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Teaching Mindfulness Meditation to Adults with Severe Speech and Physical Impairments: An Exploratory Study

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Abstract

People with severe speech and physical impairments may benefit from mindfulness meditation training because it has the potential to enhance their ability to cope with anxiety, depression, and pain and improve their attentional capacity to use brain-computer interface systems. Seven adults with severe speech and physical impairments—defined as speech that is understood less than 25% of the time and/or severely reduced hand function for writing/typing—participated in this exploratory, uncontrolled intervention study. The objectives of this study were to describe the development and implementation of a six-week mindfulness meditation intervention and to identify feasible outcome measures in this population. The weekly intervention was delivered by an instructor in the participant's home, and participants were encouraged to practice daily using audio recordings. The objective adherence to home practice was 10.2 minutes per day.

Exploratory outcome measures were an n-back working memory task, the Attention Process Training-II Attention Questionnaire, the Pittsburgh Sleep Quality Index, the Perceived Stress Scale, the Positive and Negative Affect Schedule, and a qualitative feedback survey. There were no statistically significant pre-post results in this small sample, yet administration of the measures proved feasible and qualitative reports were overall positive. Obstacles to teaching mindfulness meditation to persons with SSPI are reported, and solutions are proposed.

Introduction

Over four million people in the U.S. who live with disabilities significantly impacting communication would potentially benefit from Augmentative and Alternative Communication (Beukelman & Mirenda, 2013). A subset of this group, roughly estimated at 10%, have severe speech and physical impairments (SSPI) that result from varied congenital, acquired, or neurodevelopmental disorders. These include late-stage amyotrophic lateral sclerosis (ALS), brainstem stroke, severe traumatic brain injury, cerebral palsy, muscular dystrophy, Rett syndrome, spinal cord injury, and Parkinson's disease. This population presents with a spectrum of functional limitations, ranging from partial impairment to complete paralysis and loss of mobility in the arms, trunk, legs, and pelvic organs (Hochberg & Anderson, 2012). At the far end of the spectrum is total locked-in syndrome, which is characterized by the absence of all voluntary movement (Hochberg & Anderson, 2012). While people with SSPI constitute a heterogeneous group by the nature of their diverse etiological disorders and injuries, all are unable to rely on natural speech or writing for communication (Beukelman & Mirenda, 2013).

Brain-Computer Interface (BCI) is being developed as a possible access communication method for people with SSPI; however, individuals must have certain sensory, motor, cognitive and communication skills to successfully use the technology (Wolpaw & Wolpaw, 2012). As the field of BCI advances (Hochberg & Anderson, 2012; Wolpaw & Wolpaw, 2012), potential areas for improvements in user performance are being identified. Multiple participant factors have been hypothesized to affect BCI performance: cognitive status, attention, motivation, medications, fatigue, mental health, pain interference, and a lack of regular practice opportunities (Kleih, Nijboer, Halder, & Kubler, 2010; Moore, Keogh, & Eccleston, 2012; Morris, So, Lee, Lash, & Becker, 1992; Polich & Kok, 1995). Investigation into how focused training may impact these moderating variables of effective BCI use, such as attention and distraction, has been sparse (Käthner, Wriessnegger, Müller-Putz, Kübler, & Halder, 2014; Taylor, Forney, Gavin, Anderson, & Davies, 2013). Attention is a multidimensional cognitive capacity that is needed for information processing, including communication (Petersen & Posner, 2012; Sohlberg & Mateer, 1987). Sustained attention (vigilance) is necessary to use a BCI over long periods, and is affected by arousal on the wake-sleep continuum, motivation, and stress (B. S. Oken, Salinsky, & Elsas, 2006). If BCIs are to fulfil their primary goal of providing essential communication and control options to people with severe disabilities (Wolpaw & Wolpaw, 2012), then factors relevant to successful use, including the users' attention (Wolpaw & Wolpaw, 2012) need to be addressed (Fried-Oken, Mooney, Peters, & Oken, 2013).

Mindfulness meditation (MM) training may positively influence many domains, including attention, but it has not been studied in people with SSPI. Randomized controlled trials (RCT) in clinical and non-clinical populations have demonstrated that standardized MM interventions improve factors relevant to successful BCI use such as anxiety (Bohlmeijer, Prenger, Taal, & Cuijpers, 2010; Hofmann, Sawyer, Witt, & Oh, 2010; Lengacher et al., 2012; Specia, Carlson, Goodey, & Angen, 2000), attention (Lutz et al., 2009), depression and negative affect (Anderson, Lau, Segal, & Bishop, 2007; Grossman et al., 2010; B. S. Oken, Miller, Goodrich, & Wahbeh, 2014; Sephton et al., 2007; Specia, et al., 2000), fatigue (Grossman, et al., 2010), sleep (Andersen et al., 2013; B. Oken, Yu, Neuendorf, Wahbeh, & Hutchison, 2014), pain (Brown & Jones, 2013; Reiner, Tibi, & Lipsitz, 2013), and anger (Specia, et al., 2000). In fact, MM has been shown to improve accuracy with BCI systems in healthy populations (Eskandari & Erfanian, 2008; Lakey, Berry, & Sellers, 2011). Thus, while meditation clearly improves factors relevant to successful BCI use in non-SSPI populations, the feasibility of using MM to improve BCI system accuracy in people with SSPI has not been evaluated.

In addition to potentially improving BCI performance, MM may also benefit people with SSPI in other ways. Quality of life in this population is often reported to be in the same range as in age-matched healthy individuals (Lule et al., 2009), yet people with SSPI still face unique emotional struggles. Emotional coping techniques may be particularly beneficial during the initial stages of adjusting to the onset of severe disability (Lule, et al., 2009) when people typically deal with significant anxiety, denial, depression, and internalized anger (Glover-Graf, Millington, & Marini, 2012). People with SSPI may also chronically suffer from anxiety (Grossman, et al., 2010; Ozanne, Graneheim, & Strang, 2013), depression (Grossman, et al., 2010), fatigue (Grossman, et al., 2010), and pain (Hirsh, Kratz, Engel, &

Jensen, 2011; Vogtle, Malone, & Azuero, 2013). These are all areas that are known to be improved by MM in non-SSPI populations, as was cited in the previous paragraph. MM has also been successfully applied to clinical populations dealing with similar symptoms. An RCT demonstrated positive benefits of meditation in persons with multiple sclerosis (Grossman, et al., 2010), and studies with less rigorous methodologies have shown benefits of meditation in traumatic brain injury (Bedard et al., 2012; Johansson, Bjuhr, & Ronnback, 2012) and stroke (Johansson, et al., 2012; Lawrence, Booth, Mercer, & Crawford, 2013). MM training has also been explored in people with aphasia resulting in improved reaction times in a cognitive task (Orenstein, et al, 2012). These studies demonstrate that MM may be feasible and potentially beneficial for people with SSPI.

MM may also be useful for people with SSPI because of their interest in non-pharmacological approaches to health care (Carlson & Krahm, 2006; Oppenheim, 2009). U.S. adults with functional limitations pursue complementary and alternative medicine significantly more than those without limitations (Okoro, Zhao, Li, & Balluz, 2012). Over half of US adults with functional limitations (51.3%) discussed complementary and alternative medicine with conventional medical professionals, in comparison to 37.9% of adults without limitations (Okoro, et al., 2012). Furthermore, medications can negatively affect cognitive functioning in people with SSPI (Johnson, 2013; B. S. Oken et al., 2006), which would be detrimental for BCI use and would likely be undesirable for individuals. Therefore, healthcare practitioners working with adults with SSPI would benefit from being informed about MM and its potential benefits as a non-pharmacological treatment.

Thus, the evaluation of MM for people with SSPI is warranted because of its potential for enhancing BCI performance, improving quality of life and other mental health symptoms, and addressing the interest people with SSPI have in complementary and alternative medicine. The long-term goal of the research presented here is to determine whether MM improves attention and other health factors that affect someone with SSPI's quality of life and ability to effectively use BCI. As a first step toward this long-term goal, this paper aims to 1) describe the development of an MM training specific for people with SSPI, 2) describe the implementation of administering the training to people with SSPI, 3) provide clinicians with sufficient details to implement the training directly with their clients, and 4) identify feasible outcome measures in this population.

Methods

The methods described here were pursued within the context of an interdisciplinary research endeavour that is developing a P300-based BCI communication system for persons with SSPI (B. S. Oken et al., 2013; Orhan, Erdogmus, Roark, Oken, & Fried-Oken, 2013).

Participants

A convenience sample of participants was recruited from an ongoing BCI communication study for people with SSPI (Fried-Oken, Mooney, Peters, & Oken, 2013; B. S. Oken, et al., 2013; Orhan, et al., 2013). Participants for the BCI study were recruited through the ALS Center of Oregon, the ALS Association of Oregon and SW Washington Chapter, and the outpatient Neurology and Augmentative and Alternative Communication clinics at Oregon

Health & Science University (OHSU). Participants met the following inclusion criteria: (1) diagnosed by a neurologist with a brain or neuromuscular disorder producing severe disability; (2) age between 18 and 75 years; (3) capable of participating in one- to three-hour experimental interactions; (4) literate in English; (5) adequate vision and hearing; (6) speech that is understood less than 25% of the time (as assessed by the referring speech-language pathologist) and/or severely reduced hand function for writing and/or typing. Additionally, as part of the inclusion criteria for participation in the BCI Communication study, all participants were administered the RSVP™ BCI Clinical Screening protocol (Fried-Oken, et al., 2013). A multidisciplinary clinical team of seven individuals representing five disciplines identified requisite skills necessary for the BCI RSVP™ Keyboard. They chose questions and subtests from existing standardized instruments for auditory comprehension, reading and spelling, and then they modified them to accommodate non-speaking response modalities. They also developed novel tasks to screen visual perception, sustained visual attention, and working memory. Questions were included about sensory skills, positioning, pain interference, and medications. The RSVP™ BCI screening protocol is a brief, repeatable technique for patients with different types of SSPI to identify the presence/absence of skills for BCI use (Fried-Oken, et al., 2013).

Both the BCI communication and MM studies were approved by the Institutional Review Board at OHSU, and all participants provided informed consent. Participants with SSPI authorized a relative or caregiver to sign the consent forms on their behalf, via yes/no signals or other means of communication.

Procedures

In total, there were nine visits conducted at each of the participant's homes. All were completed within 10 weeks, and each visit lasted no longer than two hours. There were two researchers directly involved with participants in this study: a research associate Masters Level Speech and Language Pathologist who holds Certificates of Clinical Competence (RA-SLP) and a research assistant mindfulness meditation practitioner (RA-MM) trained in Buddhist meditation with previous experience teaching secular one-on-one MM with adults enrolled in other RCT's (B. S. Oken, et al., 2014; Wahbeh, Lane, Goodrich, Miller, & Oken, 2014; Wahbeh & Oken, 2014).

Both RA's attended initial visits to facilitate and establish reliable communication between the RA-MM and participants with SSPI. The RA-SLP provided training to ensure the RA-MM demonstrated adequate mastery in use of each participant's unique reliable yes/no communication modality (i.e., looking up for yes, down for no). The RA-SLP and RA-MM conducted the process of informed consent, explaining the study details to the participant and answering questions. Following significant instruction, participants then completed the adapted version of the n-back task to establish baseline difficulty task, i.e., hardest n-back with accuracy greater than 80% that would be used for subsequent visits (see below Computer-based Working Memory Task).

Within two weeks' time the RA-MM returned to participant's residence to complete a Baseline Visit. This visit began with the n-back task at the previously established difficulty level defined at the Initial Visit. Participants were then given two options about how they

would like to fill out the questionnaires: internet-based completion or in-person administration. If participants chose the internet option, they were emailed a link to a questionnaire hosted by SurveyMonkey Inc. If participants chose in-person administration, the RA-MM utilized a PowerPoint presentation to demonstrate the Likert scales. After reading the question aloud, she instructed the participant to choose a response. There were a variety of non-verbal response techniques: one participant used a LiteWriter™ to type numerical responses; another person wrote the numbers with her toe; one person was able to point to responses on the paper surveys with his finger; and for the final two people, the researcher read the series of response numbers aloud (i.e. “1, 2, 3, 4, 5”), and they expressed their “yes” motor cue when their desired response was said.

After the Baseline Visit, the RA-MM returned to the participants' homes once a week for six weeks to administer the MM training sessions. When the training period was complete, an Endpoint Visit was conducted, which was exactly the same as the Baseline Visit, except it also included a subjective report form.

Questionnaires

The chosen outcome questionnaires are widely used as standardized assessments of domains that have been beneficially impacted by mindfulness meditation interventions.

The *Perceived Stress Scale (PSS)* is a commonly used 10-item self-report instrument that measures respondents' perceived stress in the past week (Cohen, Kamarck, & Mermelstein, 1987). It has good internal reliability (alpha .76) and strong construct validity. An example question is, “How often have you been angered because of things that were outside of your control?” Participants respond with “never” (0), “almost never” (1), “sometimes” (2), “fairly often” (3), or “very often” (4), and four of the questions are reverse-scored. The global score ranges from 0-36, with higher scores indicating greater perceived stress.

The *International Positive and Negative Affect Schedule Short Form (I-PANAS-SF)* is a 10-item self-report instrument that measures affect (Thompson, 2007). The 10-item survey was chosen over the original 20-item form (Watson, Clark, & Tellegen, 1988) due to communication constraints with this population. Furthermore, the *I-PANAS-SF* has good test-retest reliability (alpha .84, $p < .01$), as well as strong convergent, cross-cultural, and criterion-related validity (Thompson, 2007). The survey is composed of five words that represent positive feelings (alert, inspired, determined, attentive and active) and five words that represent negative feelings (upset, hostile, ashamed, nervous and afraid). Participants are asked to indicate the extent to which they “generally feel this way” or “feel on average” using the responses “very slightly or not at all” (1), “a little” (2), “moderately” (3), “quite a bit” (4) or “extremely” (5). A composite score between 5 and 25 is generated for both positive and negative affect with higher numbers indicating more of that affect.

The *Pittsburgh Sleep Quality Index (PSQI)* measures sleep quality and disturbances in a 1-month time span with 19 items that yield seven component scores: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). The standard PSQI also contains five clinical questions not included in the PSQI score to be

answered by the roommate or bed partner (i.e. spouse or other intimate partner), but those were excluded due to participants' typical living situations (Buysse, et al., 1989). The global score ranges from 0-21, with higher scores indicating greater difficulty in all areas. The test-retest reliability of the global score is .85 ($p < 0.001$), and internal consistency is high. Example questions include “How long (in minutes) has it taken you to fall asleep?” and “How often have you had trouble sleeping because you cannot breathe comfortably?”

The *Attention Process Training II Attention Questionnaire (APT-II)* assesses an individual's perception of their attention function in everyday activities (Sohlberg, Johnson, Paule, Raskin, & Mateer, 1994). This questionnaire is based on a previous questionnaire (Ponsford & Kinsella, 1988) and asks the participants to rate frequency of occurrence for different attention problems. The attention problems are related to difficulty sustaining, switching, and dividing one's attention, as well as dealing with distraction. It supplies a numerical indicator summarizing the overall frequency of perceived attention problems, which is helpful for comparing performance after the treatment condition (Sohlberg, McLaughlin, Pavese, Heidrich, & Posner, 2000). Only Part One was administered because it required participants to respond to statements such as “I can only concentrate for very short periods of time” with one of five answers: “not a problem” (0); “only gets in the way on occasion (less than once a week)” (1); “sometimes gets in the way (about 1-3 times per week)” (2); “frequently gets in the way (is a problem most days)” (3); “is a problem all the time (affects most activities)” (4). The 12 items (0-4 points each) are totalled, for a global score ranging from 0-48, with higher scores indicating greater attention problems. Part Two requires lengthy verbal descriptions of frequent and frustrating breakdowns in daily attention ability (citing examples involving routine complex motor activities). Part Two was neither appropriate for administration to people with SSPI nor would it add beneficial information to the purpose of this study.

The *Credibility/Expectancy Questionnaire* is a standardized instrument that assesses participant intervention expectancy and rationale credibility in clinical outcome studies (Deville & Borkovec, 2000). The wording was minimally modified to assess attitudes towards MM specifically. The scale has a high internal consistency ($\alpha=.84$) and good test-retest reliability (.75 credibility; .82 expectancy). An example credibility question is “At this point, how logical does mindfulness meditation training seem?” Participants respond using a Likert scale from “not at all” (1) to “very much” (9). An example expectancy question is “At this point, how much do you really *feel* that the mindfulness meditation training will help you to reduce your stress?” and participants were asked to respond on the same 1 – 9 Likert scale. Expectancy assessment is essential in non-blinded controlled intervention studies (B. S. Oken, 2008). Credibility is additionally used here as a self-rated outcome measure since it reflects how much the participant's attitudes changed as a result of the intervention. Higher scores reflect higher credibility and expectancy.

A subjective report form was used to collect feedback about participants' experiences in the study. The questions were formulated by the MM research team to solicit specific feedback about the intervention and regarding future study improvements. The questions are listed in Table 1.

Computer-based Working Memory Task

Attention, including sustained attention and ability to hold a target letter in mind, are both critical for calibration and use of most BCI presentation paradigms, including the rapid serial visual presentation paradigm (RSVP™) used in these studies (Orhan, et al., 2013). With this in mind, and because of the limited number of tests that could be performed in this population, a decision was made to utilize a visual working memory assessment that also requires sustained attention. The n-back task is a common experimental paradigm for assessing working memory requiring on-line monitoring, updating, and short-term retention of information (Owen, McMillan, Laird, & Bullmore, 2005). The most common n-back paradigm entails observing a sequence of stimuli and responding when a stimulus matches an item presented n items previously, where n is a pre-defined integer, usually 1, 2 or 3 (Owen, et al., 2005), thereby acquiring both reaction time and accuracy data, the latter affected by timely responses. Since it was not possible to measure reliable reaction times in this population and the usual n-back paradigm would result in impaired accuracy because of slow response, the task was adapted to present sequences of letters and solicit a “yes” or “no” response at the end of each sequence by asking questions such as, “Did you see the same letter repeated twice in a row?” (1-back) or “Did you see the same letter repeated two letters apart?” (2-back).

The RA-MM took many steps to assure that each participant understood the task: verbally read through the directions for the 1-back; showed the participant several series of letters on a sheet of paper to provide visual examples of 1-back series, as well as series that did not fulfil the criteria; presented the written directions on a computer screen for the participant to read; asked participants if they understood the instructions and waited for confirmation of comprehension; and then presented six computer-based practice sequences and discussed each response.

The n-back paradigm included a practice set of six 20-letter sequences and a test of twenty 20-letter sequences, and this format is the same for a 1-back, 2-back, and 3-back. All letters in the alphabet were included, and a randomization tool was used to generate sequences of 20 letters. Each practice and test series were created so that 50% met the instruction's criteria (“yes” responses) and 50% did not fulfil the criteria (“no” responses), the order of which were assigned randomly. The paradigm was also structured so that the conditions were met in beginning, middle, and end of the sequences (roughly one third each).

Before each series of letters, a red fixation cross was presented in the same location for 1 second. The letters were then presented for 400 ms in the centre of the screen, and there was no inter-stimulus interval. The letter font was *Monospaced*, size 160 (visual angle of 5.5 degrees on a monitor that had a diagonal of 30 degrees). When participants responded at the end of each sequence, the test administrator would simply mark their response and press a button to advance to the next sequence. There were no breaks unless the participants requested one.

At the Initial Visit participants began with the 1-back level and then progressed to the 2-back and 3-back levels based on their performance. When participants achieved less than 80% accuracy, progression to the next level ceased. The hardest n-back level where there

was still greater than 80% accuracy would be used for pre- and post- outcome assessments at the subsequent visits.

MM Overview and Curriculum

A very basic MM intervention was implemented with the first two participants to gauge feasibility and guide intervention development. There were six weekly 60-minute trainings, and at each one, the facilitator read a one-page script containing the definition and description of mindfulness, “paying attention in a particular way: on purpose, in the present moment, and non-judgmentally” (Kabat-Zinn, 1982). The guided meditations were all 20 min in length, and the topics for each week were as follows: 1-*Mindfulness of Sounds*; 2-*Mindfulness of Breath*; 3-*Loving Kindness Meditation*; 4-*Mindfulness of Thoughts*; 5-participant choice; 6-participant choice. Once feasibility of this simple MM intervention was confirmed, a more complex curriculum was developed and used for the remainder of participants.

The MM intervention used for the remaining participants was based on a previously published intervention (Wahbeh, Lane, Goodrich, Miller, & Oken, 2014) and was adapted for people with SSPI. The non-SSPI version was shown to decrease stress, depression, neuroticism, and negative affect in chronically stressed older adults (B. S. Oken, et al., 2014). The training entails six weekly 90-minute training sessions conducted in a one-on-one format at a research lab. Multiple adaptations were made to the curriculum for people with SSPI including:

1. The caregivers were present with two participants for the sake of communication assistance, as well as for participants' physical needs and safety. In one instance, a participant's mother and sister observed the trainings.
2. Several informal mindful awareness exercises were adapted. For example, the “Raisin Exercise” where participants follow verbal instructions to experience slowly eating a raisin with all their senses was modified to the “Flower Exercise” because most participants with SSPI had feeding tubes and were on ventilators. The RA-MM brought live flowers to the first training sessions and verbally guided participants through a process of mindfully observing the flower. The instruction included phrases such as the following:

“What I would like you to do is focus on the object and just imagine that you have never seen anything like it before. Imagine you have just dropped in from Mars this moment and you have never seen anything like it before in your life...Seeing the texture...sharpness, smoothness, softness...And if, while you are doing this, any thought comes to mind about ‘what a strange thing we are doing’ or ‘what is the point of this?’ or ‘I don’t like this,’ then just noting them as thoughts and bringing your awareness back to the object...”

3. In the original curriculum, the home practice awareness exercises Pleasant and Unpleasant Events Calendars entail mindfully observing one's thoughts, emotions and physical sensations associated with a pleasant or unpleasant event and then

recording their observations by hand on a sheet of paper. The participants with SSPI were instructed to mindfully observe pleasant/unpleasant events, and they were given the option to record their experiences in electronic format or with the assistance of a caregiver. They were also informed that it was acceptable if they were not willing or able to record their experience since we wanted to minimize the burden on participants. They were told that the most important thing was to experientially engage in the mindfulness exercise.

4. Adherence was measured with objective data using the iMindr iPod device. iMindr is a previously reported custom software application developed for iPod Touch devices (Apple, Inc.) (Wahbeh, et al., 2014; Wahbeh, Zwickey, & Oken, 2011). The application contained all of the home-practice guided meditations, and collected data on the date, time, and duration of listening. This methodology was successful when used with combat veterans with post-traumatic stress disorder (Wahbeh, et al., 2011) and stressed older adults (Wahbeh, et al., 2014), but it had not been previously used with this population. Participants and their caregivers were shown how to use the iPod Touch devices, and were told that the device would record when and for how long they listen to the guided meditations. Participants were also told that some people benefit from keeping a record of their practice because it may be helpful to track one's progress in developing a regular meditation routine. As an optional activity, interested participants were given paper and/or electronic copies of daily practice logs to record their practice.

4) Handouts were altered to remove references to motor function and to be sensitive to participants on mechanical ventilation; sentences regarding one's sitting meditation posture and/or about using the body as a way to awareness were removed. For example, sentences such as "Have you ever noticed how the breath changes with our moods?" and "Become aware of and adjust your posture and facial expression" were deleted. The facilitators offered to email and/or provide paper copies of all the handouts to the participants.

5. The guided meditations differed slightly from the original intervention. The main practice in Week 1 and 2 of the original intervention is a guided body scan meditation. This was excluded because some participants had extremely limited physical sensations. In place of the body scan, the participants with SSPI practiced mindfulness of sound, in which they were instructed to direct their attention to ambient noise and/or music of their choice. Also, a meditation on loving-kindness was presented as an option for home practice since it was positively received in the basic intervention that was implemented with the first two participants. Loving-kindness meditation entails mindfully directing attention toward a loved one, oneself, someone whom a person finds difficult, and the whole world, while silently repeating the following or similar phrases, "May I/you be free from fear and anxiety. May I/you be at ease. May I/you be happy and well." Loving-kindness meditation has the potential to reduce pain, anger, and psychological distress (Carson et al., 2005), so it was deemed worthy of including with this population. All guided meditations included in the intervention are listed in Table 2.

6. The RA-MM personally practiced the guided meditation along with the participant, which allowed for close monitoring and support. This differed from the original intervention because the RA-MM would typically leave the room during meditation.
7. In the original intervention, the RA-MM engages in approximately 10-20 minutes of dialogue with participants at the beginning of the training sessions, and this was also true in the adapted intervention, though communication techniques were modified. The RA-MM often asked yes/no questions based on the experiences and barriers that new meditators often face. For instance, new meditators often report that they are frustrated because their mind wanders away from the object of focus (e.g., sound or breath). So for SSPI participants that can convey yes/no responses, a conversation may go as follows:

Facilitator “Are you noticing that your mind wanders away from focusing on the breath during the meditation?”

Participant [Yes sign]

F “That is very normal. The mind naturally wanders, and our only task is to be a witness, or observer, of our experience, and when our attention drifts away from the breath, we very gently guide our attention back. The goal of meditation is not to create a special state of relaxation; rather, we are simply bringing interest and curiosity to the process of training our minds to pay attention. When you notice that your mind wanders, are you able to bring it back sometimes?”

P [Yes sign]

F “That is a wonderful starting place. Learning to focus our minds on an object takes time, practice, and patience. When your mind does wander, do you ever get frustrated?”

P [Yes sign]

F “Again, this is very normal. As you may remember, the definition of mindfulness is ‘paying attention in a particular way: on purpose, in the present moment, and *non-judgmentally*.’ The last component—trying to be non-judgmental—is really difficult. For many people, this is the most challenging aspect of learning mindfulness, and also the most important. Whenever we’re learning something new, it’s essential that we are kind to ourselves. Does your mind ever wander because you start falling asleep?”

P [No sign]

F Alright. If you do experience this in the future, we can discuss it then.”

(More details about the MM intervention are given in Table 3.)

Results

Seven participants (5 males) participated in the study, and there were no drop-outs despite concurrent medical problems, multiple caregivers per participant, and even one hospitalization. Participants' diagnoses resulted from cerebral palsy ($n=2$), amyotrophic lateral sclerosis ($n=2$), brainstem stroke, spinocerebellar ataxia, and muscular dystrophy. Participant descriptions and demographics are listed in Table 4. Participant communication modalities included: verbal; hand gestures; eye movement; eye blinking; partner dependent communication; and speech generating devices (SGD's) controlled by a variety of means (eye gaze, a foot-operated roller-ball mouse, a chin switch, a standard mouse, a touch screen, and an arm pointer). The RSVP™ BCI screening protocol results are given in Table 5.

Administration of surveys and the n-back task to seven people with SSPI was feasible. Administration of surveys was much quicker than expected—completion of all five questionnaires with Likert scales took no more than 15 minutes total, and the qualitative feedback at the end took 10-20 minutes. Survey completion was satisfactory and the system of presenting Likert scales with PowerPoint and then using “yes” and “no” responses was effective. As expected, there were no significant mean pre-post changes in this small sample (all p values > 0.05). Individual outcome data are presented in Table 6. There was much intersubject variability in all the outcome measures some of which were well within normal ranges but, for example, over half had PSQI scores suggesting poor sleep or asleep disorder. All participants completed the six meditation trainings. The iMINDr program successfully tracked objective adherence, and all participants listened to some guided meditation practices outside the trainings. They listened to guided meditations for an average of 10.2 minutes per day (range 0.4-18.1 minutes/day). There were no obvious relationships between improvement from meditation and demographic information, minutes practiced, or baseline characteristics. Although no formal qualitative data analyses were performed, participants' comments meaningfully convey the impact of the intervention, as well as aspects of the study that can be improved. All participants shared at least some positive comments, and there were no adverse events or reported problems in the study. For example, three separate participants (whose participant ID numbers correspond to those listed in Table 4) shared the following about their experiences:

Participant #3: “It helped some with my emotions toward artificial breath...I am able to focus now on the feeling of breathing in—chest up and down, diaphragm expanding—not just rumbling or artificial breath. I get frustrated with being sore for a long time, so I'll focus on the coping space, and that will help. I focus on what it feels like and then try to let it go...When I get upset, the meditation helps with keeping me off autopilot—I don't just react, I think through what the issue is.”

Participant #5: “I believe it reduced my stress level by focusing my attention on the here and now, non-judgmentally, without thoughts of the past, and without planning for the future. Just experiencing the present moment. ‘There is no right way to meditate’... ‘If you are able’...self-accepting. Moment by moment; breath by breath. Being alive...I learned to focus my attention on my breathing, my thoughts (they come in unstoppable ‘waves’), my bodily sensations, the sense of the body as a whole, the sense of hearing, the sense of space, the sense of air

surrounding the body and skin, the feelings of any unpleasantness, irritation, or anger-charged emotions, the identity of those people that I have difficulty relating to, as well as those that I love. I learned to recognize times when I react ‘automatically,’ or in an emotion-charged way, that I could stop and breathe, then respond in a more productive and effective manner.”

Participant #3: “[Meditation] helped me to cope with family stress and the stress of wanting to get better...meditation helps to break up the monotony of my daily routine, which is always the same thing—wake up, do exercises, move to chair, etc...I liked the Loving Kindness meditation the best. I like to focus on being well and happy, and it also gives me the opportunity to try to forgive others. It's the hardest thing to do...focusing on breathing is helpful for me. Since the [ventilator] machine is a regular rhythm, it's a soothing thing to focus on. Also, I have chosen two words to go with the in-breath and the out-breath: happy and well.”

There were also several suggestions about how the study could be improved. One participant reported, “It was difficult to get staff on board to press the play button [on the iPod Touch],” and several other participants shared the same sentiment. Multiple participants commented that lengthening the overall duration of the study or scheduling greater time between training sessions to allow for more practice would have been better. Finally, a participant with extreme chronic pain suggested that guided meditation explicitly about coping with pain would have been valuable.

Discussion

Teaching a MM intervention to people with SSPI is feasible, and the qualitative feedback suggested that participants were receptive and had positive experiences. Not only was the curriculum seemingly beneficial, but participants were motivated to practice on their own between training sessions. Participants practiced an average of 10.2 minutes per day. This is less than half the practice time of a comparable intervention in a group of non-disabled but stressed 50-85 year olds (B. S. Oken, et al., 2014).

This was not a controlled trial, and no outcome measures demonstrated change (as expected due to the small sample size). Results were confounded by concurrent medical and other life events that also contributed to the variability in practice time. However, the feasibility of administering the questionnaires and an adapted n-back task was confirmed. While the n-back has been used widely in experimental psychology research, in research with SSPI the task was not adapted to account for the delayed speed of participants' responses (Schreuder et al., 2013).

For future clinical trials, it is likely that a well-planned single subject design study with repeated assessment before and after the intervention would be useful (Gast & Ledford, 2010). A single subject design would better manage the likely small number of participants, and the necessity of multiple pre- and post-intervention outcome assessments would enable better analyses that account for frequent medical problem exacerbations and multiple caregivers in the SSPI population. While a single subject design may be best suited for this population, if one did want implement an RCT with a larger number of participants and

assessment visits, an active control would be necessary. A viable active control in this population could be a podcast intervention that controls for time and attention effects that we have piloted with people with SSPI.

Improving the home practice meditation system would also be helpful. While all participants listened to some guided meditation outside the training, many participants encountered obstacles using the guided meditation audio device. In the future, guided meditations should be presented in the most accessible manner possible for each participant. All but one participant needed to rely on a caregiver to play the guided meditation on the iPod Touch device. Gaining cooperation was especially difficult with less attentive and/or multiple caregivers, as was the case with the participant with the least average meditation practice (0.4 min per day). The six other participants averaged 14 minutes of practice per day (lowest was 7 min per day). Working with each participant individually to determine the most accessible means of listening to audio would be helpful. For example, some participants could have listened without assistance if the audio was downloaded onto their personal computers. Other participants would have been more easily aided from their caregivers if they were able to listen to a CD rather than an iPod Touch since the technology was daunting to some. These alternative listening options would have prohibited the collection of objective adherence data, yet removing obstacles to meditation practice may be more important.

As was suggested in the qualitative feedback, it may be helpful to include a greater variety of meditations and more curricula directly aimed at issues specific to persons with SSPI. For instance, many participants experience significant chronic pain, and there are meditation practices and mindfulness techniques explicitly for coping with pain (Brown & Jones, 2013; Reiner, et al., 2013). Furthermore, abody scan meditation may be beneficial for some participants in this population. The body scan is included in the original one-on-one intervention (Wahbeh, et al., 2014); however, it was excluded from the present study because some participants' conditions (e.g., brainstem stroke) may result in extremely little physical sensation. Yet other participants, such as those with cerebral palsy, may have benefited from this practice. In the future, it may be worthwhile to include it as an optional meditation practice.

In addition, there were some design limitations to this exploratory study that should be addressed in future research. Besides the uncontrolled study design, a larger diversity of questionnaires and assessments could be used in future studies including questionnaires on mindfulness, pain, and depression. If testing time can be longer, individual measurements of working memory and sustained attention could be used instead of the adapted n-back, and other measures of attention that might be sensitive to meditation could be added. Ideally, a separate, blinded researcher with no other contact with participants would administer outcome measures. For this study the RA-MM assisted with survey completion and administered the Baseline and Endpoint Visits which could have biased the outcomes.

In conclusion, future research on meditation for persons with SSPI is warranted. Due to the positive findings of MM studies with related populations, as discussed in the Introduction, it is realistic to hypothesize that persons with SSPI will benefit emotionally and cognitively

from learning mindfulness meditation. This study demonstrates the feasibility of administering pre-post outcome measures of working memory, attention, sleep, stress, and affect. We encourage clinicians and researchers to implement this standardized curriculum in their practice and research in order to learn more about its efficacy and potential applications.

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Table 1
Subjective Feedback Questionnaire

<u>Question</u>	
1	How did the study go for you?
2	If you had it to do over, would you participate again? (If no, why not?)
3	Would you recommend the study to a friend?
4	Do you feel you benefitted from the study? (If so, would you please offer descriptive examples from different arenas of your life?)
5	Do you think your <i>stress level</i> improved as a result of the study? If yes, can you offer examples? (If this question seems redundant from the previous answer, feel free to proceed to next question.)
6	Do you think your <i>attention abilities</i> improved as a result of the study? If yes, can you offer examples? (If this question seems redundant from the previous answer, feel free to proceed to next question.)
7	What do you think would have helped you receive more benefit from the study?
8	Do you have any other suggestions about how we might improve the study?
9	Do you have any comments about particular meditation practices (mindfulness of sound, mindfulness of breath, coping with difficulty meditation, loving kindness meditation, breathing space)? Did some resonate more than others, and if yes, why?
10	Would you be interested in being contacted in the future for news publications? (We would contact you to let you know about the opportunity, and you could say "yes" or "no" at that point, when you know more details.)
11	On a scale of 1-10 (1 = extremely challenging, 10 = extremely easy), how easy it was for you to stay focused on the meditation.
12	If there was a tool to help you stay in the meditative state, would you use it?
13	What do you think would help you meditate more effectively?
14	Do you have any other thoughts, comments, or suggestions?

Table 2
Guided meditation and instruction audio tracks

<u>iMINDr guided meditations (time)</u>		<u>In-training instructional recordings (time)</u>	
1	Introduction (5:58)	1	Coping space instructions (4:49)
2	Mindfulness of sounds (20:39)	2	Closing meditation (3:25)
3	Mindfulness of breath 10 min		
4	Mindfulness of breath 30 min		
5	Coping with difficulty meditation (30:25)		
6	Breathing space (4:02)		
7	Loving kindness meditation (20:12)		

Table 3
Study visit and curriculum outline

Activity	Duration	Component Parts
Initial Visit	2 hours	Introductions and communication establishment Consent discussion and signing n-back task
Baseline Visit	2 hours	n-back task Questionnaire administration: APT-II Attention Questionnaire, the Pittsburgh Sleep Quality Index (PSQI), Perceived Stress Scale (PSS), the Positive and Negative Affect Scale (PANAS), and Credibility/Expectancy Questionnaire (OR online questionnaire completion outside of visit time)
MM Training #1	90 min	Overview of meditation training Summary: Automatic pilot Meditation: Mindfulness of sounds (20 min) Definition and description of mindfulness Flower exercise Lesson on how to use iPod Touch Home practice explanation for Week 1
Home Practice	25 min/day	Meditation: Mindfulness of sounds (20 min) Awareness exercise: Mindfulness of a routine activity OR "As much as you are able"
MM Training #2	90 min	Discussion of Week 1 home practice Discussion of tips for meditation Meditation: Mindfulness of sounds (20 min) Summary: Dealing with barriers Introduction to the breath as an anchor of awareness Meditation: Mindfulness of breath introduction (10 min) Home practice explanation for Week 2
Home Practice	35 min/day	Meditation: Mindfulness of sounds (20 min) and Mindfulness of breath (10 min) Awareness exercise: Pleasant events calendar OR "As much as you are able"
MM Training #3	90 min	Discussion of Week 2 home practice Meditation: Mindfulness of breath (30 min) Summary: Focusing on mindfulness of breath Introduction to the breathing space Meditation: Breathing space (4 min) Home practice explanation for Week 3
Home Practice	45 min/day	Meditation: Mindfulness of breath (30 min) and Breathing space (4 min) 3 ×/day Awareness exercise: Unpleasant events calendar OR "As much as you are able"
MM Training #4	90 min	Discussion of Week 3 home practice Meditation: Sitting with difficulty Summary: Allowing and letting be Introduction to the coping space Home practice explanation for Week 4
Home Practice	45 min/day	Meditation: Sitting with difficulty (30 min) and/or Loving kindness (20 min) AND Breathing space 3 ×/day Awareness exercise: Coping space whenever needed OR "As much as you are able"
MM Training #5	90 min	Discussion of Week 4 home practice Meditation: Participant's choice between Sitting with difficulty (30 min) or Loving kindness (20 min) Summary: Thoughts are not facts Discussion of the following: how to see thoughts differently; how to challenge negative thoughts; what to do when feelings are overwhelming; how to use the breathing space as an initial step toward skilful action directed at achieving internal or external change; how mindfulness can be applied to overall health and wellbeing Home practice explanation for Week 5
Home Practice	45 min/day	Meditation: Mindfulness of Sounds (20 min), Mindfulness of Breath (30 min), Sitting with difficulty (30 min) and/or Loving kindness (20 min) AND Breathing space 3 ×/day Awareness exercise: Coping space whenever needed OR "As much as you are able"
MM Training #6	90 min	Discussion of Week 5 home practice Meditation: Participant's choice between Sitting with difficulty (30 min) or Loving kindness (20 min) Summary: Using what has been learned to deal with future difficulties Discussion of how to incorporate mindfulness into mundane daily living

<u>Activity</u>	<u>Duration</u>	<u>Component Parts</u>
		Home practice explanation for Week 6
Home Practice	45 min/day	Meditation: Mindfulness of Sounds (20 min), Mindfulness of Breath (30 min), Sitting with difficulty (30 min) and/or Loving kindness (20 min) AND Breathing space 3 ×/day Awareness exercise: Coping space whenever needed OR “As much as you are able”
Endpoint Visit	2 hours	n-back task Questionnaire administration: APT-II Attention Questionnaire, the Pittsburgh Sleep Quality Index (PSQI), Perceived Stress Scale (PSS), the Positive and Negative Affect Scale (PANAS), Expectancy Questionnaire, and Qualitative Feedback

Table 4

Demographic information by participant.

<u>ID</u>	<u>Diagnosis</u>	<u>Age^a</u>	<u>Gender</u>	<u>Education^a</u>	<u>Marital Status</u>	<u>Living Situation^b</u>
1	Brainstem stroke	43	M	14	Single	Home
2	ALS	65	F	14	Widowed	Home
3	ALS	50	M	15	Married	CF
4	Muscular Dystrophy	27	M	12	Single	CF
5	Spinocerebellar ataxia, Parkinson's Disease	62	M	21	Married	Home
6	Cerebral palsy	55	F	12	Single	CF
7	Cerebral palsy	25	M	12	Single	Home

^a Age and education are measured in years

^b Participants either lived at home with their families or in a care facility (CF)

Table 5

Results of RSVP BCI Screening Protocol (Fried-Oken et al 2013):

ID	Yes/No	Hearing	Pain	Vision	Visual Perception	Auditory Comp	Reading Comp	Spelling	Visual Attention	Motor Function
1	Eye gaze	WFL-H ^b	None reported	WFL-V ^c	100%	100%	100%	100%	100%	Incomplete LIS ^d ; Seated in power W/C ^e
2	Foot up/down; SGD ^a	WFL-H	None reported	WFL-V	100%	100%	100%	100%	90%	Incomplete LIS; Seated in power W/C
3	Verbal; SGD	WFL-H	Yes; denies impact on concentration or memory	WFL-V	100%	100%	100%	90%	100%	Incomplete LIS; Seated in bed
4	Eye gaze; Verbal; SGD	WFL-H	Yes; denies impact on concentration or memory	WFL-V	100%	100%	100%	100%	100%	Incomplete LIS; Seated in W/C
5	Head nod; thumbs up/down	WFL-H	Yes; denies impact on concentration or memory	WFL-V	100%	100%	100%	100%	100%	Incomplete LIS; Seated in power W/C
6	Head nod; SGD	WFL-H	None reported	WFL-V	100%	100%	100%	100%	100%	Incomplete LIS; Supported seating; frequent uncontrolled facial and respiratory muscle movements
7	Head nod; eye gaze	WFL-H	Yes; reports negative impact on concentration or memory	WFL-V	87%	100%	100%	80%	90%	Incomplete LIS; Seated in bed

^aSGD = Speech Generating Device^bWFL-H = no reported hearing loss; no use of hearing aids; both participant and caregiver report adequate conversational hearing skills for daily function^cWFL-V = no reported vision loss or use of corrective prescription glasses; both participant and caregiver report vision adequate for daily function; no reports of other vision problems including diplopia, hemianopsia, cataracts or macular degeneration.^dLIS = Locked-in syndrome^eW/C = wheelchair

Table 6

Outcome measures before and after meditation, as well as average number of minutes participants practiced per day.

ID	Mdt min/day ^a	Mdt total days ^b	PSS		PANAS (positive)		PANAS (negative)		PSQI		Cred		APT-II		n-back	
			Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
1	7.1	23	6	0	24	25	8	5	1	4	-	-	19	1	2	75
2	5.6	16	16	17	20	17	8	7	3	5	-	-	11	13	2	95
3	13.0	17	24	15	16	16	16	11	12	10	25	25	6	7	2	80
4	17.1	25	10	8	13	15	8	5	9	4	12	12	3	12	2	70
5	18.1	35	5	3	15	17	5	5	6	4	15	23	0	0	1	60
6	.4	9	38	34	6	16	19	21	17	13	19	20	24	18	2	65
7	10.0	21	21	29	22	14	10	15	11	14	20	7	30	31	1	75

^a Calculated by the total days in training (from Training #1 to Endpoint visit) divided by the total number of minutes participants meditated.

^b The total number of days that participants listened to guided meditation recordings, including 6 days of training.