Case Report

Learning with Trisomy 21: Life Skills Training of a Child with Down's Syndrome

Halima Khurshid[1], **Ayesha Jabeen**[2]

[1,2]*School of Professional Psychology, University of Management & Technology, Lahore.*

Abstract

Trisomy 21 is one of the commonly identified genetic causes of Intellectual Disability. Such children experience a lack of attention and neglect by parents and teachers due to their slow response to intervention, which sometimes becomes demotivating for caregivers. However, with the recent medical advances and institutional support, avenues have been opened to help overcome the challenges related to Down's Syndrome. The present case study highlights the life skills training of a 7 year old child with Down's Syndrome, studying in a special education institute of Lahore. The post-assessment showed that consistent practice of behavior modification procedures led to significant improvements in the adaptive functioning of the child.

Corresponding Author | Halima Khurshid, Lecturer, School of Professional Psychology, University of Management & Technology, Lahore. **Email:** halima.khurshid@umt.edu.pk

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Introduction:

Down's Syndrome, also referred to as Trisomy 21 is the commonest genetic condition caused by an extra chromosome 21 and a total of 47 chromosomes instead of 46. Trisomy 21 is associated with Intellectual Disability and comes with neurological and language delays along with physical, cognitive, and social challenges as well as functional limitations.[1] There exists no cure for this condition however, the problems can be managed through early intervention to improve receptive expressive skills and cognitive skills such as thinking, solving problems, and decision making. Furthermore, basic life skills can also be taught to make them independent in eating, drinking, dressing, and managing other living skills.[2] In the domain of life skills, such children need intensive training as these skills are developed at a slower rate as compared to their age equivalent peers. The range of life skills in such children vary based on individuals, opportunities, and support provided by the family, school and community.[3]

Children's abilities to care for themselves have been found to correlate with intellectual functioning. The demands on the caregivers of children having Down's Syndrome are significantly higher, as they must actively participate in the care of the child due to the delay in development and the limitations in functional skills[4]. The living skills like self-management, dressing, toileting, and grooming are often considered as distal indications for quality of life as these skills are important for independence and meaningful participation in the community.[5]

When it comes to children with disabilities, it is imperative to understand the cultural impact of a disability and the stigma attached to it. Giving birth to a child with a disability is largely perceived as 'God's will' or a divine punishment upon the parents in the wider community. The literature suggests that life for such children in developing countries like Pakistan is defined by rejection, burden, and suffering.[6] There is also qualitative evidence that suggests that children with disabilities

are more likely to be neglected and excluded from teaching and learning in mainstream schools in many Southern contexts.[7] With the growing number of individuals with disabilities, there arises a need to teach these children with life skills training programs. There is empirical evidence to promote independent living in these individuals.[8] There has been seen a rise in the treatment-oriented approach after the 1970s which has given more opportunities to individuals with disabilities to be independent and feel integrated into their communities to lead a meaningful life. Several strategies such as prompting, modeling, reinforcement, shaping, and chaining have proved to be effective to teach life skills.[9] However, individuals with Down's Syndrome often face difficulties in maintaining and generalizing the skills so, it is vital to practice to make sure that the skill is learned. Given this, the training programs for teaching functional skills must be consistent across different settings. This case study also aims to highlight the importance of teaching life skills training programs to a child with Down's Syndrome and how consistent management and continuous practice helps a child to be independent.

Case Report:

The current case study was seen during September – December 2019. The consent was taken from the school administration as the teacher referred the case to the trainee clinical psychologist. The client was a 7 year old boy who belonged to middle socioeconomic status and lived in a nuclear family system alongside his parents and two siblings. The client was admitted to the Special Education Training Centre two years ago. Typical Mongolian appearance and anecdotal records supported the diagnosis of Down's Syndrome (Figure 1). The child's delivery was normal with a full-term 9 months' pregnancy. The client was the youngest of three siblings. No history of psychiatric or congenital disorders was reported in the family.

His parents were not related to each other, and the mother was 34 years old at the time of the child's birth. The parents came to know about the problem two years after their child was born when he delayed in achieving milestones (Table 1). The parents did not consult any doctors but started managing and taking care of him in the home. At the age of 5, the client formally started his schooling from the place of referral and had been studying there for 2 years. A semi-structured clinical interview with the teacher and anecdotal record revealed information that the child could not walk on his own in the school setting but could walk independently in his home as reported by her mother. The teacher did not try to make him independent in the school; sometimes she held his hand herself and other times she asked any other child to hold his hand whenever the child wanted to go anywhere. She also reported that the previous teacher of the child used to hold the child's hand, made him write alphabets, and occasionally used to complete his classwork in his notebook. The teacher tried to make him indulge in different tasks but he experienced difficulty in paying attention to a task for more than 19 sec in different activities such as coloring, blocks building, cutting, and pasting requiring on average 2 to 4 minute completion time. Moreover, he was observed by the therapist to be reluctant to walk independently in front of his teacher but used to walk on his own with minimal aid in the absence of the teacher along the hallway to the dining room. The client's fine motor skills were more affected but his gross motor skills were fine. Portage Guide to Early Education (PGEE) suggested the overall discrepancy of the child between his chronological age and functional level to be 6-7 years. The most affected areas involved language and cognitive (Table 2). The assessment revealed the suspected problem of the client to be Intellectual Disability affecting social, conceptual, and practical domains (Table 3). The child was observed to be quiet and uninvolved in any activity with his fellows. Although, he smiled often but did not interact with other children. The management plan was devised by keeping in mind the strengths and needs of the child. The targets included rapport building and maintaining, increasing attention span, shaking hand, hand holding was decreased and independent walking was increased from the classroom to the dining area, waving bye-bye was taught, non-verbal communication was enhanced through finger playing on poems, fine motor skills were enhanced through beads activity, toothpicks insertion into the holes of cinnamon bottle and appropriate pencil grip was taught from holding the pencil between his four fingers to holding it between two fingers through the use of assistive technology (use of clothes pin (clip).

Table 1: *Developmental Tasks, Client's Age of Achievement and Normal Age of Achievement of the Tasks*

Developmental Tasks	Client Age of Achievement	Normal Age of Achievement
Control head and neck movement	Approximately 8 months	4 – 6 months
Sitting without aids	Approximately 8 months	6 months
Crawling	Approximately 1 year	6 – 9 months
Walking	Approximately 1 and ½ year	12–14 months
One-word Speech	Approximately 3 years	13–18 months
Bladder Control	Approximately 4 years	2.5–3 years

Figure 1: *Illustration of Child's Facial Features with Down Syndrome*

Table 2: *Areas and Functional Level of the Child on PGEE*

Areas	Functional Level
Socialization	3-4 years
Self Help Skills	3-4 years
Motor Skills	2-3 years
Cognitive Skills	1-2 years
Language Skills	0-1 years

Table 3: *Severity of Child's Problem in the Social, Conceptual and Practical Domains*

Social	Conceptual	Practical
Severe Speech Impairment /- could only produce sounds like cooing	Hindrance due to verbal language	Cannot go to canteen
Moderate level of non-verbal skills – gives social smile	Fine Motor skills – Underdeveloped	Moderate degree of assistance required in self-help care
Child to child interaction – below average	Gross Motor Skills – Well developed	
Child to adult interaction – average	No appropriate pencil grip, Could only scribble	
Performance on musical poems in music class – average	Severe cognitive impairment	

Discussion / Therapeutic Outcome

In the current case assessment modalities of a single case-study design were employed. The total number of individual sessions conducted with the client was 12 including two follow-up sessions and the duration of each session was approximately 40 minutes. The child was involved in two group sessions in which the tasks given in individual sessions were practiced. A detailed session was also taken with the teacher in which she was psyhoeducated about the targeted behavioral intervention of the child by bibliographic material. However, due to the unavailability of parents, sessions were not conducted with them. The basic aim of the intervention was to provide him life skills training by using behavior modification techniques such as reinforcement, prompting, contingency management, differential reinforcement, graduated guidance and modeling. These strategies have been found effective in modifying the behavior of Down's Syndrome children in various studies.[9] The maximum success was achieved in attention span, shaking hands and independent walking. Researchers suggest that DS children tend to adapt to the skills being taught to them consistently[10]. The reason for achievement was the client's compliance and her mother's deep concern. Mounting evidence suggests that parents having special children experience hopelessness, burnout, and disappointment due to the magnitude of the success they expected[4]. In the current case, the mother's resilience and consistency in applying the intervention strategies in collaboration with the therapist resulted in a fruitful outcome[9]. However, the least success was achieved in learning appropriate pencil grip as the client had less developed fine motor skills that were consistent with his medical history. Therefore, follow-up activities such as the use of clothespins, inserting coins in the box and beading activity were suggested to the teacher. DS often presents with the issue of movement fluency, axial control, and atypical laterality, associated with motor delays. Overall, significant improvement had been observed using the behavior modification techniques to teach living skills to the client. The client improved not only in the socialization domain but also in learning readiness skills (attention) and independent functioning (independent walking) as reported by the client's teacher (Table 3). The current case has demonstrated that practice leads to automatization of the skills which later on can be accessed as part of some more

Table 4: *Recording of Behavior Pre and Post management*

Areas	Goals	Pre-Management	Post Management
Learning Readiness Skills	Attention Span	19 seconds average in one-minute activity	30 seconds average in one-minute activity
Socialization Tasks	Handshaking	0	7 times in 10 sessions on verbal reminders
Motor Tasks	Not holding hand during walking	0	6 times in 10 sessions on verbal reminders 4 out of 7 on verbal reminders
Socialization Tasks	Waving bye-bye	0 Held it with four fingers from the edge	Held it between thumb and forefinger with the help of a clothespin
Academics	Pencil grip		

complex tasks. Therefore, teaching them skills with consistency and patience can bring rapid improvements.

Conclusion:

There is a scarcity of intervention-based empirical evidence on the effectiveness of behavior therapy for children with neurodevelopmental disorders in our culture. This case study has demonstrated that the use of consistent behavioral modification strategies, and mutual collaboration among parents, teacher and the therapist can bring positive outcome in the child's adaptive skills.

References:

1. Thompson T, Talapatra D, Hazel CE, Coleman J, Cutforth N. Thriving with Down syndrome: A qualitative multiple case study. J Appl Res Intellect Disabil. 2020 ; 33(6): 1390-404.
2. Siddiqui A, Ladak LA, Kazi AM, Kaleem S, Akbar F, Kirmani S. Assessing health-related quality of life, morbidity, and survival status for individuals with down syndrome in Pakistan (DS-Pak): Protocol for a web-based collaborative registry. JMIR Research Protocols. 2021 ;10(6):e24901.
3. Al-Bahadli ES, Adai MG. Burdens on Caregivers of Children with Down Syndrome in Middle Euphrates Region of Iraq. Indian Journal of Public Health Research & Development. 2019 ;10(2):1-10
4. Sarwar A, Jabeen A. Neglectful Parenting: A Child Overdosed with Phenergan Syrup. J Liaquat Uni Med Health Sci. 2018; 17(03):195-7.
5. Singal N. Challenges and Opportunities in Efforts towards Inclusive Education: Reflections from India. Int J Incl Educ. 2019; 23:827–840.
6. Bennett KD, Dukes C. A Systematic Review of Teaching Daily Living Skills to Adolescents and Adults with Autism Spectrum Disorder. J Autism Dev Disord. 2014; 1(1): 2–10.
7. Oxelgren UW, Westerlund J, Myrelid Å, Annerén G, Johansson L, Åberg M, et al. An intervention targeting social, communication and daily activity skills in children and adolescents with Down syndrome and autism: a pilot study. Neuropsychiatric Disease and Treatment. 2019;15:2049.
8. Kabashi L, Kaczmarek L. Educating a Child with Down Syndrome in an Inclusive Kindergarten Classroom. J Child Dev Disord. 2019; 5(2):4
9. Whiting M, Nash AS, Kendall S, Roberts SA. Enhancing resilience and self-efficacy in the parents of children with disabilities and complex health needs. Prim Health Care Res Dev. 2019; 20(1):e33.
10. Malak R, Kostiukow A, Krawczyk-Wasielewska A, Mojs E, Samborski W. Delays in Motor Development in Children with Down Syndrome. Med Sci Monit. 2015; 21: 1904-10.