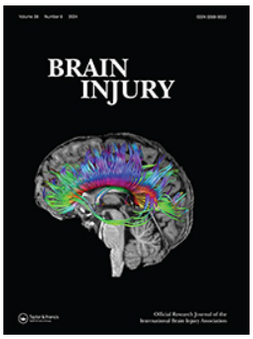

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An online self-study mindfulness-based stress reduction course for people suffering from mental fatigue after an acquired brain injury

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ABSTRACT

Objective: The Mindfulness-Based Stress Reduction (MBSR) program has shown promising results for people suffering from mental fatigue after an acquired brain injury. The aim was to evaluate the feasibility of a MBSR program performed as an online self-study course for this group of people.

Methods: Sixty participants who had suffered an acquired brain injury with lasting mental fatigue were randomized to an online MBSR course or to a waitlist control group. They answered self-report questionnaires before start and after the course.

Results: Sixteen completed the MBSR program. With the repeated ANOVA no significant difference between groups was found, although there was a significant change in time (the repetition factor). The post-hoc paired t-test indicated a significant reduction and a large-to-median effect size in mental fatigue ($p = 0.003$, d = 0.896), depression ($p = 0.038$, d = 0.569) and anxiety ($p = 0.030$, d = 0.598) for the MBSR group. No significant changes were found for the control group.

Conclusion: An online self-study MBSR program for people suffering from mental fatigue after an acquired brain injury can be a feasible option for those suffering from less severe mental fatigue and emotional symptoms, while others may require a program adapted to their needs.

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MBSR; mindfulness; mental fatigue; depression; acquired brain injury

Introduction

Fatigue is a significant long-term or chronic problem after an acquired brain injury as stroke, traumatic brain injury (TBI), brain tumor or brain inflammation (1–4). Prevalence of fatigue is, for stroke estimated to be between 26% and 77% and for TBI between 45% and 73% (4). Fatigue is regarded as a primary symptom and is distinguishable from depression (4). In addition, fatigue is reported as one of the most troublesome symptoms (5) resulting in difficulty taking part in everyday activities with reduced quality of life (2,6–8) as well as reduced work ability (9,10).

When suffering from long-term pathological mental fatigue, patients have a reduced capacity to continue a mental activity repeatedly and a reduced ability to restore the energy in response to performed activity, and the energy is not restored after sleep or an extended rest while, by contrast following a non-pathological mental fatigue people will recover after rest and sleep (11). With use of the Mental Fatigue Scale (MFS) we have recognized the mental and co-occurring cognitive difficulties linked to the pathological mental fatigue concept (12,13). The MFS includes cognitive and emotional difficulties and sensory symptoms which are the consequence when endurance and the mental energy level is reduced; as a result, fatigue will be perceived (14). In addition, this is often compounded by an emotional burden with feelings of hopelessness and despair and difficulty coping with stress if the fatigue is not relieved. From clinical experience, it can take several years of frustration, self-doubt and despair to find the right balance between rest and activity. However, the person will appear normal, the fatigue they describe goes far beyond anything imaginable by a person not suffering from this.

There is currently no specific recommended treatment for mental fatigue after an acquired brain injury. Pharmacological (15) and non-pharmacological reports (16–19) have shown promising results for alleviating fatigue. As people's needs and personal preferences differ, different treatment options may be of considerable usefulness while we still have no cure for pathological mental fatigue. In addition, many people are not offered any treatment whatsoever and they therefore seek help. This is our experience from several treatment studies and from clinical work. With non-pharmacological treatments, fatigue as well as the emotional burden can be alleviated. This has been shown for fatigue after TBI with blue light therapy (16,17) and adapted cognitive behavioral therapy (20,21). We have collaborated with the group-based Mindfulness-Based Stress Reduction program (MBSR) in our research work and have produced promising results for patients suffering from metal fatigue after TBI and stroke, with reduced mental fatigue and emotional distress as well as improved cognitive function (18,19). Similar results have been reported by other researchers for diseases affecting the brain

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using the MBSR program (22–27). Furthermore, MBSR is reported to be a clinically effective method for alleviating a wide range of conditions as stress, depression, pain, and fatigue, with the aim of helping people to cope better with their difficulties (28,29).

The MBSR is a group-program based on meditative practices and psychological and educational theories (30). MBSR was developed by Jon Kabat Zinn in 1979 and is about training mindful attitudes – including living in the present moment – with attention, compassion, without striving nor judging (29). MBSR is a program with clear guidelines relating to content and for the competence of the teacher (31,32). MBSR is an eight weekly session group program, including a whole day's retreat. It also includes home assignments with daily guided meditation sessions and practices with the intention to introduce mindfulness into daily life. Meditation and gentle yoga are practiced during the meetings and at home between the weekly sessions. During the meetings (2–2 ½ hrs depending on number of participants), discussions lead by the teacher is included, with the purpose on exploring patterns of behavior, thinking and feeling and learning about alternative ways of approaching and coping with life. The MBSR program can contribute to well-being and could be a therapeutic option for those who have suffered from an acquired brain injury and who struggle with long-term mental and cognitive difficulties (18,22,23). An alternative with a group face-to-face or live online MBSR is an online self-study MBSR program, and it has been possible to follow this program for a long time now (The MBSR Online Course – Sounds True). However, it does not allow for interaction with group members, although recorded audios and videos is presented with the intention to assist the participant with learning from the psycho-educative part of the program, which takes place mainly during the group discussions. In this study, we have developed a very similar MBSR program in Swedish, following the MBSR curriculum, with the intention to evaluate the feasibility of following the online self-study program when suffering from mental fatigue after an acquired brain injury. As we have previously found the MBSR program to be helpful for people suffering from long-term fatigue after acquired brain injuries (18,19), we sought to evaluate a self-study program. This can also be a viable alternative particularly when it is difficult or not possible to find a MBSR course nearby. In addition, some people may prefer a self-study program as it involves carrying out the practice at home in a safe place. A long journey to the course location is often reported and this, combined with the effort involved in taking part in the discussions can prove to be demanding for some people suffering from mental fatigue. An online course also gives the person the opportunity to stop, rest, repeat parts of the prerecorded videos, and extend the program for a longer period if necessary. We have developed an online self-study program together with certified MBSR teachers. We have followed the MBSR curriculum in this study, including 45-minute mediation sessions and home-assignments as, according to our previous MBSR studies (18,19) this alternative has proven to be possible for patients to follow with the exception of the group discussions. The draw-back of a self-study program is the lack of personal support and the interaction with group members. We have to our knowledge not found any previous studies with a self-study online MBSR program for participants suffering from mental fatigue after an acquired brain injury. As alternative treatment options for fatigue is scarce, this study can contribute and can be a source of inspiration and can serve to build knowledge for the development of alternative treatment options in the future.

The aim of this randomized pilot study is to evaluate the feasibility of a MBSR program performed as an online self-study course for those suffering from mental fatigue after an acquired brain injury.

Methods

Participants were recruited through an advertisement on the Swedish Stroke Association's website and in the Facebook group for people with mental fatigue after an acquired brain injury. Participants were consecutively included from September 2019 to March 2020. Those who were interested contacted the research team and a neuropsychologist with long-term experience with acquired brain injuries and rehabilitation. They were interviewed by telephone and e-mail to confirm the diagnosis and were informed about the study.

The inclusion criteria were age between 20 and 70 years; having suffered from an acquired brain injury such as stroke, traumatic brain injury (TBI) including concussion, encephalitis or meningitis or benign brain tumor at least 6 months prior to inclusion and suffering from mental fatigue as defined with the cutoff score from the Mental Fatigue Scale sum of score at 10.5 or above (13). Exclusion criteria were clinically diagnosed with severe depression and/or anxiety, or psychiatric illness as this requires clinical treatment, or language problems as having reduced the cognitive ability to understand and follow the program. They were also excluded if they had participated in a MBSR course previously. The study was approved by the Swedish Ethical Review Authority (2019–02690). All participants signed an informed consent for the study and were informed that they could withdraw at any time without giving a reason.

After the participants had declared their interest in participating, they received written information and, if they so wished further information over the telephone. They answered questionnaires concerning background data as age, gender, education, diagnosis, time since acquired brain injury, working hours as a percentage of full-time and whether they had previous experience of mindfulness and/or yoga. They also answered the three self-report questionnaires; Mental Fatigue Scale (MFS) (13), Comprehensive Psychopathological Rating Scale (CPRS, depression and anxiety) (33) and the Brunnsviken Brief Quality of Life (BBQ) (34). The MFS has been evaluated for people with an acquired brain injury (12,13). A value above 10 indicates a significant problem with mental fatigue. The questions included are the following: generalized fatigue, fatigue related to mental activities, mental recovery time, concentration and memory problems, slowness of thinking, stress sensitivity, emotional sensitivity (tearfulness) and irritability, reduced initiative, light and sound sensitivity and sleep problems. The questions have a high internal consistency (12,13). The CPRS was used for depression and

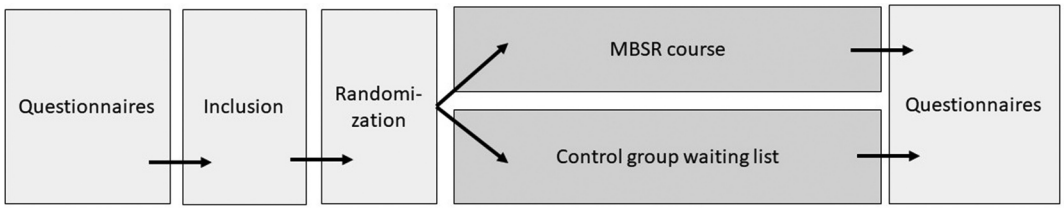

Figure 1. Study design.

anxiety (33). Mild depression has been associated with a rating of between 6.6 and 9.5, moderate between 10 and 17 and severe ≥17.5 (35). The CPRS depression scale is identical to the Montgomery Åsberg Depression Rating Scale (MADRS) except that the rating is doubled in the MADRS (36). The BBQ scale measures importance-adjusted satisfaction across six life areas as leisure, view on life, creativity, learning, friends and friendships and view on self. BBQ displays high concurrent and convergent validity and good reliability and it is able to differentiate between clinical and healthy groups, and is also sensitive to change (34).

Once the questionnaires had been returned and the participants were accepted for inclusion, they were randomized to either the MBSR or the waitlist control group, using the randomization function in Excel.

The same questionnaires (MFS, CPRS, and BBQ) were answered after the MBSR course or after the same period of 8 weeks spent on the waitlist (Figure 1).

For evaluation of the program's user-friendliness, they answered a questionnaire about a) to what extent have you been able to follow the program (every day/some days/week/less regularly), b) will you continue using MBSR in the future (yes/no) c) did the course meet your expectations (yes/no) d) how satisfied are you with the program (satisfied/less satisfied/not at all satisfied).

MBSR group

The MBSR group consisted of 30 participants and after inclusion they were sent a login to a website with access to the MBSR program online – this was also available for download. On the website, the MBSR program was presented with eight weekly sections, with a duration of approximately 1 ½ –2 hours, and a whole day in silence. The sections were available as recorded audio files and videos providing information about the sessions, instructions for the practices and meditation sessions along with information and instructions regarding the specific theme of the sessions. The meditation sessions included body-scan (designed to systematically, region by region, cultivate awareness of the body), sitting meditation with a duration of 20 and later 45 minutes (awareness of the breath and systematic widening the field of awareness to include awareness of the body, feeling tone, mental states and thoughts), breath space and gentle Hatha yoga, with an emphasis on mindful awareness of the body. Yoga sitting on a chair was also included as an alternative, if someone preferred that due to physical limitations. They were also encouraged to take care and to discover personal capabilities and limitations, as the aim in the program is to explore body and mind with care and friendliness with the intention to gain an awareness of the person's actual state. The participants were encouraged to take part in daily meditations with a duration of approximately 45 minutes/day and the weekly homework in-between the weekly sessions. If they preferred, they were encouraged to start off with shorter meditations, with the intention to establish a daily routine with meditations, and then gradually increase the length of time. Meditation is all about the intention of doing, without striving toward particular goals nor judging what is good or bad, merely taking the time, carrying out the practices and exploring oneself at that particular moment with friendliness. All this is according to the MBSR curriculum. In addition, there is a text booklet available on the website offering extra support, as which practices to carry out each week and explanations outlining the themes. Several of the texts in the booklet are recorded audio files, to simplify everything for those who prefer listening, as reading can often prove to be difficult when suffering from mental fatigue. If necessary, participants were given the opportunity to seek advice and support from a psychologist in the event of discomfort or side-effects.

The control group

The control group consisted of 30 participants who were instructed to continue as usual without any additional instructions, for the duration of the program, 8 weeks. If after the program, the participants in the control group wished to participate in a MBSR course they were sent a login to a website and were given access to the MBSR program.

Statistics

Background data were analyzed with t-test and chi-square. For the main analysis, a two-factorial ANOVA with time as a repeated factor and group as a between-factor were used. For post-hoc analysis, paired t-test was used for pre- and post-comparisons/group. Effect size was calculated with partial eta square, η^2 and Cohen´s d. SPSS 25.0 was used for statistical calculations.

Results

Forty-five women (75%) and 15 men (25%) participated in the study. There was an even distribution between the groups with no difference in age, sex, education, diagnosis, working hours calculated as a percentage of full-time, previous experience of mindfulness or yoga, and baseline rating on MFS, CPRS (depression, anxiety) and BBQ (Table 1). In total 16

Table 1. Demographic and background data and pre-rating on mental fatigue (MFS), depression and anxiety (CPRS) and quality of life (BBQ) scales. Mean, standard deviation (sd), frequency.

	MBSR	Controls	p-value
Participants included	30	30	
Age in years, mean	46.4 (12.3)	47.3 (11.2)	0.760
Sex, (females/males)	25/5	20/10	0.136
Higher education - high school/university	9/21	7/23	0.559
Diagnosis (stroke/TBI/ meningitis-encephalitis/brain tumor)	14/10/ 4/2	12/14/ 2/2	0.685
No work/part-time work/ full-time work	20/8/2	15/13/2	0.439
Years after injury, mean	5.3 (5.7)	5.4 (5.2)	0.991
Previous experience of mindfulness/yoga (yes/no)	23/7	26/4	0.317
MFS, mean	23.7 (4.7)	21.6 (5.6)	0.112
Depression, mean	9.2 (3.6)	8.3 (3.8)	0.381
Anxiety, mean	8.4 (4.0)	7.9 (2.8)	0.557
BBQ, mean	39.7 (18.3)	43.1 (13.8)	0.416

participants completed the MBSR program and answered the questionnaires after the program, while 14 did not complete the course. In the control group, 29 repeated the questionnaires after 8 weeks.

The repeated ANOVA including between- (group comparison) and within-subject factors (time/repetition of questionnaires) revealed no significant difference between the groups and no interaction effect. Only the repetition factor (time) was significant (Table 2). The post-hoc test (paired t-test) showed a significant reduction in MFS, depression and anxiety for the MBSR group, with large to medium effect size. No significant change in BBQ was detected. No significant change was found for any of the questionnaires for the control group (Table 3).

No background data regarding age, sex, diagnosis and working hours as a percentage of full-time/sick leave differed between those completing the course and those who did not. The rating on MFS for those completing the program did not differ significantly (t-test 0.676) from those who did not complete the program. Among those who completed the MBSR course, 81% had a university degree and 88% had previous experience of mindfulness or yoga. For those not completing the course 57% had a university degree and 64% had previous experience of mindfulness and yoga.

Questions concerning evaluation of feasibility

Of the 16 participants who answered the evaluation after the MBSR program, 11 out of 16, reported that they had carried out meditative practices every day. Two participants answered 'A few times/week' and three answered 'Less often.' Thirteen out of the 16 participants were very satisfied, or satisfied with the program and will continue with the practices. Two participants were less satisfied and one was not at all satisfied.

Discussion

The online MBSR program for people suffering from mental fatigue after an ABI was feasible for those who completed the course. The post-hoc analysis showed a reduction for the MBSR participants in their mental fatigue, depression and anxiety with large-to-medium effect size. The control group did not change significantly. A majority of those who completed the program carried out meditation regularly between the weekly sessions and was satisfied with the MBSR program.

However, half of the participants did not complete the MBSR program. This shows that some difficulties were encountered when participating in an online self-study MBSR program by oneself. The reasons here for not continuing can only be speculative. We do not have any comments from those who dropped out since, and according to the ethical rules they could cancel without providing any comments. Many people can encounter problems related to their mental fatigue, which may be a hindrance to them. They may find it difficult to initiate activities. They are likely to be easily fatigued and may thus find that the sessions as well as the

Table 2. A repeated two-factorial ANOVA, F-value, p-value and effect size (E).

	Time	Interaction	Group
MFS, mental fatigue	F = 13.333, p = 0.001 E = 0.234	F = 2.492, p = 0.122 E = 0.055	F = 0.331, p = 0.568 E = 0.008
CPRS, depression	F = 10.408, p = 0.002, E = 0.195	F = 2.850, p = 0.209, E = 0.036	F = 019, p = 0.891, E = 0.000
CPRS, anxiety	F = 0.924, p = 0.342, E = 0.021	F = 2.662, p = 0.110, E = 0.058	F = 0.000, p = 0.992, E = 0.000
BBQ, quality of life	F = 2.406, p = 0.128, E = 0.054	F = 1.746, p = 0.194, E = 0.040	F = 1.130, p = 0.294, E = 0.026

Effec size; partiell eta square: η^2, 0.01 small, η^2 = 0.06 medium, η^2 = 0.14 large.

Table 3. Comparison for each group separately (includes only those who answered both pre and post) with paired t-test with p-value and effect size Cohen´s d (d). Mean and standard deviation (sd) before and after MBSR/control time and numbers completing both pre- and posttest.

	MBSR				Control			
	Pre	Post	p-value	d	Pre	Post	p-value	d
Completing	30	16			30	29		
MFS	23.5 (3.3)	20.8 (4.8)	0.003	0.896	21.7 (5.6)	20.7 (6.1)	0.113	0.304
Depression	8.7 (2.8)	7.4 (3.2)	0.038	0.569	8.5 (3.8)	7.9 (4.0)	0.064	0.358
Anxiety	8.5 (2.5)	7.5 (2.7)	0.030	0.598	7.9 (2.8)	8.1 (4.0)	0.625	0.091
BBQ	45.7 (20.1)	51.3(19.6)	0.074	0.499	42.9 (14)	43.4 (16.2)	0.851	0.035

Cohen´s d: 0.2 small, 0.5 medium, 0.8 large.

meditation sessions are too long. The home assignments may also be too demanding. Those who dropped out had a lower level of education and had less experience of meditation and mindfulness. This may have been a contributing factor to their not completing the course. However, their rating on MFS at baseline was similar as for those who completed the program. From our previous MBSR studies, with traditional face-to-face groups with mental fatigue participants, the number of drop-outs was not significant (18,19). Participating in a group may provide support from the teacher and fellowship and support from the other participants which is absent when carrying out the MBSR as a self-study program. This may have been important for those who did not continue the program alone. The group effect is less well understood, but is an important factor – according to the eastern mindfulness tradition, it is learning to understand human suffering in a wider perspective, that many experience similar difficulties and the feeling of not being alone (37). A few contacted the psychologist by phone for advice how to encounter the meditations. No side effects were reported, except struggling with their mental fatigue.

Discussions during the program, as well as support and sharing experiences with others was not included in the online program. However, the reason for offering an online program is related to few opportunities for participating in a MBSR program or other rehabilitation alternatives for mental fatigue. People may live a long way away from the center where the MBSR is delivered. It may also take time waiting for a group to start, as it can take time to recruit enough participants for a group, especially delivering a MBSR program for a specific group, as here for mental fatigue after an acquired brain injury. With an online self-study MBSR program, it is possible to start at any time. Some prefer a particular day of the week and time of the day and it may suit them better doing the MBSR course by oneself. Others want to participate in the program alone at home in a safe environment without interaction with others. The program can be followed on a day and at a time of their choice, videos/audios can be divided up into sections and repeated and it is possible to extend the program to add extra weeks if needed. From this perspective, a MBSR program with a face-to-face group, a live group online or online as a self-study can all be useful alternatives, all according to personal preferences. In this study, we also wanted to evaluate whether it was possible to deliver MBSR as a self-study program, and we found that this is possible for some. Rehabilitation options are scarce and this study can contribute to build knowledge and offer inspiration for future studies. However, this MBSR program is not adapted to mental fatigue. A program adapted to mental fatigue, including education about mental fatigue and common symptoms, meditation sessions and psychoeducation similar to the MBSR program, could be an interesting option. In addition, it may be useful to make the program less intensive with biweekly meetings, as suggested by McKechnie (38). Future research may result in more specific and helpful rehabilitation options for those suffering from mental fatigue.

Limitations of this feasibility study included the limited numbers of participants. Future studies with more participants, and also participants with other neurological illnesses who suffer from mental fatigue is warranted. In addition, the high number of dropouts needs to be managed and understood. There were also comparatively few men who participated in this study, and this shows the need to better adapt programs to men. Few men is also reported from other mindfulness studies, with men making up roughly 25% of the class (39,40). Thus, future work should consider potential obstacles for involvement and explore ways to encourage more men to attend mindfulness programs. Using a waitlist control group was chosen, as we wanted to explore the online self-study MBSR program and not to compare it with other control activities, as it can be difficult to find a proper activity not having any impact on fatigue.

In conclusion, this study shows that it is feasible for some to take part in this online self-study MBSR course with the basic curriculum including the meditations and the various themes, for people suffering from lasting mental fatigue after an acquired brain injury, and to alleviate mental fatigue and emotional distress. This study also shows the importance of developing programs that are better adapted to suit those who need personal support and who struggle with mental fatigue. However, many patient groups suffer from mental fatigue and treatment is warranted. An online self-study MBSR program can be an option for rehabilitation after acquired brain injuries when the fatigue and emotional burden are long-lasting or lifelong.

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Disclosure statement

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