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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 struggles 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.

Figure 1: Caregiver Burden Inventory (CBI; Novak & Guest, 1989)

Time Dependency Items	
He/she needs my help to perform many daily tasks	①②③④
He/she is dependent on me	①②③④
I have to watch him/her constantly	①②③④
I have to help him/her with many basic functions	①②③④
I don't have a minute's break from his/her chores	①②③④
Development Items	
I feel that I am missing out on life	①②③④
I wish I could escape from this situation	①②③④
My social life has suffered	①②③④
I feel emotionally drained due to caring for him/her	①②③④
I expected that things would be different at this point in my life	①②③④
Physical Health Items	
I'm not getting enough sleep	①②③④
My health has suffered	①②③④
Care giving has made me physically sick	①②③④
I'm physically tired	①②③④
Emotional Health Items	
I feel embarrassed over his/her behavior	①②③④
I feel ashamed of him/her	①②③④
I resent him/her	①②③④
I feel uncomfortable when I have friends over	①②③④
I feel angry about my interactions with him/her	①②③④
Social Relationships Items	
I don't get along with other family members as well as I used to	①②③④
My care giving efforts aren't appreciated by others in my family	①②③④
I've had problems with my marriage (or other significant relationship)	①②③④
I don't get along as well as I used to with others	①②③④
I feel resentful of other relatives who could but do not help	①②③④
Total Score:	

Scores near or above 36 indicates a greater need for respite and other services.

Comments:

Results

Ethnicity		Sum of Squares	df	Mean Square	F	Significance
Total Score	Between Groups	51925.178	3	17308.393	95.159	<0.001
	Within Groups	56749.306	312	181.889		
	Total	108674.484	315			
Gender	Between Groups				143.49	
	Within Groups					
	Total					
Total Score	Between Groups	51981.614	2	25990.807	5	<0.001
	Within Groups	56692.87	313	181.127		
	Total	108674.484	315			

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

Ethnicity		Effect Size	Upper 95% CI	Lower 95% CI
Total Score	Omega-squared Fixed-Effect	0.472*	0.391	0.533
	Omega-squared Random-Effect	0.23*	0.177	0.276
Gender	Omega-squared Fixed-Effect	0.474*	0.396	0.537
	Omega-squared Random-Effect	0.311*	0.247	0.367

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

- Race** – No significant differences were found in the total inventory score across different races.
- Ethnicity** – A significant difference in total inventory scores was identified across different ethnicities, indicating a notable impact of ethnic factors on caregiver burden. The fixed effect of 0.472 (95% CI: 0.391-0.533) and a random effect of 0.230 (95% CI: 0.177-0.276) were observed, signifying the statistical significance of ethnicity in influencing caregiver burden.
- Gender** – The gender of the caregiver resulted in significant differences in the total inventory scores, indicating gender-related variations in caregiver burden. The fixed effect of 0.474 (95% CI: 0.396-0.537) and a random effect of 0.311 (95% CI: 0.247-0.367) demonstrated the statistical significance of gender in shaping caregiver burden.

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.