

Association Between Financial Barriers to Care and Caregiver Burnout

Rana, S. [1,3], Lenz, S. [1,2], Rapley, J. [1], Baribeau, D. [1]

- 1) Bloorview Research Institute
- 2) University of Toronto
- 3) York University

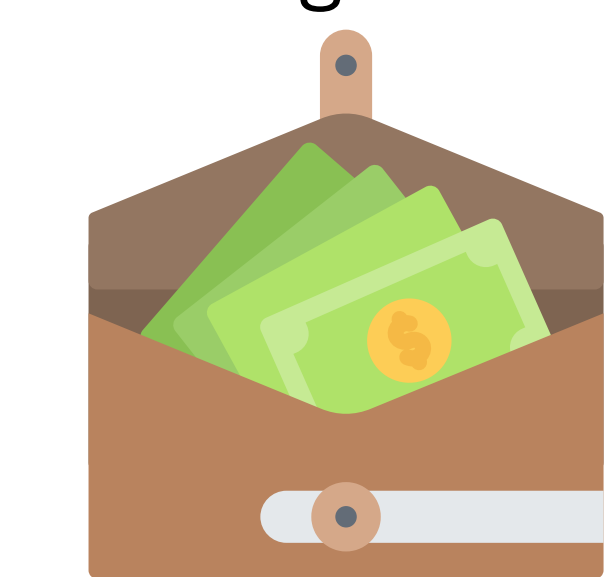
Background

Caregivers of children with neurodevelopmental disorders (NDDs) face an increased risk of burnout, leading to adverse health outcomes.²



BUT...

Many intervention programs have substantial **out-of-pocket costs**, creating **financial barriers** for families in accessing care.¹



Objective

Find out the prevalence of financial barriers to accessing care, and its association with the experience of caregiver burnout.



WHO: Children aged 6-18 with NDDs

WHERE: Holland Bloorview Psychopharmacology program

HOW: Documented in medical records by the treating clinician during the consultation visit



Methods

1. Review medical records from children with NDDs and complex behavioural care needs seen in the Psychopharmacology program between 2019-2023.



2. Define variables.

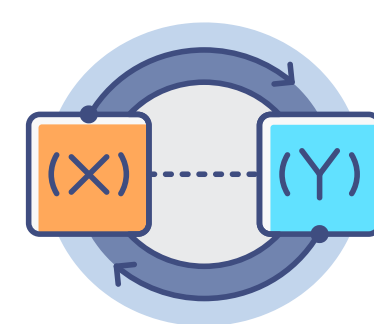
Financial barriers: Clinician documentation and social services received (e.g., ACSD, Ontario Works, or Ontario Disability Support Program).



Caregiver burnout: Clinician documentation and circumstantial evidence.



3. Conduct Chi-Square contingency test to determine whether an association is present.



4. Conduct a multivariate logistic regression, and test for confounding variables.



Challenges

Clinician did not always include whether client was facing financial barriers to care. Burnout was also not always explicitly stated.

Missing Data

Financial barriers to care reported as missing information: 18%

Caregiver burnout reported as missing information: 2%

Included those cases where burnout or financial barriers were not explicitly stated; but understood based on the description of the situation.



Table 1: Demographic Data as per First Visit

	N	Percentage	Mean
Age	343		10.17
Sex			
Male	282	82.22%	
Female	61	17.78%	
Diagnosis			
Autism	312	90.96%	
ID	93	27.11%	
Genetic Condition	35	10.20%	

Financial barriers to care are significantly associated with caregiver burnout in families with children with neurodevelopmental disorders (NDDs).



Results

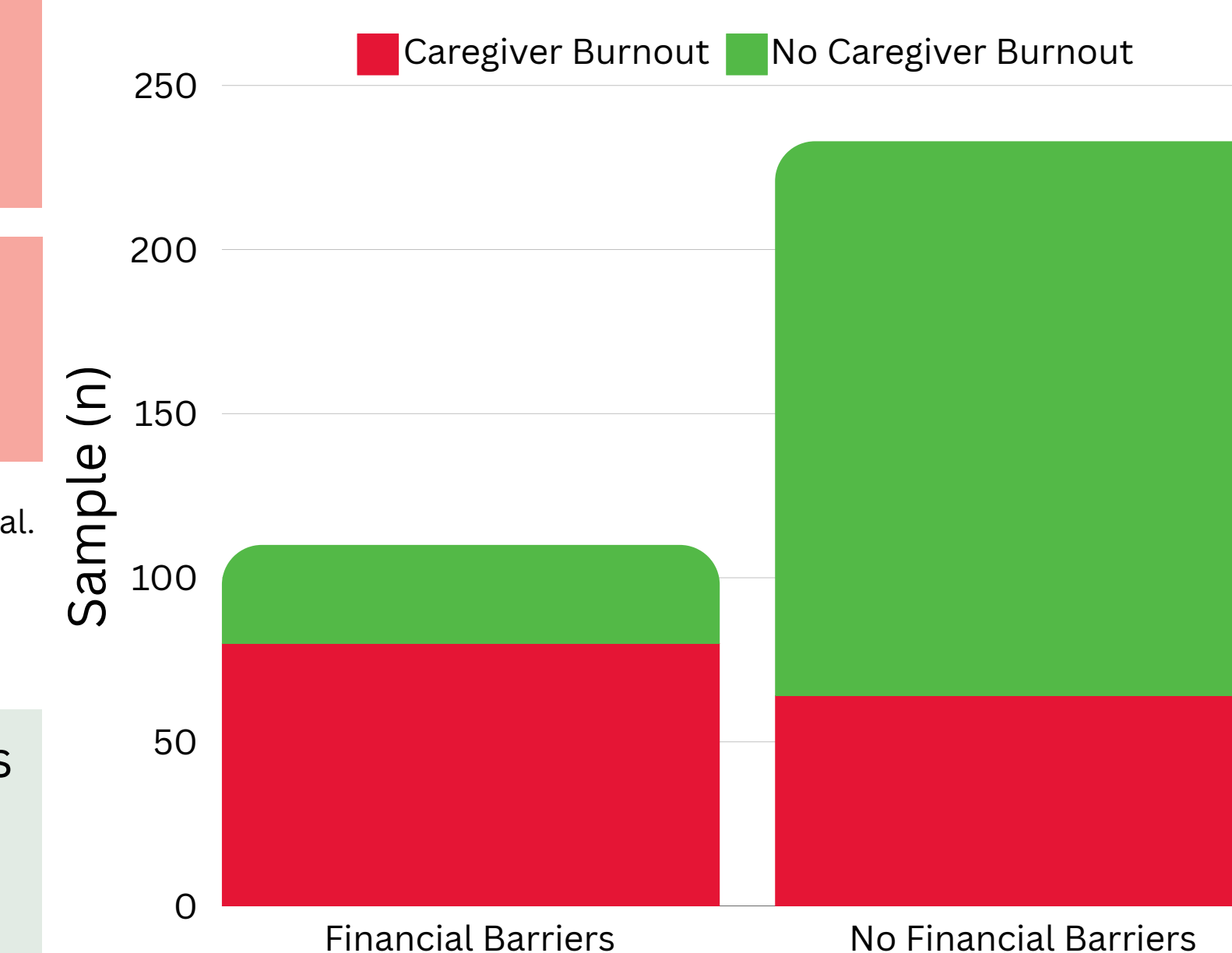
42% of caregivers were experiencing burnout.

32% caregivers reported financial barriers to care.

Missing data was included in denominator making up total.

$\chi^2 = 62.841$; $p < .0001$

Strong association: financial barriers may be an important contributor to caregiver burnout among families of children with NDDs.



What if something else is contributing to burnout?

Age, presence of aggressive behavior, and presence of an intellectual disability were hypothesized to be potential confounding variables

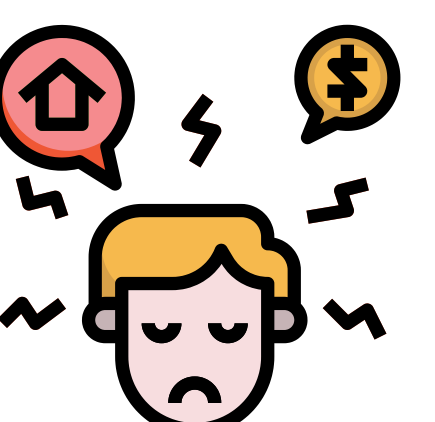
Table 2: Univariate and Multivariate analysis of different predictors

Predictor	Univariate		Multivariate	
	OR (95% CI)	P-value	OR (95% CI)	P-value
Financial Barriers to Care	7.04 (4.28-11.86)	<0.001	6.31 (3.79-10.75)	<0.001
Presence of Aggression	3.43 (2.03-5.97)	<0.001	2.61 (1.47-4.77)	0.001
Intellectual Disability	1.73 (1.10-2.72)	0.02	1.45 (0.85-2.48)	0.2
Age	0.96 (0.77-1.19)	0.7	0.96 (0.75-1.24)	0.8

The multivariate model showed adequate discrimination with an AUC of 0.76. **Financial barriers were associated with the greatest odds of parent burnout.**

Conclusion

Many families of children with NDDs face financial barriers to care, closely associated with caregiver burnout. addressing these financial challenges is crucial to supporting families.



Relevance

Comprehensive care should include support for caregivers' mental health, respite access, and financial resource navigation to reduce caregiver burnout.



Systems are needed to ensure equitable access to therapies and services for children with NDDs, and gaps in demographic data need to be addressed.



Acknowledgements

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References:

- 1) Brunt, S., Nevill, R., & Mazurek, M. O. (2024). Associations Among Autism Symptom Domains and Facets of Caregiver Strain. *Journal of autism and developmental disorders*, 54(4), 1507-1516. <https://doi.org/10.1007/s10803-022-05885-5>
- 2) Lindly, O. J., Shui, A. M., Stotts, N. M., & Kuhlthau, K. A. (2022). Caregiver strain among North American parents of children from the Autism Treatment Network Registry Call-Back Study. *Autism: the international journal of research and practice*, 26(6), 1460-1476. <https://doi.org/10.1177/13623613211052108>

Holland Bloorview
Kids Rehabilitation Hospital

YORK
UNIVERSITY