GAVIN PUBLISHERS

Journal of Psychiatry and Cognitive Behavior

Afzal S, et al. J Psychiatry Cogn Behav 2: JPCB-112.

DOI: 10.29011/2574-7762.000012

Research Article

Socio-Demographic Characteristics and Adaptive Functioning Profile of Children with Intellectual Disability in Pakistan

Samreen Afzal[1], Salma Malik[2*], Imtiaz Ahmad Dogar[1], Shaista Irshad[1], Irum Siddique[1], Nighat Haider[1], Mohsin Ali Cheema[3], Michelle Durham[4],Muhammad Waqar Azeem[5]

[1]Department ofPsychiatry and Behavioral Sciences, Punjab Medical College, Faisalabad, Pakistan

[2]Department of Child and Adolescent Psychiatry, Institute of Living, Hartford, CT, USA

[3]Fatima Memorial Hospital, Lahore, Pakistan

[4]Department of Child and Adolescent Psychiatry, Boston University Medical Center, Boston, MA, USA

[5]Sidra Medical and Research Center,Department of Psychiatry, Weil Cornell Medical College-Qatar

[*]**Corresponding author:** Salma Malik, Department of Child and Adolescent Psychiatry, Institute of Living, Hartford, CT, USA. Tel: +18605450780, Fax: +18605457556; E-Mail: salma.malik@hhchealth.org

Citation: Afzal S, Malik S, Dogar IA, Irshad S, Siddique I, et al. (2017) Socio-Demographic Characteristics and Adaptive Functioning Profile of Children with Intellectual Disability in Pakistan. J Psychiatry Cogn Behav 2: 112. DOI: 10.29011/2574-7762.000012

Received Date: 8 May, 2017; **Accepted Date:** 1 June, 2017; **Published Date:** 8 June, 2017

Abstract

Objective: The objective of this study is to assess the socio-demographic characteristics and measure adaptive functioning of children with Intellectual Disability (ID) in Pakistan.

Background: The study was conducted from January 2011 till December 2013 in the Outpatient Clinic of Psychiatry and Behavioral Sciences District Headquarter (D.H.Q.) Hospital affiliated with Punjab Medical College in Faisalabad, Pakistan.

Subject and Methods: 170 children with (ID) were included in this cross-sectional study. Demographic information from the participants was recorded and the Portage Guide to Early Education (PGEE) was administered. The results were obtained by using SPSS-17.

Results: One hundred and seventy children with ID participated in the study. About Sixty-two percent of participants were male (105) between 1-10 years of age. Most parents had consanguineous marriages, 106 (62.4%). Ninety-six mothers reported prenatal stress and injury while 66 mothers reported post-natal infections in their children. Physical disability was present in 98 (57%) at time of birth. Among physical co-morbidity, epilepsy and movement disorder were reported most frequently. Eighty-one percent of children showed behavioral issues and communication disorders. In the assessment of adaptive functioning of children with ID, their developmental ages in areas of cognition was 1 year of age and language development was around 2 years of age while motor skills, socialization and self-help development was around 4 years of age.

Conclusion: Deficits in adaptive functioning are highest in children with cognitive and language delays. There was a high association between these deficits and children who were the product of consanguineous marriages, and children with pre- and postnatal complications. There was also an association with psychiatric co morbidity. Early individualized educational programs are recommended to enhance the functioning and help with the continued development of these children.

Keywords: Adaptive Functioning; Intellectual Disability; Socio-Demographic

Introduction

A precise and consistent definition of intellectual disability is critical because of its impact on assessing the prevalence of those with Intellectual Disability (ID). However, despite the importance of consistency, ID is not always defined in the same way across research studies or service agencies, even within the same state [1,2]. While some definitions rely on IQ scores alone to classify individuals with ID, some only use adaptive functioning for classification, and others include both IQ scores and measures of adaptive skills [2,3].

ID is defined in the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) by the American Psychiatric Association (APA) as a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains on mild, moderate, severe and profound level.

ID overall general population prevalence is approximately 1 % and its rate varies by age (DSM-V). According to the World Health Organization, the true prevalence rate of total mental retardation (MR, now known as Intellectual Disability) in industrialized countries comes close to 3% 4, but in the United States range has been between 1% to 3% [5,6,7]. The ARC National Research and demonstration center (1982) published the prevalence of MR in which they clearly established relationship between poverty and mental retardation. Malnutrition, lead poisoning and lack of prenatal care are some of the factors that may contribute to the disproportionate frequency of mental retardation.

Cognitive skills are generally measured by directly testing an individual. Adaptive functioning. It refers to skills in conceptual, social and practical domains that an individual is able to demonstrate on a daily basis [8]. Knowledge about adaptive skills is critical to research, treatment and vocational planning and is required for the diagnosis of an intellectual disability, together with cognitive testing [8,9,10]. However, there is no universally accepted measure of adaptive behavior suitable for all age groups and diagnostic groups.

There are various adaptive behavior measures administered to individuals with intellectual disability or developmental delays which include: The Vineland Adaptive Behavior Scales-Classroom Edition (VABS-Classroom) [11], the Scales of Independent Behavior-Revised (SIB-R), the Adaptive Behavior Scale-School-Second Edition (ABS S: 2) [12] and Portage Guide to Early Intervention. This study is focused on the widely used PGEE.

The Portage Guide to Early Intervention is a program in which teachers instruct mothers in their homes in an effort tohelp promote the development of young children with developmental delays and is used in more than 60 countries. Anecdotal and empirical evidence pertaining to the effects of the Portage Guide generally give favorable reports by parents and professionals alike [13].

Certain socio-demographic variables are found to be associated with intellectual disability. A twelve year follow up study with 415 infants found that prenatal problems can result in multiple problems in child development. Deficits can result when the fetus does not develop properly in utero; moreover, prenatal causes of intellectual disability include congenital infections; prolonged maternal fever in the first trimester; exposure to anticonvulsants or alcohol; and untreated maternal Phenylketonuria (PKU) [14]. Complications of prematurity, especially in extremely low-birth-weight infants, or postnatal exposure to lead can also cause Intellectual Disability [15]. Kolevzon, Gross &Reichenberg [16] conducted meta-analysis on a total of 446 infants born between1979 and 1999 which indicated several contributing factors as listed below: Perinatal causes involving late pregnancy(complications of pregnancy, diseases in mother such as heart and kidney disease and diabetes and placental dysfunction),during delivery (labor)(severe prematurity, very low birth weight, birth asphyxia, difficult and/or complicated delivery and birth trauma), neonatal (first 4weeks of life) (septicemia, severe jaundice, hypoglycemia). Postnatal problems (in infancy and childhood) involved brain infections such as tuberculosis, Japanese encephalitis, and bacterial meningitis. Other factors such as head injury, chronic lead exposure, severe and prolonged malnutrition and gross under stimulation can also contribute to the deficits[17,18].

Study by Chapman, et al. shows that older maternal age was associated with increased risk of mental retardation. This age effect was only seen in the lowest education group. In terms of risk for the population, it was younger mothers with 12 years of education or less whose births were associated with the greatest proportion of Intellectual Disability [19]. It is important to have social support networks for those with ID in order to build healthy relationships. The support groups usually consisted of members of their own family. The social support is valuable in that they have access to immediate attention and services, while they can also be limiting in that there are a limited number of same age peers and therefore a lack of opportunity to make friends. The current study aims to confirm the trends in socio demographic association of intellectual disability. A secondary aim is to identify the developmental age of children with ID in adaptive functioning areas of self-help, cognitive, motor, language and socialization.

Methodology

This was a cross sectional study conducted at an outpatient clinic in Pakistan after obtaining approval from the Institutional Research Committee. Participants included 170 children from ages of 1 to 20 years of age with a diagnosis of ID. After obtaining informed consent patients were recruited from the Department of Psychiatry and Behavioral Sciences DHA/Allied Hospitals, PMC, Faisalabad.

Demographic variables were recorded, detailed relevant history was takes and bio-data forms completed. Intern psychologists had been trained to administer and score the PGEE. The PGEE was administered to children and relevant information was gathered from the mothers of the children. The data were entered and analyzed using IBM SPSS-17.

Results

Results showed that out of 170 children, 61.8% were male (Figure 1,2&3).

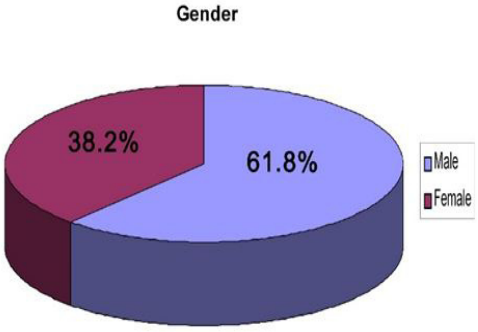

Figure1: Results Showed that out of 170 children, 61.8% were Male.

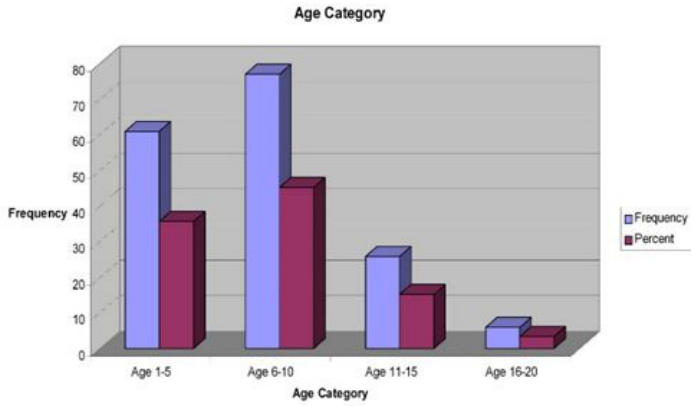

Figure 2: Most Participants were between 1-10 years of Age.

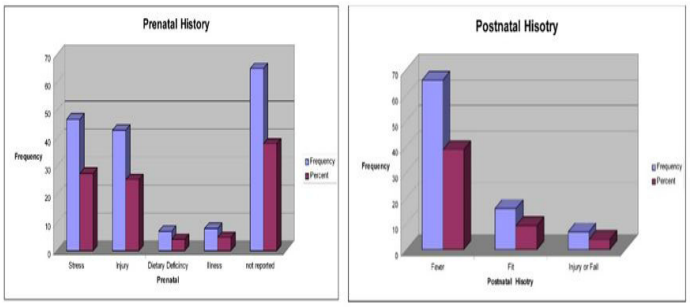

Figure 3: The Prenatal Stress and Injury and Postnatal Infections.

Most of children did not show any physical disability at the time of birth. Following (Table 1) shows the co-morbid psychiatric problems.

	Frequency	Percent	Valid Percent	Cumulative Percent
Behavioral Problem	**81**	**47.6**	**47.6**	**47.6**
Anxiety	2	1.2	1.2	48.8
Depression	2	1.2	1.2	50
Communication Disorder	**19**	**11.2**	**11.2**	**61.2**
Other	1	0.6	0.6	61.8
not reported	65	38.2	38.2	100
Total	170	100	100	

Table 1: Co-morbid Psychiatric Problem.

121 (71.2%) parents of children with intellectual disability have social support,whereas 118 (69.4%) did not take any technical assistance ever (Table 2).

	Frequency	Percent	Valid Percent	Cumulative Percent
Epilepsy	24	14.1	14.1	14.1
Movement Disability	19	11.2	11.2	25.3
Other	4	2.4	2.4	27.6
not reported	121	71.2	71.2	100
Total	170	100	100	

Table 2: Associated Physical Illness.

Assessment of Adaptive Functioning

While assessing adaptive functioning of children with ID, out of 170 children the physical age range is 1-10 years old. Their developmental ages in different areas are as follows(Table 3-7):

Age	Frequency	Percent
1- 12 months	36	21.17
13- 24 months	18	10.50%
25- 36 months	14	8.20%
36- 48 months	14	8.20%
47- 60 months	14	8.20%
61- 72 months	23	13.50%
Missing	51	30%
Total	170	100%

Table 3: Cognitive Area.

Age	Frequency	Percent
1- 12 months	9	5.20%
13- 24 months	22	12.90%
25- 36 months	9	5.20%
36- 48 months	9	5.20%
47- 60 months	19	11.10%
61- 72 months	14	8.20%
Missing	85	34.10%
Total	170	100%

Table 4: Language Area.

Age	Frequency	Percent
1- 12 months	13	7.60%
13- 24 months	9	5.20%
25- 36 months	12	7.00%
36- 48 months	19	11.10%
47- 60 months	24	14.10%
61- 72 months	30	17.60%
Missing	63	37%
Total	170	100%

Table 5: Socialization Area.

Age	Frequency	Percent
1- 12 months	9	5.20%
13- 24 months	12	7%
25- 36 months	15	8.80%
36- 48 months	23	13.50%
49- 60 months	28	16.40%
61- 72 months	21	12.30%
Missing	62	36.40%
Total	170	100%

Table 6: Motor Category.

Age	Frequency	Percent
1- 12 months	8	4.70%
13- 24 months	15	8.80%
25- 36 months	13	7.60%
36- 48 months	19	11.10%
49- 60 months	34	20%
61- 72 months	34	20%
Missing	47	27.60%
Total	170	100

Table 7: Self Help Category.

Discussion

The identification and assessment of severe intellectual disability can be more readily identified, but those with milder disability are less easily recognized; assessment measures take into account the importance of determining a person's actual functional abilities in key areas of day to day living and learning by systematic observation of that individual in ordinary settings, and the use of information from those who know the person well such as parents, health care workers, teachers [4].

Adaptive functioning of children having special needs has been assessed through administration of adaptive functioning tools. Multiple adaptive functioning tests have been used to ascertain the developmental age such as the Vineland adaptive behavior scale [11] and portage guide to early intervention [13]. We selected portage guide to early intervention in our study to assess child functioning in five areas (self-help cognition, socialization, motor and language). The Portage Guide did not only help us in evaluation but also in management aspects.

In this study, out of 170 children most of the children were male and between the age range of 6 to 10 years and the majority were the eldest child in the family. A Turkish study reveals that prevalence of mental retardation is 12.1 % in the general population, in males, 15.1 % and in female, 9.1 % [20]. Our results indicate the majority ofchildren were the result of a consanguineous marriage. This is also prevalent in other research and is known to be a risk factor for intellectual impairment. A study conducted in Lebanon found a strong association between consanguineous marriage and incidence of autosomal recessive diseases and congenital anomalies[21]. Parental age, particularly the age of mother, has been associated with intellectual disability [22] In our study 41 (24.5 %) of mothers were reported to be less than 20 years of age or above age 30; other studies have noted that this group is highly associated with intellectual impairment approximately 58.6% [23].

Parental stress is also found to be associated with increased risk factor for intellectual disability and is consistent with other research [24,25]. Fever and infections were the most common predictor of intellectual disability. This is consistent with Sharif's study who found that jaundice and fever during infancy as a major case of Intellectual Disability [26].

Leonard, et al. and Zoghbi, postulated that postnatal problems (in infancy and childhood) involving brain infections such as tuberculosis, Japanese encephalitis, and bacterial meningitis, as well as head injuries, chronic lead exposure, severe and prolonged malnutrition and gross under stimulation. These postnatal prob-

lems were consistently reported in the children in the study as well [17,18]. Epilepsy is found to be most prevalent medical disorder associated with intellectual disability in this study. This is consistent with the current literature. Epilepsy occurs in up to 18 % of people with mild mental retardation and 36 % of those with severe mental retardation [27].

Different studies show the co morbidity of intellectual disability with other psychiatric condition includes ADHD, Anxiety disorder, Autism, affective disorder, psychosis, sleep disorder, and delirium [28].Diagnosis and treatment of psychiatric disorders in individuals with intellectual disability is an important and at times neglected area of psychiatry although various studies show the co- morbidity of psychiatric disorders with ID is on par with the general population. Behavioral problems are the most co morbid psychiatric condition reported in intellectual disability and this was consistent with the results in this study.

In the assessment of adaptive functioning, results showed approximately 1 years of age for cognitive development, 2 years of age for language development and motor, self-help and socialization was about 4 years of age. We hypothesize that adaptive functioning is on target in the areas of socialization and self-help due to the strong social support in indigenous settings whereas people in these same areas may not be aware or have access to the early interventions needed to stimulate cognitive and language development. There is a great need is to educate the population about the special needs of the intellectually impaired.

Conclusion

In conclusion deficits in adaptive functioning are highest in cognitive and language development in children who were a product of consanguineous marriages and/or in children with pre-and postnatal complications. There was also a high association with psychiatric co morbidity for intellectually impaired children. Individualized educational programs are essential to enhance the functioning in order to close the gap between developmental and physical age in children with ID. A multidisciplinary approach should be adopted for the provision of services and early interventional strategies should be the focus for better outcome in children with intellectual disabilities.

References

1. Koller H, Richardson SA, Katz M (1984)The prevalence of mild mental retardation in the adult years. J MentDefic Res 28:101-107.
2. Borthwick-Duffy SA (1994) Epidemiology and prevalence of psychopathology in people with mental retardation. J Consul Clin Psych 62:17-27.
3. Whitman TL, Hantula DA, Spence BH (1990) Current Issues in behavior modification with mentally retarded persons. In Matson JL (ed) Handbook of Behavior Modification with the Mentally Retarded,Plenum PressNew York.
4. WHO (1986) Mental retardation. Meeting the challenge: Joint Commission on International Aspects of Mental Retardation. WHO Offset Publication no.86.Geneva World Health Organization.
5. Tarjan G, Wright SW, Eyman RK, Keeran CV (1973) Natural history of mental retardation some aspects of epidemiology. American Journal of Mental Deficiency 77: 369-379.
6. Munro JD (1986) Epidemiology and the extent of mental retardation. Psychiatric perspective on mental retardation 9: 591-624.
7. Luckey RE, Neman R (1976) Practices in estimating mental retardation prevalence. Mental Retardation 14: 16-18.
8. American Association on Mental Retardation (2002) Mental retardation: Definition, classification and systems of supports.
9. Fenton G, D'Ardia, Valente D, Vecchio ID, Fabrizi A, et al. (2003) Vineland adaptive behavior profiles in children with autism and moderate to severe developmental delay. Autism 7: 269-287.
10. Su CY, Lin YH, Wu YY, Chen CC (2008) The role of cognition and adaptive behavior in employment of people with mental retardation. Research in Developmental Disabilities 29: 83-95.
11. Sparrow SS, Balla DA, Cicchetti DV(1985) **Vineland Adaptive Behavior Scales**- Classroom Edition. Circle Pines, MN: American Guidance Service.
12. Lambert N, Nihira K, Leland H (1993) AAMR Adaptive Behavior Scale-School. In:2. American Association on Mental Retardation,Austin, TX.
13. Brue AW, Oakland T (2001) The Portage Guide to Early Interventionan Evaluation of Published Evidence.School Psychology International 22: 243-252.
14. Stromme P, Hagberg G (2007) Aetiology in severe and mild mental retardation: a population-based study of Norwegian children. Developmental Medicine Child Neurology 42: 76-86.
15. Piecuch RE, Leonard CH, Cooper BA, Sehring SA (1997) Outcome of extremely low birth weight infants (500 to 999 grams) over a 12-year period. Pediatrics100: 633-639.
16. Kolevzon A, Gross R, Reichenberg A (2007)Prenatal and Perinatal Risk Factors for Autism a Review and Integration of Findings. Arch Pediatric Adolescent Med 161: 326-333.
17. Leonard H, Xingyan Wen X (2002)The epidemiology of mental retardation: Challenges and opportunities in the new millennium. Mental Retardation and Developmental Disabilities Research Reviews 8: 117-134.
18. Zoghbi H (2003) Postnatal Neurodevelopmental Disorders Meeting at the Synapse? Science 302: 826-830.
19. Chapman DA, Scott KG, Mason CA (2002) Early risk factors for mental retardation: role of maternal age and maternal education. Am J Ment Retard 107: 46-59.
20. Ayoglu FN, Cabuk F, Kiran S, Ocakci A, Sahin Z, et al. (2008) The prevalence of mental retardation by gender age of diagnosis and location in Zonguldak province Turkey. Neurosciences 13:57-60.
21. KanaanZM, MahfouzR, TamimH (2008) The prevalence of consanguineous marriages in an underserved area in Lebanon and its association with congenital anomalies. Genet Test 12:367-372.

22. Sandin S, Hultman CM, Kolevzon A, Gross R, Mac Cabe JH, et al. (2012) Advancing Maternal Age is associated with Increasing Risk for Autism a Review and Meta- Analysis. Journal of the American Academy of Child and Adolescent Psychiatry 51:477-486.

23. Vashist M, Yadav R (2011) Study of Maternal Age Family History of Mental Retardation Consanguinity in Mental Retardation Various Risk Factors in Mental Retardation. Research Journal of Biology 1:7-10.

24. Baxter C, Cummins RA, Yiolitis L (2000) Parental stress attributed to family members with or without disability a longitudinal study. Journal Intellectual Developmental Disability 25:105-118.

25. Mirza I, Tareen A, Davidson LL, Rahman A (2009)Community management of intellectual disabilities in Pakistan: a mixed methods study. Journal of Intellectual Disability 53: 559-570.

26. Sharif T (2003)Jaundice fever cause mental retardation in children.

27. Stafstrom CE (2014) Epilepsy comorbidities how can animal models help? Advance Exp Medicine Biology. 813:273-281.

28. Kay J, Cowperth waite R, Klykylo W (2002) Psychiatric disorders in patients with mental retardation. Psychiatry 6: 1-12.