



## Brief Report

# An Innovative Mindfulness Program for People with Amyotrophic Lateral Sclerosis

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### Abstract

Amyotrophic Lateral Sclerosis (ALS) is a fatal progressive neurodegenerative disorder that involves the impairment and eventual death of motor neurons leading to loss of voluntary muscle control. Currently there is no cure for ALS or its progression. The devastating consequences of the disease often result in depression, anxiety, and hopelessness for the ALS patient and also for their caregivers. There are very few therapeutic interventions for enhancing quality of life in ALS patients. We developed and implemented a novel mindfulness program for people with ALS. The program included adaptations to core practices from the 8-week Mindfulness-Based Stress Reduction program and other meditations including compassion and imagery practices. The program was offered as a six-week live virtual program, meeting once a week for 90 minutes. A total of 27 people with ALS were recruited into the program. Ninety percent of the participants completed the six-week online program, attending 5 or more sessions. In post-program interviews participants shared that they found the practices to be beneficial in reducing stress and anxiety and increasing acceptance. They also appreciated the live group sessions and the sense of community that was fostered. This innovative mindfulness meditation program appears to be feasible and acceptable, and a promising intervention for people with ALS.

**Keywords:** Mindfulness; Amyotrophic lateral sclerosis; ALS; Mindfulness-based stress reduction; Quality of life; Meditation

### Introduction

Amyotrophic Lateral Sclerosis (ALS) is a progressive neurodegenerative disorder that involves the impairment and eventual death of motor neurons leading to loss of voluntary muscle control. Over time, the muscles that control movement, speech, swallowing, and breathing progressively weaken and eventually become paralyzed. While the speed of progression varies, the average life expectancy is 2-5 years after diagnosis. Currently there is no cure for ALS or its progression.

The devastating consequences of this fatal disease, including debilitating physical limitations, often result in depression, anxiety, and hopelessness not only for the ALS patient but also for their caregivers [1-3]. There are very few therapeutic interventions for enhancing quality of life in ALS patients. A few published studies with small sample sizes suggest that hypnosis [4] and short-term psychological interventions [5] can improve psychological wellbeing and quality of life.

Mindfulness-Based Stress Reduction (MBSR) is an evidence-based intervention that has been demonstrated to reduce anxiety, depression, and pain and improve quality of life in a

variety of clinical populations [6-8]. The MBSR program centers on the practice of mindfulness meditation, which involves the cultivation of an open, curious, and nonjudgmental awareness of present-moment experience [9]. MBSR is a standardized 8-week group program, meeting 2.5 hours per week, with 45 minutes of daily home practice, plus a full day of mindfulness practice. While MBSR is the most widely used mindfulness intervention in healthcare, its format is not always appropriate for every clinical population. For example, the standard format can be burdensome for people with ALS, many of whom present with severe physical limitations. In addition, some of the practices in MBSR such as yoga and eating meditation are not accessible for many people with ALS. Thus, it is important to adapt mindfulness programs to meet the needs of this specific population.

We developed and implemented an innovative 6-week on-line mindfulness meditation program for people with ALS which includes adaptations of core practices from MBSR and additional meditations, including compassion and imagery practices. This brief report includes a description of the program, participant attendance and their narrative feedback about the program.

## Methods

The program was developed and implemented by experienced and certified MBSR teachers. ALS patients were recruited from a hospital-based ALS clinic by a nurse coordinator. Caregivers were invited to participate with them if they chose to do so. Participants received email messages from the nurse coordinator and the mindfulness instructors with pertinent information prior to the program start. The program met on-line for 90 minutes, once a week for 6 weeks. To date, three programs have been run with 10-12 people per group.

Class sessions included guided meditations, didactic material on mindfulness and compassion, and group discussions. Audio recordings were made of in-class practices and were shared with participants after each class. Participants were asked to listen to the formal guided practices which were 10-15 minutes in length. They were also encouraged to informally bring mindfulness into their life (for example, integrating simple, brief relaxation practices into their day, pausing to take in beauty in their environment, etc.).

Adaptations were made to some of the foundational practices of a standard MBSR program. The body scan was shortened and included more cues for relaxation. Since ALS progressively impairs respiratory function, the formal breath awareness meditation was adapted and participants were given options to choose other anchors for attention, including paying attention to other regions of the body or opening to sound and the outside environment. Another standard practice of MBSR, the raisin eating meditation, is not accessible for many ALS patients, so we replaced it with a

different practice. The essence of the raisin-eating meditation is to focus attention in the present moment by opening through the senses. We chose an innovative way to support participants to open their senses by looking at a picture of a flower in full bloom and paying attention to the nuances of color, shape, size, and texture. They were also asked to notice what arises in their body/mind and mood state throughout the practice. Another practice included mindfulness of hearing, in which participants were asked to listen to a short piece of classical music and to cultivate presence by bringing their mind back to simply listening any time it wandered. Imagery practices involved having participants use the power of their imagination to revisit a place where they felt safe, at ease, peaceful and content. Compassion practices were also included in the curriculum, with meditations based on three components of self-compassion - mindfulness, common humanity, and kindness. More details about the program are available upon request.

## Results

Twenty-seven patients were recruited with 5 caregivers attending the program. There were 17 female and 10 male patients. There were 4 females and one male caregiver. The mean age of patients at time of diagnosis was 58.70 +/- 1.9 SEM (36-74 years old). The time since diagnosis ranged from 1 month to 10 years with a mean of 26 months +/- 5 SEM.

Ninety percent of the participants completed the six-week online program attending 5 or more sessions, suggesting that the mindfulness program is feasible.

The 20 participants in the first two programs were invited to provide feedback about the program through online interviews. After completion of the programs, 15 of the participants took part in these open-ended interviews that were conducted by a qualitative researcher. The goal was to obtain information on program acceptability and satisfaction.

All the participants who took part in the interviews expressed having positive experiences with the mindfulness program and said that they would recommend it for other people with ALS. They found the formal and informal practices to be beneficial in reducing stress and anxiety and increasing acceptance. Many of them shared that the online format of the live group sessions made it possible for them to attend, as their mobility issues would have made it impossible to come in person. They also appreciated the group support and feeling of connection. Some of the participants mentioned how participating in the program and doing the mindfulness practices helped them to change their outlook quite dramatically. Instead of focusing on what they had lost they felt they were able to more fully show up to the aspects of their lives that were still beautiful and meaningful. We include a few verbatim reports from the participants:

### **Program format**

“The format and length of program was well thought out, and just the right amount of time.”

“Zoom made it possible for me to attend - because of mobility issues it would have been near impossible to come in person for a program.”

“The small group worked well. Made it more intimate and gave sense of community...one that I think we all needed.”

“We looked forward to reconnecting with the group each week.”

“This program was exceptionally helpful. The program is worth its weight in gold.”

“Right off the top I would totally recommend that you continue to offer this program to anyone who is experiencing this ALS journey.”

### **Benefits of participating in the program**

“When I find myself in a stressful situation, I can reduce stress and anxiety instead of feeding anxiety.”

“If I get stressed, my wife will say to me “do your mindfulness practice” and it works.”

“It has helped with stress. I can regroup and relax. Sometimes I can just do the body scan and come to a point of relaxation and tension leaves the body.”

“I learned a lot. I learned different methods of meditation and to relax and reduce anxiety.”

“I am glad I participated because it was very helpful. I can't say enough how calm and relaxed it made me feel doing the practices and it is a big help.”

“When I started, I felt each time I would look backwards at all I had lost; by the end of the program, I am looking forward... a huge change, from all the things I'm missing to all the things I have.”

“It was helpful to be reminded to have a wider perspective and focus on all the things that are still good. It was also helpful to feel some ease in the body and calm the mind.”

“I am appreciating life so much more.”

### **Discussion**

The psychosocial and emotional consequences of having ALS for patients and caregivers is devastating, and there are very few interventions to support their quality of life.

A recent review suggests that there is some benefit of clinical hypnosis for people with ALS and their caregivers [10]. An early study found that people with ALS saw improvements in

depression, anxiety, and quality of life after a one-month hypnosis-based intervention, and they also reported decreases in physical symptoms, including pain and sleep disorders. Improvements in caregiver psychological wellbeing was also observed [4].

Two studies have explored mindfulness interventions for people with ALS. One study of an in-person 8-week adapted MBSR program for ALS patients showed reduced anxiety and depression as well as improved quality of life [11,12]. However, the extensive nature of the program, including the 8-week format, the requirement to attend in person, and the commitment to formal meditation practice, was found in a qualitative study to be burdensome for some of the participants, which reduces the applicability and practical usefulness of this program [13]. A second study developed and implemented a non-meditative mindfulness program and found that it led to an increase in quality of life and reduction of psychological comorbidities [14]. This asynchronous online program used a Langerian framework of mindfulness and was delivered through video and written content on a dedicated website. The content included mindfulness topics, such as a mindful view of unpredictability, new ways of perceiving symptoms and daily exercises of 2-3 minutes. It did not involve formal meditation practices or live interactive group sessions.

The innovative mindfulness program that we developed and implemented is a live virtual meditation-based group program. Based on the feedback from participants, they greatly benefited from the formal practices of guided mindfulness meditations and integrated these practices into daily life. They also greatly appreciated the small group live format and the connection they felt to others. The online format made the program accessible to those whose physical limitations would have prevented them from coming in-person. This program appears to be feasible and acceptable, and a promising intervention for people with ALS. We continue to offer the program on an ongoing basis and future plans include conducting research to examine the impact of the program on the quality of life of people with ALS.

### **Conclusion**

This innovative six-week online mindfulness meditation program appears to be feasible and acceptable, and a promising intervention for people with ALS.

### **Acknowledgements**

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