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Expressive Disclosure to Improve Well-Being in Patients with Amyotrophic Lateral Sclerosis: A Randomised, Controlled Trial

Alyssa J. Averill,

Department of Psychiatry and Behavioral Sciences, Medical University of South Carolina, 30 Bee Street, Charleston, SC 29425, alyssaaverill@msn.com, 843-810-9340

Edward J. Kasarskis, and

Department of Neurology, University of Kentucky, VA Hospital Cooper Drive B302, Lexington KY 40502, ejkasa00@uky.edu, 859-323-6792

Suzanne C. Segerstrom

Department of Psychology, University of Kentucky, 115 Kastle Hall, Lexington, KY 40506-0044, segerstrom@uky.edu, 859-257-4549

Abstract

Amyotrophic lateral sclerosis (ALS) is a terminal neurological disease associated with progressive paralysis, loss of communicative ability, and functional decline. Expressive disclosure may help people with ALS, particularly those who are emotionally or socially inhibited, meet psychological challenges associated with the disease. People with ALS ($N = 48$) were randomised to expressive disclosure about their disease or no disclosure. Psychological well-being (affect, depression, quality of life) was assessed pre-intervention and 3 and 6 months after. Results of multi-level models indicated that the group that disclosed thoughts and feelings about ALS had higher well-being than the control group at 3 months post-intervention but not 6 months. Ambivalence over emotional expression (AEE) moderated 3-month post-intervention well-being. Those low in AEE had higher well-being than those high in AEE regardless of condition. Those high in AEE who disclosed had increased well-being from pre-intervention, whereas controls had decreased well-being from pre-intervention. Expressive disclosure may be helpful for people with ALS, but only those who have difficulty expressing emotions. In addition, the intervention had only temporary effects; the dynamic challenges of ALS progression may mean that the effect of processing thoughts and feelings about the disease in one stage may not generalize to later stages.

Keywords

Amyotrophic Lateral Sclerosis; expressive disclosure; intervention; inhibition; emotional expression

Amyotrophic lateral sclerosis (ALS) is a fatal neuromuscular disease characterized by progressive degeneration of upper and lower motor neurons, which are responsible for the transmission of information from the cerebral cortex to the skeletal muscles and production

of voluntary movement of the upper and lower extremities. All people with ALS will eventually be completely paralyzed, with the exception of eye movement, and unless mechanical ventilation is initiated, respiratory weakness will be the cause of death. Three quarters of people with ALS do not survive longer than five years. The diagnosis of Amyotrophic Lateral Sclerosis (ALS) evokes a number of issues related to psychological adaptation, such as adjustment to changes in functional abilities and physical appearance, guilt about being burdensome to caregivers, loss of autonomy, and coping with the certainty of death. However, there has been a paucity of research examining the psychological aspects of this disease, and, to date, few studies have incorporated a psychological intervention for people with ALS (Hunter, Robinson, & Neilson, 1993; Sebring & Moglia, 1987), despite the suggestion that the quality of life of people with ALS is more determined by psychological and existential factors than by physical health (e.g., Roach, Averill, Segerstrom, & Kasarskis, 2009; Robbins, Simmons, Bremer, Walsh, & Fischer, 2001; Simmons, Bremer, Robbins, Walsh, & Fischer, 2000). People with ALS differ from other patient groups for whom expressive disclosure has been used as an intervention (e.g., cancer, rheumatoid arthritis, asthma) in a number of important ways, including faster disease progression, paralysis, loss of independence, inability to communicate, and universal fatality as a prognosis. The primary aim of this study is to examine the impact of a structured emotional disclosure intervention on the psychological well-being of people with ALS, a group that faces particularly acute and profound psychological challenges due to the nature of the disease.

Emotional disclosure interventions involve either writing or speaking about stressful or traumatic events over a period of three or four days (Pennebaker & Beall, 1986). Such interventions have been conducted in chronic illness populations ranging from patients with end-stage renal cancer to people with fibromyalgia (Broderick, Junghaenel, & Schwartz, 2005; De Moor et al., 2002; Harris, Thoresen, Humphreys, & Faul, 2005; Kelley, Lumley, & Leisen, 1997; Mann, 2001; Stanton et al., 2002). A meta-analysis of experimental disclosure studies ($k = 146$), including studies involving chronic illness populations, concluded that disclosure is an effective intervention with a small but positive effect size of $r = .08$ (Frattaroli, 2006). A meta-analysis of only the chronic illness studies similarly reported small but positive effect sizes of disclosure on psychological health ($d = .07$) (Frisina, Borod, & Lepore, 2004).

These effect sizes may be small because of the presence of moderators: Some people may be benefiting more from the emotional disclosure intervention than others. In particular, individual differences and social environments related to emotional openness may indicate those who are most likely to benefit. In some studies, people who were ambivalent about or avoidant of emotional expression benefited most from disclosure (Lu & Stanton, 2010; Stanton et al., 2002). Ambivalence over emotional expression also predicted more benefit from disclosure among women with chronic pelvic pain (Norman, Lumley, Dooley, & Diamond, 2004). Cancer patients whose social environments provided little opportunity for emotional expression had improvements in distress following a disclosure intervention relative to those who did not disclose (Zakowski, Ramati, Morton, Johnson, & Flanigan, 2004). Emotionally ambivalent and avoidant people may have had improved health after

disclosure because it provided an opportunity to process their negative emotions. Well-being may be most positively impacted by disclosure interventions for those who do not routinely engage in emotional expression (cf., Lumley, Tojek, & Macklem, 2002; Pennebaker, 1997).

The present study

The present study examined effects and moderators of disclosure on psychological well-being in people with ALS. This represents the first experimental investigation of this intervention in this population. It was hypothesized that disclosure participants' psychological health would be better than that of controls following the intervention. In addition, social constraints, ambivalence regarding emotional expression, and low coping through emotional approach were predicted to increase the effectiveness of the intervention.

Method

Participants

Participants were drawn from three sources: the clinic rolls of patients with ALS treated by one of the authors (EJK), the Western Ohio Chapter of the ALS Association (ALSA), and the National Registry of Veterans with ALS. Patients were eligible if they were over the age of 18, diagnosed with definite or probable ALS using El Escorial Criteria at least 6 months prior to study entry (World Federation of Neurology Research Group on Neuromuscular Diseases, 1994), and had a forced vital capacity (FVC) in the 50th percentile or higher, as this indicator of pulmonary capacity is likely to ensure that patients will survive for at least 6 months. Patients were excluded if they evidenced significant dysfunction on the Controlled Oral Word Association (COWA) test (Ruff, Light, Parker, & Levin, 1996), which might indicate executive dysfunction related to ALS (Lomen-Hoerth, 2004). All participants were able to communicate by writing, speaking, or assistive communication devices.

See Figure 1 for the CONSORT flow diagram. We characterized missing data as due to death (known to have died); dropping out (explicitly dropped out of the study); lost to follow-up (may have either died or dropped out, but unknown and no further data were contributed); or missing data (no data at that particular time point but data were contributed at a later time point). Because the key analyses were performed on all the available data from Time 1, Time 2, and Time 3, there were 57 (of 74 possible) waves of data in the intervention arm and 61 (of 74 possible) waves of data in the control arm. The number of cases with data at each wave did not significantly differ between the two arms ($\chi^2(3) = 0.19$, $p < .98$).

Measures

Demographics and controls—Participants completed a demographic questionnaire. Three additional questions assessed variables that may have had a bearing on disclosure: (1) Have you ever received treatment for psychological or psychiatric problems? (2) Do you or have you ever kept a written diary or journal? (3) Are you currently or have you ever taken antidepressant medication?

Psychological well-being—There were six measures of psychological well-being that were highly correlated with each other: positive affect, negative affect, depression, psychological QOL, existential QOL, and spirituality. After standardising scores across all time points and reversing negative affect and depression, these six scales yielded a coefficient alpha of .91 – .92 across time points and were therefore included in a composite measure for which higher scores reflected more positive affect, less negative affect and depression, better psychological and existential QOL, and higher spirituality.

Affect balance was measured with the Affects Balance Scale (ABS). Participants were asked to rate the degree to which they experienced 20 positive and 20 negative emotions during the past week. Depression was measured with the 30-item Geriatric Depression Scale (GDS). The GDS is more appropriate for use with people with ALS than other depression instruments that include somatic symptoms regularly experienced in ALS (Ganzini, Johnston, & Hoffman, 1999; Rabkin, Wagner, & DelBene, 2000). Psychological and existential QOL were measured with the McGill Quality of Life Questionnaire (MQOL), which was designed to assess the subjective quality of life of patients with terminal illness. Psychological QOL reflects the extent to which patients have experienced symptoms of depression, anxiety, sadness, and hopelessness, whereas existential QOL reflects patients' ratings of the worth and meaning of their life, their progress toward their goals, their control over their life, and the value of each day.

Ambivalence over Emotional Expression—The 28-item Ambivalence over Emotional Expression Questionnaire (AEQ; King & Emmons, 1990) was used to assess the extent to which participants feel uncomfortable or regret expressing their emotions (e.g., 'I'd like to talk about my problems with others, but at times I just can't', 'I feel guilty after I have expressed anger to someone') ($\alpha = .93$).

Emotional Approach Coping—Emotional coping was measured with an 8-item scale developed by Stanton and colleagues (Stanton et al., 2000) to assess emotional processing (4 items; e.g., 'I take time to figure out what I am really feeling'; $\alpha = .76$) and emotional expression (4 items; e.g., 'I feel free to express my emotions'; $\alpha = .89$). Because the two subscales were only correlated .61, they were used separately in analysis.

Social Constraints—The Social Constraints Scale (SCS; Lepore, Silver, Wortman, & Wayment, 1996) is a 15-item scale assessing perceived inadequacy of social support resulting in reluctance to express thoughts and feelings about a specific stressor, in this case experience with ALS (e.g., 'How often did they tell you not to think about ALS?') ($\alpha = .88$).

Procedure

Potential participants were sent letters which informed them about the study and invited them to participate. Informational letters were also sent to both the ALSA Western Ohio Chapter and the VA National Registry, and then forwarded to patients meeting the inclusion criteria described above by the staff of those agencies. Each agency was provided with 150 letters. The letters included stamped response postcards, which the patients could return to learn more about the study. Once these postcards were received, patients were contacted by

phone to describe the study in detail, confirm their eligibility including exclusion criteria, and determine whether they wished to participate.

Participants were fully screened for study eligibility either in person or by telephone (by AJA). At study entry, eligible participants gave informed consent to the study protocol, approved by the Institutional Review Board of the University of Kentucky. All patients were randomized to either the treatment condition, which involved either written or verbal emotional disclosure, or the control condition, which did not involve a disclosure exercise, but did include completion of the study measures. Random assignment was accomplished using the random number generator function of the Statistical Package for the Social Sciences (SPSS).

Participants enrolled through clinics ($N = 27$ (56%)) completed at least part of the baseline measures at the clinic and completed the rest of the study at home. Participants enrolled through VA and ALSA registries ($N = 21$ (44%)) completed baseline measures as well as the rest of the study entirely at home. Following randomization, control participants were simply asked to complete the study measures. Disclosure participants were asked either to write or talk into a tape recorder about their deepest thoughts and feelings related to their experience with ALS for 20 minutes a day for 3 days over a period of one week. Disclosure participants were provided with a packet containing written instructions for how to complete the exercise, suggestions (e.g., 'Find a quiet place where you can write undisturbed'), and paper on which to write. They were also asked to record their start and stop times for writing or speaking. Ten people in the disclosure group wrote (56%), and 8 people spoke (44%). An investigator (AJA) administered measures of affect and suicidal ideation over the phone at a short-term follow-up, recording participants' verbal responses to items, as some studies have reported a short-term increase in negative affect as a consequence of the disclosure. For disclosure participants, the call followed the last scheduled day of disclosure; for control participants, it followed 1 week after Time 1. Psychological well-being was re-assessed at 3 and 6 months after the intervention. These time points were selected based on the rationale that 'some effects [of expressive disclosure] may take days, weeks, months, or even years to emerge as significant changes on...health measures, if at all' (Pennebaker & Chung, 2011).

Statistical Analyses

The study hypotheses predicted that disclosure participants would demonstrate better psychological well-being than participants in the control group following the intervention. Data were analysed using multi-level models with time points (baseline, 3 months post-intervention, 6 months post-intervention) at Level 1 and people at Level 2 using SAS Proc Mixed (Singer, 2002). This analytic strategy allows for the use of all available data at all three time points without regard to missing data pattern. The primary hypothesis predicted a time by group interaction, where patients who engaged in emotional disclosure would show improvement in well-being relative to those who did not. The secondary hypothesis predicted three-way interactions among time, group, and individual differences (ambivalence over emotional expression, emotional approach coping, and social constraints). Individual differences were standardised and mean-centred before analysis. Results for categorical predictors and interactions are reported as t or F statistics; results for

continuous predictors are reported as gamma weights, which are analogous to unstandardised beta weights in regression. However, in this case, all variables were standardised with $M = 0$ and $SD = 1$, and so the gamma weights are also analogous to standardised beta weights. Descriptive means at individual time points were generated from the MLM results, as raw means would not be comparable either over time (if all points were included, due to differences in sample membership over time) or to the entire analysed sample (if list-wise deletion were used, due to dropping incomplete cases). The degrees of freedom for tests of individual effects in multi-level models were calculated using the between-within method, which divides the residual degrees of freedom into a within-person and a between-person portion. Therefore, the degrees of freedom for any given effect depend on the number of observations, the number of parameters being estimated, and the number of individuals in the analysis.

Results

Sample Characteristics at Study Baseline

Table 1 provides descriptive statistics for the disclosure and control groups. The analysed sample ($N=48$) included 24 disclosure participants and 24 controls. The mean age of the total sample was 60.15 years ($SD = 11.23$ years) with a range of 40 – 81 years. The sample was typically married, well-educated, and financially stable. Weight loss usually accompanies processes of muscle wasting that are characteristic of ALS, but these participants did not report significant differences in weight between their ALS diagnosis and their entry into the current study ($t(46) = 0.35, p = .73$). Independent-sample t-tests were undertaken to determine whether treatment and control groups differed from each other at study baseline. The groups did not significantly differ on the current or past use of antidepressants, current or past use of a journal, current or past participation in psychotherapy, demographic variables (age, race, gender, level of education, marital status, number of living children and their ages, current and past income level, current and pre-diagnosis weight, and living arrangements), or psychological well-being.

Effects of Disclosure on Well-Being

Although there have been reports of increased negative affect immediately after expressive disclosure (e.g., Gillis, Lumley, Mosley-Williams, Leisen, & Roehrs, 2006; Kelley et al., 1997), there were no short-term effects of the disclosure intervention on negative affect from the ABS. In a repeated measures ANOVA on baseline and immediate follow-up negative affect, there was no group effect, time effect, or interaction between time and group (all $F(1, 38) < 1$).

In the longer term, however, there was the predicted statistically significant interaction between group and time predicting psychological well-being ($F(2,69) = 4.27, p < .05$). Figure 2 depicts the results from the multi-level model. Because the well-being measure was the mean of the standardised scores, the results are expressed in standard deviation units. The intervention group experienced a significant increase in well-being from baseline (-0.031) to 3 months after (0.066) the intervention ($t(69) = 2.23, p < .05$). However, at 6 months after the intervention, well-being (-0.031) was no longer significantly different from

baseline ($t(69) = -0.59, p > .05$). In contrast, the control group experienced a significant decrease in well-being from baseline (0.0) to 3 months after (-0.164) the intervention ($t(69) = -2.13, p < .05$), but this change also did not persist at 6 months after (0.009) the intervention ($t(69) = 0.44, p > .05$). The interaction effect was robust to the inclusion of demographic controls (sex, age, time since diagnosis, and years of education; $F(2,66) = 3.89, p < .05$) and current or past journal use ($F(2,67) = 3.59, p < .05$). Within the intervention group, mode of disclosure had no effect on well-being either as a main effect ($F(1,16) = 0.15, p > .05$) or as an interaction with time ($F(2,30) = 1.35, p > .05$).

Moderators of the Effects of Disclosure

Ambivalence over emotional expression and social constraints were related to but not redundant with each other ($r = .52$) and emotional approach coping was modestly related to both ambivalence (processing: $r = -.07$, expression: $r = -.31$) and social constraints (processing: $r = -.03$, expression: $r = -.15$). Therefore, rather than creating a composite, their effects were tested in individual models.

Ambivalence over emotional expression, social constraints, and emotional approach all had main effects on well-being such that higher ambivalence and constraints and lower emotional processing (though not expression) were associated with lower well-being across the entire study (ambivalence: $\gamma = -.36$ (SE = .13), $t(43) = -2.64, p < .05$; constraints: $\gamma = -.38$ (SE = .13), $t(44) = -2.90, p < .05$; emotional approach (processing): $\gamma = .40$ (SE = .17), $t(42) = 2.34, p < .05$). Although none of the individual differences moderated the group effect across all time points (ambivalence: $F(2,64) = 2.05, p > .05$; constraints: $F(2, 65) = 1.79, p > .05$; emotional approach (processing): $F(2,62) = 1.02, p > .05$; emotional approach (expression): $F(2,62) = 0.14, p > .05$), one individual difference moderated the group effect at the 3-month follow-up, when group differences were most evident. One SD higher ambivalence over emotional expression was associated with a near doubling of the intervention effect at Time 2. In this model, the effect of the intervention compared with the control group at Time 2 was $\gamma = .40$ (SE = .14, $t(64) = 2.96, p < .05$); the additional effect of ambivalence in the intervention group at Time 2 was $\gamma = .32$ (SE = .16, $t(64) = 1.96, p = .05$). Figure 3 shows predicted well-being at Time 2 for the intervention and control groups across a range of +1 to -1 SD. The main effects of both ambivalence and expression are evident, but the effect of the intervention was more marked at higher levels of ambivalence.

Discussion

This randomized, controlled trial of an expressive disclosure intervention in patients with Amyotrophic Lateral Sclerosis found that expressive disclosure improved psychological well-being, especially for patients who were ambivalent about emotional expression. The multi-level model indicated an improvement in the intervention group of approximately 0.1 SD in well-being at 3 months post-intervention. This effect is similar to that observed in other studies of medically ill patients (Craft, Davis, & Paulson, 2012; Frattaroli, 2006).

Conversely, the multi-level model indicated a decrease in the control group of approximately 0.15 SD in well-being at 3 months post-intervention. This negative effect of being in the control group in disclosure interventions has been observed before by

investigators who concluded that this effect may occur because those in the control group were forced to actively inhibit negative thoughts and feelings they might otherwise have been able to express, which had a negative effect on well-being (e.g., Norman, Lumley, Dooley, & Diamond, 2004) or stressors related to disease progression negatively affected well-being in the control group, but the disclosure intervention had a buffering effect (e.g., Booth, Petrie, & Pennebaker, 1997). The return of both groups to pre-intervention levels at 6 months would tend to favour the former explanation in the present study. The present study also used a no-disclosure control, as opposed to active controls such as disclosing thoughts and feelings about trivial, neutral, or positive topics. Norman and colleagues (2004) suggested that a no-disclosure control would provide “a more conservative test” (p.181) of possible adverse effects of learning about and consenting to a disclosure study and then being randomized to a control group that is not asked to disclose negative, stressful, or traumatic thoughts and feelings. However, it should be noted that there was no direct measure of inhibition, and so this hypothesis awaits further testing and evidence to confirm that such findings are not spurious and what mechanisms are acting in such findings.

Ambivalence over emotional expression, social constraints, and low emotional approach coping were all related to lower psychological well-being across the course of the study (e.g., Roach et al., 2009). However, ambivalence over emotional expression was also related to a more robust response to the intervention. ‘Ambivalence over expressing emotion can take on different forms, from wanting to express but not being able to, to expressing but not necessarily wanting to, to expressing and later regretting it’ (King & Emmons, 1990). The structured, private nature of the intervention was particularly helpful to people who were unable to express emotion or who had ambivalent attitudes about expressing emotions to others. In contrast, people who were not ambivalent over emotional expression may have not needed this intervention. Those people may already have done the ‘work’ of psychological disclosure before the study. On average, participants had at least a couple of years to adjust to the diagnosis. It could be argued that during this time, participants were able to adjust psychologically to what the diagnosis meant and to process and express their emotional responses with friends and family, therefore reducing the need for an additional disclosure outlet. A recent study of emotionally expressive writing in women with Stage IV breast cancer found that expressive disclosure was most beneficial for patients low in emotional support and those more recently diagnosed (Low, Stanton, Bower, & Gyllenhamer, 2010).

The intervention effect was only evident after 3 months and not after 6 months. This intervention was somewhat different from other emotional expression interventions insofar as patients were asked to disclose their thoughts and feelings about ALS specifically and not to select the most stressful or traumatic event in their histories, which may or may not have been related to ALS. Because ALS is a fast-progressing and dynamic disease, the physical and emotional challenges related to the disease may have been different 6 months after the intervention than they were at the time of the intervention. Therefore, emotional expression interventions that focus specifically on thoughts and feelings related to this disease – and other diseases with similar courses – may need to incorporate ‘booster’ sessions to respond to changes in the situations and emotions that patients are confronting at different stages of the disease.

This study had some limitations that suggest directions for future research. First, the sample size was small, and despite our efforts to recruit people with a reasonably long prognosis, there was attrition due to death. Eight people were known to have died before completing baseline measures, 8 more were known to have died during the course of the study, and 9 more were lost to follow-up and may have died. Our data analysis strategy ensured that all data were used without regard to missing data patterns; however, one direction for future studies with this population would be recruiting a larger sample at an earlier stage in the disease so as to reduce attrition due to death. Another possible direction would be to recruit a sample large enough to enable survival analysis of the disclosure and control groups. Second, as noted above, we can only speculate as to the reason why the control group had decreased well-being after 3 months. Mechanistic studies to clarify this effect are sorely needed. A comparison of different control conditions that involve different degrees of inhibition could also be useful (c.f., Norman et al., 2004).

The present study is generalisable to people with ALS being treated in a variety of clinic settings, who have had some time to adjust to the diagnosis, report good psychological health, and are not mechanically ventilated. The results are also likely to generalize to terminally ill patients who are being cared for at home. Providing a private, structured opportunity to process one's thoughts and feelings may create the potential for a boost in psychological well-being, particularly for those who do not engage in such processing in their natural social environments. This intervention is one that can be provided at low cost and even at remote distances. For those coping with life-threatening illness, structured expressive disclosure interventions may provide an important platform for processing the most challenging aspects of disease-related experience.

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References

- Booth R, Petrie K, Pennebaker J. Changes in circulating lymphocyte numbers following emotional disclosure: evidence of buffering? *Stress Medicine*. 1997; 13:23–29.
- Broderick J, Junghaenel D, Schwartz J. Written emotional expression produces health benefits in fibromyalgia patients. *Psychosomatic Medicine*. 2005; 67:326–334. [PubMed: 15784801]
- Cohen S, Mount B, Strobel M, Bui F. The McGill quality of life questionnaire: a measure of quality of life appropriate for people with advanced disease. *Palliative Medicine*. 1995; 9:207–219. [PubMed: 7582177]
- Craft M, Davis G, Paulson R. Expressive writing in early breast cancer survivors. *Journal of Advanced Nursing*. 2012 e-Publication ahead of print.
- De Moor C, Sterner J, Hall M, Warnecke C, Gilani Z, Amato R, Cohen L. A pilot study of the effects of expressive writing on psychological and behavioral adjustment in patients enrolled in a phase II trial of vaccine therapy for metastatic renal cell carcinoma. *Health Psychology*. 2002; 21:615–619. [PubMed: 12433015]
- Derogatis, L. Affects Balance Scale. Riderwood, MD: Clinical Psychometric Research; 1975.
- Fratraroli J. Experimental disclosure and its moderators: A meta-analysis. *Psychological Bulletin*. 2006; 132:823–865. [PubMed: 17073523]

- Frisina P, Borod J, Lepore S. A meta-analysis of the effects of written emotional disclosure on the health outcomes of clinical populations. *Journal of Nervous and Mental Disease*. 2004; 192:629–634. [PubMed: 15348980]
- Ganzini L, Johnston W, Hoffman W. Correlates of suffering in amyotrophic lateral sclerosis. *Neurology*. 1999; 52:1434–1440. [PubMed: 10227631]
- Gillis M, Lumley M, Mosley-Williams A, Leisen J, Roehrs T. The health effects of at-home written emotional disclosure in fibromyalgia: A randomized trial. *Annals of Behavioral Medicine*. 2006; 32:135–146. [PubMed: 16972811]
- Harris A, Thoresen C, Humphreys K, Faul J. Does writing affect asthma? A randomized trial. *Psychosomatic Medicine*. 2005; 67:130–136. [PubMed: 15673635]
- Hunter M, Robinson I, Neilson S. The functional and psychological status of patients with amyotrophic lateral sclerosis: some implications for rehabilitation. *Disability and Rehabilitation*. 1993; 15:119–126. [PubMed: 8374156]
- Kelley J, Lumley M, Leisen J. Health effects of emotional disclosure in rheumatoid arthritis patients. *Health Psychology*. 1997; 16:331–340. [PubMed: 9237085]
- King L, Emmons R. Conflict over emotional expression: Psychological and physical correlates. *Journal of Personality and Social Psychology*. 1990; 58:864–877. [PubMed: 2348373]
- Lepore S, Silver R, Wortman C, Wayment H. Social constraints, intrusive thoughts, and depressive symptoms among bereaved mothers. *Journal of Personality and Social Psychology*. 1996; 70:271–282. [PubMed: 8636882]
- Lomen-Hoerth C. Characterization of amyotrophic lateral sclerosis and frontotemporal dementia. *Dementia and Geriatric Cognitive Disorders*. 2004; 17:337–341. [PubMed: 15178949]
- Low C, Stanton A, Bower J, Gyllenhammer L. A randomized controlled trial of emotionally expressive writing for women with metastatic breast cancer. *Health Psychology*. 2010; 29:460–466. [PubMed: 20658835]
- Lu Q, Stanton A. How benefits of expressive writing vary as a function of writing instructions, ethnicity and ambivalence over emotional expression. *Psychology and Health*. 2010; 25:669–684. [PubMed: 20204944]
- Lumley, M.; Tojek, T.; Macklem, D. Effects of written emotional disclosure among repressive and alexithymic people. In: Lepore, S.; Smyth, J., editors. *The Writing Cure*. Washington, D.C.: American Psychological Association; 2002. p. 75-95.
- Mann T. Effects of future writing and optimism on health behaviors in HIV-infected women. *Annals of Behavioral Medicine*. 2001; 23:26–33. [PubMed: 11302353]
- Norman S, Lumley M, Dooley J, Diamond M. For whom does it work? Moderators of the effects of written emotional disclosure in a randomized trial among women with chronic pelvic pain. *Psychosomatic Medicine*. 2004; 66:174–183. [PubMed: 15039501]
- Pennebaker, J. *Opening up: The healing power of expressing emotions*. New York: Guilford Press; 1997.
- Pennebaker J, Beall S. Confronting a traumatic event: toward an understanding of inhibition and disease. *Journal of Abnormal Psychology*. 1986; 95:274–281. [PubMed: 3745650]
- Pennebaker, J.; Chung, C. Expressive writing and its links to mental and physical health. In: Friedman, HS., editor. *Oxford Handbook of Health Psychology*. New York: Oxford University Press; 2011. p. 417-437.
- Rabkin J, Wagner G, Del Bene M. Resilience and distress among amyotrophic lateral sclerosis patients and caregivers. *Psychosomatic Medicine*. 2000; 62:271–279. [PubMed: 10772408]
- Roach A, Averill A, Segerstrom S, Kasarskis E. The dynamics of quality of life in ALS patients and caregivers. *Annals of Behavioral Medicine*. 2009; 37:197–206. [PubMed: 19350337]
- Robbins R, Simmons Z, Bremer B, Walsh S, Fischer S. Quality of life in ALS is maintained as physical function declines. *Neurology*. 2001; 56:442–444. [PubMed: 11222784]
- Ruff R, Light R, Parker S, Levin H. Benton controlled oral word association: Reliability and updated norms. *Archives of Clinical Neuropsychology*. 1996; 11:329–338. [PubMed: 14588937]
- Sebring D, Moglia P. Amyotrophic lateral sclerosis: psychosocial interventions for patients and their families. *Health and Social Work*. 1987; 12:113–120. [PubMed: 3583101]

- Simmons Z, Bremer B, Robbins R, Walsh S, Fischer S. Quality of life in ALS depends on factors other than strength and physical function. *Neurology*. 2000; 55:388–392. [PubMed: 10932273]
- Singer, JD. Fitting individual growth models using SAS PROC MIXED. In: Moskowitz, DS.; Hershberger, SL., editors. *Modeling intraindividual variability with repeated measures data: Methods and applications*. Mahwah, NJ: Lawrence Erlbaum Associates; 2002. p. 135-170.
- Stanton A, Danoff-Burg S, Cameron C, Bishop M, Collins C, Kirk S, Sworowski L, Twillman R. Emotionally expressive coping predicts psychological and physical adjustment to breast cancer. *Journal of Consulting and Clinical Psychology*. 2000; 68:875–882. [PubMed: 11068973]
- Stanton A, Danoff-Burg S, Sworowski L, Collins C, Branstetter A, Rodriguez-Hanley A, Kirk S, Austenfeld J. Randomized controlled trial of written emotional expression and benefit-finding in breast cancer patients. *Journal of Clinical Oncology*. 2002; 20:4160–4168. [PubMed: 12377959]
- World Federation of Neurology Research Group on Neuromuscular Diseases. El Escorial World Federation of Neurology criteria for the diagnosis of amyotrophic lateral sclerosis. *Journal of Neurological Science*. 1994; 124:96–107.
- Yesavage J, Brink T, Rose T, Lum O, Huang V, Adey M, Leirer V. Development and validation of a geriatric depression screening scale: a preliminary report. *Journal of Psychiatric Research*. 1983; 17:34–49.
- Zakowski S, Ramati A, Morton C, Johnson P, Flanigan R. Written emotional disclosure buffers the effects of social constraints on distress among cancer patients. *Health Psychology*. 2004; 23:555–556. [PubMed: 15546223]

Figure 1.
CONSORT diagram.

Figure 2.

Multi-level model results for the effect of the disclosure intervention on well-being (in SD units) at 3 and 6 months post-intervention

Figure 3.
Multi-level model results for the effect of the disclosure intervention and trait ambivalence over emotional expression on well-being (in SD units) at 3 months post-intervention

Table 1

Characteristics of the sample at study entry

Characteristic	Control Group			Disclosure Group <i>p</i> for t/χ^2		
	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>
Age (years)	23	58.8	12.6	25	61.4	9.9 .43
Race						.42
Caucasian	19			24		
African-American	2			1		
Hispanic	1					
Native American	1					
Gender						.46
Male	17			16		
Female	6			9		
Education level (years)	15		2.7	14.3	3.1	.41
Current income (US\$1000's)	\$45-50			\$50-55		.50
Prior income (US\$1000's)	\$50-55			\$55-60		.40
Marital status						.81
Single	1			1		
Currently married	19			20		
Separated	0			1		
Divorced	2			1		
Widowed	1			2		
Living Arrangement						.60
Living alone	4			3		
Living with spouse	19			22		
Number of children	3	2		2	1	.40
Weight before diagnosis (kg.)	83	17		78	15	.25
Weight at study entry (kg)	78	17		76	16	.64
Time since ALS diagnosis (mo.)	34	44		23	31	.32
Current/past antidepressants	6/2			10/4		.31/.44
Current/past journal use	3/7			1/4		.26/.23

Characteristic	Control Group			Disclosure Group <i>p</i> for t/χ^2		
	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>
Current/past psychotherapy	5/4			4/3		.61/.60