



CAREGIVER BURDEN AMONG PRIMARY CAREGIVERS OF CHILDREN WITH INTELLECTUAL DEVELOPMENT DISORDER AND ITS ASSOCIATION WITH PERCEIVED STRESS

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ABSTRACT

Background: Family is considered a main support system for children with Intellectual developmental disorder all over the world and especially in a country like India. Hence, the caregivers are mostly the parents or immediate family members of the children. Many caregivers do not adapt to the news of raising a child with special needs. They fear social embarrassment and are unable to cope with the stigma associated with intellectual developmental disorder. This in turn leads to social isolation amongst the caregivers which can lead to depression and loneliness with intellectual developmental disorder. In this study, we would mainly focus on how the caregiver burden in primary caregivers of children diagnosed with intellectual developmental disorder and its association with the stress levels.

Aims: To find out the caregiver burden in primary caregivers of children with Intellectual developmental disorder and to associate the level of caregiver burden with perceived stress.

Methods: Identify the primary caregiver of patients coming to the Department of Psychiatry and Department of Paediatrics with a diagnosis of Intellectual Developmental Disorder. Appropriate scales will be applied and data will be subjected to statistical analysis and Caregiver burden will be associated with stress of the primary caregiver.

Results: significant positive correlation was found between PSS and CBS with a r-value of 0.43 i.e. with increase in stress, burden also increases. Severe burden was related more with higher disability of IDD. When duration of disability was analysed statistically according to CBS using chi square test, significant difference was found with a p-value of 0.029. Higher PSS was related more with higher disability of IDD. When duration of disability was analysed statistically according to PSS using chi square test, significant difference was found with a p-value of 0.038. **Conclusion:** More consideration should be given to local environmental, caregiver, and child-related risk factors in the development of policy and practice for the management of burden experienced by the caregivers of children with intellectual disability.

KEYWORDS caregiver burden, perceived stress, intellectual disability



INTRODUCTION

Intellectual disability, sometimes known as mental retardation, is a spectrum condition that affects a wide range of people. In most cases, it begins before a person is 18 and is characterized by severe deficits in cognitive ability and adaptive behavior (AAIDD, 2007). The American Association for Intellectual & Developmental Disability (AAIDD, 2007) & the Diagnostic & Statistical Manual of Mental Disorders have recently accepted new names to replace the older terms "intellectual disability" & "mental retardation" (DSM- 5, 2013). With the forthcoming 11th edition of the "International Classification of Diseases" (ICD-11), the World Health Organization (WHO) has also approved a new name: "Intellectual Disability" ("Salvador-Carulla et al, 2011"). Although the change in terminology is encouraging, much more must be done to ensure that people with intellectual impairments and their caregivers/parents are shown the respect and regard they deserve in order to enhance the quality of life for themselves & their children ("Ali et al, 2008"). Identity disorder (ID) might have a genetic cause or be the outcome of a disorder that disrupts normal brain development. The majority of kids with ID don't show any symptoms until they're in preschool. Formal testing results formed the basis for the diagnosis. The probability of having a child with ID is reduced when pregnant women receive the appropriate prenatal care. The best potential level of functioning can be attained by youngsters with the aid of numerous specialists, therapy, and special education¹. Intellectual disability affects about 2% of the population in India. Between 0.22 and 32.7% of the Indian population suffers from intellectual impairment. Inherited by those closest to us, mental illness is a heavy weight. Depending on the degree of their condition, patients with mental retardation become increasingly reliant on their caregivers. For those who suffer from mental illness, family members often play a vital role in providing treatment.

They shoulder the financial burden of mental health treatment and care² in addition to providing emotional and physical support. In the realm of caregiving, it has long been acknowledged that raising a kid with a disability is a significant source of stress and strain for the family unit. Additional care for a disabled child has been shown in Western research to significantly increase parental stress and cause strain on family connections ("Banks, 2003; Slope & Turner, 1993"). These needs don't go away once a child becomes an adult, so families always have to be ready to adjust to new difficulties ("Krauss & Seltzer, 1998"). Caregivers of persons with mental illness are particularly vulnerable to stress and burnout because of the constant demands of assisting and monitoring their patients with daily tasks. The term "caregiver burden" is used to describe the significant emotional toll taken on by those who provide care for a sick loved one. There is a great deal of mental, emotional, and financial strain put on a family by having a kid with intellectual handicap. Having a child with mental retardation causes a lot of stress on a family. Social mockery and stigma are commonly cited as causes of the problems². It's common knowledge that having a lot on your shoulders can damage your marriage and your ability to spend meaningful time with your kids. However, the ability to overcome hardship as a unit aids in the recovery of both family members and the larger system³. The mental, physical, emotional, social, and financial strains of caring for a family are all well-documented. All members of the family can feel the effects of a sick or suffering individual ("Sivrikaya&iftçiTekinarslan, 2013"). Parents of such children bear the emotional weight of their children's social isolation and the sadness that results from that. It has been shown that ("Timuçin, 2018"). Expenses for the child's care and education outside of the public system may place a financial strain on the family. However, while caregiver burden has been characterized as the strain or load borne by an individual who cares for a family

member with a handicap, little emphasis has been paid to it in the literature (“Floyd & Gallagher, 1997”). The term “caregiver load” refers to the emotional and mental toll that taking care of another person can take on those who are tasked with providing such care (“Erikson & Upshur, 1989”). The impact on the caregiver's life is determined by the caregiver's own personal assessment of the burden, rather than by the assessment of other members of the caregiver's immediate family or healthcare professionals (“King, King, Rosenbaum, & Goffin, 1999”)⁴.

MATERIALS AND METHODS

Place of Study:

The study was conducted in the Department of Psychiatry, TMMC&RC, Moradabad.

Type of Study:

Observational cross-sectional study.

Study period:

This study was time bound starting from the approval of ethical committee till 30th June 2022.

Study Population:

The study was done on all diagnosed primary caregivers of patients with Intellectual Developmental Disorder presenting to the Department of Psychiatry and Department of Pediatrics OPD and IPD.

Inclusion Criteria

1. Primary caregivers of children diagnosed with intellectual developmental disorder.
2. Age of children below 18 years.
3. Willingness of the primary caregivers to participate in the study.

Exclusion Criteria

1. Primary caregivers suffering from any psychiatric morbidity either active or in remission.
2. Primary caregivers above 60 years of age.
3. Children having any other comorbidity with intellectual developmental disorder.
4. Children having any physical disability.

Methodology

1. Patients coming to the Department of Psychiatry and Department of Paediatrics with a diagnosis of Intellectual Developmental Disorder.

2. Identify the primary caregiver.
3. Detailed psychiatric interview by the consultant psychiatrist to assess for any active mental disorder.
4. Appropriate scales was applied and data was subjected to statistical analysis.

The following scales were applied:

1. Perceived stress scale-10
2. Caregiver burden scale

Statistical analysis:

Under the supervision of a statistician, the data was tallied in an excel sheet as described above. For statistical analysis, the means & standard deviations of the measurements for each group were used (SPSS 22.00 for windows; SPSS inc, Chicago, USA). The level of significance was established at p 0.05, and the chi square test was used to evaluate the difference between the two groups.

RESULTS

The present cross-sectional study was conducted in the Department of Psychiatry, TMMC&RC, Moradabad among 50 diagnosed primary caregivers of patients with Intellectual Developmental Disorder presenting to the Department of Psychiatry and Department of Pediatrics OPD and IPD. The aim of the research was to find out the caregiver burden in primary caregivers of children with Intellectual developmental disorder and to associate the level of caregiver burden with perceived stress and personality profile of the caregivers. Out of 50 children with IDD, 72% and 28% were having age of >9 and 3-9 years respectively. Hence maximum children with IDD belonged to >9 year of age.

Males (62%) were comparatively more as compared to females (38%) in this study. In 68%, 24% and 8% of the children, IDD was detected at <1-year, 1-5 year & >5 year age respectively. Most of the primary caregivers in this study were mother (74%). 76% and 24% of the primary caregivers in this study belonged to rural and urban area respectively. Only 24% of the primary caregivers in this study were illiterate while 34% were graduated. In this study, 54% of the primary caregivers were not working. Private and government job was revealed in 28% and 18%

of the of primary caregivers respectively. In this study, 64% of the primary caregivers belonged to Muslim religion.

Low, moderate and high PSS was revealed in 38%, 48% and 14% of the primary caregivers respectively (Figure 1).

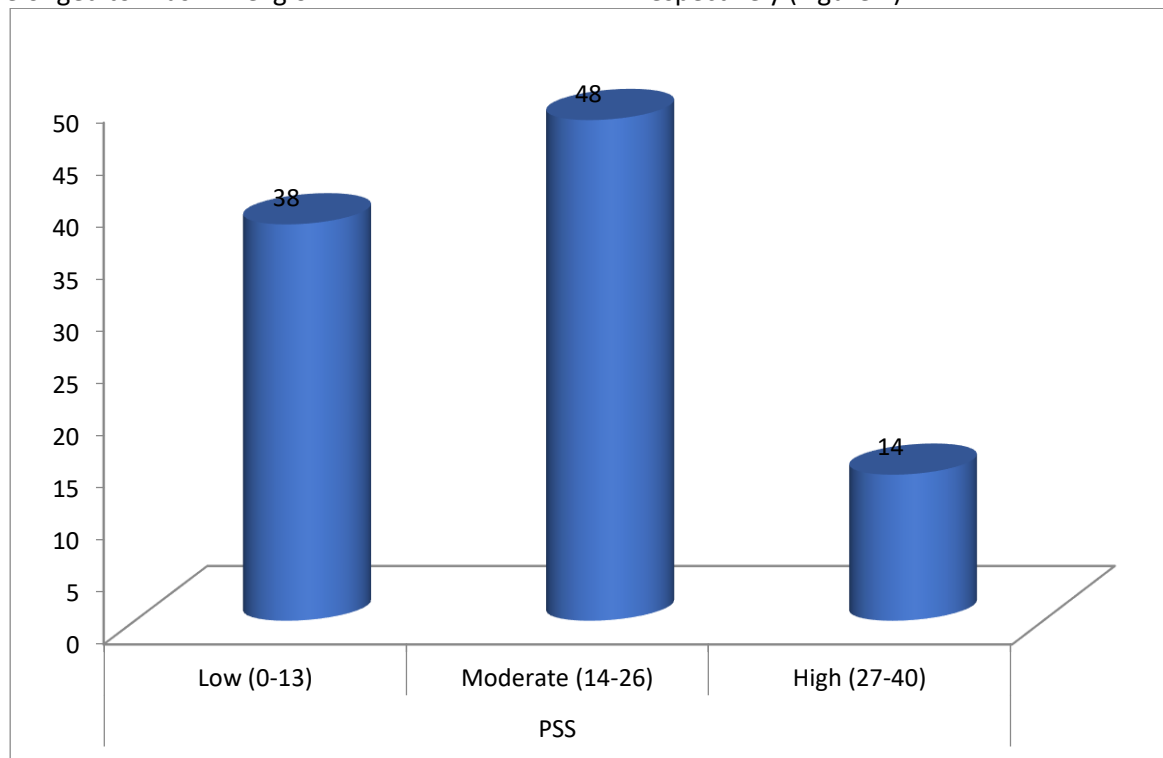


Figure 1: Perceived stress scale (PSS) among the study subjects

Severe burden was reported among 16% of the subjects while no burden was revealed in 6%. Mild to moderate burden and moderate to severe burden was revealed in 24% and 54% of the primary caregivers respectively (Figure 2).

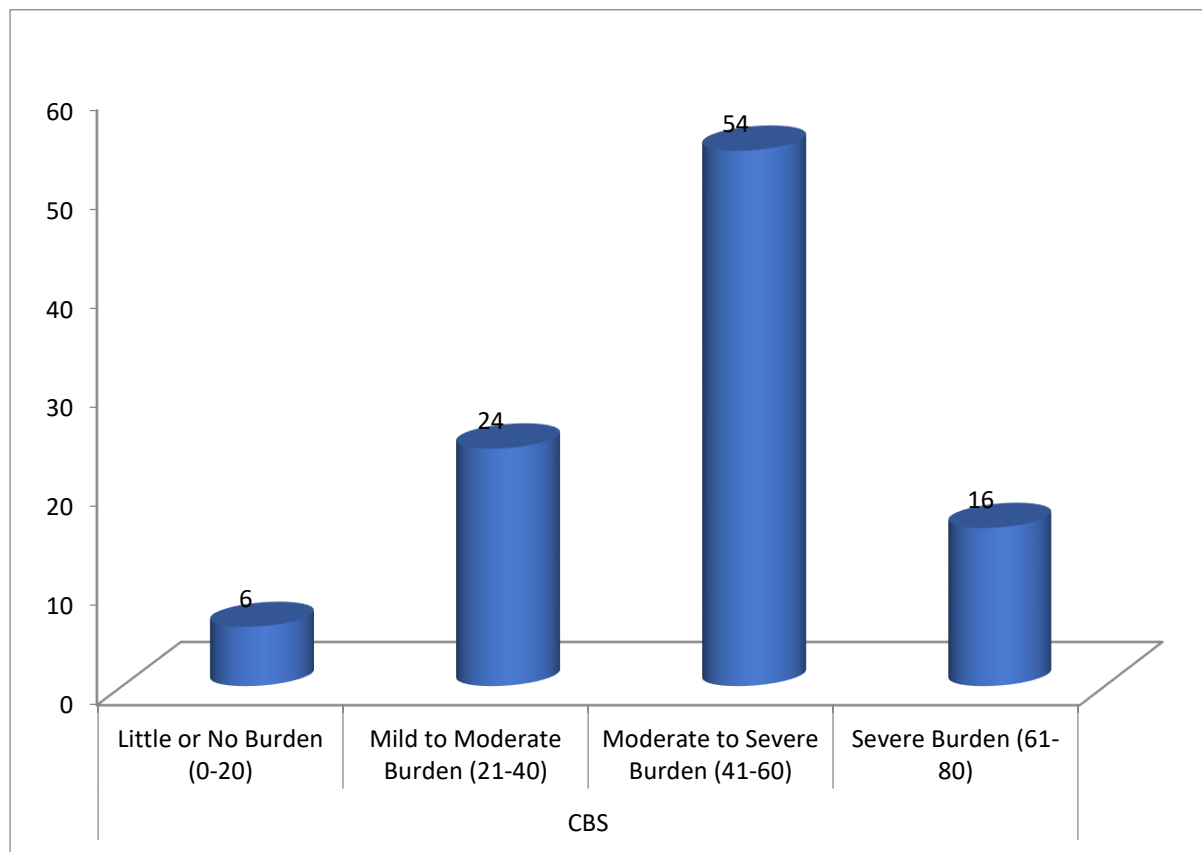


Figure 2: Caregiver burden scale (CBS) among the study subjects

According to Pearson correlation analysis, significant positive correlation was found between PSS and CBS i.e. with increase in stress, burden also increases (Table 1).

Table 1: Correlation between Perceived stress scale (PSS) and Caregiver burden scale (CBS)

Variables	r value	p value
PSS and CBS	0.43	<0.01*

*: statistically significant

In this study, moderate to severe burden and severe burden was reported among 22, 5 and 3 subjects suffering from IDD since <1, 1-5 and >5 year respectively. Hence severe burden was related more with higher disability of IDD. When duration of disability was analysed statistically according to CBS using chi square test, significant difference was found (Table 2, Figure 3).

Table 2: Association of duration of disability with CBS

CBS	Age of detection of disability			p value
	<1 year	1-5 year	>5 year	
Little or No Burden (0-20)	3	0	0	0.029*
Mild to Moderate Burden (21-40)	9	3	0	
Moderate to Severe Burden (41-60)	22	4	1	
Severe Burden (61-80)	0	5	3	

*: statistically significant

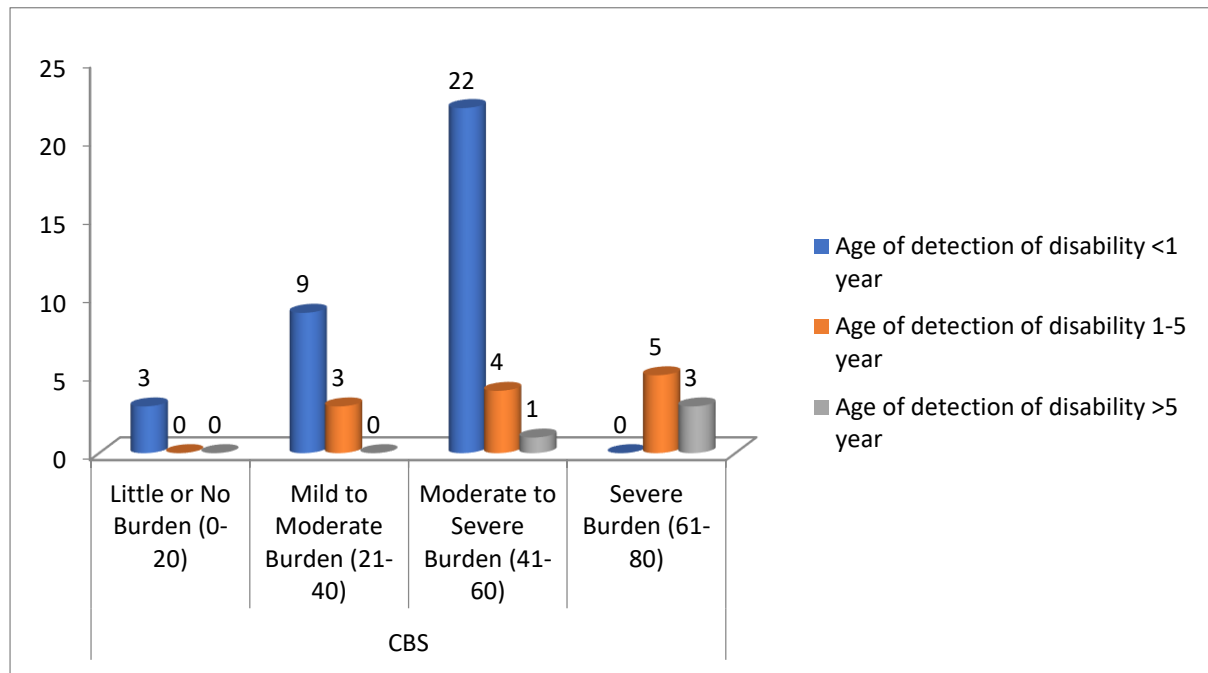


Figure 3: Association of duration of disability with CBS

In this study, moderate and high PSS was reported among 16, 3 and 4 subjects suffering from IDD since <1, 1-5 and >5 year respectively. Hence higher PSS was related more with higher disability of IDD. When duration of disability was analysed statistically according to PSS using chi square test, significant difference was found (Table 3, Figure 4).

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Table 3: Association of duration of disability with PSS

PSS	Age of detection of disability			p value
	<1 year	1-5 year	>5 year	
Low (0-13)	18	1	0	0.038*
Moderate (14-26)	16	8	0	
High (27-40)	0	3	4	

*: statistically significant

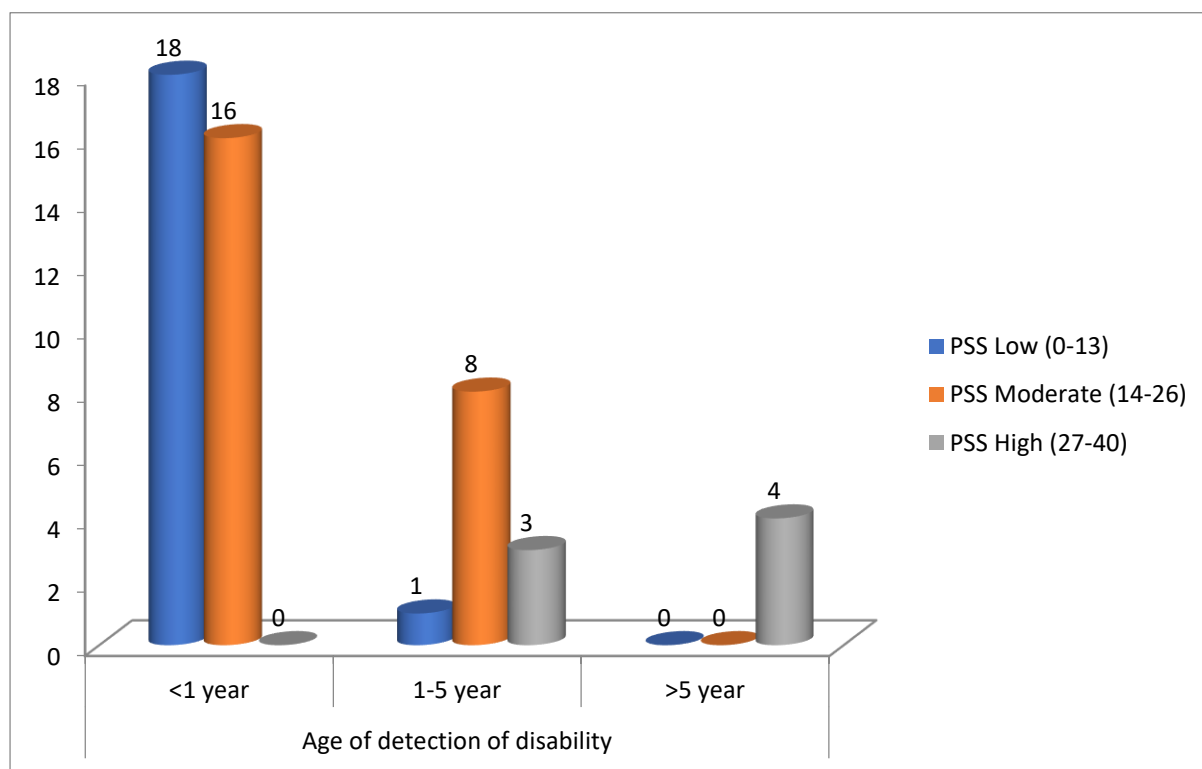


Figure 5: Association of duration of disability with PSS

DISCUSSION

The most prevalent developmental disorder is one with an intellectual handicap. The effects of intellectual disability affect the person who has it as well as their family and community. Poor intellectual or mental aptitude & a lack of daily living skills are characteristics of intellectual disability. In their daily lives, primary caregivers for people with intellectual disabilities deal with a wide variety of scenarios. They encounter difficulties in terms of their physical health, mental health, and financial health. The physical, psychological, emotional, social, and economical issues that affect family members who care for a person who is ill or disabled are referred to as the "caregiver's burden." The potential burden areas include managing finances, having a social life, a job, managing one's physical and mental health, going to school, getting an education, raising children, and interacting with people outside the family⁵.

Correlation between Perceived stress scale (PSS) and Caregiver burden scale (CBS):

The results of the Pearson correlation analysis showed a positive and statistically significant relationship between the perceived stress scale (PSS) and the perceived burden scale

(CBS), suggesting that as stress levels rose, so did perceived burden.

According to research conducted by Sharma et al.⁶, the majority of the caregiving responsibilities for children fall on the shoulders of mothers, causing them to experience increased levels of stress and other mental health problems. In the event that the youngster is healthy, they will be able to handle it. Two-thirds of mothers in our study reported depression, and more than 90% had anxiety, because of the disproportionate strain of caring for a child with a persistent condition like ID. It's important to educate and empower men so they can contribute equally to child care.

In most families, the mother is the primary caregiver for her children. Mothers are socially expected to take on the primary role of caretaker in India. The overwhelming pressure and stress could eventually cause clinical depression. Both sets of caregivers felt overwhelmed and depressed. Parents of children who are not in school experience greater levels of load and depressive symptoms than those of children who have special needs in regular schools. The non-school group caregivers reported elevated

levels of despair and burden as compared to the special school group caregivers. Most of the carers in the non-school group had a substantial load, and no caregivers had a light burden. Depression was found to have a strong correlation with the amount of stress experienced by caregivers. Previous research (Vilchinsky N. et al.) revealed similar results⁸. In another study, Baxter, Cummins, and Yiolitis (2000) revealed that the amount of stress and burden experienced by parents with a kid with an MR/DD continued to be quite high and remained so over time⁴. Seltzer, Greenberg, Floyd, Pettee, and Hong (2001) used data from the Wisconsin Longitudinal Study to show that parents of children with disabilities were not significantly different from parents without children with disabilities in terms of education, marital status, health, or psychological well-being⁴. Significant literature links emotional strain to caring for a child with a developmental disability. Additional everyday responsibilities that prevent moms of disabled children from taking proper care of themselves are associated with higher levels of stress, according to the research (Leonard, Johnson, & Brust, 1993)⁴.

Association of duration of disability with CBS and PSS

22 participants, 5 participants, and 3 participants with IDD for 1, 1-5, and >5 years, respectively, experienced moderate to severe burden & severe burden. So, greater IDD impairment was associated with a greater burden. Using a chi-square test, CBS researchers discovered a statistically significant difference in disability length. Sixteen participants, three participants, and four participants with IDD for one to five years, or one to five years, or more than five years, respectively, indicated a moderate or high PSS. Consequently, greater PSS was associated with a greater degree of IDD impairment.

Eisenhower and Blacher and Malhotra & Sharma confirmed the findings of Bunga D et al⁷, which found that the degree of the impairment across the physical care, health, financial, social, shame, and specific thinking

domains increased with the duration of ID (p-value 0.001).

Soumitra Shankar Datta et al.³ found that age of kid was clinically linked with burden in univariate analysis. Possible causes for the correlation between a child's age and their level of burden include: a larger gap between the child's physical size and developmental capacity; the disability being more obvious; the child's educational placement, especially inclusion in mainstream classrooms; the inaccessibility of babysitters and respite care providers; a dearth of resources for dealing with the challenges of preadolescence; and a lack of information about how to manage the day-to-day life of children and adolescents. The greater individual health problem among ID children, greater overprotection from the caregiver, poor family functioning, excessive time and caregiving demands that the disability places upon parents, and the caregiver's coping strategy (problem-focused coping or emotion-focused coping) may all contribute to the caregiver's negative outlook on the child's disability and the high levels of burden they experience.

CONCLUSION

Raising a child with mental retardation can be a stressful and emotionally draining experience. Numerous engagements must be honored. The emotional toll of a child's ongoing struggle is a constant burden on their loved ones. In addition, loved ones have the burden of knowing that their suffering will only increase with time. Lastly, there are a wide variety of challenges associated with raising children who have intellectual disabilities. Grief, bitterness, disappointment, and frustration are normal human responses. At times, these emotions can become a mental health problem.

It's safe to say that the effects of ID are never confined to those directly affected by the condition, but rather ripple out to include their loved ones as well. There is a disproportionate amount of stress and sadness experienced by caregivers of children with intellectual disabilities. Caregivers of children with intellectual disabilities should have access to a support system to lessen the likelihood of despair and stress.

More consideration should be given to local environmental, caregiver, and child-related risk factors in the development of policy and practice for the management of burden experienced by the caregivers of children with intellectual disability.

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