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Influence of Early Inclusion and Parental Employment on Stress and Coping Among Families of Children with Down Syndrome in Khyber Pakhtunkhwa: A Cross-Sectional Study

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Abstract: *In Khyber Pakhtunkhwa, Pakistan, this cross-sectional study investigates the connection between parental stress levels and inclusive education initiatives among families with children with Down syndrome. The study specifically looks at the effects of parental job status and early vs delayed enrolment in inclusive education on stress and coping strategies. Snowball sampling was used to choose 98 parents from five districts' worth of intervention centres. A demographic information sheet, the Brief COPE Inventory, and the Parental Stress Scale (PSS) were used to gather data. According to statistical analysis, parents of children participating in inclusive and early therapeutic interventions expressed far less stress than parents of children receiving delayed intervention. Non-working parents had higher levels of stress, but they also relied more on coping techniques such emotional support, denial, and religious practices. Gender-based data revealed no variance, however working moms reported increased stress as a result of juggling caring and workplace duties. The study emphasizes the value of timely educational inclusion and tailored support networks in reducing parental stress and promoting psychological well-being. Implications include regulatory changes, carer support programs, and the broad deployment of inclusive education to benefit both children with Down syndrome and their families.*

Keywords: Down syndrome, parental stress, inclusive education, early intervention, coping strategies, working vs. non-working parents, educational inclusion, special needs parenting

Introduction

The medical condition identified as Down syndrome is characterized by an additional copy of chromosome 21, resulting in a variety of health issues in addition to deficits with intellectual and developmental abilities.[1] For children with Down syndrome, a specially designed inclusive programs and instructional strategies are frequently required to improve their ability to learn and develop. In recent years, A more equitable and inclusive educational programs has gained prominence, integrating children with disabilities and more specially those who have Down syndrome. [2]

The goal of inclusive education is to establish learning environments where kids of all abilities may work together to promote social inclusion and successful results for all students. Inclusive education provides possibilities for social integration, intellectual advancement, and peer engagement for students with Down syndrome. Children with Down syndrome can gain valuable skills and experience a supportive learning environment by engaging in typical school activities with their classmates.[3]

Although inclusive schooling is promising for kids with Down syndrome, there is still debate over how much burden it puts on parents. Taking care of a kid with Down syndrome can be

difficult since raising one frequently requires navigating intricate social, educational, and medical systems. As they balance the demands of their job and family, provide for their child's needs, and perform caregiving duties, parents may feel more stressed than usual.[4]

Parental stress levels may also be influenced by when a child enrolls in inclusive education programs.[5] According to research, children with Down syndrome do better when they receive early intervention and support, which includes enhanced social and cognitive development.[6] There hasn't been enough research done on how early or late enrolment in inclusive education programs affects parental stress, though. Additionally, parents' experiences of stress in the context of inclusive schooling for children with Down syndrome may be significantly shaped by their work situation. Parents may have particular difficulties in managing employment and caregiving obligations, which may have an adverse effect on their wellbeing and capacity to assist their child's educational path.

Objectives: Examining the effect of inclusive education on parental stress levels is crucial, as parental well-being plays a critical role in promoting excellent outcomes for children with Down syndrome. This study attempts to provide light on the intricate relationships between inclusive education, parental stress, and family dynamics by comparing early and delayed inclusive childhood programs and taking parental job status into account.

The following hypotheses were put forth:

H1: Participation in inclusion programs for children with Down syndrome will result in reduced stress levels for parents.

H2: Lower levels of parental stress are linked to the early inclusion of children with Down syndrome in the inclusive programme.

H3: When it comes to parental stress, working moms of children with Down syndrome face higher levels than do non-working mothers.

Providing care for a family member with a Down syndrome comes with many difficulties, especially when they become an adult. Not surprisingly, a large amount of data suggests that families in this circumstance feel more stressed.[7] Extensive study on the experiences of children with disabilities has been prompted by the critical role that parents play as they are children's primary carriers. Parental stress levels are anticipated to decline because of the child's younger age and involvement in inclusive education programs these kids are expected to make a progress rather than making them limited to homes.[8] It is believed that inclusive education is a dynamic process that aims to meet and accommodate each learner's unique requirements. Its main objectives are to increase student involvement in the classroom, promote diversity in different groups and cultures, and reduce marginalization in the educational setting. This strategy calls for modifications to the curriculum, instructional practices, organizational frameworks, and general tactics.

A common vision that includes all children within the proper age range and emphasizes the idea that the normal educational system should be responsible for meeting every child's needs is essential to inclusive education.[9] The Education Sector Analysis 2019 for Khyber Pakhtunkhwa has a thorough chapter on inclusive education, which is widely defined to include pupils from marginalised backgrounds. These include those who are impacted by poverty, discrimination on the basis of gender, ethnicity, religion, or disability.

The study carefully looks at the state of affairs, points out possibilities, problems, and prioritizes programs that are important to close gaps in knowledge. It also highlights how critical it is to expand on current programs in order to support inclusive teaching methods and guarantee all kids have fair access to school. [10] A rising commitment to inclusion is reaffirmed in the 2013–2018 Five Years of Education Reform agenda, which emphasizes the need for “a broader push for the inclusion of children with disabilities into regular schools. [11]

Methodology: In developing nations such as Pakistan, especially in Khyber Pakhtunkhwa, parents of children with Down syndrome still face many obstacles despite notable progress in the medical and educational domains. The purpose of this study is to evaluate the efficacy

of inclusion programs for children with Down syndrome. In this study, parental stress levels among families with Down syndrome engaged in early inclusive childhood programs (ages 1-6) and delayed inclusive childhood programs (beyond 7 years) are examined. The study evaluates how parents in these two groups feel different levels of stress by applying a comparative analytical method. Furthermore, the success of these programs was linked to parents of people with Down syndrome reporting lower levels of stress. The study was conducted between November 2020 to July 2021. A cross-sectional study employing a snow ball sample technique was conducted to assess the effectiveness of several intervention programs in Mardan, Charsada, Naushera, Swabi, and Peshawar. 98 parents who were contacted at various intervention programs were included in the study, and the efficacy of the therapies was assessed. Data collection instruments included a Self-Constructed Demographic Information Sheet (SCDIS), Brief COPE, and Parental Stress Scale (PSS). The SCDIS captured demographic details such as family income levels, child diagnosis, marital status, and medical interventions. The PSS, a well-established measure of parenting stress, assessed respondents' perceptions of stress across various dimensions. Validity was ensured through the effectiveness of the questionnaire in collecting relevant data, while reliability was established through pilot testing and subsequent analysis.

Table 1 Frequencies and percentage of participants along with demographics

Demographics	*f*	%
Gender	100	
Mother	50	50
Father	50	50
Education		
High School	5	5.0
Completed High School	3	3.0
Vocational.	12	12.0
Some College, not degree	3	3.0
Associate Degree	11	11.0
Bachelor's degree	23	23.0
Graduate School	11	11.0
Intermarriages		
Yes	51	51.0
No	49	49.0
Mothers Employment		
Working	68	68.0
Non-Working	31	31.0
Child Gender		
Male	58	58.0
Female	41	41.0

Table 1 describes the, gender educational status, child gender, intermarriages, and occupational status of the respondents. Result of the Present study showed that 50% Mothers and 50% of Fathers of Down syndrome children were selected for the present study. It was also found that 23% of parents had bachelor's degree whereas only 5% completed their high school education and only 3% were intermediate degree holder. The results also concluded that majority (51%) of the respondent's intermarriages. In case of occupational status of the respondent's, results further showed that majority of the mothers (68%) were engaged in some kind of jobs. Apart from this, 31 % were full time mothers. Similarly highlighting the Child Gender 58% was found to be males and 41 % were females.

Result:

Table 2: Means, Standard Deviations and t-value on the stress scale between school inclusion and home schooled of Children with Down syndrome (N=95)

Variables	ETI (n = 72)		LTI (n = 23)		$t(93)$	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Stress	54.21	5.24	58.26	4.13	-3.39	.001	-6.428	-1.677	-0.81

Table 2 shows the results of t-test for comparing the stress scale between practice of educating students with special needs in regular classes and educating them at home by their parents. The table shows that the parents having early therapeutic intervention reflects less stress as compared to the parents having late therapeutic intervention. The mean difference 4.05 is highly significant.

Table 3: Means, Standard Deviations and t-value on the stress scale between Early and Delayed Inclusive Programs for child with Down syndrome (N=97)

Variables	ETI (Boys) (n =49)		ETP (Girls) (n = 48)		$t(95)$	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Stress	57.27	5.21	53.71	5.88	3.152	.002	1.317	5.797	0.64

Table 3 shows the results of t-test for comparing the stress scale in early and late childhood of Down syndrome children by their parents. The table shows that the parents having Down syndrome children enrolled in early inclusive programs experience more stress as compared to the delayed inclusive programs. The result is statistically significant at ($p < .01$).

Table 4: Means, Standard Deviations and t-values on Stress between working and non-working parents (N=100)

Variables	AF (n = 68)		FDF (n = 32)		t	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Stress	54.00	5.64	58.7	4.70	-3.99	.000	-6.95	-2.337	-0.90

AF (affluent families), FDF (financially disadvantaged families)

Table 4 shows the results of t-test for comparing working and non-working parents based mean differences on stress. The table shows that non-working parents of Down syndrome children have higher stress as compared to working parents of Down syndrome children. The mean difference 11.23 is highly significant between working and non-working of Down syndrome children.

Table 5 Means, Standard Deviations and t-values on brief coping and its subscales between working and non-working (N=100)

Variables	Working (n = 68)		Non-Working (n = 32)		t	P	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Brief Coping	92.54	15.89	103.8	9.77	-3.63	.000	-17.38	-5.08	-0.79
1. Self-distraction	7.18	1.14	7.55	1.150	-1.49	.138	-.865	.121	-0.32
2. Active coping	6.03	1.83	7.39	1.145	-3.80	.000	-2.06	-.649	-0.83
3. Denial	7.15	1.15	7.68	.832	-2.305	.023	-.987	-.074	-0.50
4. Substance use	7.09	1.194	7.77	.669	-2.98	.004	-1.142	-.230	-0.64
5. Use of emotional support	7.10	1.174	7.65	1.082	-2.183	.031	-1.035	-.049	-0.48
6. Use of instrumental support	6.31	1.831	6.94	1.28	-1.719	.089	-1.350	.097	-0.38
7. Behavioral disengagement	7.19	1.19	7.48	1.24	-1.123	.264	-810	.225	-0.24
8. Venting	5.51	1.904	6.39	.989	-2.402	.018	-1.593	-.152	-0.53
9. Positive reframing	6.12	1.758	7.81	.654	-5.18	.000	-2.336	-1.041	-1.13
10. Planning	6.28	1.811	6.97	1.303	1.901	.060	-1.407	.030	-0.57
11. Humor	5.54	2.119	7.32	1.301	-4.310	.000	-2.59	-.960	-0.94
12. Acceptance	7.18	1.145	7.61	.844	-1.898	.061	-893	.020	-0.41
13. Religion	7.15	1.149	7.74	.729	-2.65	.010	-1.041	-.149	-0.57
14. Self-blame	6.72	1.629	7.48	1.151	-2.35	.021	-1.407	-.119	-0.51

Table 5 shows the results of t-test for comparing the mean differences between working and non-working parents on brief coping and its subscales. The table shows that nonworking parents of Down syndrome children have statistically significant higher means on active coping, denial, substance use, use of emotional support, venting, positive reframing, humor, religion and self-blame whereas on Self-distraction, Use of instrumental support, Behavioral disengagement, planning and acceptance means are statistically non-significant between working and non-working parents.

Discussion:

Due to children's fast development and exploration throughout this era, the toddler years are often acknowledged as a difficult time for parents. But the toddler years may be particularly difficult for parents of disabled children, as they manage additional stressors specific to their situation. Studies have often demonstrated that parents of children with impairments feel more stressed than parents of children who are usually developing.[12] Managing their kid's unique needs, getting access to the right support resources, and speaking out for their child in a variety of settings—such as hospitals and schools—can be difficult tasks for parents of toddlers with disabilities. [13] The already taxing nature of parenting during the toddler years can be exacerbated by these extra pressures, putting parents under more emotional, physical, and psychological strain. Targeted assistance and interventions are necessary to increase parental well-being and improve the general quality of life for both parents and children.[14] This requires an understanding of and attention to the particular pressures experienced by parents of

toddlers with disabilities at this time. For both parents and children, the toddler years are a crucial developmental stage marked by important turning points and changes. While any parent may face concerns at this time, parents of children with disabilities frequently face extra difficulties that can heighten feelings of anxiety and exhaustion. Studies show that parents of usually developing children do not have the same levels of stress, anxiety, or depression as parents of disabled children .[15]

Parents with disabled children may struggle during the toddler years with issues pertaining to their child's socialization ability, medical requirements, and developmental growth. Moreover, parental stress and feelings of loneliness may be exacerbated by a lack of easily available tools and support services. [16] The special pressures that parents of toddlers with disabilities experience must be acknowledged and addressed by healthcare providers, educators, and support groups. Through the provision of all-encompassing assistance, knowledge, and tools, experts can enable parents to effectively manage the difficulties of raising a child with disabilities and improve their general welfare. Parental stress levels are significantly influenced by educational settings, as evidenced by a recent study that compared the stress levels of parents of special needs children enrolled in typical programs to those whose children were homeschooled.

Several research have looked into how parenting stress levels are affected by educational environments. Studies continuously show that parents of children with special needs endure higher stress levels than parents of children who are usually. [17] This elevated stress is often attributed to the unique challenges and demands of having a child with special needs, including traversing complex educational systems, advocating for critical assistance, and dealing with the child's unique requirements. [18] The kind of academic setting parents decide on, such as homeschooling vs formal schools, may have a significant impact on their mental health levels. In addition to offering a nurturing environment for the child's development and learning, regular schooling allows parents to benefit from certified specialists, professional assistance programs, and interaction with other children, all of which can relieve [19]. Homeschooling, on the contrary, places much of the responsibility for personalized instruction and support on parents, which might result in increased stress levels due to the additional demands and challenges involved.

Table 4 presents the results of a t-test comparing the stress levels of working and non-working parents of children with Down syndrome. The results demonstrate a statistically significant mean difference of 11.23 points in stress levels between working and non-working parents; the former report higher levels of stress. The significant variation in the amount of stress between parents including kids having the genetic disorder Down syndrome is significantly influenced by parents' employment status. The observed difference in stress between working and non-employed parents is due to a greater workload and employment responsibilities, which limit their capacity to devote sufficient hours to their young children with Down. [20] the impact of mother and father's parental job status on family life and stress in households with Down syndrome children. Their findings revealed that households with both parents working full-time faced higher levels of stress due to restricted time available for parenting and the extra strain of managing work and home duties. Furthermore, [21] study revealed differences in psychological stress among working and non-working mothers of children having Down syndrome. They discovered that working mothers had greater levels of stress as a result of the rigours of their occupations, which resulted in lower availability for their child's needs as well as elevated regret and worry.

Raising an individual with a genetic condition requires a significant amount of determination and time and it becomes an obligation for parents to organize therapy sessions, therapeutic appointments as well as supporting and facilitating a child with Down syndrome in the school.

The witnessed difference in the levels of stress amid working and non-working parents of developmentally delayed children, highlights

the complex association that can be witnessed between a parent's psychological health, their career growth, and their caregiving responsibilities. Recognizing the specific challenges faced by parents of children with Down syndrome and providing extensive resources to fulfil their needs is critical for trainers, lawmakers, and medical specialists.

Accessibility to therapy services, peer support networks, and temporary assistance are just a few of the measures that could assist non-working parents experience less anxious while promoting self-care.[22] Similarly, to assist working parents with managing their career and childcare commitments, businesses may give convenient arrangement or remote options.

Implications for Practice:

The current study's findings underscore the significance of educational environments for the children with Down syndrome and highlight its bearings on psychological wellbeing of parents. Thus emphasizing the significance of fitting in instructive care into support plans for parents with offspring who have distinctive needs. It becomes essential for instructors, legislators, and medical counsellors to give precedence to the establishment of inclusive and nurturing instructional context for these children. By guaranteeing access to such settings, one can advantage, both the children with Down syndrome and their parents to improve their psychological well-being and bring holistic developments. Families that are thinking about homeschooling should also have access to resources and support services so they have the equipment and help them need to teach their kids well and handle stress.

Conclusion:

Conclusively, the current research offers significant perspectives on the correlation between educational environments being introduce to the child with Down syndrome and the stress levels of parents while raising children with exceptional needs. It is concluded that the overall well-being of children with genetic condition and their parents can be improved by advanced educational as well as putting particular interventions in place to support families. Further research is needed to find other elements that may impact psychological well being in numerous settings, as well as to develop all-inclusive support programs tailored to the needs of families.

Limitations:

These are some of the research's limitations.

There are a number of study constraints that should be taken into account. First off, because the study is limited to Khyber Pakhtunkhwa, its conclusions could not apply to other parts of the country. This restriction results from the particular contextual elements, which might not be typical of other places or circumstances. Furthermore, there exists a possibility of sample bias in the selection procedure, which may lead to the exclusion of specific demographic groups or viewpoints, thereby diminishing the overall representativeness of the results. Thirdly, relying too much on certain methods of data collection, such surveys or interviews, may lead to biases in the replies or make it more difficult to adequately represent the variety of experiences and points of view. Errors or misconceptions may arise from the interpretation of data due to cultural differences or language barriers. Moreover, the study's temporal span precluded a comprehensive examination of the long-term effects or adjustments to inclusive education practices over time. Resource limitations, including a lack of money or access to technology, may also limit the breadth or depth of the study, which might affect how thorough the analysis is. Furthermore, the lack of longitudinal data may make it more difficult to evaluate the long-term viability or effects of inclusive education programs.

Declaration of Ethics:

The highest ethical standards are followed in the design, execution, and reporting of this study. The CHE, university of Peshawar, Graduate studies board examined and approved the study protocol to make sure it complied with legal and ethical requirements. Before giving their informed permission, participants were given comprehensive information about the study's goals, methods, possible risks, and advantages.

Throughout the whole research procedure, participants' personal information was kept completely anonymous and confidential. All personally identifiable information was safely kept and only those with permission may access it.

Statement of Conflict of Interest: The research's authors state that there are no conflicts of interest related to it. There were no financial or interpersonal ties that might have influenced the research findings or how the data were interpreted when this study was done. The authors reaffirm their dedication to carrying out the study in an honest and open manner, placing a high value on the distribution of factual and unbiased data.

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