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Addressing The Issues Faced By Children With Down Syndrome In Community Settings: Insights From Psychologists And Parents

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Abstract

The children with Down syndrome have been facing issues in community since early in life. The current study aimed at examining the issues faced in community by children with Down syndrome from the perspectives of psychologists and parents of children with Down syndrome. The study was quantitative and based on survey method using purposive sampling. A sample of participants (n=136) including psychologists (n=72) and parents (n=64) of children with Down syndrome. The results indicated that respondents provided support to children with Down syndrome who lacked financial assistance and adequate housing and transportation facilities. Furthermore, respondents agreed that individuals with Down syndrome (CDS) experienced insults, humiliation, and harassment in the community. Individuals with Down syndrome endure frustration, feelings of shame and guilt due to mistreatment in the community. Individuals with Down syndrome faced stigma and social exclusion from the community. Furthermore, respondents agreed that individuals with Down syndrome encountered social discrimination, unequal treatment, and stereotyping. Finally, respondents supported the idea that individuals with Down syndrome are prone to anxiety and depression. The findings emphasized the urgent need for policy interventions aimed at improving the socio-economic conditions of individuals with Down syndrome (CDS). Policies addressing issues such as housing, transportation, and financial support can significantly enhance the quality of life for individuals with Down syndrome and their families.

Keywords: *Down syndrome, stigmatization, social exclusion, discrimination, parental experiences, financial issues, community issues*

Introduction

Down syndrome is a genetic condition caused by an additional copy of the 21st chromosome, leading to unique difficulties in cognitive, social, and emotional growth for those affected. Anomalies in chromosomal c[1]omposition cause

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deviations from the usual developmental path, resulting in a range of physical and psychological symptoms. This article delves into the complex challenges faced by children with Down syndrome in their communities, drawing on psychological research and parental perspectives. Pathological development, as defined by Cicchetti and Schneider-Rosen (1986), refers to the lack of integration of cognitive, social, and emotional skills necessary for adaptive development. This emphasizes the challenges experienced by individuals with Down syndrome (Cicchetti & Ganiban, 1990). The article explores the psychological, social, and physical challenges faced by these children, emphasizing the necessity of comprehensive support systems.

Children with Down syndrome face societal misconceptions and negative attitudes despite improvements in institutional and cultural support, as shown by studies revealing widespread biases among adults and youth (Pace & Rasmussen, 2010). This article delves into how stigmatization affects the social inclusion of individuals with Down syndrome and its consequences on the well-being of both children and their families. The challenges persist into adulthood, impacting the elderly parents who encounter obstacles in arranging social activities and living situations for their adult children with Down syndrome. This article aims to comprehensively explore the challenges faced by children with Down syndrome in their communities by examining psychological, social, and familial factors. It seeks to lay the groundwork for future research and promote inclusivity.

Literature Review

In contrast of normal development, pathological development can be defined as a deficiency of the integration of the cognitive, social and emotional proficiencies which are necessary to attaining adaptation at certain developmental period (Cicchetti & Schneider-Rosen, 1986; Cicchetti & Ganiban, 1990). Down syndrome arises from a genetic condition characterized by having 21 sets of chromosomes instead of the usual 23 pairs. This chromosomal alteration disrupts the typical developmental trajectory, resulting in the characteristic features of Down syndrome. Common physical attributes associated with Down syndrome include low muscle tone, short stature, an upward slant of the eyes, and a single deep crease on the palm (National Down Syndrome Society, 2020).

Trisomy 21, commonly known as Down syndrome, occurs when an individual is born with an extra copy of the 21st chromosome, resulting in a range of physical and psychological challenges. However, with increased institutional and cultural support for individuals with Down syndrome and their families, there are now various options available to address these challenges (Bull, 2022). Mosaicism is another condition where children are born with one or more additional chromosomes. Down mosaic syndrome, a type of mosaicism, typically exhibits fewer symptoms compared to trisomy 21 (Toutain et al., 2020). Disparities in social skills and awareness may contribute to interpersonal tensions with peers (Karagianni & Drigas, 2022). Additionally, students with Down syndrome may encounter difficulties in executive control of working memory, making it challenging for them to comprehend and follow instructions (Sabat et al., 2020).

According to Shiner (2023) by engaging with Down syndrome children, you not only give them time but also provide your energy, care to them, to have sympathy and communicating with them are better approaches for improving them. A longitudinal study investigated that the children with Down syndrome expressed less continuity to do something, extra approaching as well as showed high threshold to stimulus as compared to the average children (Cicchetti & Ganiban, 1990; Gunn et al, 1981).

According to U.S. survey most of the adults and youth showed negative attitude toward people with DS. People report DS child would not be inclusive in normal schools, may cause an accident in the workplace as well as they would not like to spend time with DS child (Pace & Rasmussen, 2010). Poor contextual support and restrictions on the child's socio-cognitive processing may threaten the social competency development of children and teenagers with Down syndrome (Iarocci et al., 2008). These challenges encompassed deficient skills, low IQ levels, memory retention issues, communication difficulties, behavioral obstacles, passivity, and distractions. Moreover, the findings suggested that there was no notable disparity in viewpoints between special education teachers and psychologists regarding the educational difficulties experienced by students with Down syndrome (Amin et al., 2023).

A study in Rome reveals that there is a critical requirement for Down syndrome adults for social inclusion, facility of appropriate support services, living arrangements as well as additional support teachers and therapists (Bertoli et al., 2011). Children with Down syndrome faces more social difficulties in which vocabulary has been seen a central predictor of societal problems in the Down syndrome children (Næss & Lyster, 2017). Children with Down syndrome have speech making problems e.g. voice, speech fluency. They have trouble encoding, shaping and sequencing the movement for speech (Kumin, 2006). Numerous dimensions of referential communication are mostly problems for Down syndrome (Abbeduto et al., 2006).

Parents and society do not openly accept children with Down syndrome that makes many challenges for them (Jain & Ragas, 2002). Youth with DS have low quality of life as compared to normal youth as reported by caregivers (Xanthopoulos et al., 2017). A cross sectional study among caregivers explores that caregiver of people with Down syndrome reports low quality of life related to psychological domain, family income is a significant aspect for increasing quality of life (Amaral et al., 2020).

According to Jokinen and Brown investigation the aging of parents with Down syndrome needs more support for them as well as their family especially for adults with Down syndrome. To settle social life and living arrangement of children with Down syndrome become challenge for aging parents as well as for whole family (Jokinen & Brown 2005; Bertoli et al., 2011).

According to Huiracocha et at., (2017) with the absence of social support, and the pervasive stigmatization is challenging for children with DS as well as their families, hamper development of constructive and empowering adjustments which would assist the children with DS as well as their families.

Parents of Down syndrome children also become a ground to be excluded in social activities due to stigmatization as well as their jobs are also at risk as they need more time and energy for their childcare (Greenwood & Smith, 2018). Stigmatization threatens the individual’s dignity as well as it consequences such as discrimination, less access to health services, social isolation and social injustice. This frequent destruction of human rights should be listed in bioethical debate (Godoi & Garrafa, 2014). Stigma produces isolation, feelings of inferiority, shame, low life acceptance and viewpoint, social hostility, loss of employment, declined financial resources and fear of the future. It impacts negatively on the parent’s health of Down syndrome parents (Amorim & Shimizu, 2022).

A mother of Down Syndrome child reports a variety of experiences and emotions such as initial acceptance of DS child, developing behavior, health progress as well as financial issues (Pillay & Leonard, 2012). A study in Pakistan explores that parent of children with Down syndrome report more stress and anxiety than the parents of healthy children (Jameel et al., 2016). When a frustrating task is given to children with DS showed more frustration and orientation towards the experimenter without requesting any help (Jahromi & Kasari, 2008).

Children with DS have emotional, behavioral problems as well as they report less favorable in health-related quality of life (Van Gameren-Oosterom et al., 2011). Parents report poorer social and physical, psychological wellbeing of children with DS as well as they report quality of life poorer in school environment also (Shields et al., 2018). The constructive role of family, chance of social collaboration with peers as well as programs that encourage adaptation are identified as facilitator for physical activity of children with DS (Barr & Shields, 2011).

Despite the various studies on the problems faced by Children with Down Syndrome, it is revealed that there is still considerable gap in literature on addressing the various issues faced by Children with Down Syndrome in community settings from the perspective of psychologists and parents in South Punjab, Pakistan.

Research Methodology

Research Design

A quantitative study based on the survey method was conducted. The population was all the parents and psychologists in Southern Punjab, Pakistan.

Population and Sample

All the parents and psychologists for the students with autism spectrum disorder residing in the south Punjab constituted the population for this study. Sample of study was selected using simple random sampling technique. Sample of the present study contained total 136 participants involving male (n=53), and female (n=83); psychologists (n=72) and parents (n=64) of children with Down syndrome.

Instruments

The researcher tried to collect data using a quantitative (questionnaire) survey. However, a self-designed survey was used to collect data. The Cronbach's alpha coefficient for the questionnaire was (N=136, N (Items) = 11, α=.83. The researcher distributed the questionnaire to respondents in groups and individually. Those who could not be reached in person were immediately contacted by telephone. The instrument had been divided into two sections. The first section covered attributes of children with Down syndrome. Second section covered the Issues Faced by Children with Down syndrome (CDS) in Community including lack of financial support, housing and transportation facilities, insult, humiliation and harassment, personal and family issues, frustration due to bad treatment in community, shame and guilt, social exclusion, stigmatization, social discrimination, unequal treatment and stereotyping, and anxiety and depression.

Ethical Considerations

Informed consent was taken from the participants who took part in the study. They were assured that their information will be kept confidential and will be used for only research purpose. Their right to privacy was maintained and they were treated with respect and dignity. No harm and injury was promised to them. Their right to withdraw from the research was assured.

Results

The gathered data were analyzed utilizing SPSS, where both descriptive and inferential statistics were employed to assess the outcomes. Frequencies and percentages were calculated to present the demographic information and responses to the questions. Additionally, the independent sample t-test and one-way analysis of variance were utilized to identify disparities in instructors' opinions based on demographic factors.

Table 1 Frequency Distribution at the Basis of Demographics

Title	Description	Frequency	Percentage (%)
Gender	Male	53	39
	Female	83	61
Age of Respondents	21-30 Y	61	44.9
	31-40 Y	46	33.8
	41-50 Y	27	19.9
	51-60 Y	2	1.5
Designation	Psychologists	72	52.9
	Parents	64	47.1
Profession Qualification	Bachelors	22	16.2
	Master	57	41.9
	M.Phil.	52	38.2
	PhD	5	3.7
Area of Posting	Rural	49	36
	Urban	87	64
Division of School	Lahore	16	11.8
	Multan	15	11
	Rawalpindi	4	2.9
	Sargodha	8	5.9
	Bahawalpur	12	8.8
	DG Khan	57	41.9
	Faisalabad	8	5.9
	Gujranwala	5	3.7
	Sahiwal	11	8.1
Experience	1-5 Y	53	39
	6-10 Y	53	39
	11-15 Y	13	9.6
	>15 Y	17	12.5
		136	100

Table 1 Frequency Distribution for Issues Faced by Children with Down syndrome (CDS) in Community

Sr #	Statements of Questions	SA f(%)	A f(%)	UD f(%)	DA f(%)	SDA f(%)	M	SD
1	CDS lack financial support	83(61)	42(30.90)	8(5.90)	2(1.50)	1(.70)	4.50	.74
2	Housing and transportation facilities are not up to the mark.	42(30.90)	75(55.10)	15(11)	3(2.20)	1(.70)	4.13	.75
3	CDS face insult, humiliation, and harassment in community.	68(50)	53(39)	12(8.8)	2(1.50)	1(.70)	4.36	.77
4	CDS have personal and family issues.	42(30.90)	79(58.10)	12(8.8)	3(2.20)	0(0)	4.18	.68
5	CDS go through a lot of frustration due to bad treatment in community.	77(56.60)	49(36)	9(6.60)	1(.70)	0(0)	4.49	.66

Table 2 explains that the majority of the respondents opined that CDS lack financial support (92%) with M (4.50) & SD (.74). This table also elaborated that CDS face discriminatory behavior in community as respondents (89%) suggested that CDS face insult, humiliation and harassment in community having M (4.36) & SD (.77).

Table 3 Frequency Distribution for Issues Faced by Children with Down syndrome (CDS) in Community

Sr #	Statements of Questions	SA f(%)	A f(%)	UD f(%)	DA f(%)	SDA f(%)	M	SD
6	CDS feel shame and guilt due to their treatment in society.	41(30.10)	86(63.20)	8(5.90)	1(.70)	0(0)	4.23	.58
7	CDS are socially excluded from the community.	75(55.10)	47(34.60)	13(9.60)	0(0)	1(.70)	4.43	.73
8	CDS are stigmatized	45(33.10)	77(56.60)	11(8.10)	1(.70)	2(1.50)	4.19	.74

	in the community.							
9	CDS face social discrimination.	74(54.40)	51(37.50)	9(6.60)	2(1.5)	0(0)	4.45	.69
10	CDS are gone through unequal treatment and stereotyping.	53(39)	69(50.70)	9(6.60)	5(3.70)	0(0)	4.25	.74
11	CDS are prone to anxiety and depression.	76(55.90)	48(35.30)	9(6.60)	0(0)	3(2.20)	4.43	.80

Table 3 shows that most of the respondents (90%) suggested that CDS are socially excluded from the community having M (4.43) & SD (.73). They (90%) agreed that CDS are stigmatized in the community with M (4.19) &SD (.74). Respondents (92%) concluded that CDS face social discrimination having M (4.45) &SD (.69). Most of them (90%) agreed that CDS are gone through unequal treatment and stereotyping with M (4.25) & SD (.74). They (91%) believed that CDS are prone to anxiety and depression having M (4.43) & SD (.80).

Table 4 Comparison of Opinion of Respondents Based on Gender (Independent Sample t-test)

Gender	N	M	SD	Df	t	Sig.
Male	53	47.74	3.75	134	.202	.840
Female	83	47.57	5.32			

*P > .05 Level of Significance

Table 4 indicates that the empirical evidences for male (N=53, M=47.74, SD=3.75) and for female (N=83, M=47.57, SD=5.32) with t-statistics (t (134) = 0.202, P > .05) which showed that there was no significant difference in the opinions of male and female respondents about Issues Faced by Children with Down syndrome (CDS) in Community.

Table 5 Comparison of Opinion of Respondents Based on Designation (Independent Sample t-test)

Designation	N	M	SD	Df	t	Sig.
Psychologists	72	47.99	5.24	134	-.920	.359
Parents	64	47.23	4.15			

Table 5 indicates the parents' results for psychologists (N=72, M=47.99, SD=5.24) and for parents (N=64, M=47.23, SD=4.15) with t-statistics (t (134) = .920, P > .05) which showed that there was no significant difference in the opinions of psychologists and parents respondents about Issues Faced by Children with Down syndrome (CDS) in Community.

Table 6 Comparison of Opinion of Respondents Based on Area of Posting (Independent Sample t-test)

Area of Posting	N	M	SD	Df	t	Sig.
Rural	49	46.76	5.06	13	-1.624	.107
Urban	87	48.13	4.53			

*P < .05 Level of Significance

Table 6 indicates that the empirical information for rural (N=49, M=46.76, SD=5.06) and for urban (N=87, M=48.13, SD=4.53) with t-statistics (t (134) = -1.626, P > .05) which leads to the decision that there is no significant difference in the opinion of teachers from rural areas and teachers from urban areas regarding Issues Faced by Children with Down syndrome (CDS) in Community.

Table 7 Comparison of Opinion of Respondents Based on Age (One-Way ANOVA).

Age of Respondents	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	262.20	3	87.40	4.133	.008
Within Groups	2791.42	132	21.15		
Total	3053.62	135			

*P < .05 Level of Significance

Table 7 indicates that the empirical information for Between Groups(Sum of squares=262.20, df=3, Mean square=87.40) and for Within Groups(Sum of squares=2791.42, df=132, Mean square=21.15) with one way ANOVA (F (135) = 4.133, P < .05) which leads to the decision that there is a significant difference in the opinions of teachers from Between Groups and Within Groups regarding Issues Faced by Children with Down syndrome (CDS) in Community.

Findings & Discussion

The current study was aimed at examining the issues faced by children with Down syndrome from the perspectives of psychologists and special education teachers working in Department of Special Education Punjab, Pakistan. The findings revealed that children with Down syndrome lacking financial support and stigmatization were supported by most of the respondents. Children with Down syndrome faced insults, humiliation, and harassment in the community. Children with Down syndrome felt shame and guilt due to their treatment in society and excluded from the community. Children with Down syndrome faced social discrimination, unequal treatment, and stereotyping. Children with down syndrome were prone to anxiety and depression.

The research findings align with previous studies indicating that parents of children with Down syndrome often face exclusion from social activities due to stigmatization, risking their employment as they require additional time and energy for caregiving (Greenwood & Smith, 2018). Stigmatization threatened the dignity of individuals and can result in discrimination, limited access to healthcare, social isolation, and injustice, highlighting the need for consideration in bioethical debates (Godoi & Garrafa, 2014). Children with Down Syndrome faced challenges encompassing deficient skills, low IQ levels, memory retention issues, communication difficulties, behavioral obstacles, passivity, and distractions (Amin et al., 2023).

Stigma led to isolation, feelings of inferiority, shame, reduced life satisfaction, social hostility, job loss, financial strain, and apprehension about the future, negatively impacting the health of parents of children with Down syndrome (Amorim & Shimizu, 2022). Mothers of children with Down syndrome often navigated a range of experiences and emotions, including initial acceptance, behavioral and health progress, and financial challenges (Pillay & Leonard, 2012). Studies in Pakistan indicated that parents of children with Down syndrome experienced higher levels of stress and anxiety compared to parents of typically developing children (Jameel et al., 2016). Additionally, when faced with frustrating tasks, children with Down syndrome tended to display more frustration and seek assistance less often, as observed in research by Jahromi & Kasari (2008).

Furthermore, it is also revealed that there was no significant difference found on the perspectives of parents and psychologists about the community issues faced by children with Down syndrome. The results were congruent with previous studies that there were no significant differences observed between females and males, except for the concern about physical appearance, where females exhibited a higher percentage (58.5%) compared to males (47.5%). The severity of Down syndrome (DS) showed associations with intellectual performance, communication difficulties, and self-sufficiency (Islam et al., 2022).

Moreover, the findings suggested that there was no difference in viewpoints between parents and psychologists regarding the community issues faced by children with Down syndrome and the findings were supported by the previous study that there was insignificant difference between the opinion of parents and psychologists in context of educational problems faced by students with Down syndrome (Amin et al., 2023).

Conclusion

The study focused upon issues faced in the community by children with Down syndrome. The findings showed that children with down syndrome faced lack of financial support, lack of housing and transportation facilities, insult, humiliation and harassment, personal and family issues, frustration, shame, and guilt due to their treatment in society, social exclusion from the community, stigmatization in the community, social discrimination, unequal treatment and stereotyping, anxiety and depression. Parents’ involvement is also more important. Parents are interacting with the teacher of the children not only daily but sometimes to talk about the problem of their child. Parents have enough time and energy to help at my child’s school.

Recommendations

The findings emphasized the urgent need for policy interventions aimed at improving the socio-economic conditions of individuals with Down syndrome (CDS). Policies addressing issues such as housing, transportation, and financial support can significantly enhance the quality of life for individuals with Down syndrome and their families. The study highlighted the pervasive stigma, discrimination, and social exclusion faced by individuals with Down syndrome. Community awareness programs can play a crucial role in challenging stereotypes, fostering empathy, and promoting inclusion. Educational initiatives targeting schools, workplaces, and community organizations can help cultivate a more supportive and inclusive environment. Healthcare providers need to be sensitized to the specific needs and challenges faced by individuals with Down syndrome. The study underscored the importance of robust support services for individuals with Down syndrome and their families. This includes access to counseling, peer support groups, and respite care services to alleviate caregiver burden and promote well-being.

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