

# A Study of Burden, Quality of Life assessment, Psychiatry Morbidity in Terms of Depression, Anxiety, and Stress in Caregivers of Patients with Intellectual Disability

Rajiv Arora<sup>1</sup>, Sumanjeet Kaur<sup>2</sup>, Neeru Bala<sup>1</sup>, Gurinderbir Singh<sup>3</sup>

<sup>1</sup>Associate Professor, Department of Psychiatry, Government Medical College, Amritsar, Punjab, India, <sup>2</sup>Assistant Professor, Department of Psychiatry, Government Medical College, Amritsar, Punjab, India, <sup>3</sup>Junior Resident, Department of Psychiatry, Government Medical College, Amritsar, Punjab, India

## Abstract

**Background:** Psychiatric illnesses such as depression, adjustment disorders, and anxiety disorders are common in caregivers of the patients with Intellectual disability and are likely to reduce patient's quality of life (QOL).

**Objectives:** Study of Burden, QOL assessment, Psychiatry morbidity in terms of depression, anxiety, and stress in caregivers of patients with Intellectual Disability.

**Materials and Methods:** The relatives/caregivers of the patients to be involved in the study were assessed. Those meeting the inclusion criteria were further evaluated using Zarit Burden Interview, World Health Organization QOL -BREF, and Depression, Anxiety, and stress scale-21.

**Results and Conclusion:** The burden assessed as per scoring scales showed that higher the intellectual disability, more the burden severity was found in caregivers. Most of the caregivers were suffering from mild to moderate depressive symptoms, thus affecting their QOL. Routine assessment of burden and psychiatric morbidity in the caregivers will help to reduce their burden and thus help them care for their children more appropriately and efficiently.

**Keywords:** Intellectual disability, Depression, Burden, Stress

## INTRODUCTION

Individuals suffering from intellectual disability have neurodevelopmental deficits having limitations in *intellectual functioning* and *adaptive behavior*. The above-mentioned disabilities have their origin and manifest before the age of 18 years and may be associated with other related problems including neurodevelopmental (e.g., autism spectrum disorders, and attention deficit hyperactivity disorder), some other psychiatric disorders (e.g., depression, and anxiety), neurological (e.g., infantile cerebral palsy),

and medical conditions (e.g., meningitis). Intellectual functioning tested includes a wide range of mental activities such as the ability of logical reasoning and problem-solving, learning and verbal skills.<sup>[1]</sup>

Adaptive functioning encompasses three domains including the conceptual domain (language, knowledge, and memory), the social domain (empathy, social judgment, and rule-following ability), and the practical domain (self-care, organization, and daily living skills). It is estimated to range between 1–3%, with a male to female ratio of 1.6:1 in the Western world.<sup>[2]</sup> Its prevalence in developing countries is estimated to range from 10 to 15/1000 children among whom 85% have a mild intellectual disability. The etiology of intellectual disability mainly comprises of the causes related to genetic abnormalities and environmental exposure. Genetic abnormality includes single gene mutation, copy number variation, or chromosomal abnormality leading to inborn errors of metabolism, neurodevelopmental

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**Corresponding Author:** Dr Neeru Bala, Associate Professor, Department of Psychiatry, Government Medical College, Amritsar, Punjab, India.

defect, and neurodegeneration. Environment exposure such as maternal exposure to toxin/infectious agents, uncontrolled maternal medical conditions, complications related to delivery, post-natal trauma, and exposure to various toxin/infectious agents. The commonest known preventable or environmental cause of intellectual disability is fetal alcohol syndrome, most common chromosomal cause is Down syndrome and the genetic cause being Fragile X syndrome. Intelligence quotient of 70 or below suggests intellectual disability diagnosis.<sup>[2]</sup>

It is further seen that the demand of the care givers of children with developmental disability especially intellectual in nature is much more than the other disabilities. These caregivers are usually the mothers, elderly or the unemployed members of the family. These people normally never planned to be caregivers but became accidentally with the need unavoidable. The caregivers are never prepared for this role and when given the same, finds It very demanding later on. Factors that contribute to poor health outcomes of the caregivers include the severity of the disability, child's behavior, child's temperament, low self-esteem, and poor social support.<sup>[3]</sup>

It is observed commonly that the parents suffer from different emotional and psychological problems if one child is disabled in family. Attitude of the society produces stress among family members. Even marital relationships suffer excessively due to guilt, shame, blame, and anxiety.<sup>[4]</sup>

A disabled child, regardless of the type of the disability, brings difficulties into the family members. It mainly includes mental health, financial situation, education, lifestyle changes, health relationships with the family and social environment, and the child's disability. Research studies point out that mother takes on a more active role.<sup>[5]</sup> When the child showed a high level of dysfunction with more frequent episodes of anxiety and depression, parents reported more psychiatric symptomatology. In such parents, social support is inversely related to anxiety and depression, whereas behaviors of their children are positively associated with these symptoms. Mothers experience more stress than fathers, higher caregiver burden, and a low sense of coherence.<sup>[6]</sup> This may be strenuous for the parents and put a major impact on their quality of life (QOL). Caring for disabled children can be a physically and mentally strenuous resulting in compromised QOL of the carers too. Even the carers need help to cope with the physical, mental, and emotional stress, they are bearing while caring for their loving children. It is also important to note that caring for a child with a disability does not equally affect all the families. There are families who cope well despite facing a lot of adversities. A number of factors that can affect the QOL of carers which include severity of the illness of the

child, presence of behavioral problems, socioeconomic and education status of the family, low social support.<sup>[7]</sup>

The studies conducted earlier stated that the mean caregiver burden was minimal to moderate in all families. Children suffering from intellectual disability are regarded as a burden by their family members. Negative attitude of the parent leads to rejection of such disabled children. This puts adverse impact on the interactions within the family. Intellectual disabled children should be offered support by family members to cope with stressful situations and in their rehabilitation.<sup>[8,9]</sup>

Other Studies reported that stress is related to the severity of intellectual disability, being maximum in those children suffering with severe-to-profound retardation. Mothers perceived much more stress and burden in caring for their children than fathers. These studies also revealed that these caregivers also faced various kinds of challenges, such as psychological, social, and economic challenges other than poverty. Caregivers felt stressed and burdened. They suffered from sadness for various reasons including the task of giving care, worries about the future lives of their kids, and the cognitive and the behavioral changes of their children. They are even stressed because of inadequate social services for their children and the stigma attached to these disabilities.<sup>[8-10]</sup>

It is important to address stigma in cases of intellectual disability. Only few studies have been conducted in past specifically focusing on the caregiver burden and the impact on QOL of the family members rather than mental illness. Stigma associated with intellectual disability is present across all ethnic groups, although it appears to be increased among those from developing countries.<sup>[11,12]</sup> The aim of the present study conducted was to identify burden, assess QOL and psychiatric morbidity in terms of depression, anxiety, and stress in the caregivers of children with intellectual disability.

### **Aims and Objectives**

1. To study the burden in caregivers of patients of Intellectual disability.
2. To study QOL of caregivers of patients of Intellectual disability.
3. To study psychiatric morbidity in terms of depression, anxiety, and stress.

### **MATERIALS AND METHODS**

The study was conducted in the Department of Psychiatry, Government Medical College, Amritsar and Institute of Mental health Amritsar. A random sample of 50 relatives/ care givers of the patients of Intellectual disability who agreed to participate was informed about the precise aim of

the interview and a written informed consent was taken from them. The subjects of the study conducted were assessed using Zarit burden Scale, World Health Organization QOL-BREF (WHOQoL-BREF), and Depression, Anxiety, and stress scale-21 (DASS-21) questionnaire. The study did not interfere in the treatment and management of the patients. Relatives/caregivers were reassured about the confidentiality of the information given by them. Data collected was analyzed through standard statistical methods.

**Inclusion Criteria for Key Caregivers/Relatives**

1. Identified current caregivers of patients should be aged more than 18 years.
2. Caring and living with patient for more than 1 year.
3. Not suffering from any chronic illness for the past 1 year (medical/psychiatric).
4. Agreed to give informed consent.

**Exclusion Criteria**

1. Caregivers who had a cognitive impairment or an intellectual disability.
2. Children and young people <18 years.
3. Caregivers not giving consent.
4. Uncooperative caregiver.

The study sample was assessed using following documents:

**Self-Structured Sociodemographic Proforma**

*Zarit Burden interview*<sup>[13]</sup>

It is a popular caregiver self report measure used by many aging agencies. The revised version contains 22 items and each item on interview is a statement which caregiver is asked to endorse using a 5- point scale.

*WHOQOL-BREF*<sup>[14]</sup>

WHOQOL is a QOL assessment developed by the WHOQOL Group with fifteen international field centers, simultaneously, in an attempt to develop a QOL assessment that would be applicable cross-culturally.

*DASS-21 questionnaire*<sup>[15]</sup>

The Items DASS-21 is a set of three self-report scales designed to measure the emotionally states of depression, anxiety, and stress. Each of the three DASS-21 scales contains 7 items, divided into subscales with similar content.

**Statistical Analysis**

At the end of the study, the data was collected and analyzed using appropriate statistical methods.

**RESULTS**

Fifty caregivers of the patients suffering from intellectual disability were assessed. Of these 60% of the patients

suffered from mild, 22% from the moderate, and 18% suffered from severe intellectual disability.

<b>Intellectual disability</b>		
<b>Severity</b>	<b>No of patients</b>	<b>percentage</b>
Mild	30	60
Moderate	11	22
Severe	9	18
Profound	0	0

<b>Zarit Burden Interview</b>	
<b>Burden</b>	<b>No of caregivers (%)</b>
Little/no burden	9
Mild-to-moderate	19 (38%)
Moderate-to-severe	22 (44%)
Severe	0

<b>DASS-21 Questionnaire</b>			
	<b>Depression</b>	<b>Anxiety</b>	<b>Stress</b>
Mild-to-moderate	16 (32%)	12 (24%)	24 (48%)
Severe	4 (16%)	9 (18%)	9 (18%)

<b>WHOQoL-BREF</b>	
<b>Domains</b>	<b>Mean±SD</b>
Physical health	13±1.52
Psychological	12±1.45
Social relation	11±1.55
Environment	9±1.21

Of the caregivers assessed, 22 (44%) had moderate-to-severe category of burden assessed by zarit burden interview, 19(38%) of the subjects suffered from mild to moderate degree of burden, and 9 (18%) had little to no caregiver burden which was almost similar to the results of the previous studies conducted.

The results showed that 40% of the caregivers suffered from depression assessed by DASS-21 scale out of which 32% suffered from mild to moderate degree of depression and 8% suffered from severe depression.

The results showed that 42% of the caregivers suffered from anxiety as assessed by DASS-21 scale out of which 24% suffered from mild to moderate degree of anxiety 18% and suffered from severe anxiety issues.

The results showed that 60% of the caregivers suffered from stress as assessed by DASS-21 scale out of which 48% suffered from mild to moderate degree of stress and 12% suffered from severe stress issues.

The QOL of the caregivers was assessed using WHOQoL-BREF scale which concluded that out of all the four domains of the scale mentioned maximum impact was seen

on psychological domain with a mean score of  $13 \pm 1.52$ , followed by physical domain ( $12 \pm 1.45$ ), social domain ( $11 \pm 1.55$ ) and environmental domain ( $9 \pm 1.21$ ).

## DISCUSSION AND CONCLUSION

The following study conducted had an aim to assess the burden, impact on QOL and psychiatric morbidity in terms of depression, anxiety, and stress in the family members of the intellectually disabled patients. Similar studies were also conducted in the past with same aim. The results of the present study concluded that the family members of such disabled patients had significant caregiver burden on them, maximally moderate-to-severe degree in intensity. Similar results were depicted by a study conducted in India in the year 2014–2015 by Bhatia *et al.*<sup>[16]</sup> A significant impact was seen on the QOL of the caregivers, affecting maximally the psychological domain as also seen in the studies conducted in the past. One such study conducted by Chou *et al.* in the year 2009 in China interpreted the similar results.<sup>[17]</sup> On applying DASS-21 on these subjects, it was found that the caregivers suffered from significant amount of depression and anxiety due to the underlying stress related to the worsening conditions of their disabled children, their loved ones, affecting further their interpersonal relations and other aspects of their lives mainly the social and environmental domains. It was clearly noticed that this impact on the caregivers was directly related to the severity of the intellectual disability of their children and the cognitive and behavioral changes seen in them.

The study conducted had its own limitations. The sample size was small, also the subjects of the study assessed were taken from the tertiary care centers which indirectly shifted the results slightly to the severe side as being a tertiary healthcare center more sick and patients with severe disability approach the present place of the conduction of the study.

A single Intellectual disabled child in the family, severity of their illness, societal attitude can put a major impact on the emotional and the psychological health of the primary caregivers of these patients. Awareness, better accessibility to the services for these patients along with psychosocial

support of the other family members and society as a whole can help in positive adaptation.

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