

Perspective of Parental Satisfaction with Academia of Children with Down Syndrome and Intellectual Disability

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ABSTRACT

Background: Down syndrome is the disorder in which physical, mental, and functional deformity is present due to trisomy twenty one, the existence of three chromosomes instead of two normal chromosomes in human genome. Children who have intellectual disability they have neurodevelopmental deficit regards to limited in intellectual operation and adaptive behaviors. One of the safeguards variables as a favorable adaptability to a challenging conditions, like managing a handicapped kid, is marital satisfaction. Higher levels of marital happiness are linked to reduce depression levels, less parenting stress, and better parental planning (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006)

Objective(s): To find out parental satisfaction with academia of Down syndrome and Intellectual disability in Pakistan.

Methodology: A standardized tool PSCDDI is used and data were collected from special education school of Lahore and Gujranwala city. Data were collected from 385 parents of down syndrome and intellectual disable child parents through questionnaire which were provided to parents and take their opinion. After data collected we analyze the data and concluded the results.

Results: In this study we find out that parents are unsatisfied to academic performance of their child most of child and most of the parents are not sure and disagree. Down syndrome child are 38.9% and 60.9% child were intellectual disable and they are all in pre to 3rd grade. Most of the child were in the age range of 5- 8 years. The parents of DS and ID child have non-Consaginous marriage is 53.6% and 46.4% are Consaginous marriage.

Conclusion(s): The overall study of parental satisfaction towards the developmental disability of their children shows unsatisfaction. . In Pakistan parents who have their children with disability faced many challenges in society.

Keyword: Down syndrome, intellectual disability, parental satisfaction, academia

INTRODUCTION

Down syndrome is the disorder in which physical, mental, and functional deformity is present due to trisomy twenty one, the existence of three chromosomes instead of two normal chromosomes in human genome(1). In the previous years, DS were center of attentiveness. Down syndrome is the gene-transmitted disease in which prominent facial features as well as several level of comprehension disability are shown. Individual of Down syndrome have numbers of congenital abnormalities. There are three kinds of trisomy 21, Free trisomy 21, mosaic trisomy 21, and Robertsonian translocation trisomy 21. There are tests available before and after birth which are very often use for diagnosis of different disorders having same causes. For good prognosis it is important that clinical diagnosis as early as possible(2). Down syndrome is the most common chromosomopathy characterized by the regular presence of intellectual disabilities at various levels report that it is frequently accompanied with organ system and linguistic issues(3).

Children who have intellectual disability they have neurodevelopmental deficit regards to limited in intellectual operation and adaptive behaviors. These abnormalities arise and evident ago 18 years, and it is related to significant counting of associated co exist issues having mental health for example depression and anxiety, neurodevelopmental for example ASD and ADHD and also neurological for example infantile CP and different medical states. Intellectual functioning is commonly said intelligence and involve broad level of mental tasks like capacity of logical and reasoning and practical intelligence like problem solving capacity in education, spoken communication and vise versa. It evident and show their own into ability, behaviors and thinking and feelings. Particularly intellectual functioning is definable as the worldwide ability which give permission to understand reality and link with it. Intellectual functioning is generally calculated by the intelligence quotient (IQ), that mean a total result get from systematize testing (IQ test) start for judge

human intelligence. These abnormalities shows as deficiency in social and mental and daily tasks. Social abilities having individual abilities, social duties, self respect, sensible, innocence, change in social issues, and capacity to obey laws of society and follow the rules. Mental abilities include the ability to know time, money matters and language(4).

One of the safeguards variables as a favorable adaptability to a challenging conditions, like managing a handicapped kid, is marital satisfaction. Higher levels of marital happiness are linked to reduce depression levels, less parenting stress, and better parental planning (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006) (1). Down syndrome was linked to the lowest levels of behavior problems and the greatest levels of mother well-being(5). The issue of providing better support for intellectually disabled children so that they can attend mainstream education has received a lot of attention in recent years all across the world(6). Literacy is a necessary skill in today's culture. Literacy skills are especially crucial for people with intellectual disabilities (ID), who have considerable difficulties in both cognitive Adaptive and functional behavior (APA, 2013; Schalock et al., 2010) (7). Special education services are required for children with special needs who have developmental needs (tuna grahita) in accordance with the Law of the Republic of Indonesia concerning the National Education System No. 2 of 1989 (in article 11 paragraph 4 and article 38) and reaffirmed in the RI Law concerning the National Education System No. 20 of 2003 (in article 3 paragraph 1), Special education is defined as "education for students who have a level of difficulty," according to this definition (Bandi, 2006: 55)(8). The current study focused on the skills, knowledge, and attitudes that instructors need to teach children with moderate and severe intellectual impairments in inclusive and special education settings. Qualitative content analysis was performed to categorize these abilities, knowledge, and attitudes based on investigative group conversations with teachers and principals(9).

Parents of children with learning problems confront a variety

of difficulties. Due to a lack of knowledge of the handicap or difficulty in parenting the kid, these issues develop in parent-child relationships. According to Rayner and Moore (2007), parents who care for a handicapped kid endure stress and have a bad social life as a result of the increased responsibilities for lack of social support from family members when caring for others. The enormous challenges of managing these children's academic and life skills, as well as their mood swings and demanding behaviors, may add to parents' caregiver stress (Phetrasuwan & Miles 2009). Parents of children with cognitive disabilities and other impairments can confront a variety of difficulties, including greater financial and time constraints (Rogers & Hogan 2003), limitations on social life and everyday chores (Kenny and McGilloway 2007), and keeping an optimistic attitude of their children (White & Hastings 2004). Certain disability-related factors appear to be strong predictors of parental stress(10). The additional load of care has been observed to cause tremendous stress and dissatisfaction in parents of children have special needs. Stigmatization by the family environment, as well as the cumulative influence of the children on mothers, predisposes them to mental shock, as well as a variety of neurotic symptoms and other psychiatric diseases such as anxiety and depression(11).

When compared to moms of children with various mental and physical impairments, parents of children have DS often have superior Profiles of psychological well-being, including better results seen throughout their lives (e.g., Fidler, Hodapp, & Dykens, 2000; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Seltzer, Krauss, & Tsunematsu, 1993). It's crucial to separate true explanations identifying artifacts that cause between-group differences in family functioning in order to gain a better grasp of the factors connected to syndrome -effects on the family as a whole(12). The challenge of raising a kid with a developmental disability (DD) has both good and negative consequences for parents and other family members. Their happiness with providing care for children with Developmental Disable is a key component in children's overall health. The majority of studies, both in Western

and non-Western cultures, have concentrated on the influence on mothers, with little study on dads. It would be crucial to involve men as well as mothers in all forms of assistance parents of children with Developmental disabilities, such as understanding their views and perspectives, when evaluating or addressing their specific needs(13).

The well-being of mothers, as well as the parent-child connection and family functioning, is dependent on marital satisfaction. The influence of marital connection on parenting has been documented in the literature. However, few research have looked at the effect of parenting on marital satisfaction. According to family systems theory, there is a reciprocal relationship between parental and spousal subsystem functioning. As a result, the goal of this study is to look at the relationships between several parenting variables, such as parenting self-efficacy, parenting stress, co-parenting alliance, contentment with father engagement, and mothers' marital satisfaction. This study used convenience sampling from 20 nurseries to enroll a sample of 1,140 women for a cross-sectional survey. To raise mothers' marriage happiness and sustain marital relationships, measures that foster father engagement, reduce mothers' parenting stress, and improve co-parenting partnership may be employed(14).

When compared to parents of usually developing children, this group of parents is more likely to be dissatisfied with their child's care. To create a wider research sample, participants were recruited from various services in four regions across Iran. The PSCDDI (Parental Satisfaction with Caring for a Child with Developmental Disabilities Index) was used in the study. When compared to parents of normally developing children, parents of children with DDs, particularly parents of children with ASD, reported lower parental satisfaction with caring. Parental satisfaction with caregiving was shown to be significantly influenced by child behavior issues, gender, and age. These findings imply that knowing parental satisfaction with child care is critical to comprehending the difficulty of caring for a kid with Down syndrome(13).

RESULTS

Tabel 1:

What is the age of your child	3-5 years 12.4%	5-8 years 38.1%	9-13 years 37.6%	13 above 11.9%
What is the category of disability of your child	Down syndrome 38.9%		Intellectual disability 60.9%	
Which class you belong	Cousin 46.4%		Non-Cousin 53.6%	
In which class your child are studying	Pre -3 grade 95.6%	4-7 grade 3.9%	7-9 grade 0.3%	10 grade- above 0.3%

Tabel 2:

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
Do you think that I make the most of each day; live life at a slower pace	7.5%	16.1%	36.5%	36.3%	3.6%
Do you think that My personal strength and confidence has increased	12.4%	38.9%	23.8%	22.0%	2.8%
Do you think that My perspective on life has changed ___ I am more aware of what is important in life	8.0%	19.9%	42.7%	26.4%	2.8%
"Do you think that My spirituality or trust in God has increased"	12.4%	38.9%	23.8%	22.05	2.8%
"Do you think that I have become a better person___ less selfish, more tolerant, compassionate"	7.3%	13.0%	40.7%	37.0%	2.1%
"Do you think that My social and community networks have expanded"	4.4%	28.2%	41.2%	23.3%	2.8%
"Do you think that I get a sense of accomplishment in having done one's best for the child"	6.7%	24.6%	33.7%	33.4%	2.6%
"Do you think that I get pleasure in providing care for my child"	6.5%	21.0%	29.5%	33.7%	9.3%
"Do you think that My child is a source of joy and happiness in my life"	5.7%	17.9%	39.6%	26.4%	10.45%
"Do you think that My child provides me with a challenge and an opportunity to learn and develop"	6.7%	15.0%	47.9%	26.9%	3.4%
"Do you think that My child gives me love and affection"	7.0%	14.8%	28.0%	38.9%	11.4%
"Do you think that My child gives me a new or increased sense of purpose in life"	7.3%	20.7%	35.0%	30.3%	6.7%
"Do you think that Having a child has led me to develop new skills"	10.1%	64.5%	17.1%	6.7%	1.6%
Do you think that My child has strengthened our family and/ or marriage	5.7%	16.1%	18.4%	40.9%	14.0%

DISCUSSION

In present study most of the parent are not sure about their satisfaction because they are not happy to have disable child. In previous study which is conducted by Sayyed Ali Samadi in 2018

he concluded that mostly parents are disagree or give limited answer to this question(Do you think that My child has strengthened our family and/ or marriage).In this study also parents give response disagree because they think this type of child are bad fortune for their family. They think these child week

the relationship of husband and wife because both the partner blame each other to having this kind of child. In previous study it was conducted that parents have less satisfaction regarding to their caregiving and in present study mostly parents are not sure and disagree about academic performance of their child and have less satisfaction. Most parents are think that these children are punishment from almighty Allah. But some of them parents are take care of their child properly and fulfill all their needs and take care of health of their child and take proper therapy and sessions. According to prior study, parents who have a positive attitude regarding their kid's illness are better able to handle the obstacles and problems that come with raising a child with DD(15). The result of present study shows that the children among the age of 5-8 years have prevalence of down syndrome and intellectual disability is 38.1%. In previous study which is conducted by A. S. Eisenhower B. L. Baker. J. Blacher in 2005 show that at the age of 3 years children with down syndrome have lowest level of behavior problems(16).The present study shows the age of children among 3-13 years have prevalence of down syndrome but intellectual disability is 88.3%. in other article the age group 3-13 years have prevalence of developmental disabilities is 50%. In current study, it makes no difference whether the marriage is Consaginous or not in past study which were conducted by Aamara Darr in 2009 which told us Only genetic illnesses that are inherited as autosomal-recessive conditions are affected by cousin marriage. Chromosome abnormalities, sex-related diseases, and autosomal dominant diseases are unaffected by it(17). Frequency of Down syndrome is less than intellectual disability.

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