

# The Prevalence of Psychological Morbidities and the Determinant of care givers of children with intellectual disabilities, in specialized centers in Jeddah 2018

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## Abstract

**Introduction:** Intellectual disabilities are sever chronic issue that distressing the affected people and their caregivers, This study aim to assess the burden and the psychological disease of the caregivers of the intellectual disabilities patients and to find out whether there is any relation between the perceived burden and the independent variable such as age, sex, education, economic status and the type of intellectual disabilities in specialized centres in Jeddah city.

**Materials and Methods:** Through a cross sectional design a convenient sampling method was used to select the study subjects who were attending the selected centres in Jeddah during the period from 1,July to 30 sept,2018. using systemic sampling technique, a 201 caregivers were included in the study (130 Cerebral Palsy and 71 Autism), The (Zarit burden interview) and the(general health questioner 28) were used to assess the burden and the psychological disease of the caregivers.

**Main Results:** The study showed that burden and general health score were significantly correlated with the risk factors of age, marital status, number of children and monthly income of the caregivers of cerebral palsy patients, while there is no significant difference between participants of the care givers of the Autism patients. The mean of subjective and objective burden of the caregivers for the two intellectual disabilities was mild to moderate, while regarding the general health score the caregivers not suffering from any of the main domain psychological disease (anxiety/insomnia, somatic symptom, severe depression or social dysfunction).

**Conclusion:** Taking care of intellectual disabilities patients can be a burden to the caregivers as well as they suffer from negative life influence, which calls for more study in the future to increase the supports for caregivers.

**Keywords:** Caregivers, Intellectual disabilities, Burden, Psychological disease, Autism, Cerebral palsy, Saudi Arabia.

## Introduction

Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.<sup>1</sup> An intellectual disability is characterized by an intelligence quotient (IQ) below 70 (the average is 100) and significant difficulties in daily living activity such as self- care, safety, communication and socialization.<sup>2</sup> One type of Intellectual disabilities includes Autism Spectrum Disorder (ASD), a neurodevelopmental disorder that is defined as impaired social communication along with unusual restricted and repetitive behaviours.<sup>3</sup> ASD prevalence appears to be increasing globally with an estimated prevalence of 1 in 160 children worldwide.<sup>4</sup> Another type of Intellectual disabilities is Cerebral palsy (CP) .CP is major disease due to non-progressive brain injury. The disease is characterized by impaired voluntary movement and restricted cognitive ability and social developmental .It is categorized into: Spastic syndrome, Dyskinetic syndromes, Ataxic syndrome and Mixed syndromes.<sup>5</sup>

Worldwide, Intellectual disability prevalence range from 1.5 to more than 5 per 1000 live birth.<sup>6</sup> In Saudi Arabia, prevalence rate is 23.4/10,000 live births.<sup>7</sup> With increase in the numbers of children with disabilities it raised concern about burden and psychological health of the informal caregivers.<sup>6</sup>

Care givers is a person who provide the care directly to whom in need. These unpaid caregivers are usually close family members like parents. Care giver burden is multidimensional.<sup>6</sup> Informal caregivers can experience stress and depression. Mental distress, economic, and social/family components, can have negative health consequences and poor quality of life.<sup>6</sup>

Multiple studies have documented the negative impact a disable child has on the daily lives of parents or caregivers, causing difficulties at home and straining family relationships. A study conducted at university teaching hospital, Zambia on care of child with CP found that more than 50% of the participants needed help with caring.<sup>8</sup> Another study about depression among parents of indivual with CP showed 38.2% prevalence of depression.<sup>9</sup>

About autism spectrum disorder, A study conducted on Quality of life among parents of South African children with autism spectrum disorder result that QOL of parents with ASD is reduced compared with those of typically developing children across all domains.<sup>10</sup> A study about predictors of psychological morbidity in parents of children with intellectual disabilities resulted a high depression and anxiety scores and the strongest predictor of psychological morbidity was caregiver burden.<sup>11</sup>

Limited numbers of studies have been published in kingdom of Saudi Arabia about psychological morbidities in parents of disabled children. Extensive literature search showed scarcity in researchs conducted on this topic in Jeddah. The current study aimed to assess burden in

caregivers of ASD and CP patients and determine factors influencing its extent.

**Material and Methods**

Across sectional study was conducted in Autism centre and Disabled child association in Jeddah, Saudi Arabia during period of 1<sup>st</sup> July to 30<sup>th</sup> of September 2019. A total of 300 caregivers who were attending the selected centre were included in the current study by proportional 3:1 of CP: autism, the sample size was calculated using Raosoft calculator program, with the following criteria the error 5% and Confidence level of 95% was assumed. A final sample size of 201 caregiver (130 CP, 71 Autism) was calculated. the sample was selected using systemic sampling with a random start approach.

**Tool of the Study**

Using self-administered validated Questionnaire to collect the relevant data. The first part of the questionnaire included social demographics characteristics (age, sex, marital status, level of education, work, number of children, monthly income). The second and third part include two used, reliable and validated questionnaires in Arabic language. The General Health Questionnaire 28 (GHQ 28) was used to assesses somatic symptoms, anxiety, insomnia, depression and social dysfunction in four divided parts each contain 7 questions. Using the GHQ scoring result divided into negative and positive for each part. Zarit Burden Interview (ZBI) was used to assess the burden with 22 items that response ranges from 0 to 5, using the total score result categorized as little or no burden, mild to moderate burden, moderates to severe burden and sever burden. The dependent variable was the presence or absence of psychological morbidities using different parameters including GHQ 28 and the ZBI. The Independent variables were age, sex, marital status, level of education, work, number of children, monthly income.

**Results**

A among the 201 caregivers, 87.6% were female, 46.8% of them their age from 30 to 40 years with 23.8% between 20 to 30 years. 84.1% are married, 52.2% with Bachelor degree

while 46.8% have high school degree. 68.7% of caregivers are not working, 44.8% have 3 to 4 children with 61.7% their income ranges from 5000 to 10000 SR/ month (table 1).

For caregivers of children with autism (n=71), 35.2% have mild to moderate burden equally 35.2% have moderate to severe burden with 21.1% have no or little burden and 8.5% have sever burden .about domains of general health, 15.5% of caregivers positive for somatic symptoms, 31% reported anxiety/insomnia with only 7% with social dysfunction and 5.6% positive for severe depression. In determining significant factors using P\* based on independent sample t test and P\*\*based on one-way Anova, no statistically significant differences in the degree of self-burden attributed to differences in the demographic variables (p>0.05). Other than the statistically significant differences in anxiety/ insomnia (P\*=0.005), social dysfunction(P\*=0.047) attributed to educational level, there is no statistically significant differences in public health attributed to the difference in demographic values. While In caregivers of children with cerebral Palsy (n=130), 41.5% reported moderate to severe burden, 36.2% have mild to moderate burden with 13.1% with no or little burden and 9.2% with sever burden. About domains of general health, 36.9% reported somatic symptoms, 34.6% have anxiety/insomnia, 24.6% with social dysfunction and only 10% positive for severe depression. In determining significant factors using P\* based on independent sample t test and P\*\*based on one-way Anova, There are statistically significant differences in the degree of self- burden in care givers for children affected by cerebral palsy attributed to differences in demographic variables:age (P\*\*=0.008), Marital status (P\*=0.013), number of children (P\*\*=0.01), Monthly income (P\*=0.039). For general health, there was statistically significant difference in somatic symptoms attributed to differences in Marital status (P\*=0.044), and in anxiety /insomnia attributed to differences in number of child (P\*\*=0.019). There are statistically significant differences in to the difference in somatic symptoms (P\*\*=0.031) and severe depression (P\*\*=0.027) attributed to differences in Monthly income.

**Table1:** Characteristics of the sample (n=201).

Characteristics	Autism (n=71)		CP(n=130)		Total (n=201)	
	No	%	No	%	No	%
Gender:						
Males	12	6.0%	13	6.5%	25	12.4%
Females	59	29.4%	117	58.2%	176	87.6%
age:						0.0%
<20 year	3	1.5%	4	2.0%	7	3.5%
20-30 year	18	9.0%	48	23.9%	66	32.8%
30-40 year	36	17.9%	58	28.9%	94	46.8%
>40 year	14	7.0%	20	10.0%	34	16.9%
Marital status:						0.0%
Married	59	29.4%	110	54.7%	169	84.1%
Divorced	11	5.5%	17	8.5%	28	13.9%

widow	1	0.5%	3	1.5%	4	2.0%
Level of education						0.0%
High School	27	13.4%	67	33.3%	94	46.8%
Bachelor	42	20.9%	63	31.3%	105	52.2%
PhD / Master	2	1.0%	0	0.0%	2	1.0%
work:						0.0%
no working	47	23.4%	91	45.3%	138	68.7%
working	24	11.9%	39	19.4%	63	31.3%
child						0.0%
1-2 children	28	13.9%	42	20.9%	70	34.8%
3-4 children	31	15.4%	59	29.4%	90	44.8%
>=5 children	12	6.0%	29	14.4%	41	20.4%
Monthly income:						0.0%
<5000 SR	20	10.0%	20	10.0%	40	19.9%
5000 - <10000 SR	36	17.9%	88	43.8%	124	61.7%
10000+	15	7.5%	22	10.9%	37	18.4%

## Discussion

Intellectual disabilities are chronic disorders, characterized by neurodevelopmental disorders, resulting in intellectual deficits with abnormal adaptive functioning. The impaired adaptive functioning presents itself in three main domains: conceptual, social and practical, that affect individual's capacity to cope with everyday activities; which have distressing impact on the affected people as well as their caregivers.<sup>12</sup> Worldwide, the prevalence of Intellectual disability ranges between 1.5 to more than 5 per 1000 live birth.<sup>13</sup> In Saudi Arabia, the prevalence rate of intellectual disability reaches up to 2.34 per 1000 live births.<sup>14</sup>

By definition, caregivers are the persons who carry the responsibilities to meet the patients physical and psychological needs of the dependent patients. The term "caregiver burden" is used to describe the physical, emotional and financial toll of providing care. In the current study, the average score recorded on the scale of self-burden in ASD caregivers was (36.54), while, it reached up to (40.00) in CP caregivers, which indicate mild to moderate degree of burden in both groups. These results come in accordance with what had been reported among caregivers of mentally ill patients in rural area in India,<sup>15</sup> in caregivers of obsessive-compulsive neurosis in Brazil<sup>16</sup> and mentally ill patients in Palestine.<sup>17</sup> As the current study showed that among care givers of ASD 31% positive for anxiety / insomnia and 5.6% have severe depression, compare to study done in Oman, showed that depression more prevalent in care givers of ASD (48.6%) compare to normally developmental children where anxiety reach up to (46.1%), also same study showed that depression and anxiety is higher in care giver of children with intellectual disabilities<sup>(18)</sup>. Whereas in care givers of CP, 36.9 % have somatic symptoms, 34.6% positive for anxiety /insomnia, 24.6% with social dysfunction and 10% have severe depression, the same finding reported in study that published in Iran,2010 showed that having child with CP increases the risk of developing depression in mothers as much as 2.26 times.<sup>19</sup>

In the current study, the overwhelming majority of caregivers were females (87.6%), which emphasize the fact that the mothers remain the principal persons involved in the care process. Our result accords the findings of Schneider et al (2010), who reported dominance of female caregivers, they added that females are more prone to psychological burden for many reasons, first because they spend more time in caregiving than males due to their social role; second is the physiological role of oxytocin hormone which contribute in distress of the women.<sup>20</sup> A Statistical significant differences were observed in experiencing (anxiety/ insomnia, social dysfunction) among our ASD caregivers according to their educational level ( $p < 0.05$ ), where the average score was higher among low than the higher education levels. The same was reported by Zahid & Ohaeri (2010); Juvang et al (2007) who found that there was a negative correlation between caregiving burden and educational level; one of the explanatory assumptions, is that the higher the level of education, the higher is the income which helps in decreasing financial burden related to caregiving for mentally ill family member, the second assumption, is that they tend to be knowledgeable enough to deal with stressful events.<sup>21, 22</sup>

On the same line, statistically significant difference was observed in the average score of somatic symptoms in caregivers for children affected by cerebral palsy according to marital status, which comes in congruence with the findings of To'meh (2013) who addressed that objective burden was higher in divorced and widowed than married caregivers, that was explained by deprivation from shared responsibilities in case of a single, divorced or widowed caregiver.<sup>23</sup> our results showed that CP caregivers' burden in objective and subjective domains increases in older ages. The significant difference observed in the level of burden of CP caregivers according to monthly income could be understood in light of the additional costs ensued from medical care of the patients, in addition to decreased productivity of the caregivers. This finding is similar to that found in United States of America<sup>24</sup> and Ghana,<sup>25</sup> where the authors stressed that caregivers are likely undergo an extra

financial burden due to the competing needs of their incapacitated relative, and their inability to be gainfully employed.<sup>26</sup>

In the current study, the level of CP caregivers' burden was directly associated with the number of children. In this respect, Yüki (2017) stated that the observed increased burden among caregivers of patients along the past few decades could be explained by the gradual shift from extended family structure, where support was provided more easily within family members, to nuclear family structure, with limited choices for who should care for the patient.<sup>27</sup>

## Conclusions

Caregiving for Intellectual disabilities' patients is stressful for caregivers; in terms of burden, mild to moderate degrees were found in caregivers of patients with autism and cerebral palsy. In our study, females were the dominant caregivers. While the extent of burden for autism patients was influenced by educational level of the caregivers; extra factors were associated with the degree of burden for caregiving cerebral palsy patients; it included age, marital status of the caregiver, monthly income and number of children.

## Recommendations

From the findings of the current study, the following are strongly recommended:

1. Deliberate efforts should be made to establish subsidized social support for caregivers of patients with intellectual disabilities; the support should include financial and psychological domains.
2. Tailored support should be organized and directed towards caregivers with potentially higher risk of developing stress and burden namely; non married elderly caregivers, poor financial income, low educational level and increased number of children.
3. Further qualitative researches are needed to explore more factors associated with burden in caregivers of patients with intellectual disabilities.

**Conflict of Interest:** None.

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**How to cite this article:** Alhumedi N, Maimani D, Alghamdi A, The Prevalence of Psychological Morbidities and the Determinant of care givers of children with intellectual disabilities, in specialized centers in Jeddah 2018. *J Prev Med Holistic Health* 2019;5(1):27-31.