

## Research Article

# Profile of patients with intellectual disability visiting a tertiary care center in western India

Parag S. Shah\*, Srivani D. Shukla, Asha A. Patel, Shivangi S. Patel

Department of Psychiatry, Surat Municipal Institute of Medical Education & Research (SMIMER), Surat - 395010 Gujarat, India

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### \*Correspondence:

Dr. Parag S. Shah,

E-mail: drparagsshah@rediffmail.com

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### ABSTRACT

**Background:** Intellectual disability is commonly associated with variety of etio-pathological and co-morbid conditions influencing outcome of rehabilitative measures. Understanding of these factors helps in better management of disabled condition.

**Methods:** A qualitative retrospective case record review, of patients with intellectual disability, visiting psychiatry department of a tertiary care hospital, within a period of one year, was conducted to assess their epidemiological and clinical profile.

**Results:** Patients with Intellectual disability are brought to the hospital at all ages and commonly by their parents. Etiologically related various peri-natal factors (delayed birth cry and seizures being most common) as well as childhood medical conditions (epilepsy and recurrent respiratory/GI infections being most common) were commonly found in these patients. Milestones are delayed in almost 60-70% of cases whereas various physical and psychiatric conditions commonly co-existed with disability.

**Conclusion:** Clinical profile of these patients demands a comprehensive evaluation and management apart from routine IQ assessment.

**Keywords:** Intellectual disability, Assessment, Tertiary care center, India

## INTRODUCTION

Mental Retardation occurs in 2-3% of general population and is one of the most common disorders among children. Traditionally IQ testing is considered to be the standard assessment procedure for patients with Intellectual Disability.<sup>1-3</sup> Unfortunate neuropsychological aspect of mental retardation has not received enough attention despite its importance. Associated handicaps in hearing, vision, motor skills, language impairment, behavioral disturbances, inadequate motivation, and cultural deprivation may adversely influence the outcome on an intelligence test. If these factors are not taken into consideration, the general level of a child's abilities may either be under or over-estimated.<sup>4</sup>

The etiologies of mental retardation are multiple, and its prevalence can also be influenced by social, economic, cultural, racial/ethnic, and other environmental factors including the demographics of age and gender.<sup>5,6</sup> Clinically low IQ level is commonly seen as a part of a syndrome or found co-morbid with variety of other childhood medical and psychiatric disorders. Assessment of intellectual disability should not be merely by IQ assessment but include comprehensive assessment of psychological factors, diverse co-morbid conditions and deficits.

There is a dearth of studies focusing on these issues from India and so this study was planned to determine the profile of patients with intellectual disability by focusing

on areas like demographic profile, peri-natal factors, developmental history, behavioral profile & severity of intellectual disability. This study of retrospective analysis of medical records of patients with Intellectual disability will also help in planning for future prospective epidemiological studies.

## METHODS

The study was conducted at department of psychiatry of a 900 bedded tertiary care general hospital affiliated to a medical college in a major city of western India.

A qualitative retrospective case record review of all patients visiting the Department of Psychiatry for the first time, for assessment of Intellectual Disability in a period of one year, was conducted to understand their epidemiological and clinical profile. Systematic record review of all the consecutive series of patients visiting the department in one year (March 2012 to March 2013) was done by authors to check for completeness of the record sheets. Records which were found incomplete & same day assessments were excluded.

The case record sheet used to interview patients and care givers was a structured Performa eliciting qualitative information about areas like demographic profile, presenting complaints, family history, peri-natal events (like status of mother during pregnancy, labour, child at birth & first two weeks after birth), childhood medical history, developmental history (including various milestones), current behavioral profile, physical and mental examination & measurement of severity of intellectual disability. IQ assessment was performed by a trained clinical psychologist and Intellectual disability was categorized into borderline, mild, moderate, severe or profound levels as per DSM-IV TR classification.

Permission for reviewing the records was obtained from the departmental head. The review was conducted by authors who themselves were the physicians who had assessed the patients in past. Patient's identity, personal data and the content of the record review was kept confidential. Qualitative data thus gathered was pooled and results were categorized according to the area of inquiry and responses reported in the descending order of frequency.

## RESULTS

Out of 78 record sheets of last 1 year, 62 were found to be complete in all respects and included in the study. Analysis of them revealed that mean age of patients was 17.5 years (range 3 - 75), 55% of them were males, 92% were residing in urban areas and 77% of them were from higher economic strata. Majority of the caregivers consulted on their own (63%) whereas 15% of them were referred by psychiatrists from another hospital specifically for IQ assessment and 11% of them were referred by a Gynecologist (before performing

hysterectomy). Less than 3% were referred by doctors from other specialties (Pediatricians, physicians, ENT surgeons & ophthalmologists) and less than 2% from any schools. Majority of them were accompanied by their mothers (58%), followed by both the parents (22%) & other family members (15%). Intellectual disability was found in around 6% of first degree relatives and 5% of second degree relatives of patients.

**Table 1: Presenting complaints.**

Presenting complaint	Frequency (n=62)
Unable to understand routine conversations / being mentally weak	20 (32%)
Poor performance in studies	18 (29%)
Behavioral disturbances	13 (21%)
Unable to speak / speak properly	9 (15%)
Forgetfulness	5 (8%)
Hyperactivity	4 (6%)
Poor self-care	4 (6%)
Weakness in limbs	3 (5%)

Among the presenting complaints by informants (Table 1), inability to understand routine conversation / being mentally weak & poor performance in studies was the predominant complaint in 1/3<sup>rd</sup> of the cases while behavioral disturbance were seen in 1/5<sup>th</sup> of the cases. It was note-worthy that almost all of them consulted for the purpose of treatment / cure for the complaint. It was evident that all the complaints were either related to the poor intellectual / adaptive functioning or possible co-morbid conditions.

**Table 2: Peri-natal events.**

Peri-natal events	Factors	Frequency (n=62)
Mother during Pregnancy	Poor nutrition	8 (13%)
	Exposure to medications, drug abuse or irradiation	4 (6%)
	Infections	2 (3%)
Labour	Foetal distress	4 (6%)
	Pre-mature	2 (3%)
	Prolong	2 (3%)
	Assisted	1 (2%)
Child at Birth	Delayed cry	13 (21%)
	Low birth weight	5 (8%)
	Congenital anomalies	1 (2%)
First two weeks	Seizures	10 (16%)
	Respiratory distress	5 (8%)
	High grade fever	4 (6%)
	Feeding problems	3 (5%)
	Jaundice (pathological)	1 (2%)

Peri-natal events were inquired in detail to elicit possible etio-pathological factors that may have led to Intellectual disability. Table 2 shows the prevalence of variety of factors related to the mother or the child, before or after the birth, that were most commonly found in these patients. Among these factors, delayed birth cry was the most frequent (21%), followed by presence of seizures in the first two weeks after birth (16%) and poor maternal nutrition during pregnancy (13%).

**Table 3: Childhood history.**

Events	Frequency (n=62)
Seizures	17 (27%)
Recurrent respiratory / gastrointestinal infections	10 (16%)
Feeding problems	7 (11%)
Failure to thrive	5 (8%)
Significant trauma or poisoning	5 (8%)
Self-injurious behaviour	5 (8%)
Behavioural problems	4 (6%)
High grade fever with altered sensorium	2 (3%)
Neurotic traits	1 (2%)

The inquiry about the childhood medical history or behavioral history revealed that epilepsy was the most common problem, followed by recurrent respiratory / gastrointestinal infections, feeding problems / failure to thrive, trauma/poisoning and high grade fever. This

shows possible etiological events during childhood that could have led to intellectual disability (Table 3).

**Table 4: Developmental history.**

Milestones	Delayed (n=62)
Motor & sensory	41 (66%)
Personal & social behaviour	39 (63%)
Speech & language	49 (79%)
Adaptive behaviour	47 (76%)

Patients were assessed for the age of attainment of various milestones from birth to 6 years. Delay in achieving speech/language was most common (almost 80% of them), followed by adaptive behavior (76%), motor/sensory milestones (66%) and personal/social behavior (63%) (Table 4).

**Table 5: Current behavioral history.**

Behavioral problems	Frequency (n=62)
Aggression/Violence	13 (21%)
Muttering / Inappropriate laughing	8 (13%)
Hyperactivity	6 (10%)
Head banging	6 (10%)
Biting	2 (3%)

As seen in Table 5, on eliciting current behavioral problems, parents reported aggression/violence as the most common, followed by muttering/inappropriate laughing, hyperactivity and head banging.

**Table 6: Physical & mental examination.**

Physical findings	Frequency (n=62)	Psychological findings	Frequency (n=62)	General abilities	Frequency (n=62)
Hemiparesis	5 (8%)	Psychomotor retardation	23 (37%)	Identify common persons	57 (92%)
Squint	4 (6%)	Irritable mood	15 (24%)	Follow simple instructions	50 (81%)
Wide spaced eyes	3 (5%)	Disinterested / Dull	8 (13%)	Identify common objects	37 (60%)
Microcephaly	1 (2%)	Inattention	8 (13%)	Do simple calculations	17 (27%)
Muscle wasting	1 (2%)	Hyperkinetic	7 (11%)	Follow complex instructions	8 (13%)

Physical examination of these patients (Table 6) revealed findings like hemi-paresis, squint, wide spaced eyes, microcephaly and muscle wasting. These findings can be part of a syndrome (e.g. Cerebral palsy or Down's syndrome) or may be co-morbid conditions along with Intellectual Disability. Various psychological symptoms (with varied frequency) reveal the behavioral profile of patients or possible co-morbid treatable psychiatric disorders like Autism, Conduct disorder or ADHD. Patients were also examined for their general abilities / adaptive skills and were found to be able to perform some

(identifying common persons and following simple instructions) commonly whereas some with difficulty.

All the patients underwent IQ testing and psychiatric evaluation to be classified into various categories of Intellectual Disability as per the diagnostic system of DSM-IV TR for psychiatric disorders. Majority of patients were having Mild to Moderate disability, followed by Severe and few of them Profound.

**Table 7: Intellectual disabilities.**

IQ levels	Intellectual disability	Frequency (n=62)
<25	Profound	1 (2%)
20-25 to 35-40	Severe	8 (13%)
35-40 to 50-55	Moderate	25 (40%)
50-55 to 70	Mild	23 (37%)
>71-90	Borderline	5 (8%)

## DISCUSSION

Intellectual disability is one of the most frequently encountered, and most distressing, disabilities among children in most industrialized and developing countries world-wide.<sup>6,7</sup> It is more common in developing countries because of the higher incidence of injuries and anoxia around birth, and early childhood brain infections.<sup>8</sup> Although common amongst children, mental retardation is the most difficult categories of childhood disability to document epidemiologically, in part because its causes are multi-factorial.<sup>9</sup>

Patients with intellectual disability visiting the hospital for the first time had a wide age range of 3 to 75 years and a mean of 17.5 years. It shows that compared to previous studies over there it was not only children who are brought to the hospital by their parents at an early age due to possible developmental delay or poor school performance but patients can reach health services at any age and for variety of reasons.<sup>9</sup>

Unlike previous studies, there was no gender difference but it was predominantly urban and higher economic class dominated population.<sup>9</sup> Studies have consistently shown that individuals from low socioeconomic status and rural areas are over represented among those with mild mental retardation, but in this study differing finding could have been due to the profile of patient population visiting our hospital.<sup>2,5,7,10</sup>

Majority of them consulted on their own with a specific health inquiry and expectation of treatment, though only some of them were referred by other specialists with a specific request of IQ assessment / diagnostic purpose (Psychiatrists & Gynecologists), and hardly by the school persons. This shows that it is the parents who mainly bring these patients to the hospital rather being referred by professionals from health or education who may be coming in contact with them regularly. It was the mother who was the main caretaker or informant in most of the cases and father in some of them, which increases the reliability of the information and helps in planning for rehabilitative workup along with them. Surprisingly intellectual disability was also commonly found in family members of patients. Generalized complains like being mentally weak / poor in studies or specific complaints like behavioral problems or speech disturbance were the

main reasons for visit, consultation and assessment of the patients. This shows the way these patients present and the felt need by the caregivers, thus helping us in diagnosing, counseling them as well as planning services accordingly. Surprisingly most of them were not aware of having intellectual disability and expected treatment for their complaints.

Though it is difficult to find out the exact cause of intellectual disability in a given patient, various peri-natal factors were commonly found in this group of patients which could be etio-pathologically related to the condition. This shows that along with easily modifiable factors like improved maternal nutrition, better obstetric care and neonatal services can be of help in reducing peri-natal complications and intellectual outcomes in future. Peri-natal acquired causes have been associated with intellectual disability in 20% of cases in some studies to 54% in another.<sup>11,12</sup> As primary prevention is the main stay of management, focusing on each of these factors is and providing adequate treatment is important.

The childhood medical illnesses that could have led to an insult to the developing brain and intellectual disability later in life were inquired. Epilepsy and major infections were found to be the most common conditions found to be present and possibly inadequate timely treatment or prolonged illness could have led to CNS insult. Conversely, epilepsy and its treatment can have a significant effect upon an individual's physical health and psychological wellbeing. A population-based study using a learning disability register in the UK reported that the prevalence of epilepsy was 26% in adults with intellectual disabilities.<sup>13</sup>

Few of the milestones were delayed in some (possible borderline to mild disability) whereas all milestones were delayed in another (possibly moderate to severe disability). 65-75% of them had at least one area affected, showing that assessment of history of milestones is an important area of assessment and commonly affected.

Patients with intellectual disability common had behavioral disturbances or co-morbid psychiatric disorders in 10-20% of cases. Management of these patients involves assessment and treatment of behavioral issues separately along with rehabilitation. This leads to higher burden of care for family members due to stigma and little support from society.<sup>14</sup> A high prevalence of psychiatric co-morbidity has been highlighted in previous studies such as 30-40% in some and 82% in another, whereas only 1/10<sup>th</sup> have been reported to receive mental health interventions.<sup>15,16</sup>

Various physical findings and psychological findings on examination reveal possibility of a syndrome or co-morbid conditions, which necessitates thorough assessment and management by a multidisciplinary team of health professionals who can cater to the needs of these patients. A Taiwan study of people with intellectual

disabilities indicated that nearly half (47.7%) of the subjects had experienced an illness in the past 7 months and most of the morbidity was associated with neurological, psychiatric, digestive, dermatological and cardiovascular disorders.<sup>17</sup> In routine clinical practice, these patients were referred to respective specialty for respective management. Assessment of general abilities revealed that though most of them were able to perform simple tasks, complex tasks were difficult for some (possibly mild to moderate disability).

The prevalence of severity of intellectual disability was in line with existing literature and previous studies, that mild disability is more common than moderate, severe and profound in that order. Though many times mild disability is unnoticed and patients fail to reach hospital for a long time, leading to low prevalence rates compared to moderate disability (as in this study).<sup>9,18</sup>

## CONCLUSION

Thus this study brings to light the epidemiological and clinical profile of patients with intellectual disability. Further studies analyzing the correlations between the degree of intellectual disability, etio-pathological factors, developmental milestones as well as co-morbid physical and mental disorders can be useful to understand the scenario further. Findings of this retrospective case record review study can be useful to plan future quantitative / qualitative prospective studies. As this study largely depended on the information about past in the form of clinical case records of patients being interviewed by the physician, chances of recall bias may be considered.

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