health indicate worse health; higher scores on the ALSS indicate less severe disease.

The first hypothesis was that patients would express more social concern (i.e., loneliness), whereas spouses would express more financial concern (i.e., financial worry). In a model with no predictors of financial worry except for the dummy codes for patients and spouses, the intercept for patients (γ = 4.72, SE = 0.26) was lower than that for spouses (γ = 5.01, SE = 0.25); however, this was not a significant difference (t = 0.70, p = 0.49). These estimates reflect moderate financial worry (i.e., about halfway between no worry and extreme worry). For loneliness, the intercept for patients (γ = 7.63, SE = 0.17) was lower than that for spouses (γ = 8.04, SE = 0.15), but this difference was also not statistically significant (t = 1.79, p = .076). These estimates are similar to the scale scores for men (M = 7.24) and women (M = 8.07) obtained in population surveys (Silverman & Kennedy, 1985).

Actor effects: Loneliness and financial worry

The second hypothesis was that patients' psychological health would be more affected by social concern (i.e., loneliness) and spouses', by financial concern (i.e., financial worry). Table 3 shows the results of dyadic multilevel models predicting psychological health. Model 1 was an intercept-only model that estimated the average psychological health for patients and spouses. Note that higher scores indicate worse psychological health. The estimate for patient psychological health was significantly worse than that for spouse mental health (t = 3.32, p = .0013). Model 2 included change over visits. Patients' psychological health got significantly worse over visits (p = .022), and spouses' psychological health tended to get worse as well (p = .080). The difference between patient and spouse estimates was not significantly different (t = 0.89, p = .38). Model 3 included the

effects of financial worry and loneliness. Among patients and spouses, more loneliness was associated with poorer psychological health both between and within people. Loneliness effects were larger among patients, but not significantly so. More financial worry was only associated with poorer psychological health between spouses. The between-person financial worry effect was significantly larger for spouses than patients (t = 2.40, p = .018). Model 4 included adjustment for study site and gender. All effects of financial worry and loneliness remained substantively unchanged.

Table 3. Dyadic models predicting psychological health (higher scores = worse health)

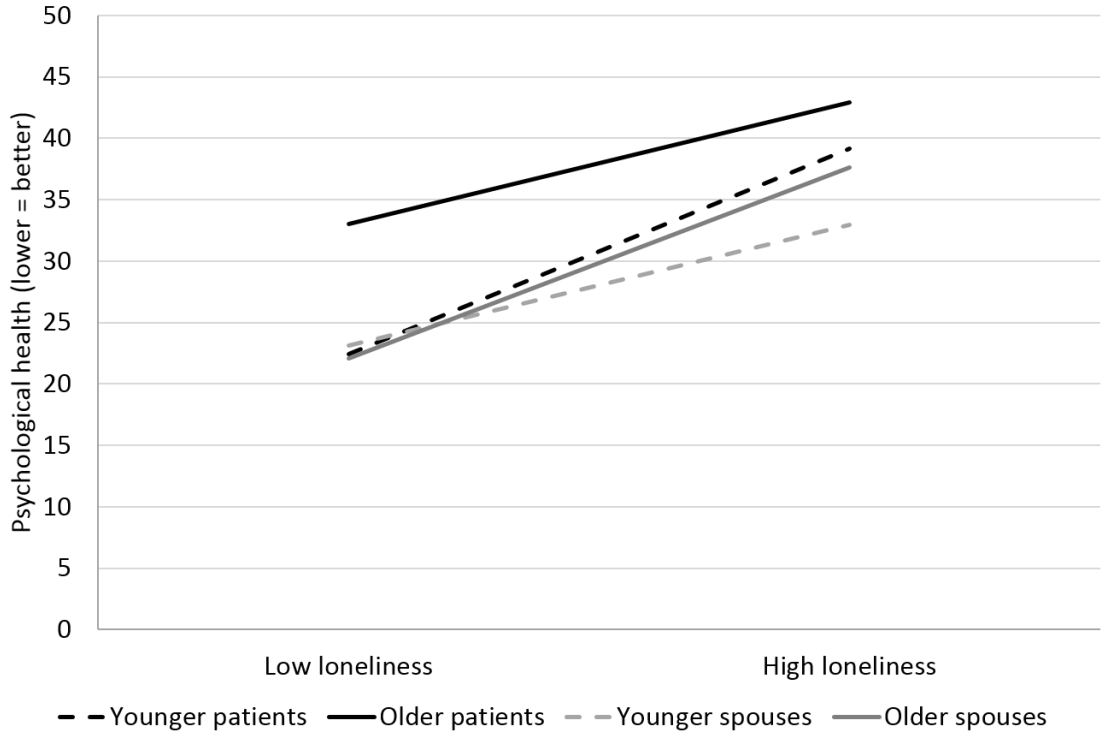
	Range	γ (SE)	γ (SE)	γ (SE)	γ (SE)
Fixed Effects		1	2	3	4
Patient intercept	0-100	33.58 (1.25)	34.75 (1.37)	34.37 (1.23)	See footnote
Patient (within)					
Visit	1-7		0.55* (0.24)	0.27 (0.21)	0.28 (0.21)
Financial worry	0-10			0.11 (0.19)	0.12 (0.19)
Loneliness	4-16			1.17** (0.27)	1.22** (0.28)
Patient (between)					
Financial worry	0-10			0.12 (0.44)	0.12 (0.19)
Loneliness	4-16			3.24** (0.65)	3.14** (0.65)
Spouse intercept	0-100	28.57 (1.14)	29.3 (1.21)	29.08 (1.03)	See footnote
Spouse (within)					
Visit			0.32+ (0.18)	0.31 (0.17)	0.31 (0.17)
Financial worry	0-10			0.08 (0.16)	0.08 (0.16)
Loneliness	4-16			0.93** (0.20)	0.92** (0.20)
Spouse (between)					
Financial worry	0-10			1.47* (0.38)	1.43* (0.38)
Loneliness	4-16			2.80** (0.61)	3.03** (0.61)
Random Effects					
Patient intercept		93.5	26.8	44.5	80.0
Spouse intercept		97.5	61.0	36.6	58.9
Patient loneliness slope				1.7	1.7
Patient-spouse intercept covariance		11.4	-1.5	-6.6	-0.1
Patient intercept-slope covariance				-1.8	0.5
Spouse intercept-patient slope covariance				-0.6	0.2
AIC		6653.6	6653.9	6433.6	6414.2

+ $p < .10$ * $p < .05$ ** $p < .0001$

Note. Model 4, which adjusted for study site and gender, yielded site-specific intercepts for patients and spouses. There was a significant effect of site for patients (F (2,101) = 5.13, p = .0076) but not spouses (F(2,99 = 1.41, p = .25). Patients in San Francisco had the best psychological health, followed by Seattle, followed by Philadelphia. There was a significant effect of gender for spouses (F(1,99) = 4.46, p = .037) but not patients (F(1,101) = 1.37, p = .24). Male spouses had poorer psychological health than female spouses.

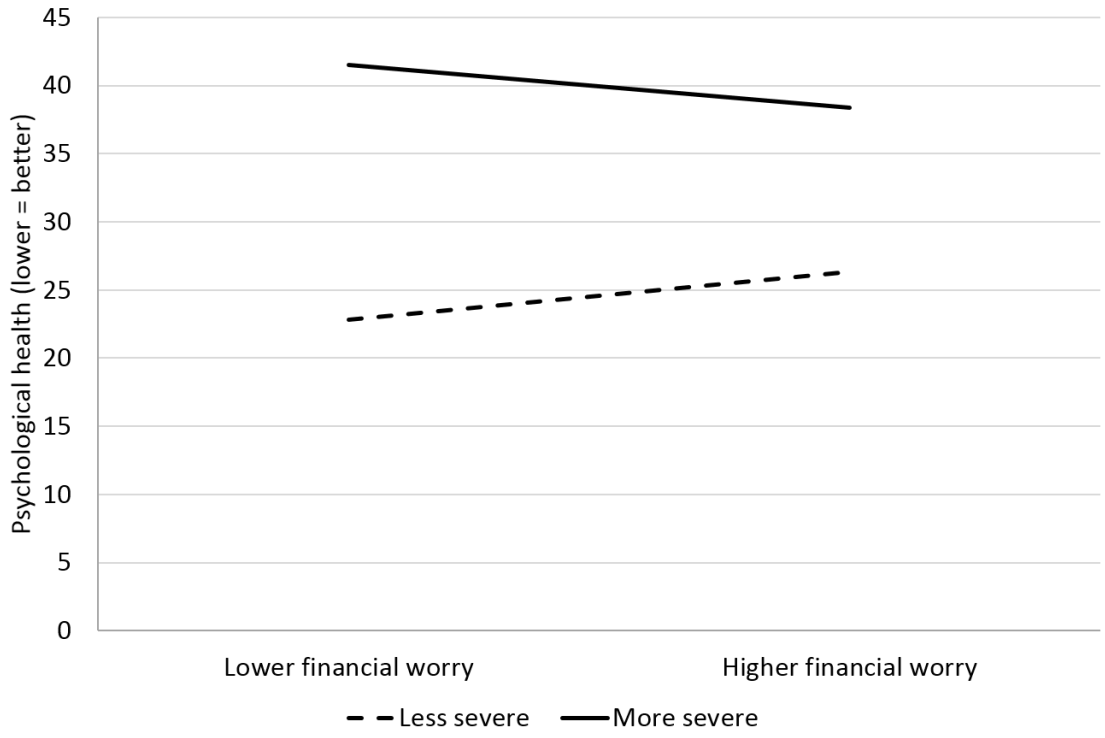
In exploratory models including the effects of age and disease severity, older patients had poorer psychological health than younger patients (γ = 0.27, SE = 0.10, p = .0089), and older spouses also tended to have poorer psychological health (γ = 0.15, SE = 0.09, p = .11), with no significant difference between patient and spouse estimates (t = 0.96, p = .34). For loneliness, there was a statistically significant interaction with patient age such that the within-patient effect of loneliness was lesser with older age (γ = -0.04, SE = 0.02, p = .029), and there was a tendency for the between-patient effect of loneliness to interact with age in the same way (γ = -0.09, SE = 0.05, p = .08). Age interactions for spouses were not statistically significant. However, the between-person interaction between age and loneliness was in the opposite direction for older spouses (γ = 0.07, SE = 0.05, p = .14), an effect which was significantly different from the interaction effect for patients (t = 2.33, p = .022). See estimated between-person loneliness slopes in Figure 1.

Figure 1. Model-estimated loneliness slopes (± 2 points) for younger (-10 years) and older (+ 10 years) patients and spouses. Intervals represent approximately ± 1 SD for loneliness and age.



For financial worry, there were no statistically significant interactions with age for either patients or spouses (all $p > .37$). For patients, disease severity did not interact with loneliness. However, a positive within-patient effect of financial worry was stronger for patients with less severe disease ($\gamma = 0.07$, SE = 0.03, $p = 0.01$). See estimated within-person loneliness slopes in Figure 2.

Figure 2. Model-estimated financial worry slopes (± 2.5 points) for patients with less severe (-10 ALSS points) and more severe disease (+10 ALSS points). Intervals represent approximately ± 1 SD for financial worry and disease severity.



Partner effects: Loneliness and financial worry

Loneliness. As in the actor model described above (Table 3, Model 3), more patient loneliness was significantly related to poorer patient psychological health (between: $\gamma = 3.05$, SE = 0.71, $p < .001$; within: $\gamma = 1.49$, SE = 0.29, $p < .001$). The same was true for spouses (between: $\gamma = 3.17$, SE = 0.63, $p < .001$; within: $\gamma = 0.96$, SE = 0.21, $p < .001$). There were also two statistically significant partner effects. Increases in patient loneliness were associated with decreases in spouse psychological health (within people: $\gamma = 0.51$, SE = 0.19, $p = .007$). That is, at times when patients were lonelier than at others, spouses had poorer psychological health. More spouse loneliness was associated with poorer patient psychological health (between people: $\gamma = 1.82$, SE = 0.76, $p = .017$). That is, patients had poorer psychological health if they had spouses who were typically lonelier than other spouses.

Financial worry. As in the actor model described above (Table 3, Model 3), more spousal financial worry was significantly related to poorer spousal psychological health (between: $\gamma = 1.44$, SE = 0.60, $p = .016$). None of the other actor or partner effects were statistically significant.

Patient survival

The third hypothesis was that patient loneliness and psychological health but not financial worry would predict patient survival. Table 4 contains the results of Cox regression models predicting patient survival from patient and, in exploratory models, spouse characteristics. Neither patient financial worry nor loneliness significantly predicted patient survival in models without (Model 1) or with (Model

2) demographic and disease covariates. Patient psychological health likewise did not significantly predict survival in the adjusted model (Model 3). Covariates were associated with survival in expected directions. Association of higher disease severity and longer disease duration with lower mortality hazard likely reflect survival bias (i.e., patients with slower-progressing disease were more likely to be alive to be recruited and to have longer-duration and more advanced disease.)

In an unadjusted model, worse psychological health was a significant predictor of shorter survival (HR = 1.23, 95% confidence interval = 1.05-1.43). In models including individual covariates, only disease duration substantially reduced the effect of psychological health. The fully adjusted model may have overadjusted for survival bias: In a model adjusting for sex, age, and onset location, patient psychological health was significantly associated with survival (HR = 1.21, 95% confidence interval = 1.03-1.42), and the effect further withstood additional adjustment for disease severity (HR = 1.20, 95% confidence interval = 1.02 – 1.41). Figure 3 shows survival for quartiles of psychological health.

Neither spouse financial worry nor loneliness significantly predicted patient survival in the model without covariates (Model 4); however, in the model with covariates (Model 5), poorer spousal psychological health significantly predicted lower mortality hazard in patients (Model 6; $p = .028$). Finally, in a model including patient and spouse financial worry, loneliness, and psychological health (Model 7), higher spousal loneliness predicted higher mortality hazard in patients ($p = .0069$) and poorer spousal psychological health predicted lower mortality hazard ($p = .0061$). However, in unadjusted models that had only spousal loneliness and

financial worry or psychological health in the model, none of these variables was a significant predictor of patient survival (financial worry: HR = 1.02, 95% confidence interval = 0.93-1.11; loneliness: HR = 1.07, 95% confidence interval = 0.93-1.22; psychological health: HR = 1.10, 95% confidence interval = 0.92-1.31).

Figure 3. Kaplan-Meier curves for quartiles of patient psychological health (1 = worst, 4 = best).

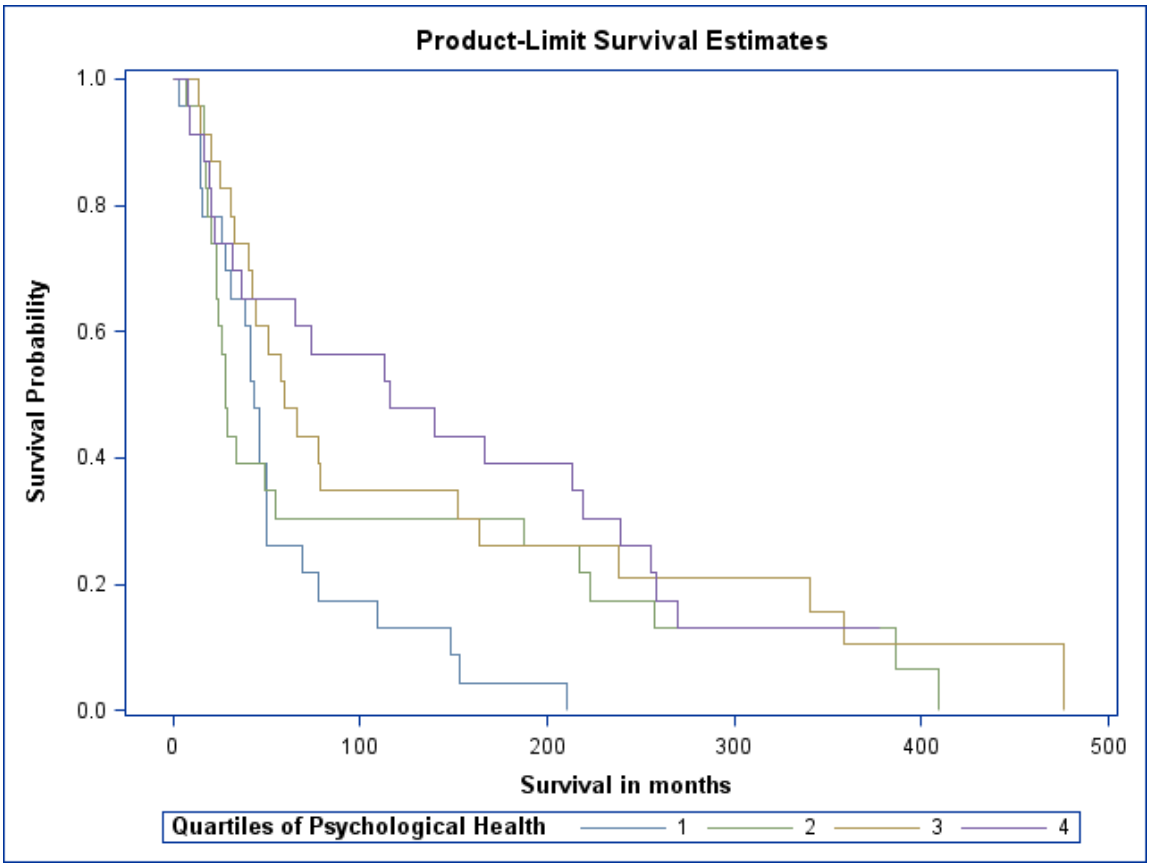


Table 4. Results of Cox regression models predicting patient survival. Hazard ratios are reported with their 95% confidence interval.

		HR (CI)	HR (CI)	HR (CI)	HR (CI)	HR (CI)	HR (CI)	HR (CI)
Covariates		1	2	3	4	5	6	7
Patient	*Unit*							
Financial worry	1 point	0.95 (0.88-1.07)	0.95 (0.82-1.12)		0.94 (0.83-1.06)	1.03 (0.91-1.18)		1.01 (0.89-1.16)
Loneliness	1 point	0.97 (0.84-1.09)	0.96 (0.82-1.12)		0.96 (0.84-1.09)	0.93 (0.79-1.08)		0.87 (0.71-1.06)
Psychological (poor) health	10 points			1.02 (0.85-1.22)			1.00 (0.83-1.20)	1.05 (0.83-1.33)
Age	1 year		1.03* (1.01-1.05)	1.03* (1.01-1.05)		1.03* (1.01-1.05)	1.04* (1.02-1.07)	1.04* (1.02-1.07)
Gender	M vs. F		1.07 (0.62-1.84)	1.17 (1.17-2.01)		1.33 (0.76-2.35)	1.31 (0.74-2.30)	1.78+ (0.97-3.28)
Disease severity	1 point		0.95* (0.92-0.98)	0.94* (0.91-0.98)		0.94* (0.91-0.97)	0.94* (0.91-0.97)	0.94* (0.90-0.97)
Disease duration	1 month		0.98* (0.97-0.99)	0.98* (0.97-0.99)		0.98* (0.97-0.98)	0.98* (0.97-0.98)	0.97* (0.97-0.98)
Bulbar onset	vs. other		1.03 (0.44-2.38)	1.00 (0.43-2.31)		1.19 (0.50-2.83)	1.01 (0.44-2.33)	1.20 (0.50-2.90)
Spinal onset	vs. other		0.89 (0.44-1.81)	0.95 (0.47-1.89)		0.97 (0.48-1.95)	0.90 (0.45-1.80)	0.84 (0.41-1.71)
Spouse	0-100							
Financial worry	1 point				1.05 (0.94-1.18)	0.89+ (0.78-1.00)		0.96 (0.84-1.09)
Loneliness	1 point				1.08 (0.94-1.24)	1.10 (0.94-1.29)		1.30* (1.07-1.56)
Psychological (poor) health	10 points						0.80* (0.65-0.98)	0.68* (0.52-0.90)

+ $p < .10$ * $p < .05$

Note: HR = Hazard ratio.

Discussion

Socioemotional selectivity theory predicts that as time remaining in life decreases, resources and goals that can be realized in the present moment, particularly social relationships that yield positive affect, become more important. Conversely, resources and goals that are focused on the future or take time to realize become less important. The present study employed multilevel dyadic analyses to test predictions of the theory in ALS patients and their spouses. Contrary to the first hypothesis of the study, patients and spouses did not differ in their levels of loneliness (which reflects concern over the adequacy of close social relationships), nor in their levels of financial worry (which reflects concern over the adequacy of financial resources). However, loneliness and financial worry affected patients and spouses differently.

Higher loneliness both as individual differences (between people) and changes over time (within people) was associated with poorer psychological health for both dyad members. Consistent with predictions, effects were larger for patients than spouses both between (γ = 3.24 vs. 2.80) and within people (γ = 1.17 vs. 0.93); however, these differences were not statistically significant. There were, however, differences between patients and spouses in the interaction between age and loneliness. In particular, for spouses, the effect of loneliness on psychological health was stronger with older age, consistent with the predictions of socioemotional selectivity theory: Although spouses did not have ALS, older spouses were also closer to the end of life, which should make them more sensitive to close social resources and the perceived lack thereof. One explanation for the different effect of

age and loneliness on patients lies in the generally poorer psychological health for older patients across all levels of loneliness (see Figure 1). It is possible that the combination of ALS and older age led these patients to be psychologically sensitive even to low levels of loneliness.

In addition, there were partner effects of loneliness. Dyads with lonelier spouses also had patients with poorer psychological health, above and beyond patient loneliness. Over time, patient loneliness covaried with spouse psychological health. These effects represent correlations, and the direction of effect may run from loneliness to psychological health (as is typical of loneliness effects in individuals) or vice versa (Lo et al., 2013). A dyad member with poorer psychological health may detach from the other member, increasing that member's loneliness (Papp et al., 2009; Zhou et al., 2011). In married couples who were not coping with chronic disease, depression and marital dissatisfaction affected each other reciprocally and across partners, and the same may be true of couples coping with ALS (Kouros, Papp, & Cummings, 2008). Couples coping with cancer and unemployment have also shown relationships between one partner's psychological health and that partner's provision of social support to the other (Manne, Taylor, Dougherty, & Kemeny, 1997; Vinokur, Price, & Caplan, 1996).

Financial worry had more limited relationships with psychological health. Consistent with socioemotional selectivity theory, financial worry affected the psychological health of spouses ($\gamma = 1.47$) to a greater degree than patients ($\gamma = 0.12$). The effect of financial worry on patients' psychological health depended on the stage of their disease: only for patients with less advanced disease did increases

in financial worry result in decreases in psychological health (see Figure 2). Disease severity may affect a patient's sense of the nearness of death and affect the value they place on future-oriented resources such as money. Finally, unlike loneliness, financial worry had strictly intrapersonal effects; partners' financial worry did not appear to have marked effects on either patients' or spouses' psychological health.

Replicating an earlier report in this sample, worse patient psychological health was associated with higher mortality risk. The two analyses differed in a number of respects: (1) the current study had a longer follow-up period (20 years vs. 3.5 years), (2) the current study treated continuous ventilation as well as death as the event of interest, (3) the current study included only a subset of study patients (90 vs. 143), (4) the current study considered survival as time since diagnosis, not time in study, and (5) the current study more narrowly defined psychological health and used it as a continuous variable rather than tertiles. The only covariate that substantially reduced the effect of psychological health in the present study was time since diagnosis, which may represent effects of survival bias. If psychological health increases longevity, then longer time since diagnosis at study entry should also be associated with psychological health. Further studies that begin assessment at the time of diagnosis are needed to avoid this confounding. Neither loneliness nor financial worry were associated with survival, even though loneliness was associated with psychological health. Finally, effects of spousal psychological health and loneliness emerged in the final model with all spouse and patient variables. Such effects should be interpreted with caution as they adjust for all other variables in the model. The meaning of a spouse's psychological health

removing after its overlap with that spouse's loneliness and financial worry and their partner's loneliness, financial worry, and psychological health is difficult to envision.

There are other limitations to this historical study. First, only total scores were available in the archived database, and so scale reliabilities for the analytic sample could not be calculated, nor could between-person and within-person reliabilities (Cranford et al., 2006). The measure of loneliness had 4 items and the measure of financial worry had 1, potentially giving loneliness a predictive advantage because it would be expected to have better reliability. Second, there were a number of deaths during data collection that affected the number of observations for some dyads. Such deaths could bias, for example, estimation of the effects of passage of time on psychological health. Third, with regard to survival analysis, this historical study may not reflect advances in current disease characteristics and survival, for example, the (albeit limited) drug treatments and advances in disease management provided by multidisciplinary clinics. Furthermore, heterogeneity in ALS presentation and prognosis is being increasingly recognized, and future studies may be able to account for such heterogeneity.

Advantages of the present study included the longitudinal, dyadic assessments, which allowed for examination of how couples were similar or different over time as well as actor-partner effects. In addition, the multi-site sample was relatively large for a study of ALS, providing adequate power to detect medium effect sizes.

In conclusion, the present study provides good support for the predictions of socioemotional selectivity theory in a strong test of the theory. By studying dyads in which one member was approaching end of life, the effects of a shorter time remaining in life could be isolated from general effects of coping with disease such as reminders of mortality and financial and social challenges. Indeed, patients and spouses reported similar mean levels of concern in social and financial domains, but they were not equally affected by these domains: Approaching the end of life reduced the impact of financial concerns and increased the impact of social concerns on psychological health. The importance of socioemotional resources not only changes as the end of life approaches, but also influences how these resources impact psychological health.

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