Factors Affecting Caregiver Burden in Informal Caregivers of Patients with Autism Spectrum Disorder

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Factors Affecting Caregiver Burden in Informal Caregivers of Patients with Autism Spectrum Disorder
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Background
Individuals with Autism Spectrum Disorder (ASD) often require lifelong care to meet their daily needs, which is typically provided by informal sources like family members as well as formal caregivers from home health agencies. The persistent stress of raising a child with ASD can potentially lead to parental burnout, highlighting the importance of understanding the challenges faced by these caregivers. Clinicians must prioritize the well-being of both the individuals with ASD and their dedicated caregivers by gaining a comprehensive understanding of the challenges they encounter. Our research aims to investigate and comprehend the specific challenges faced by caregivers of individuals diagnosed with ASD. By utilizing the Caregiver Burden Inventory (CBI; Novak & Guest, 1989), we sought to pinpoint the primary elements that contribute to caregiver burden and evaluate how it affects the well-being of caregivers. These findings can ultimately lay the foundation for targeted interventions and strategies aimed at lessening the burden on caregivers, ensuring they receive the necessary support to provide optimal care for their loved ones with ASD while maintaining their own well-being.

Methods

- This cross-sectional study spanning from November 2018 to June 2023 involved 227 caregivers of individuals with ASD in the Rowan-Virtua Regional Integrated Special Needs (RISN) Center.
- Caregivers completed all five domains of the Caregiver Burden Inventory (CBI; Novak & Guest, 1989) questionnaire upon establishing care at the RISN center.
- Primary caregivers who were ≥ 18 years old and completed the CBI were included.
- Statistical analysis was carried out using the Statistical Package for Social Sciences (SPSS) and the analysis of variance (ANOVA) test.

Results

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Score</td>
<td>Between Groups</td>
<td>51925.178</td>
<td>3</td>
<td>17308.393</td>
<td>95.159</td>
</tr>
<tr>
<td></td>
<td>Within Groups</td>
<td>56749.306</td>
<td>312</td>
<td>181.889</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>108674.484</td>
<td>315</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
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<td>Between Groups</td>
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<td>143.49</td>
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<tr>
<td></td>
<td>Within Groups</td>
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<td>313</td>
<td>181.127</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>108674.484</td>
<td>315</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 1: F-statistic for Ethnicity and Gender is significantly different between groups for total score based on ANOVA

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Effect Size</th>
<th>Upper 95% CI</th>
<th>Lower 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Score</td>
<td>Omega-squared Fixed-Effect</td>
<td>0.472*</td>
<td>0.391</td>
</tr>
<tr>
<td></td>
<td>Omega-squared Random-Effect</td>
<td>0.23*</td>
<td>0.177</td>
</tr>
<tr>
<td>Gender</td>
<td>Omega-squared Fixed-Effect</td>
<td>0.474*</td>
<td>0.396</td>
</tr>
<tr>
<td></td>
<td>Omega-squared Random-Effect</td>
<td>0.311*</td>
<td>0.247</td>
</tr>
</tbody>
</table>

Table 2: Fixed effect and random effect sizes of total score between groups for Ethnicity and Gender based on ANOVA

Discussion

- Our study conducted a comprehensive examination of caregiver burden among individuals caring for those with Autism Spectrum Disorder (ASD).
- Notably, our findings underscored the nuanced role of ethnicity and gender in the context of caregiver burden.
- While caregiver burden did not exhibit significant differences across caregivers of various races, our study sheds light on the need for a more granular understanding of the influence of ethnicity and gender on the caregiving experience.

Future Directions

- A critical next step in our research involves exploring potential financial barriers faced by caregivers and understanding how these barriers impact caregiving burden.
- Future research endeavors could enhance the depth of understanding by quantitatively measuring the effects of caregiver burden on physical health, considering parameters such as heart rate, blood pressure, and medical history.

References