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Research Article

Perceived Burden among Caregivers of Children with Intellectual Disabilities at the Telema Mental Health Center in Kinshasa City, Democratic Republic of the Congo

Germain Manzekele Bin Kitoko[1], Bives Mutume Nzanzu Vivalya[2*], Joseph Tusamba Kimpene[3], Christine Laure Babong[3], Clement Mwanza[3], Martial MumbereVagheni[1], Sam Mampunza Lusambulu[1], Magloire Nkosi Mpembi[1], Thierry Matonda-Ma-Nzuzi1 Gilbert Mananga Lelo[1], Samuel Mampunza Ma Miezi[1]

[1]Department of Psychiatry, University of Kinshasa, Kinshasa, Congo; [2]Department of Psychiatry, Kampala International University Western Campus, Ishaka, Uganda; [3]Department of Psychiatry, Telema Mental Health Center, Kinshasa, Congo

ABSTRACT

Background: Caregiving for children with disabilities contributes to the burden on family members, leading to the long-term outcomes of intellectually disabled children. The determinants of caregiving for children with intellectual disabilities have not been deeply established. This study aimed to determine the extent and factors associated with the burden of care for children with intellectual disabilities attending a mental health day center in a low-income country.

Methods: This cross-sectional study purposely screened for burden using the Zarit burden scale among forty caregivers of children with intellectual disabilities attending a mental health day center in Kinshasa, Democratic Republic of the Congo. Descriptive analyses were used to determine information on frequency rates and patterns of burden, whereas inferential analyses were performed to determine the factors associated with the burden of caring for children with intellectual disabilities.

Results: One in four caregivers of intellectually disabled children has a burden. Caregivers younger than 45 years were 3.22 times more likely to perceive the burden compared to those aged 45 or older (AOR: 3.22; 95% CI: 1.35-5.40; Fisher test=0.019). Caregivers who were unemployed were 2.16 times more likely to perceive the burden compared to those who were employed (AOR: 2.16; 95% CI: 1.67-4.18; p=0.001). Caregivers who were first-degree family members of the intellectually disabled children were 0.36 times less likely to perceive burden while caring for them compared to those who were second-degree family members (AOR: 0.36; 95% CI: 0.12-0.78; Fisher=0.043).

Conclusion: Our results highlight the high prevalence of burden among caregivers of children with intellectual disabilities. The determinants of burden that caregivers of intellectually disabled children perceived as mild and moderate burdens were the age below 45 years, employment and being married and unemployed. Our results raise a global health policy issue and reveal the need to address the perceived burden of caregivers of children with intellectual disabilities along the mainstream healthcare continuum for intellectually disabled children.

Keywords: Burden; Caregivers; Children; Democratic Republic of the Congo; Intellectual disabilities

Correspondence to: Bives Mutume Nzanzu Vivalya, Department of Psychiatry, Kampala International University Western Campus, Ishaka, Uganda; E-mail: gbinkito@gmail.com

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INTRODUCTION

Caregiving children with intellectual disabilities is associated with a greater burden on caregivers and the family network and impairs the quality of life of family members. The burden of caring for children with intellectual disabilities among parents and family members has not been formally established in low-income countries and in the Democratic Republic of the Congo (DRC), despite studies carried in developed countries showing that caregiving for intellectually disabled children affects the family dynamic [1].

Caregivers of children with intellectual disabilities reported the perceived burden in 1-3% of cases across studies worldwide. This burden is influenced by several factors, including gender, job loss, financial constraints, obesity, poor social networks loss of income, emotional distress, stigma and poor quality of life. Moreover, these factors include the severity of intellectual *disabilities* and health burdens on caregivers, age, gender and the educational level of the caregivers. However, these factors have not yet been established among caregivers attending the neurological rehabilitation centers in cities in the DRC, where previous studies reported a high prevalence of intellectual disabilities in children seeking care in mental health facilities in Kinshasa.

Despite the cultural sensitivity and perceived stigma of living with a child with a chronic and disabling illness, the determinants of the burden of caring for an intellectually disabled child are largely unknown among caregivers of children with intellectual disabilities receiving treatment at rehabilitation centers in cities in the DRC. This study is intended to create evidence in order to design specific interventions targeting the reduction of the burden of caring for children with intellectual disabilities. This study aimed to determine the magnitude and factors associated with the burden of caring for children with intellectual disabilities attending a mental health center located in Kinshasa, the capital city of the DRC [2].

MATERIALS AND METHODS

Study setting

This cross-sectional study employed a quantitative method involving caregivers of children with intellectual disabilities who attended the outpatient department of Telema Mental Health Center, a day center located in Kinshasa City (DRC), between August 2, 2018 and December 31, 2018. This center was selected as a study site since it is one of the rare health facilities providing biopsychosocial treatment to people living with physical and/or mental disabilities in Kinshasa, the capital city of the DRC. Telema Mental Health Center is a private establishment located in Kinshasa and provides with disabilities such as stroke and intellectual disability in the city and neighboring cities.

Participants

We enrolled 40 participants among the caregivers of children with intellectual disabilities who were receiving treatment at the Telema mental health center between August 2, 2018 and December 31, 2018. We included all adults aged 18 years or older who cared for the intellectually disabled child within the last six months prior to the data collection and provided written informed consent. Exclusions were caregivers of children with other forms of disabilities or those with active symptoms of a mental disorder, such as cognitive impairment.

Procedures

Two research assistants, supervised by the first author, purposefully collected data using consecutive recruitment and face-to-face interviews. Caregivers who expressed willingness to participate were asked to provide written informed consent after the research assistants offered details about the study. After giving consent, participants were administered a semi-structured questionnaire by trained research assistants, which was fluently translated into Lingala and back translated into French in an iterative process to ensure translation fidelity. Depending on the participants' preferences, interviews were conducted in Lingala or French. Data were collected anonymously. Each interview took about 35-45 minutes. All the data collection tools were written in French. All included items were selected based on their ability to capture adequate information to achieve the study objectives.

This survey was designed for socio-demographic characteristics and the Zarit burden scale. For the independent variables, we collected socio-demographic information on age, gender, educational level, occupation, marital status, family relationships and duration of caregiving for the intellectually disabled children [3].

The burden, the outcome variable, was assessed using the Zarit burden scale, with 22 items using a 5-point Likert scale for all the items (0: not at all, 1: a little, 2: sometimes, 3: often, 4: very often), evaluating the impact of intellectual disabilities in children on the caregiver's lives. A cumulative Zarit burden scale is obtained by summing up the participant's responses. The total score varies from 0 to 88. The higher the score, the greater the burden. Scores ranging between 0 and 20 indicate the absence of burden. Scores ranging between 21 and 88 show the perceived burden.

Data analysis

Statistical analyses were performed using STATA 14.0. Descriptive statistics were summarized as proportions or percentages for categorical variables and means, standard deviations, medians. Inferential analyses were performed (Fischet test) to determine the factors associated with the burden of caring for intellectually disabled children. The threshold of statistical significance was set at 0.05 indicating that only those associations between variables with a probability of less than 5% of being due to chance were considered significant. This rigorous approach ensures the reliability and validity of the results obtained, thereby providing a solid basis for decision-making in the care of intellectually disabled children.

RESULTS

We found that 11 caregivers of intellectually disabled children (27.5%) had the burden of caring for a child with an intellectual disability. The majority of caregivers with children with intellectual disabilities were female (70%), unemployed (75%), had a first degree in caring for intellectually disabled children (77.5%) and had a high level of education (95%) (Table 1) [4].

Table 1: Socio-demographic factors of caregivers of children with intellectual disabilities who were receiving treatment at Telema Mental Health Center between August 2, 2018 and December 31, 2018.

Variables	Frequency	Percentage	Burden (Mean ± SD)
Age (years)			Mean (SD): 43.40 (13.65)
<45	29	72.5	36.03 (10.08)
≥ 45	11	27.5	24.55 (1.81)
Sex			
Male	12	30	31.50 (9.43)
Female	28	70	33.46 (10.39)
Educational level			
Illeterate	2	5	26.00 (0.00)
Ever studied	38	95	33.24 (10.17)
Occupation			
Unemployed	30	75	37.64 (12.52)
Employed	10	25	32.98 (9.93)
Marital status			
Living with partners	28	70	36.64 (10.18)
Living without partners	12	30	32.98 (9.93)
Family relationship			
First degree	31	77.5	35.26 (10.22)
Second degree	9	22.5	24.67 (1.32)
Duration of medical follow-up of children with intellectual disability			
3 to 12 months	17	42.5	32.76 (10.73)
>12 months	23	57.5	32.96 (9.74)
Burden			
Absent	29	72.5	27.69 (5.43)
Present	11	27.5	46.55 (5.17)

In multivariate analyses, we found that caregivers who were younger than 45 years were much more likely to perceive the burden of caregiving than those aged 45 or older (AOR: 3.22; 95% CI: 1.35-5.40; Fisher test=0.019). The odds of caregivers who were unemployed were much more likely to perceive the burden of caregiving than those who did not (AOR: 2.16; 95%

CI: 1.67-4.18; p=0.001). The odds of caregivers who were first-degree family members of the intellectually disabled children were less likely to perceive burden while caring for intellectually disabled children (AOR: 0.36; 95% CI: 0.12-0.78; Fisher test=0.043) (Table 2).

Table 2: Factors associated with burden among caregivers of children with intellectual disabilities who were receiving treatment at Telema Mental Health Center between August 2, 2018 and December 31, 2018.

Variables	**Burden**		**AOR (95% CI)**	**Fisher test/p value**
	Absent	**Present**		
Age years				
45	11	0	1	0.019
<45	18	11	3.22 (1.35-5.40)	
Occupation				
Employed	5	5	1	0.001
Unemployed	24	6	2.16 (1.67-4.18)	
Marital status				
Living without partners	13	0	1	0.007
Living with partners	16	11	1.80 (0.95-5.34)	
Familial relationship				
Second-degree	9	0	1	0.043
First-degree	20	11	0.36 (0.12-0.78)	

DISCUSSION

This study aimed to determine the extent and factors associated with the burden of caring for children with intellectual disabilities attending a day center for mental health care in a low-income country [5]. We found that almost one in four caregivers of children with intellectual disabilities experienced strain. We also found that the determinants of caregiver burden for children with intellectual disability were being younger than 45 years, being unemployed and being a first-degree relative of the child with intellectual disability. To the best of our knowledge, this is the first databased evidence on the burden of care for children with intellectual disabilities in the DRC [6].

The finding that the majority of carergivers of children with intellectual disabilities did not perceive this is consistent with other research. Positive coping mechanisms may explain the high proportion of caregivers in our sample who do not feel burdened while caring for their first-degree relatives. Caregivers develop positive highly expressed emotions and a belief that healthcare providers can cure the child's intellectual disability [7]. The finding that the majority of participants were female also supports previous evidence that caring for children with or without disabilities is an established part of women's daily activities. We also found that being younger than 45 years of age was associated with the burden of caring for children with disabilities. The fact that the majority of study participants were younger may explain this discrepancy. The risk of perceived burden while caring for a child with intellectual disability decreases with age. Caregiver age was associated with physical burden which is supported by the previous finding that older caregivers experience greater strain and impact on their quality of life Ghazawy, E.R., Mohammed, E.S., Mahfouz, E.M. et al. [8].

Our results showed that being unemployed increased the burden on caregivers of intellectually disabled children. This is divergent from previous studies indicating the increasing rate of loss of income and jobs among caregivers of children with intellectual disabilities due to their repetitive absenteeism. A burden related to the fear of failure to fulfill marital duties could have a cumulative effect on taking care of a child with a long-term disease. Moreover, the finding indicating that being a first-degree relative to a disabled child had a protective effect on perceiving burden among caregivers of intellectually disabled children supports other research showing the importance of the family support provided to disabled children in several communities [9].

When interpreting our findings, the main limitations should be considered, such as the cross-sectional design, the university-based sample, the lack of a control group and the systematic enrollment of the participants. Another limitation is that our sample was recruited from a single institution [10].

CONCLUSION

Our findings highlight the high prevalence of strain among carers of children with intellectual disabilities. The determinants of burden perceived as mild and moderate by caregivers of children with intellectual disabilities were age below 45 years, employment and being married and unemployed, whereas being a first-degree relative showed a protective effect on perceived burden. Our findings raise a global health policy issue and highlight the need to address the perceived burden of caregivers of children with intellectual disabilities along the mainstream healthcare continuum for children with intellectual disabilities.

AVAILABILITY OF DATA AND MATERIALS

The data used to support the findings of this study is available from the corresponding author upon reasonable request.

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AUTHORS' CONTRIBUTIONS

G.M.B.K. and J.T.K. designed the study, collected data and analyzed the data in the manuscript. B.M.N.V. drafted and reviewed the manuscript and was involved in literature searching. CLB and M.M.V. were involved in correcting the collected data. C.M., S.M.L, T.M.M.N., GML, M.N.M. and S.M.M.M. were involved in intellectual content and reviewed the manuscript. The authors read, contributed to and approved the final manuscript.

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ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The academic board of the University of Kinshasa approved all procedures involving human subjects or patients. Permission to carry out this study was received from the executive director of the rehabilitation center for physical disabilities and mental health center Telema in Kinshasa city. This study was conducted according to good ethical practice based on the recommendations of the declaration of Helsinki.

CONSENT FOR PUBLICATION

We obtained a written informed consent from the study participants.

COMPETING INTEREST

The authors declare no competing interest.

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