Original Research Article

Perceived burden and treatment expectations of family members of adult individuals with Intellectual Disability

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ABSTRACT

Background: In India, most individuals with an intellectual disability live with their families. The present study examines the perceived burden of family members, treatment expectations, and awareness of disability benefits for adult individuals with Intellectual Disability (ID).
Methodology: A sample of 50 individuals registered in an Adult Psychiatry Unit was referred for intelligence assessment. The assessment was done using standardized psychological tests. Data was gathered using a semi-structured interview schedule during counselling the participants' family members. Data obtained was examined using descriptive statistics.
Results: Average age of participants was 27.5 years, and the majority 64%, were male patients. Comorbid conditions such as seizure disorder, psychosis and obsessive-compulsive disorder (OCD) were present in 46 % of the sample. Caregivers were primarily parents, and a higher level of family burden was due to behavioural problems. Half (50 %) of the sample was unaware of disability benefits.
Conclusion: Findings indicate the need to address caregiver burden and plan psychosocial rehabilitation and improve awareness about disability benefits and its implications more consistently across India.

Keywords: Intellectual disability, caregiver burden, disability benefits, tertiary care hospital

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INTRODUCTION

According to the definition given by the American Association on Intellectual and Developmental Disabilities (AAIDD), "Intellectual disability is characterised by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18" [1]. Intellectual disability (ID) has replaced the term mental retardation, and the definition of ID focuses on the strengths in adaptive behaviours [2]. Similarly, the severity levels (mild, moderate, severe, and profound), defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), are based on adaptive functioning in the conceptual, social, and practical domains [3]. The prevalence of ID is 1.04% (ranges from .05 to 1.55 %) across the life span [4-5]. The aetiologies of ID are multiple, and its prevalence can also be influenced by social, economic, cultural, racial, age, gender and other environmental factors [6-7]. Co-morbidity between ID and a wide range of psychiatric disorders and health problems in adults, adolescents, and children have been reported [8-10], often due to communication limitations and limited access to health care [11-12].

"Burden is a state of emotional, mental and physical exhaustion caused by excessive and prolonged stress, occurred when the parents felt overwhelmed and unable to meet constant demands" [13]. There is no denying that the families or individuals taking care of an individual with ID will be experiencing a drain in many aspects, including emotional and financial.

Even in the past, many individuals with ID have lived with their families and continue to do so [14-16]. Parents' role, such as the primary caregiver to such an individual, is continuous and lifelong [17]. Providing for everyday needs and coordinating service use are the two main primary functions of caregivers [18]. For a parent, particularly a mother, taking care of a child with ID can be often stressful, and it also affects the family members in their everyday life.

The supervision of the daily requirements of a child with ID can be "far-reaching, restrictive, and disruptive," and it can either be economical, social or emotional [19] and; the limitations in the availability of resources may differ in families.

There are increasing numbers of adults with ID living into middle and old age who are cared for by their parents, and there are demands and challenges faced by parents of such individuals [20]. The Social Care Institute for Excellence initiated 'The Road Ahead' project to explore the information needs of young people with ID and their parents and identified many aspects of transition that may be different for such individuals. For example, they may not have had any experience managing their own money, may face some barriers to establishing independent social lives, lack of access to transport or communication technology, and lack access to a peer group and are less likely to gain paid employment [21]. In India, the National Trust for the welfare of persons with autism, cerebral palsy, mental retardation, and multiple disabilities Act [22] has developed a compressive plan to address similar needs and care services.

Sometimes, the caregiver might not know how to support or give the required attention and care to a person with an ID because of insufficient knowledge and training. The awareness about the causes and interventions of ID are low, and services are primarily concentrated in urban areas [23]. Due to a lack of knowledge, they might even be unaware of community resources or know-how to avail of them.

In India, most individuals with ID have not been identified formally, and even those identified, the majority are stigmatised and undermined by the rest of society. Hence, individuals with an ID are not given the same opportunities compared to people without ID [24-25]. Their families experience stress and burnout since individuals with ID are mostly looked after exclusively by their parents and families.

Since individuals with ID have difficulty understanding life's experiences, the family members are to be sensitised about the condition and the disability benefits of the individual with ID [26]. In the present study, therefore, we aim to examine the perceived burden of family members, expectations from treatment and awareness of disability benefits among family members of individuals with ID.

METHODOLOGY

The study adopted a hospital-based cross-sectional design. A purposive sampling technique was used. Adult individuals with ID referred from the outpatient services of one of the adult psychiatry units in a large tertiary care hospital in South India were recruited. Data for this study came from consecutive referrals for assessment of intelligence between July 2013 and October 2013 (N=50). The referrals were made to the Clinical Psychology consultants of that Unit. A detailed evaluation was carried out by postgraduate trainees (MPhil clinical psychology) and was verified by senior consultants. IQ assessment was done by trainees using the Vineland Social Maturity Scale or Wechsler's Adult Performance Intelligence Scale or, Binet Kamat Test [27-29] as indicated for each case under the supervision of a consultant clinical psychologist. All tests have been tested for Indian norms and are routinely used in the Indian context for assessments and certifying people with ID. Following the assessment, an in-depth interview was conducted with the caregivers using a semi-structured interview schedule designed for the study and used by the MPhil trainees to obtain relevant information about caregiver burden, treatment expectations, and awareness of rehabilitation and disability benefits. Information provided by the caregiver was recorded on a predesigned proforma, and case files were also reviewed to collect relevant information such as the annual income of the family members and other relevant socio-demographic details.

The data obtained was analysed both quantitatively and qualitatively. Descriptive statistics such as frequency and percentages were used to describe socio-demographic variables, clinical profile, caregiver burden, treatment expectations and awareness of rehabilitation and disability benefits. The qualitative analysis consisted of content analysis of interviews to identify the major themes of caregivers' burden, treatment expectations, and awareness of rehabilitation and disability benefits.

RESULTS

Table 1: Socio-demographic Profile of the Sample of Adults with Intellectual disability (N=50)

Categories	N	%
Age		
16-25	27	54
26-35	17	34
36-45	02	04
46-55	02	04
56-65	02	04
Gender		
Male	32	64
Female	18	36
Marital Status		
Married	06	12
Single	44	88
Years of Formal Education		
Illiterate Population	33	66
6-10	17	34
Special School		
Attended	04	08
Not attended	46	92
Vocational Training		
Received	02	04
Not Received	48	96
Employment		
Employed	08	16
Unemployed	42	84
Family Types		
Nuclear	44	88
Joint	06	12
Family Members Occupation		
Professionals, Managerial, Small	13	26
Business	02	04
Clerical	18	36
Labour (manual/skilled)	17	34
Unemployed		
Annual Income of the Family (in Rupees)		
0-19999	22	44
20000-39999	21	42
40000 and above	07	14

The clinical profile of participants indicated that 16% had profound ID, 14 % had severe ID, 18 % had moderate ID, and 52 % had mild ID. In addition, half of them had other co-morbid conditions such as psychosis, bipolar affective disorder, obsessive-compulsive disorder (30%), seizure disorder or organic disorder (14%) and mild obesity with bulimia (2%). Around 48 % of the participants required specific care in activities of daily living (ADL) and self-help care. Thirty per cent of them needed vocational training and special education. At the same time, 12% required help in both self-help skills and behaviour modification and around 10 % required medication and help in self-care.

In terms of perceived burden, qualitative analysis of the interviews indicated a higher level of family burden (80 %) was due to behavioural problems like constant anger and aggression, poor personal care, unable to carry out responsibilities, financial constraints (14%), age-related factors (4%) and due to physical and emotional abuse (2%). Most of the caregivers' relationships with patients were both parents (50%), mothers only (16%), and family members such as sisters, brothers, grandfather (22%), wife (4%) and husband (4%). Resources available were in the form of family support in 60 % of the cases, 8% had financial backing, extended family support in 6%, workplace support around 10 %, financial support in 2 % and pension benefits in 2 %.

The most common expectation from the treating team was disability certificate only (32 %). Though the majority of caregivers did not have any expectations from other sectors (80%), some expected benefits like disability welfare schemes (4%), pension (4%), special school and vocational training (2%), medication (8%) and legal aid (2%). Only 42% per cent were partially aware of disability benefits. Four per cent had enquired about a legal case (over property issues and the possibility of applying for divorce in the future). IQ assessment was done for all the participants, and caregivers were psycho-educated; Disability certification was processed for only 92% of the adults with ID.

DISCUSSION

Intellectual disability (ID) poses diverse consequences for individuals and the family and society they live in [30]. Findings from this study show that most participants were below twenty-five years, suggesting that they present late to treatment because of lack of awareness, poor accessibility or affordability, and stigma associated with professional help-seeking. Male predominance in this sample could be because ID is slightly more common in males than females [4, 31], or males are more readily brought for help (32). In this study, most of the participants were uneducated, unmarried and unemployed and were looked after by the family members. Specific care required by them was mostly in daily living and self-help skills, thereby increasing dependence and caregiver burden, which has also been indicated in other studies [33,30]. Co-morbid conditions are frequent and pose an additional challenge in intellectually disabled adults [34-35].

Individuals with ID experience significant challenges in their adult life, and their caregivers, typically a spouse or elderly parents, experience significant burdens [36]. As the number of older adults with ID continues to grow, families and community agencies face the challenge of supporting these adults. They experience health concerns, restricted access to health care, fewer financial resources, and a lack of suitable jobs compared to adults without long-term disabilities. Besides, they have very few social support systems outside the family [18] and often, they are at the risk of abuse at the hands of others, harming their emotional well being [37], thereby generating a more significant family burden. Thus, most individuals with ID have a lifelong need for support. Modifying the living environments and assistive technologies to help them perform everyday functions in their current settings has increased the quality of life for adults with ID [38]. However, in India, such facilities are limited, and only families from upper socioeconomic strata can afford them. In this study, caregivers also reported burden due to behavioural problems, abuse and financial constraints. Parents' physical and psychological resources run down when the demands of caregiving increase; this is particularly true for elderly caregivers [39]. Literature indicates a negative impact of burnout on the caregiver's mental health, which can also take a toll on their physical health [40].

The most common expectation from the treating team was to obtain disability certification to ease the financial strain on the family. It must be noted that most of the family members in the study had an annual income below Rs. 20,000. Further, it has also been reported that most patients with ID were brought to tertiary care hospitals only for certification purposes [41]. In this study, treatment mainly was sought, expecting vocational guidance, behavioural symptoms management, daily living activities, medication, and being normal like others. In order to prevent unnecessary expenses and expenditure on ineffective interventions, families were educated about authentic evidence-based interventions or treatments.

The current study shows poor awareness about disability benefits and emphasises the importance of such awareness. Half of the caregivers were unaware of disability certification. A majority of the population was from urban belonging to lower socioeconomic status. Due to inadequate information and communication concerning the various aspects of legislation, the family members were not aware of all of the benefits provided by the government. The remaining half showed little awareness about travel concessions and pension benefits, children's education allowance, and availing guardianship. Therefore the little knowledge of the benefits they acquired may be on the account of its usefulness in their daily lives, such as concession on travel, tax benefits, and pension [42]. However, a limitation is that the caregiver has very little knowledge about the Acts and Rights of persons with intellectual disability [26,42]. Hence, their many struggles availing the much-needed benefits and timely assistance.

Family members explained the various benefits and concessions given by the Central and State Governments to individuals with ID, such as travel concession by bus/train, escort, maintenance allowance, the income tax deduction for parents [23,43] and mobilizing of funds for economic empowerment (e.g., NHFDC) [22]. They were also sensitised regarding socioeconomic rehabilitation highlighting vocational training and job placement services.

Reducing burden among carers will need a multipronged approach and can be achieved with the efforts of different stakeholders [44]. Thus, in this study, family members were educated about ID, co-morbid psychiatric conditions, rehabilitation measures and their caregiver burden were addressed. In addition, adaptive coping strategies were discussed to mitigate the effect of burnout and improving their wellbeing. A distinctive aspect of adult individuals with ID is "planning for their future and quality of life after the parent is no more" [45]. For adult IDs with less severe disability, adopting support services to improve their functioning may help. For those with severe disability, institutionalised care may be necessary [45]. Therefore, adequate preparation for the same is critical to ensure the transition of care is enabling rather than rendering the adult survivor of ID more vulnerable.

CONCLUSION

Despite the small sample size limiting the generalizability of findings, and no standardised measure was used to assess caregiver burden, the study findings have important implications. Very few studies have focused on adults with ID and their families. There is a need to acknowledge and provide for the emotional needs of parents and caregivers. Assisting family members to accept the problem, improving adaptive coping patterns to reduce stress and burnout and linking families to appropriate rehabilitation services are essential.

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