

Social and Financial Burden on Primary Caregivers of Children Living with disabilities Attending Psychiatric Outpatient Clinic. Khartoum State, Sudan.

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Abstract

Stress among primary caregivers of children living with disabilities is devastating and leads to difficulty interacting with the community and negative psychological consequences. The study aimed to assess the social and financial burden on primary caregivers of children living with disabilities. A descriptive cross-sectional hospital-based study was done at three outpatient psychiatric clinics in Khartoum, Sudan, from January to March 2019; 300 primary caregivers of children living with disabilities that met selection criteria recruited by simple random sampling method using interview questionnaire and Zarit burden interview scale and Data analyzed by SPSS version 22. This study revealed that most caregivers experienced financial and social burdens (42.0%) and (77.7%) respectively; besides, primary caregivers need special assistance and attention because they become frustrated by the heavy burden. This finding revealed that a comprehensive assessment required and provision of formal and informal support to those families is needed.

Keywords: burden; primary caregivers; disabilities; Sudan.

Introduction

World Health Organization (WHO) defined disability as "any restriction or deficiency of ability to perform an activity in the manner or within the kind considered normal for a human being (Darsana & Suresh, 2017; Park & Seo 2016).

Mental health is more than the mere deficiency of mental disorders. It includes subjective well-being, perceived self-efficacy, autonomy, skill, intergenerational dependence, and recognition of the capability to realize one's intellectual and emotionally possible. It is a state of well-being whereby persons recognize their abilities, can cope with the everyday stressors of life, work creatively and fruitfully, and make contributions to their societies. Furthermore, mental health is about enhancing the skills of individuals and societies and enabling them to accomplish their self-determined objectives. Such individuals function well in the community, are accepted within a group, and are generally satisfied with their lives (Hailemariam, 2015).

In contrast, mental illness is characterized by disturbances in thoughts, emotions, behavior, and relationships. In other words, mental illness is a health problem that significantly affects how a person feels, thinks, behaves, and interacts with others (Hailemariam, 2015). According to WHO, more than one billion people with disabilities include about 15 percent of the world's population or approximately one in seven persons. An estimated 93 million children, or around one in twenty of those under 15 years of age, live with moderate to severe disabilities. These disabilities include autism spectrum disorder (ASD), cerebral palsy, intellectual disability (ID), and developmental delays. Children with intelligent developmental disabilities (IDD) are at risk for health problems, psychopathological and behavioral problems (Tara & Andrea, 2017). One billion people have a disability; at least 1 in 10 is a child (100 million children), and 80% live in developing countries (UNICEF, 2017). An intelligence disability is the most common developmental disability -nearly 6.5million people in the United States have some level of ID. More than 545.000 are ages 6-21 (Seng et al., 2010; Yu, Yap & Liew, 2018). Children's mental health problems significantly impact the social, familial, educational, and leisure domains of their parents' lives, creating challenges and burdens for them.

Many studies have revealed that parents of children with psychiatric disorders experience both objective and subjective burdens. The objective burden denotes the disrupted daily life routines of the family and the restrictions on the social, occupational, and familial fields of quality of life, which arise from the child's illness. The subjective burden refers to the relatives' many psychological reactions, such as anxiety, anger, and depression. It should be notice that the parents' emotional reactions could affect the child's symptomatology, which can, in turn, increase the parents' emotional experience (Burke & Heller, 2017; Peer & Hillman, 2014). Siblings have the longest-lasting familial relationship when a disability is present; siblings may fulfill unique roles related to their brother or sister with disabilities, such as caregivers and advocates. (Burke & Heller, 2017). Parents of children with disabilities report higher levels of stress than parents of typically developing children. Factors related to increased stress levels include financial challenges which the level of parental education may exacerbate, social support, psychological distress, child's diagnosis, and child behavioral problems, (Tara & Andrea, 2017).

Previous studies have shown that objective and subjective aspects of family burden correlate with patient characteristics, such as severity of symptoms and number of hospitalizations, and family environment and support. In addition, variables related to illness perception, such as insight into the illness and internalization of parents' stigma,

were also found to be positively associated with the family burden experienced by parents of children with psychiatric disorders (Ohayon, Pijnenborg, Ben-Pazi & Goldzwei, 2017).

This research work was done to assess the social and financial burden experienced by the family caregivers looking after their children diagnosed with intellectual developmental disabilities, routinely attending psychiatric clinics for follow-up. It demonstrates social health outcomes and economic impacts due to the lifelong caregiving of a family member with disabilities.

Materials and methods

Study Setting

A descriptive cross-sectional hospital-based study design was used. The study was conducted in three outpatient psychiatric clinics after ethical approval was obtained. Caregivers who have children diagnosed with IDD were recruited from psychiatric clinics at Soba University Hospital (SUH), Altegani Almahi specialized psychiatric hospital, and Omdurman Military hospital.

Inclusion Criteria

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

Exclusion Criteria

- Children with the non-established diagnosis;
- Children with psychological disorders (psychosis, schizophrenia, personality disorder);
- Children given care in institutions;
- Caregivers with known mental health problems during caregiving;
- Caregivers suffering from life stress before having a disabled child.

Sampling procedure

The total of caregivers attending the clinics in the two months of our work was 1320. The sample size was calculated in consonance with the formula below:

$$n = N/1+N(e)^2 = 1230/1+(1230 \times 0.05^2) = 301.8$$

Where n is the sample size, N is the population under investigation and e is the level of precision. Data was collected from the 300 randomly selected caregivers by the researchers and trained personnel using an interview questionnaire and Zarit burden interview scale (after approval taken from the author). It was divided into subscales by psychiatric expertise to; social burden (7 items: 4, 6, 11, 12, 13, 21, 22), financial burden (3 items: 2, 15, 16). These numbers involved questions that match with each burden. The collection of data lasted for a period of two months, starting from January to March 2019. Pretest for validity and reliability was done using Cronbach's alpha (Seng et al., 2010; Yu, Yap & Liew, 2018) on 10% of the study sample to test internal consistency, reliability, and construct validity of the questionnaire and zarit burden scale.

The collected data was then coded, entered, and analyzed using the statistical package for social science (SPSS) version 22. Significance for data analysis was considered as $P \leq 0.05$. Frequencies and percentages, and P-values were calculated for socio-demographic characteristics of primary caregivers and their burden.

Results

Table 1

Background characteristics on the family member caregivers

Gender of family Caregiver	Frequency	Percentage
Female	271	90.3%
Male	29	9.7%
Age of Caregivers		
20-25yrs	7	2.3%
26-30	31	10.3%
31-35	61	20.3%
36-40	120	40.0%
More than 40	81	27.0%
Residence		
Urban	204	68.0%
Rural	96	32.0%
Mothers Education		
Illiterate	29	9.7%
Khalwa (equivalent to kindergarten)	6	2%
Primary school	120	40%
Secondary school	82	27.3%
University	56	18.7%
Post university	7	2.3%

Table 2

Social burden of family members caregivers (n=300)

Physical burden of caregivers	Frequency	Percentage	P-value
No burden	15	5.0%	
Mild to moderate burden	233	77.7%	
Moderate to severe burden	44	14.7%	0.000
Severe burden	8	2.7%	
Total	300	100%	

Seven items (4, 6, 11, 12, 13, 21, and 22) were used to assess the level of social burden using a 5-point Likert scale. 77.7% of caregivers were suffering from social burden with a high significance P-value (0.000). This was considered in the range of mild to moderate burden according to the Zarit scale.

Table 3

True caregiver (n=300)

Who is a true caregiver	Frequency	Percentage
Father	6	2.0%
Mother	273	91.0%
Sister	3	1.0%
Brother	2	0.7%
Grandmother	7	2.3%
Aunt	9	3.0%
Total	300	100%

Table 4

Financial burden family members caregivers (n=300)

Financial burden of caregivers	Frequency	Percentage	P-value
No burden	96	32.0%	0.000
Mild to moderate burden	126	42.0%	
moderate to severe burden	75	25.0%	
Severe burden	3	1.0%	
Total	300	100%	

Three items (2, 15, 16) were used to assess the level of financial burden using a 5-point Likert scale. 42.0% of caregivers were suffering from financial burden with high significance, P-value (0.000). This was considered to range from mild to moderate burden according to the Zarit scale

Table 5

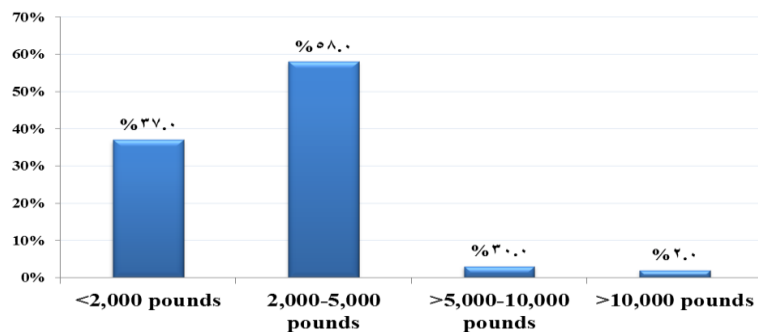
Relationship between time spent looking after ID patient and burden

Time spent	No burden	Mild to moderate burden	Moderate to severe burden	Severe burden	Total	p. value
1-4 hours	2 (25.0%)	5 (62.5%)	1 (12.5%)	0 (0%)	8(2.7%) (100%)	.0867
5-8 hours	7 (38.9%)	8 (44.4%)	3 (16.7%)	0 (0%)	18(6.0%) (100%)	
>8 hours	92 (33.6%)	113 (41.2%)	61 (22.3%)	8 (2.9%)	274(91.3%) (100%)	
Total	101 (33.7%)	126 (42.0%)	65 (21.7%)	8 (2.7%)	300 (100%)	

91.3% of caregivers spent more than 8hours looking after their ID patients. 42.0% experienced mild to moderate burden and 21.7% moderate to severe burden. (total 65.4% experienced some sort of burden)

Figure 1

Family income



This figure showed that 37%+58% (95%) had family income between <2000-5000 pounds per month, which is low for a family with a disabled family member.

Discussion

The study revealed that the majority (90.3%) of actual caregivers were females and, at the same time, mothers in their middle age between (36-40) years of age. Most of them (68.0%) were residents in urban areas and less educated (40.0% had primary school only, table 2). Nighnty percent of the caregivers were mothers, and 83% of these mothers were housewives with no financial income, and they also had to take the household jobs. It was also observed that most of the families had low income, which aggravates the financial stress due to the special needs of the disabled family member (Fig 1). In this research, it was found that 42% of family caregivers were suffering from financial burden stress with nobody to give them support. They were more active in their child's care and bear most of the associated burden. That was why they tended to give themselves little time to adjust, as the child with the disability continues to require ongoing care. This finding agreed with some studies that showed that mothers tended to make more effort than their fair share, and their actions were often limited (Kerenhappachu & Godishala, 2014). Parents of children with disabilities reported higher levels of stress than parents of typically developing children. Factors related to increased stress levels include financial challenges, level of parental education may exacerbate social support, psychological distress, extent of a child's disability, and child behavioral problems (Tara & Andrea, 2017). Most of these factors (financial challenge, low level of education, absence of social support, child's disability, and behavior) were prominent in caregivers' mothers in this study.

Furthermore, 77.7% of caregivers were found to bear a load of social burden. When they were asked how burdened did they feel in caring for disabled, they said that they felt embarrassed by the behaviors of their disabled, and this affected their involvement in the community negatively, they did not have as much privacy as they would like, their social life suffered a lot, they also felt uncomfortable about having friends over because of their disabled children, they could do a better job in caring for their disabled (items 4, 6, 11, 12, 13, 21, 22, respectively) (Table 2.). They said that sometimes they felt ashamed, embarrassed, stigmatized from child behavior, especially when they had guests or in transportation when traveling from one place to another, or when they felt community rejection, isolation from all social activities, they had no recreation-leisure time and neglected other children ($p=0.000$, table 2.). Stressing social health outcomes and economic impact due to lifelong caregiving of a family member with disabilities was reported (Heather & Elizabeth, 2014). Parents of children with disabilities were vulnerable to associative stigma in the form of shame, embarrassment, and social censure, presumably due to the causal relationship between parental practices and children's body structure, behaviors, and development (Cantwell, Muldoon & Gallagher, 2015).

Regarding financial burden, 42.0% of caregivers experienced the feeling that they did not have enough time for themselves, they did not have sufficient money to care for their children living with disabilities in addition to the rest of their expense, and would be unable to take care of their relatives much longer (item 2, 15, 16 respectively). They said that due to shortage of money, they could not continue to do the follow-up, were unable to do investigations required because they were expensive and not included in the health insurance, in addition to interrupted medicine intake which was due to very high cost or inavailability of the drug, in addition to the average child needs. In this study it was observed that 8% of the mothers were divorced (separated), (table 2.). The

study done in United States of America demonstrated the greater likelihood for divorce in parents of children with an ASD which was 24% as compared to the standard international rate of 14% because this was found to affect spousal relationship, leading to decreased marital satisfaction (Johansson, Andershed & Anderzen-Carlsson, 2013).

In this study (61.0%) of disabled children were males. This finding agreed with that report which showed that intellectual disability affects about 1.8% of children and youth and is more prevalent in males than in females (Stewart, Falah Hassani, Poss & Hirdes, 2017). It was found that addition 91.3% of caregiver (Table 5) spent more than eight hours/day which means an average of more than 48 hours/week. In a study done in Sweden it was revealed that family members spent an average of 22.5 hours/ week on ID care-related activities, which is far less than the finding in this research (Johansson, Andershed & Anderzen-Carlsson, 2013). This is probably due to the government support and provision of centers of welfare equipped with facilities and trained qualified staff to those disabled children which is not available in The Sudan.

Conclusion

The results concluded that the primary caregivers of children living with disabilities suffered from different levels of social and financial burden while caring for their children especially as they were mostly illiterate, living in rural areas away from services and living on low income. This finding revealed that a comprehensive assessment required and provision of formal and informal support to those families is needed.

Relevance for clinical practice:

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Ethical approval: Permission was taken from the responsible in outpatient psychiatric clinic.

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