MINDFULNESS FOR PARENTS OF CHILDREN WITH SPECIAL HEALTHCARE NEEDS

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by
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Background and Significance

Throughout the literature, children with special healthcare needs (CSHCN) have been identified as those with an increased risk of chronic physical or mental health conditions that necessitate care above and beyond that which is typically required (Ghandour et al., 2022; McPherson et al., 1998). More recently, children with medical complexity (CMC) are those children who have a high level of need, intensive and persistent medical conditions, substantial functional limitations, preponderant medical care resource consumption, and make up less than 1% of the population (Cohen et al., 2011). One in five families has a CSHCN, and nearly 20% of children under 18 are identified as having a special health care need (U.S. Department of Health & Human Services, Health Resources & Services Administration, Maternal & Child Health, 2019). Parents of CSHCN and CMC have increased susceptibility to stress-related and mental health disorders, as they are at a 500% increased risk of struggling with mental health difficulties over parents of healthy children (Bayer et al., 2021). Parents with children experiencing chronic medical concerns reported a significantly higher level of parenting stress than their counterparts with healthy children, with a direct correlation between level of stress and level of the child’s treatment complexity (Cousino & Hazen, 2013). Mindfulness mitigates parenting stress in parents of children with an assortment of healthcare concerns, including attention-deficit/hyperactivity disorder, developmental disabilities, ASD, cerebral palsy, chronic medical conditions (Cousineau et al., 2019; Khoshvaght et al., 2021; Lunsky, et al., 2021; Ruskin et al., 2021).

Statement of Purpose and PICOT Statement

The purpose of this quality improvement (QI) project was to assess the efficacy of an intervention including mindfulness practice in the form of a weekly mindfulness group for parents of CSHCN and CMC in a mental health practice in the Twin Cities metro area. The project seeks to answer the PICOT question: In parents of CSHCN and CMC (P), does the introduction of mindfulness practices during a weekly parenting group (I) compared to pre-group stress levels (C) affect the stress level of parents (O) over a 6-week period (T)? The objectives for this project are as follows:

1. The Parental Stress Scale (PSS) score for the total group of parent participants will improve by $\geq 10\%$ from baseline to follow-up, with lower scores indicating less parenting stress.
2. At least 20% of the parent participants in both in person and virtual groups will indicate an intention to incorporate one or more mindfulness practices into their daily routine at follow-up.

Review of the Literature

An extensive literature review identified barriers to support parents of CSHCN and CMC, some methods to reduce these barriers, and mindfulness as a potential helpful intervention. Parents with CSHCN and CMC experience complex, unique, and systemic barriers in accessing support and assistance for their personal mental health. Roterg et al. (2020) identified that within the very nature of caregiving, parents of CSHCN and CMC are often overwhelmed with the increased responsibilities of caring for their child or children with extraordinary needs, in addition to the regular responsibilities and activities of day-to-day life, making accessing support difficult to incorporate within their time parameters. In a randomized controlled trial, Whittingham et al. (2015) ascertained that requiring physical attendance produced a significant barrier to parental participation in mindfulness intervention programs for parents of CSHCN.
To reduce barriers to receiving support, Bazzano et al. (2013) suggested collaborating with parental caregivers, from the development of the intervention through its execution. This collaboration was successful in their community-based approach to implementing a mindfulness-based program (Bazzano et al. 2013). In a between-subjects experimental study, Portnoy et al. (2022) demonstrated that mindfulness interventions for parents of children with chronic health conditions are equally effective face-to-face and virtually, decreasing the barrier of requiring physical presence in a specific geographical location to experience the intervention benefits.

The literature supports mindfulness as an intervention to support parents of CSHCN and CMS. The results of a randomized controlled trial indicated parenting interventions that included a manualized mindfulness-based stress reduction component, as opposed to the typical parenting intervention (Early Start Denver Model), demonstrated greater and longer-term improvements in parental stress measures within parents of children with ASD (Weitlauf et al., 2020). In a quasi-experimental study, Rayan and Ahmad (2016) observed substantial improvements in reported parental stress and depression measures (Cohen’s $d$ between 0.42 and 0.85, $p < 0.01$) after a brief mindfulness-based intervention with parents of children with an ASD diagnosis.

In summary, parents of CSHCN and CMC experience extraordinary stress and are at significant risk of a number of psychosocial difficulties. Mindfulness has been shown to positively impact mental health and stress levels which is an identified need with parents and families of CSHCN and CMC. Mindfulness is an intervention demonstrating effectiveness within the literature for this population and deserves further exploration and study.

**Methods**

**Project Design**

This QI project utilized a pre-and-posttest design to evaluate the impact of implementing a support group with mindfulness-based interventions, aimed at decreasing parental stress of parents with CSHCN and CMC. To evaluate the effectiveness of this intervention, participants were asked to complete the Parent Stress Scale (PSS) before and after the intervention (Appendix A). Target participants were identified as parents over the age of 18 who were primary caregivers of CSHCN and CMC between the ages of birth and 25 years. Exclusionary criteria consisted of parents who were not primary caregivers, whose children did not meet the criteria of CSHCN or CMC, and whose children were no longer living at home.

**Intervention**

A 90-minute weekly support group that included mindfulness exercises was offered for parents of CSHCN and CMC that lasted six consecutive weeks between 2/13/2024 through 3/21/2024. The groups were offered in two formats: in person in an outpatient mental health clinic in Plymouth, Minnesota, and virtually online via Zoom. The group was leader-facilitated and included a variety of weekly topics that pertain to the population. Evidence-based mindfulness exercises included mindful breathing, facilitated body scans, mindful meditation, and progressive relaxation.

**Measurement Tools and Data Analysis**

Using a confidence interval of 95% and a margin error of 5%, GPower*3 identified a minimum sample size of 35 participants for a fully-powered study (Faul et al., 2007). While 18 participants completed the pretest survey, only 11 completed the follow-up survey. Therefore the study did not achieve the minimum sample size of 35 to be a fully-powered study. The PSS, initially published by Berry and Jones (1995), is an 18-item survey that is valid and reliable for use with parents of children with chronic health conditions with satisfactory internal consistency ($\alpha = .84$), as well as convergent validity with parental anxiety ($r = .44$) and parental depression ($r$...
indicating the PSS is a valid and reliable instrument with parents of CMC (Zelman & Ferro, 2018). The possible range for the PSS is between 18 and 90 with higher scores indicating higher levels of parenting stress (Louie et al., 2017).

The primary outcome variable was the PSS scores measuring parental stress. The secondary outcome variable was the participants’ intention to incorporate mindfulness practices into their daily routines. Demographic information collected included age, gender, race, state of residence, education level, marital status, employment status, income, number and ages of all children under the age of 18 in the home, and type of health insurance. Additional variable data collected included the number of CSHCN in the home, ages when CSHCN were diagnosed, diagnoses, any medical technology needed for CSHCN, other supports available to parents, any transportation difficulties, an opportunity to describe the amount/level of care needed for CSHCN and an opportunity to share anything they thought would be helpful in understanding their situation. Descriptive statistics were used to provide a synopsis of the sample. IBM SPSS version 27 was used for statistical analysis. Statistical significance was defined as \( p \leq 0.05 \).

Ordinal level data collected from the PSS Likert scale at baseline and follow-up were analyzed using the Wilcoxon signed-rank test with Vargha and Delaney (\( A \)) effect size measures used to determine the level of clinical significance using values of small (0.56), medium (0.64) and large (0.71). Ratio-level data was analyzed using the paired \( t \)-test with Cohen’s \( d \) used to determine effect size with values of small (0.2), moderate (0.5), and large (0.8).

**Evaluation**

**Overall Demographics**

There were 11 participants who registered for the groups and completed both the pre-and-post PSS surveys, as well as the demographic survey. Four participants (36.4%) attended via Zoom and 7 participants attended virtually (63.6%). The predominant age group was 45-54 (54.5%, \( n = 6 \)), followed respectively by 35-44 (27.3%, \( n = 3 \)), 25-34 (9.1%, \( n = 1 \)) and 55-64 (9.1%, \( n = 1 \)). The sample was predominantly female (90.9%, \( n = 10 \)), with 9.1% male (\( n = 1 \)). The ethnicity was non-Hispanic (100%, \( n = 11 \)) and the race was White (100%, \( n = 11 \)). The predominant state of residence was Minnesota (63.6%, \( n = 7 \)), with one participant each from Maine (9.1%, \( n = 1 \)), Missouri (9.1%, \( n = 1 \)), New York (9.1%, \( n = 1 \)), and Wyoming (9.1%, \( n = 1 \)). The predominant participant income was $50,000-$80,000 (54.5%, \( n = 6 \)), followed by less than $20,000 (18.2%, \( n = 2 \)) and more than $80,000 (18.2%, \( n = 2 \)), and between $20,000-$50,000 (9.1%, \( n = 1 \)). The predominant household income was $75,000-$125,000 (63.6%, \( n = 7 \)), followed by more than $125,000 (27.3%, \( n = 3 \)) and prefer not to answer (9.1%, \( n = 1 \)).

Most participants were married (90.9%, \( n = 10 \)), with one being single (9.1%, \( n = 1 \)). The predominant education level was Master’s Degree (45.5%, \( n = 5 \)), followed by Bachelor’s Degree (27.3%, \( n = 3 \)), some college without a degree (18.2%, \( n = 2 \)), and Associate’s Degree (9.1%, \( n = 1 \)). Most participants were employed outside of the home (72.7%, \( n = 8 \)), followed by being a paid parent of their child (27.3%, \( n = 3 \)). The predominant number of children in the homes of participants was 2 (45.5%, \( n = 5 \)), followed by 1 (27.3%, \( n = 3 \)) and 3 (27.3%, \( n = 3 \)).

**Parental Stress Scale (PSS)**

When comparing individual items from pre-and-posttest timepoints on the PSS survey, the Wilcoxon Signed Rank Test indicated that the only question that had a statistically significant improvement score was, “If I had it to do over again, I might decide not to have children” (\( p = 0.46, A = 0.32 \)). While not statistically significant, there were ten questions that had a large effect on their scores: “I am happy in my role as a parent” (\( p = 0.26, A = 0.96 \), “I feel close to my children” (\( p = 0.56, A = 1.09 \)), “I enjoy spending time with my children” (\( p = 0.28, A = 1.09 \)),...
“My children are an important source of affection for me” \((p = 0.46, A = 0.96)\), “I am satisfied as a parent” \((p = 0.32, A = 0.96)\), “I sometimes worry whether I am doing enough for my children” \((p = 0.16, A = 0.82)\), “Having children leaves little time and flexibility in my life” \((p = 0.43, A = 0.91)\), “It is difficult to balance different responsibilities because of my children” \((p = 0.26, A = 0.96)\), “The behavior of my children is often embarrassing or stressful to me” \((p = 0.48, A = 1.36)\), and “Having children has meant too few choices and too little control over my life” \((p = 0.74, A = 1.59)\).

The primary objective of this project was an improvement in the combined PSS scores of participants by at least 10% from baseline to follow-up. A paired \(t\)-test was used to assess pre- and post-total group PSS scores. There was a moderate to large, statistically significant decrease \((t = 2.362, p = 0.04, d = 0.7)\) in the overall PSS score from baseline \((M = 52.36, SD = 13.76)\) to follow-up \((M = 47.18, SD = 10.46)\).

**Mindfulness Usage**

Overall mindfulness usage was compared at pre-and-posttest timepoints with a Likert scale question and results were examined using the Wilcoxon Signed Rank Test. There was a very large statistically significant increase in the usage of mindfulness in participants \((p = 0.007, A = 1.73)\). The secondary objective, that at least 20% of participants would intend to incorporate mindfulness into their routine daily, was assessed using descriptive statistics. The predominant frequency of intention to use mindfulness was daily (36.4%, \(n = 4\)), followed by multiple times per week (27.3%, \(n = 3\)), weekly (18.2%, \(n = 2\)) and occasionally (18.2%, \(n = 2\)).

**Conclusions**

The purpose of this QI project was to assess the efficacy of a 6-week parent support group with a mindfulness component practice for parents of CSHCN and CMC in decreasing their parenting stress. The first objective to improve the PSS score for the total group of parent participants by \(\geq 10\%\) from pre- and post-intervention, with lower scores indicating less parenting stress, was met. The second objective that at least 20% of the parent participants would indicate an intention to incorporate one or more mindfulness practices into their daily routine at follow-up, was also met.

**Stakeholder Recommendations**

The parent support group with mindfulness had a positive impact on the stress of parents of CSHCN and CMC, with PSS scores decreased overall for the group of participants, as well as an increased intention to use mindfulness. Creating opportunities for parents of CSHCN and CMC are additional ways to add value to mental health programming. Implementing a regular support group for parents may provide parents a tangible way to feel connected, increase the use of mindfulness, and decrease parenting stress.

**Strengths and Limitations**

A strength of this project is the statistical and clinical significance demonstrated for the primary and secondary objectives. However, the use of a convenience sample, the failure to meet the threshold for a fully powered study, and the lack of diversity in race, ethnicity, and gender of participants are noted limitations. In summary, this QI Project supports the use of mindfulness as an intervention for parents of CSHCN and CMC, even though the number of participants did not allow for a fully-powered study. Further studies are needed to better understand this population and interventions that provide them with support. The inherent complications of parenting CSHCN and CMC make these studies difficult. However, it is essential to support the caregivers of such a vulnerable population to ensure the wellbeing of these families.
References


[https://doi.org/10.1542/peds.2021-056150d](https://doi.org/10.1542/peds.2021-056150d)


### Appendix A

**Parental Stress Scale**

The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.

1 = Strongly disagree 2 = Disagree 3 = Undecided 4 = Agree 5 = Strongly agree

<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
</tr>
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<tbody>
<tr>
<td>1</td>
<td>I am happy in my role as a parent.</td>
</tr>
<tr>
<td>2</td>
<td>There is little or nothing I wouldn't do for my child(ren) if it was necessary.</td>
</tr>
<tr>
<td>3</td>
<td>Caring for my child(ren) sometimes takes more time and energy than I have to give.</td>
</tr>
<tr>
<td>4</td>
<td>I sometimes worry whether I am doing enough for my child(ren).</td>
</tr>
<tr>
<td>5</td>
<td>I feel close to my child(ren).</td>
</tr>
<tr>
<td>6</td>
<td>I enjoy spending time with my child(ren).</td>
</tr>
<tr>
<td>7</td>
<td>My child(ren) is an important source of affection for me.</td>
</tr>
<tr>
<td>8</td>
<td>Having child(ren) gives me a more certain and optimistic view for the future.</td>
</tr>
<tr>
<td>9</td>
<td>The major source of stress in my life is my child(ren).</td>
</tr>
<tr>
<td>10</td>
<td>Having child(ren) leaves little time and flexibility in my life.</td>
</tr>
<tr>
<td>11</td>
<td>Having child(ren) has been a financial burden.</td>
</tr>
<tr>
<td>12</td>
<td>It is difficult to balance different responsibilities because of my child(ren).</td>
</tr>
<tr>
<td>13</td>
<td>The behavior of my child(ren) is often embarrassing or stressful to me.</td>
</tr>
<tr>
<td>14</td>
<td>If I had it to do over again, I might decide not to have child(ren).</td>
</tr>
<tr>
<td>15</td>
<td>I feel overwhelmed by the responsibility of being a parent.</td>
</tr>
<tr>
<td>16</td>
<td>Having child(ren) has meant having too few choices and too little control over my life.</td>
</tr>
<tr>
<td>17</td>
<td>I am satisfied as a parent.</td>
</tr>
<tr>
<td>18</td>
<td>I find my child(ren) enjoyable.</td>
</tr>
</tbody>
</table>

(Adapted from Berry and Jones, 1995)