

OPEN

Exploring the Use of Educational Material About Shoulder Dysfunction

A Quality Improvement Project in People With Amyotrophic Lateral Sclerosis

Katherine Burke, PT, Amy Swartz Ellrodt, PT, Jason Levine, PT, Taylor Adams, PT, Rebecca Allis, PT, Ian Macmurdie, and Sabrina Paganoni, MD, PhD

Abstract: Shoulder pain is a common secondary complication of amyotrophic lateral sclerosis (ALS) that can contribute to functional decline and decreased participation in daily activities. The purpose of this study was to assess the effectiveness of an educational brochure aimed at improving knowledge regarding shoulder pain and dysfunction in people with ALS. Participants completed a preintervention survey with questions regarding their knowledge of how ALS may affect their shoulders. After completing the presurvey, they were mailed a brochure that described shoulder health and range of motion and stretching exercises. Four weeks after receiving the brochure, participants were then asked to determine the effectiveness of the educational materials in terms of impact on shoulder-related knowledge and self-efficacy with regard to prevention of shoulder pain and dysfunction. More than 50% of participants reported pain, decreased range of motion, or weakness in at least one shoulder since being diagnosed with ALS. All participants were interested in receiving educational materials, and all agreed that the brochure was easy to interpret and understand, with most (87%) reporting that it was helpful. Educational brochures are one strategy to improve awareness about shoulder health and to educate patients with ALS about exercises that may help reduce shoulder pain and dysfunction.

Key Words: Amyotrophic Lateral Sclerosis, ALS, Shoulder Pain, Stretching, Patient Education

(Am J Phys Med Rehabil 2018;97:379–382)

Pain is a common secondary complication of amyotrophic lateral sclerosis (ALS). Pain can develop from musculoskeletal causes (e.g., limited mobility, loss of range of motion (ROM), difficulty with positioning in bed or in a wheelchair) and/or neurologic dysfunction (e.g., spasticity).¹ It is estimated that pain occurs in people with ALS at a frequency ranging from 24% to 78%,^{2,3} and it has been shown to occur at any stage of the disease.^{3–5} Higher pain levels have been correlated with a reduction in quality of life.⁶

Common sites for pain development include the back, neck, and shoulder region.^{1,7} Ho et al.² reported that 45% of people with ALS have experienced neck and shoulder pain. Those with shoulder pain were more likely to have proximal upper limb weakness and were more likely to report pain in other body regions. For most people with shoulder pain, the cause was undefined (67%); however, 18% had adhesive capsulitis, 11% reported rotator cuff injuries, and 4% had tendinitis. Only half of those with shoulder pain reported being treated for their shoulder pain, which is consistent with other reports suggesting that pain is an often underestimated and neglected symptom in ALS.³ To date, despite the high prevalence of pain, there are no trials evaluating optimal treatment of pain in persons with ALS.⁸

Shoulder pain related to ALS can be difficult to treat because of multiple contributing factors including muscle weakness and atrophy, impingement from positioning, and pre-existing orthopedic conditions. However, despite the progressive nature of ALS, interventions can be implemented that may prevent and treat shoulder pain and stave off decline in function.¹ Current recommendations for people with ALS emphasize regular stretching and ROM exercises for the shoulder.¹ Instructions for stretching and ROM exercises evolve over time in patients with ALS to adapt the program to accommodate for progressive muscle weakness and atrophy. It is usual clinical practice to encourage active ROM in early stages of the disease and then modify the program to incorporate caregiver assistance. In the late stages of the disease, caregivers are trained to perform passive stretching/ROM exercises. Loss of available ROM, subluxation, and contractures in the shoulder are frequent complications of ALS that could likely be prevented by instituting such exercises early in the disease process.⁷ In addition, these exercises may aid in the prevention of adhesive capsulitis of the shoulder.^{9,10} Exercise combined with use of shoulder approximation sleeves can further help minimize shoulder pain.^{1,7}

Given the high risk of shoulder pain in individuals with ALS, patient and caregiver awareness is critical to prevent

From the Massachusetts General Hospital, Neurological Clinical Research Institute (NCRI), Boston, Massachusetts (KB, ASE, SP); Massachusetts General Hospital, Institute of Health Professions (IHP), Boston, Massachusetts (JL, TA, RA, IM); Spaulding Rehabilitation Hospital, Boston, Massachusetts (SP); and VA Boston Healthcare System, Boston, Massachusetts (SP).

All correspondence should be addressed to: Sabrina Paganoni, MD, PhD, Harvard Medical School, Neurological Clinical Research Institute (NCRI), Massachusetts General Hospital, 165 Cambridge St, Suite 600, Boston, MA 02114.

SP has been funded by the NIH (Career Development Award 2K12HD001097-16).

Financial disclosure statements have been obtained, and no conflicts of interest have been reported by the authors or by any individuals in control of the content of this article.

Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's Web site (www.ajpmr.com).

Copyright © 2018 The Author(s). Published by Wolters Kluwer Health, Inc. This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

ISSN: 0894-9115

DOI: 10.1097/PHM.0000000000000885

and/or manage shoulder problems. Through improving knowledge and self-efficacy, persons with ALS may be better equipped to prevent or address potential shoulder issues and incorporate preventative measures into their treatment plans.

The goals of this study were to develop an educational brochure about shoulder health that could be widely distributed across ALS care centers and to explore the impact of the brochure on shoulder-related knowledge and self-efficacy in a small group of patients with ALS.

METHODS

Participants

For this study, we targeted a group of people with an ALS diagnosis who were seen by a physiatrist at an ALS Multidisciplinary Clinic between January 2015 and February 2016. Patients who were receiving mechanical ventilation via tracheostomy were not considered eligible. Eligible participants were contacted regarding interest in participating in the study via opt-in mailing informing them of the study. The study was approved by the Partners Human Research Committee. Given the exploratory nature of the study, there was no power analysis.

Educational Material

The educational material (brochure; available for download as Supplementary Figure, Supplemental Digital Content, <http://links.lww.com/PHM/A544>) was designed by a team of student physical therapists in collaboration with experienced ALS clinicians. The brochure described shoulder health in ALS and discussed exercises to help prevent shoulder pain and dysfunction. The recommendations in the educational material were based on current clinical practice standards related to shoulder dysfunction secondary to muscle atrophy.

Surveys

Patients who agreed to participate were asked to complete a preintervention survey with five-point Likert scale questions regarding shoulder weakness, pain, and ROM. After completing the presurvey, participants were mailed a color copy of a brochure. Four weeks after receiving the brochure, participants were then asked to complete a postintervention survey with five-point Likert scale questions to determine the effectiveness of the educational materials in terms of impact on shoulder-related knowledge and self-efficacy with regard to prevention of shoulder pain and dysfunction. Answer options for all five-point Likert scale questions were the following: strongly agree, agree, neutral, disagree, and strongly disagree. Surveys were given either in paper form, over the phone, or using a digital version on RedCap software.

RESULTS

Participants

A total of 38 eligible patients were identified, but 10 died before being contacted for possible enrolment in the study (Fig. 1). One patient was excluded because of frontotemporal dementia and inability to understand study procedures. Four were excluded because their English was not their primary

language (for this pilot study, the brochure and surveys were only available in English). Of the remaining 23 eligible participants, 16 (70%) agreed to participate and completed the preintervention survey. Most participants were right-handed (94%), and the mean (range) age was 58(27–76) yrs. One patient deceased during the study, and 15 (94%) of 16 completed the postintervention survey.

Prevalence of Shoulder Dysfunction

Preintervention surveys revealed a high prevalence of shoulder pain and dysfunction among study participants since being diagnosed with ALS: 50% had experienced pain in either shoulder (“agree” or “strongly agree”), 75% noticed weakness in at least one of their shoulders, 63% could not lift at least one of their arms above shoulder height without assistance, 50% were not able to put on a shirt independently, and 75% noticed reduced ROM in at least one of their shoulders. Three participants (19%) reported use of adaptive aids for feeding, two (13%) used of splints for their hands, and four (25%) used a positioning device such as a mobile arm support.

Despite the high prevalence of shoulder issues since their ALS diagnosis, only 50% of study participants agreed or strongly agreed that they have received care for either a right or a left shoulder problem since their diagnosis of ALS. Among those receiving treatment for shoulder pain, management strategies included stretching (63%), ROM exercises (63%), strengthening exercises (13%), splinting (13%), medications (13%), using ice or heat (6%), soft tissue mobilization techniques (6%), and/or positioning strategies (6%) with arm on pillow. Only a few participants were being seen by physical therapists (19%), occupational therapists (19%), medical doctors (6%), and massage therapists (6%) for treatment of shoulder pain or dysfunction. None of the study participants were being seen by an acupuncturist or pursuing complementary and alternative medicine therapies for the treatment of shoulder pain at the time of the preintervention survey.

Twenty-five percent of participants reported that they did not feel informed about how ALS can impact the shoulder and 25% also reported that no health care professional had discussed with them how ALS may affect shoulder health. Only approximately 50% of participants reported that they knew how to address shoulder pain or problems that may develop in the future. All 16 participants either agreed or strongly agreed that given simple strategies to prevent shoulder dysfunction, they were likely to use them and all reported being interested in receiving educational materials about shoulder problems associated with ALS, including relevant prevention and management techniques.

Impact of the Educational Material on Shoulder-Related Knowledge

One participant died before completing the postintervention survey leaving 15 participants in the study. Thirteen (87%) of these 15 responders either agreed or strongly agreed that they were likely to use some of the strategies from the brochure to manage shoulder pain/dysfunction in the future (two responders were neutral and none disagreed with this statement). Fourteen (93%) either agreed or strongly agreed

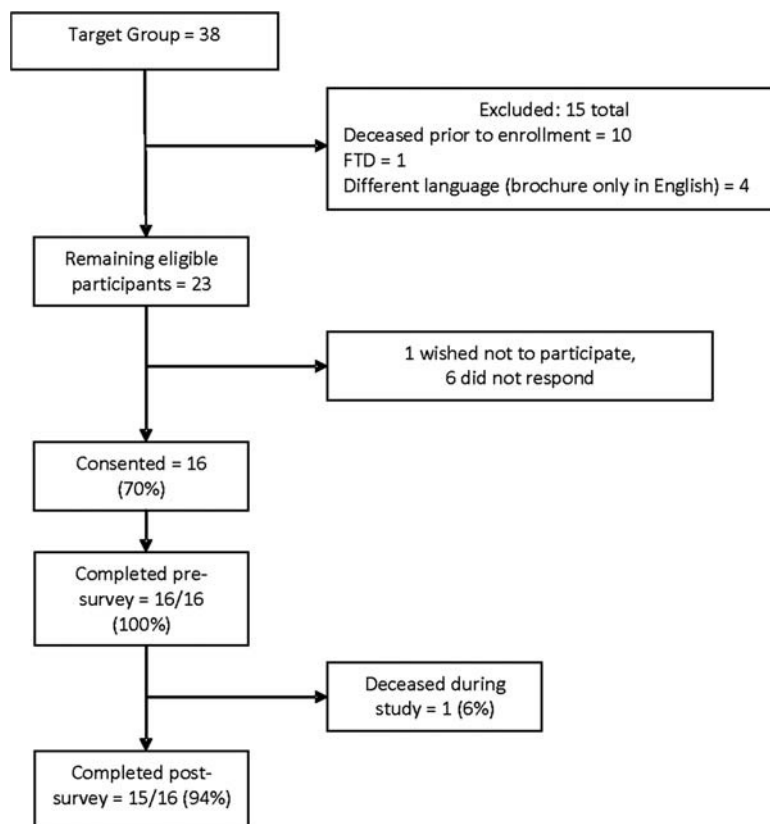


FIGURE 1. Study flow chart. FTD, frontotemporal dementia.

that they had begun to use some of the strategies from the brochure to manage shoulder pain and/or prevent dysfunction, one was neutral.

Most responders (87%) either agreed or strongly agreed that the brochure was easy to understand and 87% either agreed or strongly agreed that the brochure was helpful (the other two (13%) were neutral). All responders (100%) either agreed or strongly agreed that the photos and diagrams in the brochure were easy to interpret and understand.

DISCUSSION

In this study, we developed an ALS-specific educational brochure about shoulder health and exercises that may be used by patients with ALS to prevent and/or manage shoulder pain.

More than 50% of study participants reported pain, decreased ROM, or weakness in at least one of their shoulders since being diagnosed with ALS. The high prevalence of shoulder pain and dysfunction in our cohort is consistent with previous studies.²⁻⁵ Although shoulder pain is a common problem in ALS and has a negative impact on quality of life,⁶ little evidence is available to guide its treatment⁸ and management strategies mostly rely on clinician's experience.^{1,7,11} Clinical recommendations for prevention and treatment of shoulder pain in ALS emphasize regular stretching and ROM exercises that should be started early in the course of the disease.^{1,7} Patients who were receiving treatment for shoulder pain in our cohort were indeed performing stretching and ROM exercises.

Education about these exercises is often conducted by physical therapists who see patients as part of routine multidisciplinary care in ALS clinics. These recommendations are consistent with studies finding that the most commonly reported pain-relieving strategy by patients with ALS were movement and exercise, which subjectively improved pain in 40% of people.⁵ Only a few patients in our study were receiving additional treatment modalities.

Because awareness is one of the first steps in initiating a lifestyle intervention such as preventative exercise, we developed a brochure to inform patients with ALS about how ALS may affect their shoulder health and to educate them about exercise options to prevent/manage shoulder pain. Most study participants found the brochure to be helpful, supporting the use of this specific tool as one method for educating people with ALS on shoulder dysfunction. Many participants reported that they had begun to use information from the brochure for shoulder care, supporting our hypothesis that the brochure would result in increased knowledge and self-efficacy. These findings suggest that there is a need for increased education regarding shoulder health in ALS. People with ALS value educational brochures and are willing to participate in simple measures to prevent shoulder pain. By improving knowledge and self-efficacy, individuals with ALS may be better equipped to prevent or address potential shoulder issues and incorporate preventative measures into their treatment plans. This may in turn improve overall quality of life for people living with ALS by relieving pain and improving ROM for appropriate

positioning and functional use of the upper limbs, although we did not directly test the impact of the brochure of health outcomes as part of this study.

Limitations and Future Directions

Our study has several limitations including size and the fact that the educational brochure was provided only in English. We did not ask participants to perform the exercises and did not assess whether compliance with exercise improved clinical outcomes. Future research is needed to evaluate the impact of shoulder exercises on shoulder pain, functional use of the upper limbs, participation in activities of daily living, and quality of life in people with ALS.

CONCLUSIONS

Shoulder pain and dysfunction are common in ALS, highlighting the importance of raising awareness about this topic in the ALS community. An ALS-specific brochure about shoulder health was developed and found to be effective at increasing patient awareness and self-efficacy.

REFERENCES

1. Paganoni S, Karam C, Joyce N, et al: Comprehensive rehabilitative care across the spectrum of amyotrophic lateral sclerosis. *NeuroRehabilitation* 2015;37:53–68
2. Ho DT, Ruthazer R, Russell JA: Shoulder pain in amyotrophic lateral sclerosis. *J Clin Neuromuscul Dis* 2011;13:53–5
3. Hanisch F, Skudlarek A, Berndt J, et al: Characteristics of pain in amyotrophic lateral sclerosis. *Brain Behav* 2015;5:e00296
4. Rivera I, Ajroud-Driss S, Casey P, et al: Prevalence and characteristics of pain in early and late stages of ALS. *Amyotroph Lateral Scler Frontotemporal Degener* 2013;14:369–72
5. Wallace VC, Ellis CM, Burman R, et al: The evaluation of pain in amyotrophic lateral sclerosis: a case controlled observational study. *Amyotroph Lateral Scler Frontotemporal Degener* 2014;15:520–7
6. Pizzimenti A, Aragona M, Onesti E, et al: Depression, pain and quality of life in patients with amyotrophic lateral sclerosis: a cross-sectional study. *Funct Neurol* 2013;28:115–9
7. Majmudar S, Wu J, Paganoni S: Rehabilitation in amyotrophic lateral sclerosis: why it matters. *Muscle Nerve* 2014;50:4–13
8. Brettschneider J, Kurent J, Ludolph AL, et al: Drug therapy for pain in amyotrophic lateral sclerosis or motor neuron disease. *Cochrane Database Syst Rev* 2013;5:CD005226
9. Drory VE, Goltsman E, Goldman Reznik J, et al: The value of muscle exercise in patients with amyotrophic lateral sclerosis. *J Neurol Sci* 2001;191:133–7
10. Lewis M, Rushanan S: The role of physical therapy and occupational therapy in the treatment of amyotrophic lateral sclerosis. *NeuroRehabilitation* 2007;22:451–61
11. Karam CY, Paganoni S, Joyce N, et al: Palliative care issues in amyotrophic lateral sclerosis: an evidenced-based review. *Am J Hosp Palliat Care* 2016;33:84–92