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## Impact of Mindfulness Education and Resources on Stress in Parents of Children with Autism Spectrum Disorder

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**Documentation of Mastery of DNP Program Outcomes**

**Manuscript: Impact of Mindfulness Education and Resources on Stress in Parents of  
Children with Autism Spectrum Disorder**

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## **Abstract**

The purpose of this project was to reduce stress levels of parents of children with autism spectrum disorder (ASD) by teaching them mindfulness practices and education on free and accessible methods to integrate mindfulness into their daily lives, as well as the benefits of mindfulness in reducing stress and improving psychological well-being.

Parents of children with ASD experience high levels of stress and numerous research studies support the use of mindfulness techniques to reduce stress levels in adults. The participants in this project included mothers who have at least one child with ASD who attend the Thompson Autism and Neurodevelopmental Center (TANC) at the Children's Hospital of Orange County (CHOC). These mothers were recruited via e-mail by the leader of a hospital-sponsored "moms' group" for parents of children with ASD. The intervention was a 20-minute educational presentation and handout on the benefits of mindfulness, specific techniques, and available free mobile mindfulness applications held prior to a scheduled meeting. Prior to the education, participants completed an anonymous pre-survey via REDcap on their mobile devices including the Perceived Stress Scale (PSS-10) and demographic questions.

The pre-education survey results found that most participants experienced moderate to high stress levels. None of the participants completed the post survey despite multiple efforts with e-mail reminders sent by TANC representative before and after the holidays in December 2023. The participants voiced their appreciation for the education upon completion of the session.

**Keywords:** Autism Spectrum Disorder, Mindfulness, Stress

## **Background and Significance**

Autism spectrum disorder (ASD) is a lifelong condition where individuals experience deficits in social communication and often present with repetitive behaviors and restricted interests (Maenner et al., 2023). According to the Centers for Disease Control and Prevention (CDC), data from the year 2020 shows the prevalence of ASD is 1 in 36 children aged 8 years old across the United States with a median age of diagnosis at 49 months (Maenner et al., 2023). The prevalence of ASD in the United States has increased from previous years (Maenner et al., 2023). More children receiving diagnoses means more caregivers are receiving the news that their child has ASD, which may lead to questions, challenges, and uncertainty among many other emotions.

The care required for a child with ASD varies greatly. Some children with ASD may perform daily functions such as toileting, eating, and talking independently, whereas others may utilize alternative methods of communication and require more intensive supportive care throughout the day. Having a child with ASD impacts the entire family unit. Research has shown that parents of children with autism spectrum disorder experience significantly greater levels of stress, depression, and anxiety compared to parents of neurotypical children (Cachia et al., 2016). It is important to also recognize the impact that poor mental health has on the physical health of individuals. Chronic stress has powerful negative effects on human health and aging and contributes to the development of numerous physical and psychological conditions including cardiovascular disease, metabolic syndrome, diabetes, and depression (Osborne et al., 2020). On a cellular level, a caregiver that experiences significant stress has been proven to age at a faster rate; due to the shortening of telomeres (Lin & Epel, 2022). The chronic stress faced by parents

of children with ASD does not only negatively affect their own health, but also their marital relationships, and their child's behavior (Cachia et al., 2016).

Due to ASD being a lifelong condition, parental stressors may be related to finances, social isolation, and stressors related to a child that requires constant care and support into adulthood (Marsack-Topolewski et al., 2021). A systematic review by Agarwal et al., (2022) explored the stress and anxiety related to the transition phase from childhood to adulthood for parents of children with ASD. This review found that among young adults with ASD, only 58% are gainfully employed after high school, 25% are isolated socially, only 36% attend some college or enroll in vocational education, and over 25% do not receive any services to support positive adult outcomes.

Caregiving for a person whose disability requires intensive care requires extensive time, effort, and cost. A cross-sectional analysis on caregiver burden of parents of adult children with ASD reported a positive correlation between greater dependence for activities of daily living (ADLs) and greater caregiver burden (Marsack-Topolewski et al., 2021). Financial challenges were also noted as a significant reported stressor in this study (Marsack-Topolewski et al., 2021).

As of 2021, the economic value of the role of a family caregiver caring for an adult relative is \$600 billion (Reinhard et al., 2023). Healthcare systems expect these caregivers to provide unpaid care to their child from birth until adulthood, and in some circumstances lifelong. These caregivers often neglect themselves and prioritize the family's health and well-being above their own, leading to inadequate self-care (Marsack-Topolewski et al., 2021). It is crucial to implement effective ways to promote the health and well-being for caregivers in our society as our healthcare system and overall community depends on these individuals on a large scale.

## **Mindfulness-Based Stress Reduction (MBSR)**

Mindfulness based stress reduction was made famous by Jon Kabat-Zinn who defines mindfulness as “the awareness that emerges through paying attention on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment by moment” (Kabat-Zinn, 2003, p.145). Mindfulness originated from concepts in Buddhist traditions but has caught the attention of western culture in recent years because of its known benefits to mental health and the wide accessibility of mindfulness practice tools with the help of technology (Misitzis, 2020). The standardization of mindfulness into specific mindfulness-based stress reduction (MBSR) interventions has transformed this from a philosophical concept into a clinical intervention. MBSR intervention includes practices such as mindful meditation, body scan, and seated meditation (Schuman-Olivier et al., 2020).

Numerous studies with high levels of evidence have displayed effectiveness in reducing stress levels of adults through the utilization of mindfulness-based stress reduction interventions. Studies including the systematic review by Cachia et al. (2016) and randomized control trials from Dykens et al. (2014) and Weitlauf et al. (2020) saw positive improvements in various psychosocial outcomes in parents who have children with ASD through mindfulness intervention techniques.

Free mobile applications to practice mindfulness that are available to anyone with access to the Apple App Store or Google Play includes UCLA Mindful (Winston, 2011-2023), Smiling Mind (Smiling Mind, 2024), and the Healthy Minds Program (Healthy Minds Innovations Inc, 2022).

**PSS-10**

The Perceived Stress Scale (PSS) is an instrument used to measure perceived stress levels (Cohen et al., 1983; Cohen & Williamson, 1988). The PSS was first developed by Cohen as a 14-item scale and was later revised into a 10-item version that has been utilized widely (Cohen et al., 1983; Cohen & Williamson, 1988). Psychometric properties of the PSS-10 have been found to be appropriate with adequate reliability and validity (Baik et al., 2019; Cohen & Williamson, 1988).

**PICOT Question**

In parents of children with autism spectrum disorder, what is the impact of education on mindfulness techniques on self-reported perceived stress levels and mindfulness practice over a 4-week period?

**EBP Purpose**

The purpose of this project was to educate parents of children with ASD about the benefits of mindfulness on stress reduction and introduce free resources such as mobile-based applications as an accessible and affordable way to practice mindfulness consistently.

**Summary of Literature**

The literature supports the effectiveness of mindfulness-based stress reduction with parents of children with ASD, and the benefits of implementing this project. The literature revealed multiple effective methods to deliver mindfulness education and reduce stress. The



mindfulness course created by Jon-Kabat Zinn is a standardized 8-week mindfulness- based stress reduction course (Schuman-Olivier et al., 2020). The randomized control trial by Champion et al. (2018) showed a decrease in stress levels via the perceived stress scale (PSS-10) after practicing mindfulness via a mindfulness mobile application in healthy adults after 4 weeks. Although the PSS-10 scores measured stress over the 30-day period, there was a decrease in stress levels as early as 10 days into the study (Champion et al., 2018). Throughout this study, participants engaged with the mindfulness app by participating in meditation exercises for 10-20 minutes per day (Champion et al., 2018). Finally, a brief 5-minute mindful breathing technique performed in a randomized control trial by Moline et al. (2022) presented almost immediate effects of reduced distress when performed prior to their child's venipuncture. The literature presents a variety of methods to practice mindfulness that are effective in decreasing stress and improving psychological well-being.

### **Evidence Based Practice Model**

The evidence-based practice (EBP) model utilized in the project design and execution is the Iowa Model of evidence-based practice. The Iowa Model has been revised since its creation and includes a step-by-step process as well as a feedback loop (Iowa Model Collaborative et al., 2017; Melnyk & Fineout-Overholt, 2019).

This model clearly displays how to plan an evidence-based project and the requirements needed to move forward. This project involves the mental health of caregivers. Evidence shows high levels of stress experienced by parents of children with ASD during the COVID-19 pandemic (Corbett et al., 2021). This issue is current and triggered an interest in mindfulness as a

modality to reduce stress in parents who have children with ASD. The Iowa Model guided me through the process of developing this EBP project.

## **Methods**

### **Inclusion Criteria**

1. Adult (18+)
2. Mother of at least one child with autism spectrum disorder
3. Mother of a child who attends the Children's Hospital of Orange County (CHOC)  
Thompson Autism and Neurodevelopmental Center (TANC)
4. Access to a mobile Android or iOS device

### **Recruitment**

The social worker responsible for the hospital-sponsored group for mothers who have a child with ASD emailed members inviting them to participate in an educational session prior to a scheduled meeting in November 2023. This mom's group at TANC is currently exclusive to English speaking mothers who have a child with ASD.

### **Intervention**

A 20-minute educational presentation on the evidence-based benefits of consistent practice of mindfulness took place prior to a scheduled mom's group meeting at the Thompson Autism and Neurodevelopmental Center at the Children's Hospital of Orange County (CHOC). A handout on the benefits of mindfulness, specific techniques, and available free mobile mindfulness applications was given to all parent participants during this session. As the participants arrived,

they filled out the pre-educational anonymous survey via a Quick Response (QR) code link. This survey consisted of the PSS-10 questionnaire and anonymous demographic questions.

During the educational session, resources to practice mindfulness such as free mindfulness mobile-based applications were introduced and a two-minute guided mindfulness meditation from the “UCLA Mindful” mobile application was practiced as a group to provide the group with an introduction to mindfulness practice. The participants were all given a handout for reference with QR codes to download the mindfulness application as well as additional QR codes with links to two other mindfulness applications available free for use via a mobile device. As a group, the five-finger breathing technique was also reviewed as a technique to practice mindfulness with limited time and resources. The evidence-based benefits of consistent practice of mindfulness were reviewed and participants were encouraged to incorporate mindfulness into their daily lives to reduce stress levels.

Two weeks later, the participants were sent a follow up email from a TANC member thanking them for attending the session and encouraging mindfulness practice. Another email at four weeks post-educational session was sent with a link to the post-education survey which included the PSS-10 questionnaire and questions about mindfulness practice in the past four weeks.

### **UCLA Mindful Application**

The UCLA Mindful application was created by the University of California, Los Angeles Mindful Awareness Research Center. This free to use mobile-based application is available for download in the “App Store” for iPhone users or via “Google Play”. Guided mindfulness meditations are available in 14 different languages via this application. There are also videos that explain how to practice mindfulness for the beginner and information on the benefits of

mindfulness backed by research. If one prefers to utilize a timer and practice mindfulness without guidance, there is also a timer that can be utilized within the application. (Winston, 2011-2023)

Diana Winston, the creator of the UCLA Mindful mobile application refers to it as “Mindful Meditations”. She provided instruction about the proper use of the application for best results. Best practice is to direct individuals who are new to mindfulness practice to the introductory videos within the app. Noting that there has not been a clear consensus as to how long one should practice mindfulness for the best results, 5-10 minutes was recommended as a starting point for practice. As an introduction to practice it was determined to include one brief mindfulness meditation utilizing the mobile app during the educational session. (D. Winston, personal communication, August 3<sup>rd</sup>, 2023)

### **Five-Finger Breathing Technique**

A meta-analysis by Laborde et al. (2022) highlights voluntary slow breathing or VSB, which has been proven to increase parasympathetic nervous control of the heart. VSB influences the parasympathetic nervous system to decrease anxiety and arousal, as well as improve cardiopulmonary and neuroendocrine functions, and increase relaxation and resilience (Laborde et al., 2022). This technique is defined as breathing at a slower pace, 6 breath cycles per minute compared to spontaneous breathing at 12 to 20 breath cycles per minute for the average adult (Laborde et al., 2022).

The five-finger breathing technique is performed by holding out one’s palm and tracing one’s fingers with the opposite hand. The purpose is to focus on the slow and purposeful breathing while inhaling when tracing one’s palm towards the fingertips and exhaling when tracing away from the fingertips

This technique has been widely used in a variety of settings and has been introduced as a technique to promote relaxation (Cleveland Clinic, 2023). This simple breathing technique can be utilized by adults and children (Cleveland Clinic, 2023).

### **Permission to use the Perceived Stress Scale (PSS-10)**

I received permission to utilize this instrument free of charge for student use for my evidence-based project to measure perceived stress levels of caregivers. I was approved after submitting my request for use via Mapi Research Trust. (*Mapi Research Trust*, 2024)

### **Data Collection**

All surveys were completed via Research Electronic Data Capture (REDCap) and participants logged in with a unique identifier (Harris et al., 2009). REDCap is a software built for research teams that allows for the secure collection and storage of data (Harris et al., 2009). The pre-educational session survey was completed anonymously via scanning of a QR code on the participants' personal mobile devices. All the data was inputted by the participants and participants signed in by creating their own username. To protect privacy, there was only one in-person educational session with direct contact with the participants. Follow-up reminders to practice mindfulness and complete the follow-up questionnaire were sent out to a group email of those who participate in the moms' group by a TANC representative.

### **Ethical Considerations**

This evidence-based project was approved by the Institutional Review Board of the University of San Diego, Hanh's School of Nursing and the Children's Hospital of Orange County (CHOC). Steps noted above were taken to protect the privacy of participants.

### **Description of Participants**

There were five participants who attended the educational session and completed the pre-session survey. Most (80%) of the participants were in the ages 36-48 years old and one individual was 49–64-years-old. Most (80%) identified as Hispanic or Latino. Less than half (40%) of the participants identified as holding a master's degree as their highest level of education, 40% identified as holding an associate degree and one individual with a bachelor's degree.

The participants also completed questions about their personal mindfulness practice in the past four weeks prior to the educational session. The majority (3/5) endorsed practicing mindfulness via breathing techniques or a combination of breathing techniques and mobile-based mindfulness tools such as via a mobile application. The baseline perceived stress scale scores displayed 2/5 of the individuals to be categorized into the “high perceived stress category”, 2/5 of the individuals scored in the “moderate stress” category and 1 individual scored in the “low stress” category. Due to the low numbers of participants, there is no way to bring conclusions to the data presented. There are many factors that may have contributed to the perceived levels of stress that these individuals experienced.

### **Post Implementation Results**

Unfortunately, there was no post-survey participation. Therefore, there is no post-intervention data to evaluate the impact of this project's mindfulness education and resources on the participants' stress levels and mindfulness practice participation over the course of 4 weeks.

### **Project Limitations**

This project was limited in several ways. The sample size was small, and limited to those who chose to arrive early for the scheduled group meeting. The group leaders would not allow presentation during a meeting.

To protect the privacy of the participants, the agency did not allow direct contact with participants following the in-person educational session. This prevented any personalized follow-up in request for post-survey participation. Additionally, the timing of the project was around the winter holidays and better feedback may have been received at another time of year. There are many variable factors that contribute to stress in an individual. The pre-implementation survey was administered in person and indicated elevated rates of stress. Post implementation survey required the participants to log on and complete questions on their own time schedule. This may have contributed to a lack of post-implementation follow up.

### **The Literature on Poor Survey Response**

A meta-analysis by Wu et al. (2022) evaluated online survey response rates and noted the significant increase in online surveys in recent years compared to other methods of survey distribution. The mean response rate from the evaluated studies in this meta-analysis showed a 44.1% response rate for online surveys in education-related fields (Wu et al., 2022). This meta-analysis found higher response rates when the sample size was smaller, and the individuals utilized personal contact methods such as in-person or direct contact via phone to distribute surveys. (Wu et al., 2022). Additionally, phone surveys accompanied by an online survey and pre-contacting participants yielded more responses (Wu et al., 2022).

A mixed methods study by Wiley et al., (2018) was done to collect qualitative and quantitative data about parent stress and the caregiver experience for caregivers of children with ASD, caregivers of children who were deaf, and caregivers with a child who have ASD and are also deaf. In this study, the surveys were requested through the mail with telephone follow up to encourage participation (Wiley et al., 2018). The overall response rate was 18% (Wiley et al., 2018). It is unclear why the response rate was so low.

We know that caregivers of children with ASD experience various stressors and challenges in addition to the busy lifestyle of a mother raising her child/children. The demands of motherhood with various commitments and priorities may have contributed to poor response to this project survey.

### **Implications for Future Practice**

Although there were no post-intervention responses, the pre-intervention surveys found that the need for stress reduction is high with the majority experiencing moderate to high levels of stress. Several participants were already practicing mindfulness techniques, yet they came early to a scheduled meeting to learn more about mindfulness and stress reduction. One participant had used mindfulness techniques 5-10 times in the past four weeks. It is unclear whether daily participation is reasonable for this population as there was no post-intervention feedback to evaluate if daily mindfulness practice is something that these participants would be able to implement into their busy lives.

There are a variety of free apps and other techniques that are without cost to participants. The educational presentation costs include time of the professional providing the education, handouts, and parent time. This project is low-cost to re-create and there is a great need for stress



reduction measures for this population. This project may be replicated in the future with a larger sample size.

### **Discussion**

The caregiver of a child with autism spectrum disorder is truly their biggest champion of care. These caregivers display powerful advocacy for their child and hold a strong sense of connection with their child's emotions. They are the best resource in knowing how to make their child feel the safest in an environment that is unfamiliar and intimidating. For a child with a different way of communicating, this caregiver is the translator, the sense of comfort, and the true champion of strength in these moments of uncertainty. This underappreciated group of caregivers have a sense of strength and perspective that none of us may ever experience. Supporting this group means we are also supporting their child with ASD and their quality of life, health, and well-being. This project may inspire others to find avenues to support this group of individuals given the great amount of stress that they endure.

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