



2018

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Mandakini Sadhir

University of Kentucky, m.sadhir@uky.edu

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Repository Citation

Sadhir, Mandakini, "Mindfulness and Multiple Sclerosis" (2018). *Pediatrics Faculty Publications*. 269.

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Notes/Citation Information

Published in *Multiple Sclerosis in Children and Adolescents*. Hatim Omar, & Joshua Chalkley, (Eds.). p. 131-142.

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Chapter 10

MINDFULNESS AND MULTIPLE SCLEROSIS

Mandakini Sadhir*, MD

Division of Adolescent Medicine and Young Parent Programs,
Kentucky Clinic, Department of Pediatrics, Kentucky Children's
Hospital, University of Kentucky College of Medicine,
Lexington, Kentucky, US

ABSTRACT

Multiple sclerosis is a chronic, debilitating autoimmune condition with unknown etiology. It can have significant impact on quality of life and overall sense of wellbeing. It can be associated with poor sleep, fatigue, mental health disorders such as anxiety, depression and affect interpersonal relationships. Impact of mindfulness based interventions in mental health conditions, chronic illness as well as multiple sclerosis in adults has been widely studied. Several studies have concluded that mindfulness based intervention can be beneficial in improving quality of life, mental health and physical symptoms such as fatigue in adult patients with multiple sclerosis. Current literature suggest that practice of mindfulness based techniques improve cognitive performance, attention, social skills, academic skills, emotional regulation, self-esteem, anxiety,

• Correspondence: Mandakini Sadhir, MD. Department of Pediatrics, Division of Adolescent Medicine. 740 S. Limestone, Lexington, KY 40536. E-mail: m.sadhir@uky.edu.

stress and fatigue in adolescent population. There is, however, limited evidence about utilizing mindfulness based intervention in adolescents with chronic illness. The chapter describes practice of mindfulness and current research in treating symptoms of multiple sclerosis.

Keywords: mindfulness, multiple sclerosis, meditation, anxiety, depression

INTRODUCTION

Multiple sclerosis (MS) is a chronic immune-mediated demyelinating and inflammatory disease of the central nervous system.[1] The exact etiology of multiple sclerosis is still unknown but autoimmune, genetic, and environmental factors play important role in its development [1, 2]. Pediatric-onset multiple sclerosis represents approximately 2 to 10% of MS patients with onset in adolescence [2]. The disease in children and adolescents almost always presents in the relapsing-remittent form leading to physical and cognitive disability [3, 4] Multiple sclerosis can affect growth, identity development, cognition, social, emotional well-being and engagement with education and employment [5]. Adolescents may experience increased vulnerability as well psychological distress due to unpredictable course and extent of neurological symptoms and physical impairment [5,6] In a study, children with MS experienced more fatigue, reduced exercise capacity and impaired motor performance as compared to healthy children.[7] Fatigue was found to correlate with health related quality of life (HRQoL) [7] Cognitive impairment may be seen in pediatric MS which can affect attention, processing speed, memory and executive function [8]. In addition to physical, neurologic and cognitive impairment, children and adolescents may suffer from anxiety and depression. Similar to adult population, mood disorders may negatively impact health related quality of life (HRQOL) [9]. Recent studies suggest approximately 30% of children and adolescents with pediatric M.S have depression [9, 10]. The treatment of multiple sclerosis thus involves multidisciplinary approach

with team of neurologists, psychologists, ophthalmologists, physiotherapists, psychiatrists and pharmacologists.

MINDFULNESS

Over the years, mindfulness based interventions have drawn much attention in management of various chronic medical and mental illnesses [11]. Mindfulness meditation has its origins from ancient Eastern meditation practices and Buddhist traditions [12, 13]. Joo Kabat Zinn described Mindfulness as "Paying attention in a particular way, on purpose, in the present moment and non-judgmentally" [13]. It is considered as a process of doing regular mindful practice to cultivate awareness and acceptance of the present moment in a non-judgmental way [13]. Neuroimaging studies have demonstrated functional and structural changes in regions of brain involved in learning, memory, attention and emotional regulation as result of engaging in regular mindful practice and meditation [12,14]. Meditative techniques have been shown to increase vagal nerve output which reduces heart rate and breathing rate resulting in increased relaxation response [12,14]. Meditative practices have also shown to decrease cortisol, improve sleep and seem to have beneficial role in various chronic illnesses [14]. Research has demonstrated their efficacy in a wide range of psychological conditions [15].

One of well-known mindfulness based approach was developed by Jon Kabat Zinn and is known as Mindfulness-based stress reduction (MBSR) and Mindfulness based cognitive therapy (MBCT) [12]. Mindfulness Based Cognitive Therapy (MBCT) is a derivative of MBSR, with a greater emphasis on cognitive techniques, designed for specific mental health conditions such as recurrent depression [12, 14, 15]. This approach has been widely studied and various meta analyses have provided support for utility of MBSR in a wide range of clinical populations and health conditions [15]. Mindfulness based Stress reduction is an eight-week program with each session lasting for 2.5 hrs. The program provides mindfulness training through the practice of meditation and hatha yoga

[12, 13]. In each session, learners are taught mindful techniques and encouraged to engage in sharing of their learning experiences and difficulties to understand elements of stress [13, 15, 17]. During these 8 week sessions, program seeks to strengthen ability to focus on the present moment and accept experiences or thoughts as they arise without trying to control them [17]; explore personal experience and paying attention to its emotional and sensory aspects rather than intellectual description; fully accept personal experience with its positive as well as negative elements including feelings of pleasure, joy, frustration, rage, or uneasiness [13,17]. The participants develop the ability to actively choose which personal experiences to be lived and what elements to be focused, acted upon or examined [17]. In addition, program teaches the ability to give up all pretense of having direct control over reality [12,17]. It is thought that MBSR contributes to health and well-being by cultivating non-judgmental awareness and acceptance of one's moment-to-moment experience which can have a positive effect on the adaptation to the disease, reduce the psychological burden and improve quality of life [16]. In addition, it seems to reduce the impact of maladaptive coping strategies and fixed, reflexive behavioral, emotional and cognitive patterns [14-16].

MINDFULNESS BASED INTERVENTION IN MULTIPLE SCLEROSIS

The chronic and debilitating nature of multiple sclerosis affect quality of life in adolescents as well as in adults. In addition, mood disorders are common in adults [18] and adolescents with Multiple sclerosis [9]. Studies have investigated role of mindfulness based intervention such as MBSR in alleviating symptoms and improving quality of life in adults. Current evidence suggests improvement in symptoms such as fatigue, anxiety, depression, perceived stress and cognition when utilizing mindfulness based interventions [19-23]. In a quasi-experimental study, data was collected from adults with multiple sclerosis utilizing Multiple Sclerosis

Quality of Life- 54 (MSQOL-54) and Fatigue severity scale[24]. In the study, participants engaged in eight 2hour session of mindfulness based stress reduction and conscious yoga program. Study group was found to have improvement in subscales of quality of life that included physical health, energy, emotional well-being, health distress, health perception, and satisfaction with sexual function as well as overall quality of life and fatigue severity as compared to control group [24]. Grossman et al. in his study demonstrated that mindfulness training seemed to improve fatigue, depression in adults with relapsing-remitting and secondary progressive MS [25]. The study also showed broad feasibility, acceptance as well as satisfaction and adherence with mindfulness training program among adults [25]. In another study, Simpson et al. found evidence of improvement in perceived stress, depression, positive affect, anxiety and self-compassion immediately post mindfulness intervention [26]. At three months' post MBSR while improvements in perceived stress diminished, there was improvement in mindfulness, positive affect, self-compassion, anxiety and prospective memory [26].

A systemic review of three randomized control trial studies with 183 participants showed statistically significant beneficial effects relating to quality of life and mental health (anxiety and depression) and fatigue which were sustained at three and six months follow up [27]. Another meta-analysis of four studies fatigue that mindfulness based intervention showed improvement in fatigue with moderate effect size in the population diagnosed with multiple sclerosis, traumatic brain injury and stroke [28]. Mind body approaches such as mindful meditation also seem to have a role in protecting and improving cognitive and brain reserve in multiple sclerosis [29].

It has been hypothesized that mindfulness based interventions help people with chronic progressive disease to accept daily challenges, teach them to recognize their thoughts and feelings thereby developing acceptance and self-compassion [30]. Group dynamics may also play a fundamental role in the success of the mindfulness interventions. Decentering and self-efficacy appear to be key mechanisms leading to reduced distress [30]. Previous studies have shown that stress plays a

significant role in pathogenesis and progression of Multiple sclerosis. Persistent stress can lead to chronic elevation of cortisol and thought to further complicate response to treatment [31]. Meditative practices including mindful meditation have shown to reduce cortisol and may have beneficial role in treatment of multiple sclerosis [31].

MINDFULNESS IN ADOLESCENTS

Adolescence is marked by pubertal growth, psychosocial and cognitive development. Risk taking behaviors [32] and mood disorders [33] are common during this period. Mindfulness based interventions have found to be feasible and acceptable in children and adolescent population [34, 35, 39]. Various studies have shown that mindfulness training and practice in adolescents improves their emotional regulation, attention, cognition, social interaction, sleep and overall sense of well-being [34]. Mindfulness based techniques have been utilized across various settings particularly in schools to address high risk behaviors as well as mental health concerns [36]. Mindfulness based interventions appear to be a promising approach for coping with symptoms related to chronic illness in adolescents. A study demonstrated beneficial effect on depression, quality of life, and acceptance of pain in adolescents with recurrent headaches [38]. Study investigating impact of mindfulness based stress reduction program in adolescents with functional somatic pain syndromes found preliminary evidence of improvement in functional disability, symptom impact and anxiety [41]. Among adolescents and young adults who were cancer survivors, mindfulness based intervention resulted in significant reduction in emotional distress and improvement in quality of life at 3 months of follow-up. In addition, participants had reduced negative attitudes toward self and demonstrated significant improvement in mindfulness skills [42].

Parents of children with chronic medical conditions or disabilities face tremendous difficulties such as child behavioral problems, financial and social barriers in addressing their children health care needs [43]. Studies show that parents undergo psychological stress that impacts their physical,

mental health and their relationship with partners, families and children [43]. Addressing parental well-being can be crucial and important part of management of child's health condition. Cognitive behavioral therapy and mindfulness based intervention show promising outcomes among parents. A study found improvement in life satisfaction with regards to spare time, relationship with children and partner when parents utilized mindfulness practice [44]. In another study, caregivers who were mostly mothers with children with special needs and various chronic condition participated in mindfulness based stress reduction (MBSR) sessions. Over the 8-week period, caregivers had overall reduction in mood disturbance and symptoms related to stress [44].

FUTURE IMPLICATIONS

Current literature suggests role of mindfulness based interventions as an adjuvant to traditional treatment of multiple sclerosis in adults. Mindfulness based intervention in adolescents have been utilized to address high risk behaviors as well as mental health concerns. While research is limited, mind-body approach seems to address some aspects of chronic illness in adolescents as well as improving wellbeing of parents and caregivers. Research is needed to investigate impact of mindfulness based intervention in improving symptoms and overall wellbeing of children and adolescents with multiple sclerosis.

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