

# Physical and Psychological Burden on Caregivers of Children with Intellectual Developmental Disabilities Attending Psychiatric Outpatient – Clinic - Khartoum State - Sudan (2019)

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## Abstract:

Stresses among caregivers of children with intellectual developmental disabilities is pervasive and linked to lower quality of life, unhealthy family functioning, and negative psychological consequences. This study aimed to assess physical and psychological burden on caregivers of children with intellectual developmental disabilities. This was a descriptive cross-sectional hospitals based study conducted in Khartoum state at three outpatient psychiatric clinics which included Soba University, Omdurman Military and Alteгани Almahi Hospitals. Simple random sampling method was used. This sample included 300 caregivers of children with intellectual developmental disabilities that met selection criteria. Data was collected by the researcher using interview questionnaire and Zarit burden interview scale and analyzed by SPSS version 22. From the total of 300 caregivers, 273 (90.0%) were mothers, 274 (91.3%) of caregivers spent more than 8hours with their disabled children per day. Regarding caregivers burden, the physical burden was experienced by 102 (34.0%), while 126 (42.0%) complained of psychological burden. Family support for 154(51.3%) come from fathers of children, 273(91.0%) of them only participated in providing child needs. With respect to children with intellectual developmental disabilities 183 (61.0%) were males, disorders of 219 (73.0%) children started as early as age 0-4 years. One third of those children, 104 (34.7%) had epilepsy. Moderate disorders were observed in135 (45.0%) of the children while in 197 (65.7%) was associated with convulsions. 112 (37.3%) were using sodium valporate for treatment while some children were using other drugs. The problem was that 187 (62.3%) had no affiliation. Chi square was used to determine the correlation between burdens and socio-demographic characteristics, where the overall burden ranged from mild to moderate (53.7%). The study concluded that the caregivers of disabled children experienced physical and psychological burden while caring for their children. Family caregivers who look after other family members need special

assistance and attention; otherwise they would become totally depressed by the heavy burden.

## **Keywords:**

Caregivers, Burden, Intellectual Developmental, Disabilities

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## **1. Introduction**

Individuals with intellectual developmental disorders (IDD) are experiencing longer life expectancies, and families continue to be the primary providers of care. In 2011, 71% of individuals with severe IDD lived with a family caregiver [1]. Parents are primary sources of support and care for children with developmental disabilities. And the role continues throughout the child's life. There is an emerging group of aging parents who have raised children with disorders and now provide care and assistance to their offspring in adulthood. These ongoing responsibilities range from occasional oversight to continuing giving daily care and assistance with their especial daily requirements [2]. Individuals with intellectual developmental disorders (IDD) are now living longer with greater challenges in family care giving [3]. World Health Organization (WHO) has defined disability as "any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being" [4,5]. Children with disability means that the child having mental retardation, hearing impairment, a serious emotional disturbance, intellectual disability who require special education and services [5]. Developmental disability (DD) is defined as a disorder that typically causes behavior, communication, and social adjustment problems during the development process [6]. Intellectual disability (ID) is defined as a disability characterized by significant limitations in intellectual functioning and adaptive behavior [7]. Approximately 15% of children aged 3 to 17 years, or nearly 10 million children from 2006–2008 were reported to have a developmental disability including autism spectrum disorder (ASD), cerebral palsy, intellectual disability (ID), and developmental delays. Children with intellectual developmental disability (IDD) are at risk for health problems, psychopathology, and behavioral problems. Children with IDD are three to four times more likely to display clinically significant levels of behavioral problem than children without delays and are at higher risk for psychiatric disorders [8]. Caregiver is a person who gives help and protection to someone such as a child, an old person or someone who is ill [5]. Stress among parents and other primary caregivers of individuals with developmental disorders is pervasive and linked to a variety of adverse physical and mental health outcomes [9]. Burden explains the impact of a patient's behavior upon his/her family, household and significant others, i.e. the potentially harmful effect upon the patient's caregivers [10]. Caregiver burden is defined as "a multidimensional response to physical, psychological, emotional, social and financial stressors usually associated with the experience of caring" [11]. Burden of care has two components namely subjective and objective burden. Objective burden includes measurable effects such as economic burden, caregivers' loss of work, social and leisure activities, household disruptions such as child care, restrictions on relationships within and outside the family. National Health Interview Survey data indicate higher levels of depressive symptoms and health issues and poorer access to health care for some caregivers of adults with intellectual developmental disorders (IDD) in comparison with other families. Families with a person who has IDD often experience financial hardship because

these families may work fewer hours, quit working, or experience high care costs. Subjective burden is mainly the psychological sufferings of the caregivers themselves and is experienced by them such as depression, uncertainty, guilt, shame and embarrassment [12]. Social stigma is a sign of disgrace that sets a person apart from others, can notes another form of burden borne by caregivers and defines as discrediting and disgracing mark usually leading to negative behavior for its bearer [13]. Coping with caregiver burden is a lifelong challenge for these parents, consists of the cognitive and behavioral strategies that are employed to manage challenging demands. Coping strategies are often classified into categories depending on whether the strategy is intended to change the stressor and solve the problem, or to reduce the individual's negative emotions caused by the strain [2].

## **2. Materials and Methods**

### **2.1. Research Design**

A descriptive cross sectional hospital based study design was used.

### **2.2. Study Setting**

The study was conducted in three psychiatric clinics:

Soba University Hospital (SUH) is a tertiary hospital located in the south Khartoum state, it was established in 1975 and remained the prime hospital in training of medical students, doctors and other health care workers such as nursing and medical laboratories students, and provides health care at national level. It is a 500 bedded hospital with more than 1000 health care workers and it contains all fundamental disciplines which include internal medicine, pediatrics, obstetrics and gynecology and surgery department. In addition to that it has recently established a gastro-entriology outpatient clinic in 2011 supervised by consultants and fellows. It includes neuropsychiatric clinic for children directed by psychiatric consultants and registrars, works twice/week and see around 45 children per one clinic who come from different areas in Sudan.

Alteгани Almahi specialized psychiatric hospital is one of the largest teaching hospitals which provide Sudanese people with psychiatric and mental health services. It is located in Omdurman, near Omdurman locality and facing Alarda Street. The hospital consists of: causality department with 4 rooms for short stay, outpatient and referral department, electro-chromatography department, nutrition department and administration department. It accommodates 119 beds in causality department and 107 beds in general wards. There are 14 house officers, 17 medical officers, 10 medical registers in psychiatry and 7 consultants. Patients who attended hospital in 2017 were about (1313) and about (288) of them were diagnosed with schizophrenia. There is separate section outside the hospital for child psychiatry named Alzahra Center for Child Psychiatry, works twice /week directed by psychiatric physicians only and sees about 10 cases per clinic; three new cases and seven cases for follow up. Also center equipped with qualified staff; one nurse, social worker and psychologist provide different support and care for children and their caregivers.

Omdurman Military hospital is one of the largest military teaching hospitals. This hospital was established in 1956 and it provides medical services for military and civilian people with their families. It is located in Omdurman west of the White Nile Bridge, east Karari University, south Youth Palace and north Alfetahab Bridge. It

contains all health departments. There is a child psychiatry clinic in the pediatric division, works one day/ week, see around eight to ten cases per clinic directed by psychiatric consultant and registrar. Also clinic equipped with nurses, social workers, and psychologists provide support and care for children and their caregivers.

### **2.3. Target Population**

300 caregivers of children diagnosed with intellectual developmental disabilities were taken randomly from psychiatric outpatient clinics at Soba University hospital, Altegani Almahi psychiatric hospital at Alzahra Center for Child Psychiatry and Omdurman Military hospital. The researcher depends on diagnosis of children from follow up which is established by psychiatric consultants and physicians based on history taken, physical examination, clinical signs and symptoms and investigations such as electro-encephalogram(EEG), computed tomography (CT), magnetic resonance imaging (MRI), and intellectual test (IQ) test.

#### **2.3.1. Inclusion Criteria**

- a. The caregivers who are living with IDD children.
- b. Caregivers who gave consent and cooperation.
- c. Caregivers available at the time of sample collection.

#### **2.3.2. Exclusion Criteria**

- a. Children with non-established diagnosis
- b. Caregivers with known mental health problem during care giving (psychosis, schizophrenia, personality disorder).
- c. Caregivers suffer from life stress before having disabled child

### **2.4. Sampling Procedure**

Caregivers who have a child diagnosed with IDD were recruited from the departments of psychiatric clinics at Soba University Hospital, Altegani Almahi Psychiatric Hospital and Omdurman Military Hospital. These caregivers were assessed by interview questionnaire and Zarit burden interview scale. The collection of data lasted for a period of two months, starting from January to March 2019; data were collected five days a week from 9.00 am to 12.00 pm, Sunday and Wednesday from Soba Hospital, Monday from Military and Tuesday and Thursday from Altigani Almahi Hospital at Alzahra center for child psychiatry. Total numbers of caregivers were 300 which were distributed as 208 caregivers were taken from Soba clinic, 46 caregivers from Altigani Almahi at Alzahra center for child psychiatry and 46 from Military clinic according to the total population for each clinic per month for two months using simple random sampling.

### **2.5. Sample Size**

Sample size calculation:

To satisfy the objective of the project, the total number of subjects required (n) was calculated using the formula below:

$$n = \frac{\left(\frac{z}{d}\right)^2 \times (0.50)^2}{1 + \frac{1}{N} \left[ \left(\frac{z}{d}\right)^2 \times (0.50)^2 - 1 \right]}$$

Where: N: total population (1320) for two month

Z: 1.96

d: marginal error: 0.5

P. value: 0.05

q: p-1

n: sample size (300)

## **2.6. Methods of Data Collection**

Data was collected by the researcher and trained personnel using interview questionnaire and Zarit burden interview scale. Filling the tools of data collection within 15 minutes from each caregiver in his waiting time at each clinic without any interruption to the flow of clinics

## **2.7. Development of Data Collection Tools**

Tool one: Semi Structured interview Questionnaire prepared by the researcher:(Appendix I) Consist of socio-demographic variables of caregivers such as (age, marital status, residence area, educational level and employment status).

Tool two: knowledge of caregivers regarding disabled child (Appendix II).

Tool three: Zarit burden interview scale (Appendix III)

The original version of Zarit scale was used after taken permission from the author by contact him through email, then sent to me written permission attached with the original version of scale with different language even Arabic within 48hours after contact. The scale was developed by Zarit et al in 2010 to assess the burden experienced by the caregivers of IDD children which were 22score summation of 22 items via 5-point Likert scale items from 0-4points; (0=never, 1=rarely, 2=usually, 3=sometimes, and 4=nearly always).Total score range from 0-88; (0-20: little or no burden, 21-40: mild to moderate burden, 41-60 moderate to severe burden and 61-88 severe burden), high scores indicating greater burden. The questions focus on major areas such as caregiver's health, psychological well-being, financial, social life and the relationship between the caregiver and the child. The scale was presented to six experts' two psychiatrists, four psychologists and all of them agreed with it &, And divided to subscale falling into 4 domains; physical burden (3 items): 8, 10, 20, psychological burden (6 items): 3, 7, 9, 14, 17, 19, social burden (7 items): 4, 6, 11, 12, 13, 21, 22, financial burden (3 items): 2, 15, 16. Pretest for validity and reliability was done using Cronbach's alpha [15,16].

## **2.8. Data Analysis Plan**

The collected data was coded, entered and analyzed using statistical package for social science (SPSS) version 22. Significance for data analysis was considered as P

$\leq 0.05$ . Frequencies and percents were being calculated for socio-demographic characteristics of caregivers and disabled children. Chi-square test analysis was used to measure the strength of the association between the caregiver's demographic characteristics & burden on caregivers of IDD children.

### 2.9. Ethical Considerations

Official letter was obtained from the Graduate College Medical and Health Studies Board and Research Committee Faculty of Nursing Sciences University of Khartoum.

An official letter for approval was obtained from the research committee of Soba and military hospitals.

Formal letter was obtained from Ministry of health to Altegani Almahi for ethical clearance.

All caregivers were informed about the purpose of the study clearly without any enhancement or convincing to participate voluntarily then written consent was obtained from them.

### 2.10. Pilot Study

Pilot study was carried out on 10% which equal 30 family caregivers of the study sample to test internal consistency, reliability and construct validity of the questionnaire and Zarit burden scale. The Cronbach's alpha value was 0.715 in physical burden and 0.818 in psychological burden. The results of 10% of family were excluded from final results to avoid contamination.

## 3. Results and Discussion

The descriptive study was done to assess the burden on care givers of children with intellectual developmental disabilities attending psychiatric outpatient clinics in Soba University, Altegani Almahi at Alzahra center for child psychiatry and Omdurman military hospitals, Khartoum State. Complete data was obtained from sample size of 300 caregivers of disabled children with high response rate of 100%. The study showed the following findings as explained in the tables below (Table 1):

*Table 1. Physical burden of caregivers (n=300).*

Physical burden of caregivers	Frequency	Percent	P value
No burden	81	27.0%	0.000
Mild to moderate burden	102	34.0%	
Moderate to severe burden	95	31.7%	
Severe burden	22	7.3%	
Total	300	100%	

Three items ( 8, 10, 20) were used to assess the level of physical burden using 5-point Likert scale, 34.0% of caregiver were suffering from physical burden with highly significance P.value (0.000), considering the range of burden from mild to moderate according to Zarit scale. (Table 2)

Six items (3, 7, 9, 14, 17, and 19) were used to assess the level of psychological burden using 5-point Likert scale, the 42.0% of caregiver was suffering from psychological burden with highly significance P.value (0.000). This was considering from the range of mild to moderate burden according to Zarit scale.

**Table 2.** Psychological burden of caregivers (n=300).

Psychological burden of caregivers	Frequency	Percent	P value
No burden	101	33.7%	0.000
Mild to moderate burden	126	42.0%	
moderate to severe burden	65	21.7%	
Severe burden	8	2.7%	
Total	300	100%	

It was found that 34.0% of caregivers experienced physical burden when they were asked about dependency of child care, their health has suffered due to involvement with disabled children, and requirement of care (item 8, 10, 20) respectively, according to those questions know what the disease can be acquired when caring of disabled child. Their answers were hypertension, diabetes, disc prolapse, hernia, gastritis, hypotension, malaria, recurrent headache (p= 0.000). This finding was similar to the finding which suggested that providing care to a family member with intellectual disability within the family home can have an adverse effect upon carers, both physical and psychological health. It was also found that comparing health outcomes of carers' of children with intellectual disability with age-matched non-care giving peers showed that carers' were significantly more likely to report experiencing higher rates of arthritis, diabetes, high blood pressure, osteoporosis, cardiovascular diseases, obesity and activity limitation than their non-care giving peers [14]. Children may require special equipment, medical care, and programming and at the same time; family income may be low because care giving responsibilities make it difficult for the two parents to work outside the home [16].

In this research work about 42% of the present study caregivers suffered from psychological burden when the researcher asked them about feeling stressed by caring of disabled children and other responsibilities, afraid of what the future holds for them and more strained when beside the patient, your disabled child seems to expect you to take care of him/her; as if you were the only s/he could depend on, you have lost control of your life since your disabled child illness, uncertain to what to do about disabled child (item 3, 7, 9, 14, 17, 19) respectively. They said that they experienced stress, anxiety, depression specially mothers of child with autism, down syndrome, epilepsy because of poor access to health care, scarcity of some medications in pharmacy and inability to pay for them. This lead to deterioration of child health, inability to continue on follow up because of low socioeconomic status, and families with more than one disabled child suffered more (p= 0.000). Similarly 47-50% prevalence of psychological disorders was observed among caregiver parents in low and middle income countries such as Kenya, Kuwait, Qatar and India [17]. Likewise it was found that Parents caring of children with intellectual disabilities (IDs; e.g. Autism and Down syndrome) often reported higher depressive symptoms when compared with parents of typically developing children[ 18]. Another study showed that the type of disability is related to the stress and subsequent burden experienced by parents, specifically parents of children with autism who reported more stress than parents of other disabilities because autism is a debilitating, life-long neurological developmental disorder characterized by social deficits, restricted interests and repetitive behaviors' and IQ less than 70 and limitations in adaptive behavior before the age of 18 years [19,20].

#### 4. Conclusion

The current study concluded that the caregivers of disabled children experienced physical and psychological burden while caring them. Family caregivers who look after other family members also need special assistance and attention, otherwise they become totally depressed by the over burden.

## Conflicts of Interest

The authors declare that there is no conflict of interest regarding the publication of this article.

## Author contributions

Conceptualization: A.H.; Methodology: A.H.; Software: A.H.; Validation: A.A.; Formal analysis: A.A.; Investigation: A.A.; Resources: A.A.; Data Curation: A.H.; Writing – original draft preparation: A.A.; Writing – review and editing: A.A.; Visualization: A.A.; Supervision: A.A.; Project administration: A.H.; Funding acquisition: A.H.

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