What are the benefits of yoga/ meditation/ mindfulness for patients with motor neurone disease?

Evidence search report

Completed: 13th August, 2024

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Evidence search: What are the benefits of yoga/ meditation/ mindfulness for patients with motor neurone disease?. Claire Field. 13th August, 2024. UK: University Hospitals Bristol & Weston Library & Knowledge Services.

Summary

There isn't huge amounts of really current evidence published on this topic but the search found a number of systematic reviews, RCTs and other studies. Some of the evidence includes other disorders as well. Some benefits stated include the value of yoga, meditation, and mindfulness as complementary therapies in managing neurodegenerative diseases, improving psychological well-being, and enhancing quality of life for patients but they state that further research is crucial to solidify these findings and optimize their application in clinical practice.

THe following results may be of particular interest:

1. SYSTEMATIC REVIEWS

04. Adams, J. et al (2018) Critical Review of Complementary and Alternative Medicine Use in Amyotrophic Lateral Sclerosis: Prevalence and Users' Profile, Decision-Making, Information Seeking, and Disclosure in the Face of a Lack of Efficacy. Neurodegnerative Diseases.

II RCTs

03. Pagnini, F et al (2017) Meditation training for people with amyotrophic lateral sclerosis: a randomized clinical trial. European Journal of Neurology.

IV QUALITATIVE STUDIES

03. Marconi, A et al (2016) The experience of meditation for people with amyotrophic lateral sclerosis and their caregivers - a qualitative analysis. Psychology, Health & Medicine

V. CASE STUDIES

01 Subbappo, R (2015) Iyengar Yoga Therapy Intervention for Ischial Pressure Ulcers in a Patient with Amyotrophic Lateral Sclerosis: A Case Study. J of Alternative and Complementary Medicine.

Contents

4. Teaching mindfulness meditation to adults with severe speech and physical impairments: An exploratory study.

5. Meditation Training for People with Amyotrophic Lateral Sclerosis and Their Caregivers

iv. Qualitative Studies

1. Flexibility to manage and enhance quality of life among people with motor neurone disease

2. User perspectives on a psychosocial blended support program for partners of patients with amyotrophic lateral sclerosis and progressive muscular atrophy: A qualitative study.

3. The experience of meditation for people with amyotrophic lateral sclerosis and their caregivers – a qualitative analysis

4. The experience of meditation in ALS: A qualitative study about the efficacy of a mindfulness meditation protocol with ALS subjects and caregivers.

v. Case Studies

1. Iyengar Yoga Therapy Intervention for Ischial Pressure Ulcers in a Patient with Amyotrophic Lateral Sclerosis: A Case Study

2. Iyengar Yoga Therapy as an Intervention for Cramp Management in Individuals with Amyotrophic Lateral Sclerosis: Three Case Reports

vi. Articles

1. Mindfulness, depression and quality of life in amyotrophic lateral sclerosis.

D. Search strategy

E. Disclaimer

A. Search terms and notes

Natural language and subject headings were combined and the following search strategy used:

- Yoga OR meditate* OR mindful* OR movement OR “breath work”
- “motor neuron* disease” OR MND OR “amyotrophic lateral sclerosis” OR ALS OR “progressive muscular atrophy"

The following resources were searched:

1. AMED
2. CINAHL
3. Cochrane
4. EMCARE
5. PubMed

Sources searched (number of results in brackets):
RefWorks (21)

Date range: 2014-2024

Limits: Humans, English

For full search strategy see Section D below.

Please acknowledge this work in any resulting paper or presentation as:
Evidence search: What are the benefits of yoga/ meditation/ mindfulness for patients with motor neurone disease?. Claire Field. 13th August, 2024. UK: University Hospitals Bristol & Weston Library & Knowledge Services.

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C. Search results

i. Systematic Review/Meta Analysis/Scoping Review

1. **Exploring the potential of mindfulness-based therapy in the prevention and treatment of neurodegenerative diseases based on molecular mechanism studies.**
Wu C. Feng Y. Frontiers in Neuroscience 2023;17(pagination):

Available online at this link

Neurodegenerative diseases (ND) have received increasing attention due to their irreversibility, but there is still no means to completely cure ND in clinical practice. Mindfulness therapy (MT), including Qigong, Tai Chi, meditation, and yoga, etc., has become an effective complementary treatment modality in solving clinical and subclinical problems due to its advantages of low side effects, less pain, and easy acceptance by patients. MT is primarily used to treat mental and emotional disorders. In recent years, evidence has shown that MT has a certain therapeutic effect on ND with a potential molecular basis. In this review, we summarize the pathogenesis and risk factors of Alzheimer's disease (AD), Parkinson's disease (PD), and amyotrophic lateral sclerosis (ALS), relating to telomerase activity,

epigenetics, stress, and the pro-inflammatory transcription factor nuclear factor kappa B (NF-kappaB) mediated inflammatory response, and analyze the molecular mechanism basis of MT to prevent and treat ND, to provide possible explanations for the potential of MT treatments for ND.

2. **Feasibility, Acceptability, and Efficacy of Mindfulness Training in People With Upper Motor Neuron Disorders: A Systematic Review**
Korupolu Radha Malik Aila Ratcliff Chelsea Robinson-Whelen Susan Taylor Heather B. Archives of Physical Medicine and Rehabilitation 2022;103(12): 2410-2428.

Available online at this link

Objectives: This systematic review aims to gain a comprehensive understanding of the feasibility, acceptability, and efficacy of mindfulness-based interventions (MBIs) on depression, anxiety, fatigue, and health-related quality of life among individuals with upper motor neuron disorders (UMNDs).; Data Sources: PubMed, PsycINFO, Excerpta Medica Database, and Cumulative Index to Nursing and Allied Health Literature were searched for relevant studies published between January 2001 and June 2021.; Study Selection: Clinical trials published in English evaluating MBIs in adults with the 4 most common UMNDs (multiple sclerosis, brain injury including stroke, spinal cord injury, amyotrophic lateral sclerosis) were included.; Data Extraction: Two reviewers independently performed the risk of bias assessment using standardized tools and extracted desired data electronically.; Data Synthesis: A total of 44 studies were included: 26 randomized controlled trials, 10 nonrandomized controlled trials, and 8 pre-post intervention studies. The average ± SD duration of MBIs was 8±2 weeks. On average, 85%±14% of participants completed the MBI, and the retention rate at follow-up was 80%±16%. Only 14% of the studies delivered MBIs virtually, and feasibility metrics were similar to in-person studies. Among studies reporting acceptability data, most participants reported satisfaction with the MBI. Randomized controlled trials that evaluated the effects of MBI on depression, anxiety, fatigue, and quality of life revealed greater relative improvement in these outcomes among MBI participants compared with controls, with differences greater when compared with passive control than active control participants. None of the studies included in this review studied dose response.; Conclusions: Based on current data, MBIs are feasible and offer a promising approach to address the biopsychosocial needs of individuals with UMNDs. MBIs are associated with a high acceptance rate among participants, with notable improvements in depression, anxiety, fatigue, and quality of life post intervention. Future studies are needed to evaluate alternate models of delivery of MBIs and the dose-response relationship. (Published by Elsevier Inc.)

3. **Psychological interventions for people with motor neuron disease: a scoping review**
Zarotti Nicolo Mayberry Emily Ovaska-Stafford Noora Eccles Fiona Simpson Jane. Amyotrophic Lateral sclerosis & Frontotemporal Degeneration 2021;22(1-2): 1-11.

Available online at this link

OBJECTIVE: Motor neuron disease (MND) is a rapidly progressive neurodegenerative condition with no known cure. MND can affect every aspect of a person's life and has been associated with a wide range of psychological difficulties, which can occur from pre-diagnosis through to

the condition's later stages. However, very little research has been conducted on psychological interventions for people with MND (pwMND). This paper aimed to provide the first review specifically targeting psychological interventions in MND and offer potential directions for future research. Methods: A scoping review was carried out across five major databases (PubMed, PsycINFO, CINAHL, Academic Search Ultimate, and Cochrane Library) until 1st of March 2020. Results: From an initial return of 1278 citations, 10 papers were included in the review. These included three randomized controlled trials (RCTs), two quasi-experiments, three uncontrolled pretest-post-test designs, one single case study, and one qualitative secondary analysis. The existing studies focused on a limited number of psychological outcomes and did not take into account site of MND onset or level of depression/anxiety before intervention. Implications for clinical practice are discussed and suggestions for future research are provided. Conclusions: The literature on psychological interventions is still extremely sparse. Mindfulness-based stress reduction (MBSR) and cognitive behavioral therapy (CBT) based on the stress-coping model show promise in RCTs, but require further evaluation. The need for further development and evaluation of psychological interventions to improve the well-being of pwMND cannot be overstated, particularly as the struggle toward the discovery of an effective treatment for MND continues.

4. **Critical Review of Complementary and Alternative Medicine Use in Amyotrophic Lateral Sclerosis: Prevalence and Users' Profile, Decision-Making, Information Seeking, and Disclosure in the Face of a Lack of Efficacy**
Adams Jon Lee Michael Peng Wenbo. Neurodegenerative Diseases 2018;18(4): 225.

Available online at this link

Background: Despite a lack of evidence of clinical efficacy for complementary and alternative medicine (CAM) use in amyotrophic lateral sclerosis (ALS), these medicines remain popular around the world. Objective: To examine the prevalence and cost of CAM use in ALS and CAM users' profile, decision-making, information seeking, and disclosure among ALS patients. Methods: A comprehensive literature search was conducted of MEDLINE, CINAHL/SCOPUS, and AMED databases from their inception to April 2018. This review followed PRISMA guidelines and employed a quality scoring system to assess the included papers. Results: Seven papers met the inclusion criteria and were thematically analysed. ALS patients utilized a range of CAM therapies and/or products, with acupuncture and vitamins being the most frequently reported. CAM modalities were often employed concurrently with conventional medications throughout the disease process. Although some ALS patients reported positive experience regarding CAM use, many were reluctant to disclose their CAM use to their clinicians. Research focusing on CAM use in ALS remains ad hoc and restricted to only a few countries. The rigour and quality of this research field to date has been varied, predominantly drawing upon regional/localized data and failing to report CAM users' characteristics. Conclusion: A proportion of ALS patients report utilizing CAM concurrently with conventional treatments. Such use, set amidst a dearth of evidence for the efficacy of CAM in ALS, poses potential direct and indirect risks to patient care, and medical providers should be mindful of and enquire about CAM use when treating ALS patients. Keywords Amyotrophic lateral sclerosis * Complementary and alternative medicine * Review * Prevalence * Decisionmaking * Information seeking * Disclosure; Introduction Amyotrophic lateral sclerosis (ALS) is a

neurodegenerative disease primarily affecting the motor system and characterized by progressive degeneration of the motor neurons 1, 2]. The prevalence of ALS cases ...]

5. **Symptomatic treatments for amyotrophic lateral sclerosis/motor neuron disease**
Ng Louisa Khan Fary Young Carolyn A. Galea Mary. Cochrane Database of Systematic Reviews 2017;(1):

Available online at this link

We searched the Cochrane Database of Systematic Reviews (CDSR) on 15 November 2016 for systematic reviews of symptomatic treatments for MND. We assessed the methodological quality of the included reviews using the Assessment of Multiple Systematic Reviews (AMSTAR) tool and the GRADE approach. We followed standard Cochrane study (review) selection and data extraction procedures. We reported findings narratively and in tables.

6. **Associations between psychological factors and health-related quality of life and global quality of life in patients with ALS: a systematic review**
van Groenestijn Annerieke C. Kruitwagen-van Reenen Esther T. Visser-Meily Johanna M. A. van den Berg Leonard H. Schroder Carin D. Health & Quality of Life Outcomes 2016;14(1): 107.

Available online at this link

OBJECTIVE: To systematically identify and appraise evidence on associations between psychological factors (moods, beliefs, personality) and Health-related QoL (HRQoL) and/or global QoL in patients with Amyotrophic Lateral Sclerosis (ALS). METHODS: A systematic review was conducted in several online databases (PsycINFO, EMBASE, PubMed and CINAHL) up to October 2015. Articles were included if they reported associations between psychological factors (moods, beliefs and personality) and HRQoL and/or global QoL in an ALS population. The search was limited to empirical studies, published in English, which provided quantitative data. The methodological quality of the included articles was assessed. RESULTS: In total, 22 studies were included. Mood was investigated in 14 studies, beliefs in 11 studies and personality in one study. Fifteen different psychological factors were extracted and assessed using 24 different measures. Twelve different QoL measures were used in the selected studies, subdivided into seven different HRQoL measures and five different global QoL measures. Higher levels of anxiety and depression appeared to be related to a poorer HRQoL, whereas a higher level of religiosity seemed to be associated with better global QoL. No conclusive associations were found for confusion-bewilderment (mood), spirituality, mindfulness, coping styles, hopelessness, perception of burden, cognitive appraisal (beliefs), neuroticism, extraversion, openness, agreeableness and conscientiousness (personality), due to insufficient or inconsistent evidence. Religiosity and spirituality appeared to become more positively associated over time. CONCLUSIONS: Our results suggest that higher levels of anxiety and depression are related to a poorer HRQoL, whereas higher levels of religiosity appeared to be related to better global QoL. Associations might change during the disease course. This review supports the importance of psychological factors with regard to ALS care. Further research is needed to supplement the available evidence and to investigate how psychological factors can be modified to improve QoL. REVIEW REGISTRATION NUMBER: PROSPERO 2015:CRD42015027303.

ii. RCTs

1. **Acceptance and Commitment Therapy plus usual care for improving quality of life in people with motor neuron disease (COMMEND): a multicentre, parallel, randomised controlled trial in the UK.**
Gould R. L. McDermott C. J. Thompson B. J. Rawlinson C. V. Bursnall M. Bradburn M. Kumar P. Turton E. J. White D. A. Serfaty M. A. Graham C. D. McCracken L. M. Goldstein L. H. AlChalabi A. Orrell R. W. Williams T. Noad R. Baker I. Faull C. Lambert T. Chhetri S. K. Ealing J. Hanratty A. Radunovic A. Gunawardana N. Meadows G. Gorrie G. H. Young T. Lawrence V. Cooper C. Shaw P. J. Howard R. J. Andreou P. AndroulakiKorakaki D. Blakeley C. Bridges G. Campbell I. Davenport B. Dee A. Drewry N. Flood J. Fox A. Girling M. Glew R. Hartley N. Hocking S. Howell M. Keetharuth A. Makin S. Marsh J. Mayberry E. McDonald A. McPartland R. Meldrum S. Mobley A. Murphy D. O'Brien M. C. Oliver M. Patel D. Phipps E. Read J. Roberts R. Rooney N. Smith C. Statham J. Thompson C. Varma P. Walker A. M. Waterhouse S. The Lancet 2024;403(10442): 2381-2394.

Available online at this link

Background: Motor neuron disease is a progressive, fatal neurodegenerative disease for which there is no cure. Acceptance and Commitment Therapy (ACT) is a psychological therapy incorporating acceptance, mindfulness, and behaviour change techniques. We aimed to evaluate the effectiveness of ACT plus usual care, compared with usual care alone, for improving quality of life in people with motor neuron disease.

2. **An online non-meditative mindfulness intervention for people with ALS and their caregivers: a randomized controlled trial**
Pagnini Francesco Phillips Deborah Haulman Anne Bankert Matthew Simmons Zachary Langer Ellen. Amyotrophic Lateral Sclerosis & Frontotemporal Degeneration 2022;23(1-2): 116-127.

Available online at this link

Objectives: Mindfulness-based interventions seem to be effective in promoting QOL of ALS patients and caregivers, but most require substantial time. In the Langerian approach, mindfulness can be easily promoted with mental tasks and short lectures. This study aims to explore the impact of an ALS-specific online Langerian mindfulness training program on QOL of ALS patients. Methods: We developed and tested with an Randomized Controlled Trial (RCT) a 5-week active learning mindfulness program. Participants were recruited from the ALS clinic at Penn State Health and online and were randomly assigned to either the mindfulness group or a wait-list control group. The primary outcome was the patient's QOL after the treatment. 3 and 6-month follow-ups, together with anxiety, depression, care burden, and physical function, assessed at all times for both patients and caregivers, were explored as secondary outcomes. Results: 47 ALS patients and 27 caregivers were recruited. Among the ALS patients, the experimental group reported higher levels of QOL at the end of the treatment (d = 0.54). Moreover, they showed lower values of depression, anxiety, and negative emotions, compared to the controls, over time. The caregivers from the mindfulness group reported lower scores of care burden, depression, and anxiety, with higher values of energy and emotional well-being over time. Conclusions: This small RCT provides preliminary evidence that this intervention leads to an increase of QOL and a reduction in psychological

comorbidities in ALS patients and caregivers. Given the relatively short time commitment, it may be easily implemented by the ALS community.

3. **Meditation training for people with amyotrophic lateral sclerosis: a randomized clinical trial.**
Pagnini F. Marconi A. Tagliaferri A. Manzoni G. M. Gatto R. Fabiani V. Gragnano G. Rossi G. Volpato E. Banfi P. Palmieri A. Graziano F. Castelnuovo G. Corbo M. Molinari E. Riva N. Sansone V. Lunetta C. European Journal of Neurology 2017;24(4): 578-586.

Available online at this link

BACKGROUND AND PURPOSE: Studies investigating psychological interventions for the promotion of well-being in people with amyotrophic lateral sclerosis (ALS) are lacking. The purpose of the current study was to examine the use of an ALS-specific mindfulness-based intervention for improving quality of life in this population. METHODS: A randomized, open-label and controlled clinical trial was conducted on the efficacy of an ALS-specific meditation programme in promoting quality of life. Adults who received a diagnosis of ALS within 18 months were randomly assigned either to usual care or to an 8-week meditation training based on the original mindfulness-based stress reduction programme and tailored for people with ALS. Quality of life, assessed with the ALS-Specific Quality of Life Revised scale, represented the primary outcome, whilst secondary outcomes included anxiety and depression, assessed with the Hospital Anxiety and Depression Scale, and specific quality of life domains. Participants were assessed at recruitment and after 2, 6 and 12 months. The efficacy of the treatment was assessed on an intention-to-treat basis of a linear mixed model. RESULTS: A hundred participants were recruited between November 2012 and December 2014. Over time, there was a significant difference between the two groups in terms of quality of life (beta = 0.24, P = 0.015, d = 0.89). Significant differences between groups over time were also found for anxiety, depression, negative emotions, and interaction with people and the environment. CONCLUSIONS: An ALS-specific meditation programme is beneficial for the quality of life and psychological well-being of people with ALS. Copyright © 2017 EAN.

iii. Studies

1. **Medical Dance/Movement Therapy in the Infusion Room: A Model for Individual Sessions with Adults in Active Treatment**
Millrod Eri. American Journal of Dance Therapy 2020;42(1): 61-89.

Available online at this link

A dance/movement therapy (DMT) program was implemented in a medical setting that is relatively new to medical DMT and in a format that is not covered in DMT literature. Dance/movement therapy sessions were conducted with adult patients in active treatment for cancer or amyotrophic lateral sclerosis in the infusion room of an outpatient cancer center. The sessions were offered in individual format rather than in group format, which led to the development of a model for individual DMT in the infusion room. The model consists of six components that guide patients to develop the attitudes and skills to cope with their disease while in active treatment. Patients start with mindfulness exercises and a therapist guided movement warm-up, and progress to mindful moving. Patients eventually direct their

own movements and use symbolic and expressive movements to access and express thoughts and feelings that are held in the body or in the unconscious, before ending with reflections and verbal discussions. A limitation of the model is that it is based on conducting DMT with a small number of patients at one medical facility and may not be viable in a more culturally diverse population.

2. **Yoga education program for older women diagnosed with sarcopenia: A multicity 10-year follow-up experiment**
Pandya Samta P. Journal of women & aging 2019;31(5): 446-469.

Available online at this link

This article reports a multicity yoga education program (YEP) experiment aimed at improving gait speed, muscular strength, and functional performance in Asian and African older women diagnosed with sarcopenia. Posttest gait speed and muscle strength scale scores were higher, and the six functional performance tests scores were above average for women who were from Asian cities; middle class; currently married; living with spouse, children, or kin; with good self-rated health; who regularly attended the YEP lessons and regularly self-practiced. Instructors' self-practice record was the strongest predictor of higher posttest scores. The YEP is an effective long-term prevention for sarcopenic older women.

3. **Mindfulness, physical impairment and psychological well-being in people with amyotrophic lateral sclerosis**
Pagnini Francesco Phillips Deborah Bosma Colin M. Reece Andrew Langer Ellen. Psychology & Health 2015;30(5): 503-517.

Available online at this link

Objective:Mindfulness is the process of actively making new distinctions, rather than relying on habitual or automatic categorisations from the past. Mindfulness has been positively associated with physical well-being, better recovery rates from disease or infections, pain reduction and overall quality of life (QOL). Amyotrophic lateral sclerosis (ALS) is a rare, progressive and fatal neurodegenerative disease, clinically characterised by progressively increasing weakness leading to death, usually within five years. There is presently no cure for ALS, and it is considered one of the most genetically and biologically driven illnesses. Thus far, the aims of psychological studies on ALS have focused on understanding patient – and, to a lesser extent, caregiver – QOL and psychological well-being. No previous study has investigated the influence of psychological factors on ALS. Methods:A sample of 197 subjects with ALS were recruited and assessed online twice, with a duration of four months between the two assessments. Assessments included measurements of trait mindfulness, physical impairment, QOL, anxiety and depression. The influence of mindfulness as predictor of changes in physical impairments was evaluated with a mixed-effects model. Results:Mindfulness positively influenced the change of physical symptoms. Subjects with higher mindfulness experienced a slower progression of the disease after four months. Moreover, mindfulness at first assessment predicted higher QOL and psychological well-being. Conclusions:The available data indicate that a psychological construct – mindfulness – can attenuate the progress of a disease that is believed to be almost solely biologically driven. The potential implications of these results extend well beyond ALS.

4. **Teaching mindfulness meditation to adults with severe speech and physical impairments: An exploratory study.**
Goodrich Elena Wahbeh Helane Mooney Aimee Miller Meghan Oken Barry S. Neuropsychological Rehabilitation 2015;25(5): 708-732.

Available online at this link

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 (SSPI) - 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 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 practise 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.

5. **Meditation Training for People with Amyotrophic Lateral Sclerosis and Their Caregivers**
Pagnini Francesco Di Credico Chiara Gatto Ramona Fabiani Viviana Rossi Gabriella Lunetta Christian Marconi Anna Fossati Federica Castelnuovo Gianluca Tagliaferri Aurora Banfi Paolo Corbo Massimo Sansone Valeria Molinari Enrico Amadei Gherardo. Journal of Alternative & Complementary Medicine 2014;20(4): 272-275.

Available online at this link

Objectives: Amyotrophic lateral sclerosis (ALS) is a progressive and fatal neurodegenerative disease that is clinically characterized by progressive weakness leading to death by respiratory insufficiency, usually within three years. Although the patient's intellect and personality usually remain unimpaired, as the disease progresses, the patient becomes immobile, develops wasting, and speech becomes impaired, often resulting in social isolation and a high degree of psychological suffering. Mindfulness meditation has proven to be effective technique for reducing distress in many chronic diseases. However, to date, no study has investigated the effect of mindfulness meditation on patients with ALS. Design: A mindfulness meditation training program for ALS patients needs to consider the particularities of ALS symptoms, including the loss of muscular functions and difficulties in respiration, together with the subsequent emotional impairments. With these caveats in mind, a modified protocol, based on original mindfulness meditation interventions, has been created specifically for the ALS population. This article describes the protocol and preliminary results.

iv. Qualitative Studies

1. **Flexibility to manage and enhance quality of life among people with motor neurone disease**
Ando Hikari Cousins Rosanna Young Carolyn A. Disability & Rehabilitation 2022;44(12): 2752-2762.

Available online at this link

To identify influential factors for quality of life (QoL) among individuals with motor neurone disease (MND) and explore how regulatory flexibility and psychological flexibility may contribute towards maintaining and improving QoL. Semi-structured interviews were conducted with 26 individuals with MND. Thematic analysis, using both inductive and deductive analyses, was employed to examine subjective QoL in view of previous understanding of QoL. Four factors were important for the QoL of participants: perceived illness prognosis, sense of self, concerns for significant others, and life to enjoy. These factors reflected psychological stress caused by MND, the participant's value system, and their beliefs about life. In optimising QoL, both regulatory flexibility and psychological flexibility were essential to maintain and enhance QoL. Often, regulatory flexibility was perceived among those employing a mindful approach, and psychological flexibility was found to involve savouring positive experiences. People with MND reported that seeking ways to both maintain and enhance their QoL is crucial, and that this may be accomplished by increasing flexibility through mindfulness and savouring. (171/200 words) People with motor neurone disease (MND) seek to maintain quality of life (QoL) following changes caused by the condition, whilst attempting to enhance QoL by maximising their positive experiences. Regulatory flexibility is essential to maintain QoL and it was closely associated with mindful approach so that MND is not perceived as an inevitable threat to QoL. Psychological flexibility was found to enhance QoL and it involves savouring positive experiences, while abandoning fault-finding of the current situation. Positive inter-personal interactions can encourage people with MND to engage with mindfulness and savouring for favourable outcomes in terms of QoL; current support services should orient towards both mindfulness and savouring.

2. **User perspectives on a psychosocial blended support program for partners of patients with amyotrophic lateral sclerosis and progressive muscular atrophy: A qualitative study.**
De Wit J. Vervoort S. C. J. M. Van Eerden E. Van Den Berg L. H. VisserMeily J. M. A. Beelen A. Schroder C. D. BMC Psychology 2019;7(1) (pagination):

Available online at this link

Background: Partners are often the main caregivers in the care for patients with amyotrophic lateral sclerosis (ALS) and progressive muscular atrophy (PMA). Providing care during the progressive and fatal disease course of these patients is challenging and many caregivers experience feelings of distress. A blended psychosocial support program based on Acceptance and Commitment Therapy was developed to support partners of patients with ALS and PMA. The aim of this qualitative study is to gather insight into experiences with different components of the support program (program evaluation) and to discover what caregivers gained from following the program (mechanisms of impact).

3. **The experience of meditation for people with amyotrophic lateral sclerosis and their caregivers – a qualitative analysis**
Marconi Anna Gragnano Gaia Lunetta Christian Gatto Ramona Fabiani Viviana Tagliaferri Aurora Rossi Gabriella Sansone Valeria Pagnini Francesco. Psychology, Health & Medicine 2016;21(6): 762-768.

Available online at this link

There is a lack of studies about psychological interventions for people with amyotrophic lateral sclerosis (ALS) and their caregivers. We investigated the experience of a meditation training program tailored for ALS needs. People with ALS (pALS) and their caregivers that joined a meditation program for ALS were interviewed at the end of the program. Verbatims were analyzed with a qualitative approach. Both pALS and their caregivers reported a positive impact on their psychological well-being, promoted by an increase in acceptance and non-judgmental attitude. Furthermore, coping strategies seem to improve, with a positive effect on resilience skills. The ALS meditation training program seems to be an effective psychological intervention for the promotion of well-being in pALS and their caregivers.

4. **The experience of meditation in ALS: A qualitative study about the efficacy of a mindfulness meditation protocol with ALS subjects and caregivers.**
Pagnini F. Lunetta C. Tagliaferri A. Marconi A. Fossati F. Gragnano G. Gatto R. Fabiani V. Rossi G. Sansone V. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration.Conference: 25th International Symposium on ALS/MND.Brussels Belgium.Conference Publication: (var.pagings) 2014;15(SUPPL. 1): 89-90.

Available online at this link

Background: Amyotrophic lateral sclerosis (ALS) is a progressive and fatal neurodegenerative disease, clinically characterized by progressive weakness leading to death by respiratory insufficiency, usually within three years. Although the patient ' s intellect and personality usually remain unimpaired, as the disease progresses the patient develops a worsening disability and impairment of the speech, often resulting in social isolation and a high degree of psychological suffering. The combination of ALS with progressive dependence and immobility might elicit feelings of despair, depression and anxiety. To date, some of the most promising clinical treatments for the reduction of distress are based on mindfulness meditation practices, in particular the Mindfulness-Based Stress Reduction (MBSR), developed by Jon Kabat-Zinn. This program has proven useful to reduce stress levels and promoting resilience.

v. Case Studies

1. **Iyengar Yoga Therapy Intervention for Ischial Pressure Ulcers in a Patient with Amyotrophic Lateral Sclerosis: A Case Study**
Ribeiro Subbappa. Journal of Alternative & Complementary Medicine 2015;21(9): 578-582.

Available online at this link

Background: Although some research suggests that the formation of pressure ulcers is rare in patients with amyotrophic lateral sclerosis (ALS), several patients have nonetheless

developed this problem. To date, however, no case reports in the literature have described patients with ALS who develop ischial pressure ulcers. Outside of the ALS literature, evidence suggests that ischial pressure ulcers frequently develop in wheelchair users and also in patients treated in various health care settings. Case description: A patient diagnosed with ALS reported the development of ischial pressure ulcers after consistent immobility for 1 year (32 months after her ALS diagnosis). This patient, who was sitting on the wounds, was treated with ointment and morphine; the latter was ineffective in controlling the pain. Moving the patient from sitting to supine, lateral, or semilateral positions, either on the bed or wheelchair, to separate the ulcers from the surface of the chair or bed was deemed impossible because of exaggeration of other symptoms, including shortness of breath and pain in other parts of the body. A new method of postural alignment was developed to alleviate the pain associated with the pressure ulcer. This method, Iyengar yoga therapy, which uses props to reposition a patient, alleviated pain and healing of two pressure ulcers of the patient after 3 weeks of starting this intervention. Conclusion: Although the ischial pressure ulcers were successfully treated in a patient with ALS, further study is necessary to investigate the effectiveness of this postural alignment intervention in ALS and other patient populations for the management of ischial pressure ulcers.

2. **Iyengar Yoga Therapy as an Intervention for Cramp Management in Individuals with Amyotrophic Lateral Sclerosis: Three Case Reports**
Ribeiro Subbappa. Journal of Alternative & Complementary Medicine 2014;20(4): 322-326.

Available online at this link

Objectives: Patients with amyotrophic lateral sclerosis (ALS), a neurodegenerative disease of motor neurons, experience cramps at all stages of the illness. There is, at present, no effective medication to control the cramps and no agreement on how to treat the symptom in ALS patients. Subjects: Three individuals who were diagnosed with ALS and reported suffering cramps in various parts of the body, which limited their activities or affected their sleep were invited to try Iyengar yoga. Intervention and outcome: Yoga therapy, composed of stretching, breathing, and relaxation exercises, was prescribed for each case, based on the subject's physical disability and the presence of other symptoms. Although two subjects experienced cramps during the first therapy session, all three subjects reported the complete cessation of cramping within 3 weeks to 8 weeks of therapy. One of the subjects developed cramps in the hand after discontinuing yoga therapy for 7 months. However, the symptom stopped within 2 weeks of resuming yoga therapy. Conclusion: The alleviation of cramps in these three subjects indicates the possibility of yogic intervention for the management of cramps in individuals with ALS, but further research is necessary to understand the effectiveness of yoga therapy and to determine the exercises that are more prone to lead to cramping in some ALS individuals.

vi. Articles

1. **Mindfulness, depression and quality of life in amyotrophic lateral sclerosis.**
Lou J. S. European Journal of Neurology 2017;24(7): 881-882.

Available online at this link

D. Search strategy

Ovid Emcare <1995 to 2024 Week 32>

1 (Yoga or meditate* or mindful* or movement or "breath work").ab,hw,kf,ti. 144291

2 exp motor neuron disease/ 6634

3 exp amyotrophic lateral sclerosis/ 5276

4 exp progressive muscular atrophy/ 79

5 exp yoga/ 3875

6 exp meditation/ 4232

7 exp mindfulness/ 6771

8 ("motor neuron* disease" or MND or "amyotrophic lateral sclerosis" or ALS or "progressive muscular atrophy").ab,hw,kf,ti. 15012

9 1 or 5 or 6 or 7 146170

10 2 or 3 or 4 or 8 15128

11 9 and 10 470

12 11 and 2014:2024.(sa_year). 278

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Evidence search: What are the benefits of yoga/ meditation/ mindfulness for patients with motor

neurone disease?. Claire Field. 13th August, 2024. UK: University Hospitals Bristol & Weston Library & Knowledge Services.