Journal of Health Psychology
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J Health Psychol published online 4 November 2014
DOI: 10.1177/1359105314554819

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http://hpq.sagepub.com/content/early/2014/10/31/1359105314554819

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Journal of Health Psychology
1–10

DOI: 10.1177/1359105314554819
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Effect of a short-term psychological intervention on the anxiety and depression of amyotrophic lateral sclerosis patients

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Abstract

This study evaluated the effectiveness of a psychological intervention in amyotrophic lateral sclerosis patients, consisting of four semi-structured sessions of cognitive behavioural therapy combined with counselling techniques. An intervention group and a control group were established. The Hospital Anxiety and Depression Scale was used to assess levels of anxiety and depression. In total, fifty-four patients took part. Prior to the intervention, the intervention group displayed rates of 63.3 and 36.7 per cent for anxiety and depression, respectively, falling to 16.7 and 10.0 per cent afterwards. The psychological intervention demonstrated potential for the reduction of levels of anxiety and depression in amyotrophic lateral sclerosis patients.

Keywords

anxiety, clinical health psychology, depression, health psychology, psychological distress

Introduction

Without life-sustaining treatment, death usually ensues in amyotrophic lateral sclerosis (ALS) patients within 3–5 years of the onset of the disease, due to respiratory muscle insufficiency (Lechtzin et al., 2001; Ringel et al., 1993). As the disease advances, patients notice the progressive loss of voluntary motor control and limitations in life-sustaining abilities, such as breathing, swallowing and communicating. The psychological impact of the disease on patients and their carers has been relatively well studied, and issues such as anxiety, depression, hope, coping style and spirituality have been explored in some depth (Pagnini, 2013). However, the real extent of psychological disturbances for ALS patients is still the object of debate (Huey

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et al., 2010; Kurt et al., 2007) and the results in previous studies vary greatly (Rabkin et al., 2000), with rates of depression ranging between 0 and 75 per cent (Chio et al., 2004; Rabkin et al., 2005) and those for anxiety between 0 and 30 per cent (Kurt et al., 2007).

According to Lazarus and Folkman's (1984) stress and coping model, psychosocial adjustment to serious illness is determined by cognitive appraisal and coping strategies. In ALS, the impact of the symptoms and the lack of a curative treatment require important adaptive mechanisms: Patients have to adjust their internal needs to new external demands (Van Groenestijn et al., 2011). These coping strategies, together with cognitive appraisal and social support, predict more than 60 per cent of the variance in psychological adaptation to ALS (Matuz et al., 2010) and they should therefore be considered among the objectives for healthcare teams.

For other serious life-threatening illnesses, the efficacy of cognitive behavioural therapy (CBT) and counselling-based psychological intervention programmes has been demonstrated (Goodwin et al., 2001; Parker et al., 2008). In ALS patients, it is accepted that medical treatment is not sufficient for overall care (Kurt et al., 2007; Traynor et al., 2003), and many studies concerned with psychological issues in ALS conclude that patients and carers could benefit from particular psychological interventions (Wijeskera and Leign, 2009). However, longitudinal studies and those concerning treatments and interventions are rare (Pagnini, 2013). This deficiency has led to the publication of intervention models aiming to reduce the impact of this devastating disease. Recent studies on the use of meditation (Pagnini et al., 2014a), hypnosis (Palmieri et al., 2012) and expressive disclosure (Averill et al., 2013) have reported results pointing to a reduction of patient and carer suffering. To improve patient care, more research on the psychological issues is therefore required (Pagnini et al., 2012; Simmons, 2014). The aim of this study is to evaluate the possible benefits of a psychological intervention based on a combination of CBT and counselling techniques, as part of a multidisciplinary approach to the care of ALS patients.

Patients and methods

This study took place in an ALS referral unit from June 2007 to December 2009. Patients diagnosed with probable or definitive ALS (Brooks et al., 2000) who were clinically stable and managed at our respiratory care unit were eligible to participate.

Previous pulmonary disease, dementia and the non-reception of psychopharmacological treatment were exclusionary criteria. The last criterion was included in order to maintain homogeneity with regard to the management of anxiety and depression since most of the patients' treatment included antidepressants and/or ansyolitic drugs. These were prescribed and controlled by the psychiatrist attached to the unit.

Informed consent was obtained from each subject who took part in the study, and the study protocol was approved by the hospital's ethics committee.

Assessment measures

Clinical and functional assessments were made at two different times over the course of the progression of the disease. Patients' physical impairment was evaluated with the Revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R; Cederbaum et al., 1999). This scale consists of 10 items, assessing ability with regard to breathing, salivation, speech and climbing stairs. Scoring is based on a 5-point scale (4 = 'normal' and 0 = 'no ability'). Bulbar involvement was defined as the presence of dysphagia, dysarthria, drooling and/or alterations in videofluoroscopy and was assessed with the Norris scale bulbar subscore (NBS; Norris et al., 1974) which ranges from 39 (normal state) to 0 (total dysfunction). Depression and anxiety were measured using the Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983). This 14-item self-rating scale, which has four possible responses for each item, consists of two subscales: depression (HADS D) and anxiety (HADS A). Scores of 0–7 indicate that participants are not depressed or anxious, 8–10 indicates a mild mood disturbance, 11–14

indicates moderate depression or anxiety and 15–21 severe depression or anxiety.

Study design

The study design centres on a psychological intervention which forms part of the care protocol implemented by the multidisciplinary team of the respiratory care unit. To perform the study protocol, every patient was offered the opportunity of receiving psychological care during one of their outpatient appointments at the unit.

The patients who agreed to take part and were able to come to the hospital constituted the intervention group (IG). The number and frequency of interventions varied in accordance with the psychological needs of each family. For this group, the pre-intervention assessment of the variables was undertaken at the first intervention session, and the post-intervention assessment took place after the four intervention sessions had been completed.

The control group (CG) was constituted by patients who, despite indicating that they would have liked to take part in the intervention programme, were unable to come to the hospital on a periodic basis, or would have had considerable difficulty in doing so. For the CG, the initial assessment of the variables took place on the occasion on which they were offered the opportunity to form part of the study, which was during one of the periodical medical check-ups. These patients only came to the unit when they had a medical appointment. The post-intervention assessment for this group took place during the next outpatient appointment, between 3 and 6 months after the pre-intervention assessment.

Study groups

IG management. Patients were considered to have completed the short-term intervention after 4 sessions. The sessions lasted approximately an hour, with 15–25 days between each session. Although this did not form part of the study, after the four sessions had been completed, patients and family members were offered the opportunity to receive further psychological care throughout the course of the disease from the same psychologist.

Patients assigned to the IG attended an *initial diagnostic impact session.* In this interview, patients explained their understanding of what ALS is, enabling the identification of possible distorted thoughts and unrealistic perceptions of the gravity of the disease. This session enabled the following to be established: what was known, what desires for information existed, the patient's coping style, the presence of denial mechanisms and/or a conspiracy of silence, that is, an agreement by family members and/or professionals to hide the true gravity of the situation from the patient. Furthermore, the quality of family relationships was evaluated, along with feelings of being a burden for the family, the perceived social support and their financial situation. Afterwards, a separate session was undertaken with the family members without the patient being present. During this session, needs and resources were identified, along with their previous and current relationship with the patient, the presence of a conspiracy of silence, coping mechanisms and perceived social support. A key objective of this session was to facilitate emotional expression, forming the starting point for the programme.

The second interview was a *psychoeducation session* about their illness, followed by an explanation of the relationship between thoughts, activities, physical feelings and mood. Later on, and in accordance with the principles of CBT, the patients were trained to detect distorted thoughts and to use the process of cognitive restructuring and emotional management strategies. They were trained to recognize their own emotional experience – that is, to know what they felt and to be able to put a name to their emotions – and also in emotional self-regulation techniques. From the behavioural point of view, the importance of clear and honest communication with the family and healthcare team was stressed, as was the importance of continuing with leisure and social activities in order to avoid becoming isolated. Role-playing was used to practise strategies for explaining in social interactions what their condition is, given that

patients are subjected to constant questions on this. When necessary, thoughts which encouraged denial were dealt with and the family members were trained to detect warning signs of denial mechanisms in another separate family-only session. Conspiracies of silence were also addressed when present.

Although a standardized intervention plan was followed, every session was adjusted to fit the specific circumstances, needs and characteristics of the individual patient.

The *third session* mainly consisted of assessing patient knowledge in relation to some therapeutic points: the procedures for the respiratory muscle aids, the percutaneous endoscopic gastrostomy feeding tube, the invasive ventilation procedures and any distorted thoughts concerning these. At the end of this session, an opportunity was given to discuss these issues with the medical team. The decision-making process for the moment at which these procedures would be required was discussed and the information requested by the patient and the family was provided. Just as in the second session, future functional deterioration and alternative communication methods were discussed, the patient's coping style and current emotional state permitting. The maintenance of social and leisure activities was encouraged.

To complete the intervention plan, the patient had to attend at least four sessions. In the *fourth session*, in order to consolidate treatment changes and prevent relapse, participants were trained in problem-solving and self-esteem improvement. The post-intervention assessment was undertaken after this fourth session.

From this point onwards, the interventions took place according to the specific needs of the patient and the family, with any such sessions not forming part of the study. Additional details of the methods and equipment are provided in the online Supplemental Material.

CG management. Patients assigned to the CG only received individualized psychoactive drug treatment prescribed by a psychiatrist. The study variables were recorded when the patient came to the respiratory outpatient clinic for respiratory assessments as part of the periodic monitoring of their illness.

Statistics. Binary and categorical variables were summarized using frequency counts and percentages. Continuous normally distributed variables were expressed as mean ± standard deviations (*SD*s).

To evaluate the differences between the two groups, the χ^2 test was used for categorical data. Student's *t*-test was used for the normally distributed quantitative variables and the Mann–Whitney *U* test for those which were not normally distributed. To evaluate the post-intervention changes in the levels of anxiety and depression, an analysis of variance (ANOVA) for multiple measures was carried out. McNemar's test was used in order to study the changes between the two assessment points in the number of subjects who presented anxiety and depression. Effect sizes were calculated using Cohen's *d*. The Pearson correlation coefficient was used to determine whether there were correlations between scales. Statistical significance was taken as $p < 0.05$.

Results

A total of 62 patients attended the initial interview. Four refused the offer of psychological care and four were excluded from the study for not receiving psychopharmacological treatment. Of the remaining 54 patients, 30 patients formed part of the IG and 24 the CG.

The intervention lasted a mean of 11.85 ± 10.85 weeks. In the CG, the second evaluation took place 20.86 ± 13.16 weeks after the first interview. At the beginning of the study, there were no differences between the IG and the CG in the demographic or clinical data, nor mechanical ventilation needs. A difference between the two groups was only found in the case of time since diagnosis up to the initial assessment, which was higher in the CG (28.3 ± 39.2 vs 54.3 ± 50.6; $p = 0.019$) (Table 1). At the time of the final evaluation, there were still no significant differences found between the two groups with regard to their clinical

Table 1. Demographic data and clinical characteristics for the whole group, both for those who participated in the short-term psychological intervention and for those who did not, at the time of the first psychological evaluation.

	All patients	Intervention group	Control group	*p* value*
Male/female	16/38	8/22	8/16	0.323
Age (years)	63.1 ± 9.7	60.6 ± 9.3	66.2 ± 9.5	0.053
Time since onset of symptoms (months)	54.6 ± 47.9	44.8 ± 42.2	71.4 ± 53.1	0.099
Since diagnosis (months)	38.1 ± 45.1	28.3 ± 39.2	54.3 ± 50.6	0.019
Spinal/bulbar onset	35/19	20/10	15/9	0.573
ALSFRS-R	16.1 ± 10.1	17.4 ± 9.5	14.6 ± 10.5	0.360
NVS/NIV/tracheotomy	16/22/16	10/11/9	6/11/7	0.880
NBS	25.6 ± 12.4	28.9 ± 10.8	22.1 ± 13.5	0.118
FVC (L)	1.5 ± 1.1	1.5 ± 1.1	1.5 ± 1.1	0.915
%FVC (%)	53.6 ± 30.1	51.7 ± 33.5	55.7 ± 26.8	0.708

ALSFRS-R: Revised Amyotrophic Lateral Sclerosis Functional Rating Scale; NVS: no ventilatory support; NIV: non-invasive ventilation; NBS: Norris scale bulbar subscore; FVC: forced vital capacity; %FVC: predicted FVC; MIC: maximum insufflations capacity; PCF: peak cough flow; PCF_{MIC}: manually assisted PCF; PCF_{MI-E}: mechanically assisted PCF; PEmax: maximum expiratory pressure; PImax: maximum inspiratory pressure; SD: standard deviation.
Data are expressed as mean ± SD for continuous variables and number for categorical variables.
The spirometric values for the tracheotomy patients were obtained before the tracheotomy was performed.
*Chi-square test, Student's *t*-test or Mann–Whitney *U* test.

Table 2. Clinical characteristics for the whole group, for those who participated in the short-term psychological intervention and those who did not, at the time of the second psychological evaluation.

	All patients	Intervention group	Control group	*p* value*
ALSFRS-R	13.6 ± 9.5	15.4 ± 9.7	11.2 ± 9.1	0.155
NVS/NIV/tracheotomy	12/24/18	7/12/11	5/12/7	0.755
NBS	26.1 ± 13.1	28.3 ± 12.5	22.8 ± 14.1	0.361
FVC (L)	1.4 ± 1.1	1.3 ± 1.1	1.5 ± 1.1	0.763
%FVC (%)	45.5 ± 27.3	44.6 ± 26.4	46.4 ± 25.7	0.852

ALSFRS-R: Revised Amyotrophic Lateral Sclerosis Functional Rating Scale; NVS: no ventilatory support; NIV: non-invasive ventilation; NBS: Norris scale bulbar subscore; FVC: forced vital capacity; %FVC: predicted FVC; MIC: maximum insufflations capacity; PCF: peak cough flow; PCF_{MIC}: manually assisted PCF; PCF_{MI-E}: mechanically assisted PCF; PEmax: maximum expiratory pressure; PImax: maximum inspiratory pressure; SD: standard deviation.
Data are expressed as mean ± SD for continuous variables and number for categorical variables.
The spirometric values for the tracheotomy patients were obtained before the tracheotomy was performed.
*Chi-square test, Student's *t*-test or Mann–Whitney *U* test.

situation (i.e. physical impairment and mechanical ventilation needs) (Table 2).

Effects of the intervention on anxiety and depression

At the first interview, 24.1 per cent of the total number of patients displayed mild anxiety, 40.7 per cent moderate anxiety and 13 per cent severe anxiety. The levels of depression were as follows: 25.9 per cent mild, 35.2 per cent moderate and 7.4 per cent severe. There were no significant differences between the levels of depression in the two groups (9.83 ± 3.94 vs 8.88 ± 4.43, respectively; $p = 0.405$), but the IG displayed higher levels of anxiety (12.10 ± 3.53

Table 3. HADS subcomponents of anxiety and depression. Differences between the first interview and the second evaluation for the intervention group and the control group.

	Intervention group			Control group			
	Pre	Post	*p* value	Pre	Post	*p* value	Eta^2
Anxiety	12.10 ± 3.53	7.40 ± 3.77		8.79 ± 4.03	9.42 ± 3.71	0.000*	0.457
% (*n*) classified as anxious†	63.3	16.7	0.000**	41.7	39.3	0.500**	
Depression	9.83 ± 3.94	6.23 ± 3.68		8.88 ± 4.43	9.58 ± 4.49	0.000*	0.354
% (*n*) classified as depressed†	36.7	10.0	0.005**	50.0	46.4	1.000**	

HADS: Hospital Anxiety and Depression Scale; ANOVA: analysis of variance; SD: standard deviation.
Data are expressed as mean ± SD for continuous variables and number for categorical variables.
†Percentage of patients with moderate or severe anxiety/depression.
*ANOVA for multiple measures.
**McNemar's test.

vs 8.79 ± 4.03, respectively; $p = 0.002$). Neither patient age ($p = 0.328$) nor time since diagnosis ($p = -0.148$) displayed a relationship with this difference.

At the post-intervention evaluation, the anxiety levels of IG patients fell from 12.10 ± 3.53 to 7.40 ± 3.77, as did the levels of depression, from 9.83 ± 3.94 to 6.23 ± 3.68. The percentage of patients with moderate and severe anxiety fell from 63.3 to 16.7 per cent ($p = 0.001$) and that of those with moderate or severe depression fell from 36.7 to 10.0 per cent ($p = 0.005$). In the CG, anxiety levels rose from 8.79 ± 4.03 to 9.42 ± 3.71, while no significant changes were found with regard to the levels of depression. The rate of anxiety and depression in the CG had not decreased at the time of the second evaluation ($p = 0.500$ and 1.000, respectively) (Table 3).

For depression, the effect size measured as a standardized mean difference of Cohen's *d* was 1 (95% confidence interval (CI) = 0.230, 2.77). This is a large Cohen's effect size, and this also indicates that the mean of the IG is equivalent to the 84th percentile of the CG. With regard to anxiety, there is also a large effect size according to Cohen's rationale ($d = 1.417$; 95% CI = 0.650, 2.184), with the mean of the IG group being approximately equivalent to the 92nd percentile of the CG.

At the final evaluation for both groups, it was found that anxiety and depression were not related to the type of ventilation, level of physical function or respiratory ability. Only in the IG was there a negative correlation between depression and manual and mechanical assisted peak cough flow (PCF_{MIC} and $PCF_{MI\text{-}E}$; $p = 0.040$ and $p = 0.021$, respectively).

Discussion

Our four-session psychological intervention may be helpful in the reduction of levels of anxiety and depression in clinically stable ALS patients. Despite the fact that the mean depression scores for the whole group are in the mild HADS range, almost 40 per cent of the patients are in the moderate and severe ranges and more than half of the patients presented clinically significant anxiety. Although there are some prior studies which found similar levels of depression and anxiety (Hogg et al., 1994; Houpt et al., 1997), most studies of this type have reported lower levels (Huey et al., 2010; Kurt et al., 2007). Reasons for these differences could include the use of small and heterogeneous samples and the use of different evaluation instruments (Pagnini et al., 2014b; Rabkin et al., 2000). The use of psychological assessment measures which are not specific to ALS may lead to symptoms typical as part of the

progression of the disease (such as fatigue, weakness, loss of appetite and insomnia/hypersomnia) being mistaken for symptoms of depression (Pagnini et al., 2014b). This may be the reason for the high incidence of depression found in our sample and it may also be why some studies have concluded that those patients with the greatest disability and with the disease at the most advanced stages are those who display the greatest levels of anxiety and depression (Goldstein et al., 2004; Simmons et al., 2000). Others, however, have affirmed that other variables, such as coping skills (Chio et al., 2004; Tramonti et al., 2012), the relationship between the patient and the carer (Mock and Boerner, 2010), existential or spiritual needs (Chio et al., 2004) and socioeconomic status (Chio et al., 2004) are those which have the strongest links to the emotional state of these patients. In our study, those patients with a tracheotomy did not display higher levels of anxiety and depression than those patients with non-invasive ventilation (NIV) or without breathing aids, which is in agreement with those studies which found no relationship between levels of anxiety and depression with the progression of the disease (Goldstein and Abrahams, 2013; Goldstein et al., 2004; Robbins et al., 2001). Similarly, no relationship was found between time since diagnosis, degree of disability, illness progression and the type of respiratory muscle aid, on the one hand, and greater levels of psychopathology, on the other.

On the basis of these results, it can be said that levels of anxiety and depression in ALS patients can only be explained from a multifactorial point of view and that the difficulties which the disease poses necessarily require the action of a multidisciplinary team. Such multidisciplinary care also increasingly requires greater specialization. Advances in medical procedures enable ALS patients to live longer, but they also increase the level of disability associated with the progression of the disease and, consequently, the difficulties faced by health professionals and carers. Such difficulties not only affect psychological and emotional assessment, but also cognitive and behavioural evaluation, as disability increases (Goldstein and Abrahams, 2013). The clinical repercussions of these problems are considerable, as they directly affect whether the treatment nominally chosen by the patient is really based on their values and desires.

Most studies providing data on the quality of life and psychological well-being of ALS patients and their carers conclude that an emotional intervention is required (Averill et al., 2007; Chio et al., 2004; Kurt et al., 2007; Pagnini, 2012, 2013) and that these patients would benefit from particular psychological interventions (Wijeskera and Leign, 2009). Recent studies have reported an improvement in the psychological well-being of ALS patients and their carers after following a mindfulness meditation training programme, suitably adapted to the difficulties associated with the disease (Pagnini et al., 2014a), and also after hypnosis-based treatment (Palmieri et al., 2012). It has also been reported that patients with difficulties in expressing their emotions improve their psychological well-being after sharing their thoughts and feelings regarding their experience with ALS (Averill et al., 2013).

In our study, to improve the emotional well-being of these patients and establish an intervention plan, we looked for similarities in other fields and with other diseases, where levels of anxiety and depression are also high and where the patient's independence and life is under threat. We found that with cancer and dementia patients and those in palliative care programmes, cognitive behavioural therapy and counselling are well established and the positive effect they have has been scientifically demonstrated (Goodwin et al., 2001). Cancer patients who receive such psychological therapy experience significant improvement in self-efficacy, defined as having the confidence to perform the behaviour necessary to reach a desired goal (Bandura, 1997; Daniels and Kissane, 2008). Individuals with high self-efficacy seek preventive care, maintain more fluid dialogue with their medical team and demonstrate a better understanding of the problems associated with the disease and how to deal with these effectively (Meyer and Mark, 1995).

Although there are no other studies with ALS patients with which we can directly compare our results, it is likely that the reduction in levels of anxiety and depression in our patients is related to some of these issues and that the intervention has modified their coping styles. Part of our intervention consisted of facilitating emotional expression, so that the patient can identify their own emotions and thus be able to employ emotional self-regulation strategies which are more suited to living with ALS. It may be that, as was the case in a previous study (Averill et al., 2013), such discussion enables the patient to deploy their personal resources more effectively when faced with this disease and thus reduce their emotional suffering. Moreover, patients with dementia improve their knowledge of their disease and acquire better coping skills after brief psychotherapy, counselling and social support interventions (O'Connor et al., 2008), and it may be the case that the patients in our study obtained similar benefits. Therefore, in our view, such an approach could also be useful for pulmonology teams, which, by including mental health professionals within them, could thus provide care which addresses the specific needs of each patient. In this way, due attention can be paid to the full range of patient requirements, whether these are physical, psychological or spiritual.

Some limitations restrict the generalizability of the study findings. The study does not have a randomized CG and it is likely that those who were most interested in receiving psychological support or those who were most anxious or depressed had a higher presence in the IG and that this may have facilitated a greater impact for the intervention. Our data show higher levels of anxiety in the IG when compared with the CG at the start of the study, and this may be the cause of the results obtained. In order to obtain more reliable results, the intervention would need to be repeated with a larger sample.

To our knowledge, the results are generally consistent with and expand on the findings reported in the handful of published studies evaluating the psychological state of ALS patients, and it is the first to describe a short-term psychological intervention based on CBT and counselling which is specific to ALS patients.

Acknowledgement

We would like to thank Professor A. Oliver for her helpful comments on the statistical analysis.

Funding

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

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