

ORIGINAL ARTICLE

EXPLORING THE IMPACT OF INTERVENTIONS ON THE PSYCHOLOGICAL WELL-BEING OF PARENTS OF CHILDREN WITH DOWN SYNDROME IN KHYBER PAKHTUNKHWA, PAKISTAN

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Background: Despite the significant advancements in medical and educational fields, children with Down syndrome and their parents still encounter numerous challenges in Developing countries like Pakistan, particularly in the Khyber Pakhtunkhwa area. This study hypothesized that prolific intervention programs instituted to support parents in dealing with these challenges will experience a reduction in parental stress levels. **Methods:** Cross-sectional descriptive research was carried out using a Purposive sample approach between 15th June 2020 and 05th January 2023 to evaluate the impact of several intervention programs for parents at different special education centers in Mardan, Charsada, Naushera, Swabi, and Peshawar. The research included 105 parents who were approached through these intervention programs and the success of these programs were evaluated across five dimensions: Social, psychological, cognitive, religious, and educational aspects. The interview-based parenting Intervention Questionnaire (IBPIQ) was used to gather information concerning the efficacy of these interventions, and the parental stress scale was administered to measure parental stress. **Results:** The results of the study showed that there is no significant correlation between Parental intervention programs and reduced levels of parental stress. While a weak positive correlation (social impact: 0.212) was found whereas psychological p -values = 0.065, educational p -values = -0.058, cognitive p -values = -0.067, and religious impact p -values = 0.101 were non-significant. **Conclusion:** After an extensive review of various intervention programs for parents of children with Down syndrome in Pakistan, this study concluded that these Intervention programs did not significantly benefit the parents. As a result, stress levels among Down syndrome's parents did not lessen, regardless of their involvement in these interventions.

Keywords: Down syndrome; Intervention Programs; Special Education; Parents

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INTRODUCTION

Down syndrome is the most common and identifiable chromosomal condition associated with intellectual disabilities.¹ It occurs when a cell development accident results in an extra chromosome, making 47 instead of the usual 46 chromosomes. Diagnosis typically takes place shortly after birth through a chromosome test.² The perplexing truth is that children with Down syndrome are a remarkably exceptional and singular creation of Allah, and as such, they should receive unequivocal love, esteem, and meticulous attention.³ In recent years, the domain of Down syndrome intervention and education has experienced a significant surge of advancements, empowering these children to live profoundly gratifying and unpredictable lives.⁴

Parental interventions include varied approaches and are expected to support parents raising children with Down syndrome. The purpose of such programs is to facilitate parents by equipping them

with the necessary means and support to overcome the inimitable dares associated with raising a child with Down syndrome. These techniques may be classified into three groups: educational interventions, behavioural treatments, and supportive interventions. By arming parents with the knowledge and resources to support their child's development, these approaches enable parents to encourage their child's progress in areas like self-sufficiency, behaviour management, and communication.⁵ Studies show that children with Down syndrome can make significant progress in their language and communication skills when they participate in a parent education program focused on evidence-based therapies.⁶

Peer support groups, counselling, and respite care for parents of children with Down syndrome can help them exchange experiences, learn from one another, and give support to one another. However there is no one-size-fits-all approach, and treatments should be customized to the individual requirements of each family.⁷ Early intervention can promote

greater skills, linguistic, motor, and cognitive development, as well as minimize health difficulties like respiratory and ear infections.⁸ While a variety of interventions can assist parents of children with Down syndrome, research findings have been inconsistent. For instance, a parenting program did not considerably enhance the behaviour of their children with disabilities such as Down syndrome or lessen parental stress.⁹ The results of child development were not considerably improved by a parental awareness program.¹⁰ To be beneficial, these programs must be adapted to each child's and parents' unique and distinct requirements. These projects may be implemented far more triumphantly in aiding parents of children with Down syndrome with more research, study, assessment and evaluation.

The main objective of this research was to achieve increased awareness of the potential advantages and opportunities that an intervention program may present for parents of children with Down syndrome. Additionally, the study aimed to determine the efficacy of these programs that may benefit the parent community by fostering acceptance and a better understanding of plummeting stress levels.

Informal care is more closely associated with certain developmental and behavioural outcomes than institutional care. However, according to recent research psychological support from social networks may have a beneficial influence on parents' well-being, and specific parts of their lives and families may assist in alleviating the consequences of stress.¹¹ Extensive research showed that informal care is more strongly linked to several developmental and behavioural outcomes than formal care¹². They also suggested that social network collaboration might raise skill levels among people getting assistance from informal careers. Surprisingly, mothers and fathers of pre-kindergarten children with Down syndrome were more likely to have supportive social networks that significantly shaped their interpersonal behaviours as parents, rather than broader family well-being or child growth. Higher levels of social support are related to improved parental, family, and child developmental outcomes.¹³ Moreover, programs that incorporated counselling were shown to be more successful than those that did not.¹⁴

MATERIAL AND METHODS

This descriptive cross-sectional study was conducted between 15th June 2020 and 05th January 2023 in Swabi, Mardan, Charsada, Nowshera, and Peshawar, located in Khyber Pakhtunkhwa. A total of 105 parents of children with Down syndrome, who attended special education institutions or centers were interviewed. The study maintained total anonymity so that respondents could

voice their honest views without worrying about revealing private data that would skew their responses. The researcher arranged preliminary appointments with the parents as well as with the educational officials through phone calls. During the introductory sessions, the research objectives were briefed by the researcher to the parents who were assured that their privacy would be respected while dealing with their personal information. To ensure that the participants felt comfortable giving their opinions, the researcher decided to speak with the parents privately at their convenience place. Formal declarations of consent were obtained for this investigation from the parents of the children with Down syndrome as well as the significant authorities. Additionally, the educational authorities were persuaded that their identities would remain private which was essential to gathering reliable data. Based on the socioeconomic traits that allowed the respondents to be grouped into categories, a demographic information sheet was constructed. The traits that were taken into account included age, gender, income, family status, education, religion, and the position of the Down syndrome kid in the home. Other questions covered school placement and medical intervention. This allowed a deeper understanding of the respondent's background. A total of 19 closed-ended and open-ended questions comprised the questionnaire.

The present study comprised a sample of 105 parents having children with Down syndrome. The children with Down syndrome were categorized based on their dependency on parents, ranging from 0–15 years old, with 21% being 0–5 years old, 38.1% being 6–10 years old, and 41% being 11–15 years old. There were 52 mothers and 53 fathers in the sample, accounting for 49.5% and 50.5% of the total respectively.

All respondents agreed that a supportive learning environment should be provided for children with Down syndrome. Nearly 30% of children with Down syndrome were enrolled in government-funded special education classrooms, 21% attended private special education classes, and 49.5% received therapy services. In terms of societal reactions to the diagnosis, 10.5% reported denial, 21% reported contention, 47.6% reported despair, and 21% reported confusion. The results showed that 8.6% of the parents had positive expectations for the prospects of their children with Down syndrome, while 91.4% believed their children would face many barriers in their lives. Furthermore, 22.9% of the participants advised people to have an abortion if given a diagnosis of having a child with Down syndrome, while 77.1% recommended empowering them instead. Half of the parents reported that there were educational benefits for those living with Down syndrome, while the other half stated there were no such advantages. Similarly, 50.5% claimed mainstreaming could enhance and accelerate development, while 49.5%

argued it caused delays in different areas of growth.

Interview based parental Intervention questionnaire (IBPIQ) was designed and tested in the pilot study. The questionnaire focused on five different domains of the intervention program, i.e., social, psychological, educational, cognitive, and religious. Respondents rated their level of satisfaction with the intervention program using a 5-point rating system (48 questions) using coefficient alpha for a reliability score of 0.67 to assess the efficacy representing moderate internal consistency amid the items. The Parenting Stress Index (PSI) is a self-report scale comprising 18 items designed to assess parental stress. The PSI's internal consistency coefficient alpha is 0.86, indicating that the items on the scale are well associated with one another.

RESULTS

Prolific Parental intervention programs have been shown to reduce levels of parental stress. Correlation between

these types of programs and the impact they can have on parents' overall well-being.

The correlation between levels of parental stress and social impact, religious impact, and intervention program was found to be weakly positive ($r = 0.212$), which is statistically significant, as the level of significance ($\alpha = 0.05$) was greater than the p -value ($p=0.03$). However, there were no significant correlations between levels of parental stress and psychological, educational, cognitive, or religious impacts; all having a p -value higher than $\alpha (=0.05)$.

The results of the independent samples t-test indicated that there is a statistically significant difference in mean scores for types of stress between mothers ($M=8.67$, $SD=1.26$, $n=52$) and fathers ($M=9.24$, $SD=1.21$, $n=53$; $p<0.05$). Specifically, the mean score for types of stress among mothers was lower than that of fathers with Down syndrome children at the 0.05 level of significance.

Table-1: Descriptive characteristics of the interview-based parental intervention questionnaire and parental Stress Scale

Scales	No. of items	M	S.D	Coefficient alpha
IBPIQ	48	173.07	9.22	0.67
PSS	18	69.46	1.56	0.86

Table-2: Explore the demographic characteristics of different variables

Variable	f	%
Age of DS Child		
0 – 5 years	22	21
6 – 10 years	40	38.1
11 – 15 years	43	41
Pre and post-complications explained by the doctor		
No	105	100
Family medical history		
Mother	02	1.9
Father	08	7.6
Nil	95	90.5
DS Awareness		
Yes	86	81.9
No	19	18.1
Enrolment of DS intervention program		
Special education classroom (Government)	31	29.5
Special education classroom (Private)	22	21.0
Specific therapy centre.	52	49.5
Parental feeling of contentment		
Yes	105	100
DS Future outlook		
Positive future prospects	09	8.6
Future barriers	96	91.4
Advice to other people, diagnosed With Down syndrome child		
Abortion	24	22.9
Empower	81	77.1
Education Benefits for DS		
Yes	53	50.5
No	52	49.5
Mainstream Benefits to DS children		
Enhance and accelerate development	53	50.5
Delays in different areas of development	52	49.5

Note: f=frequency, %=percentage, DS=Down Syndrome

Table-3: Correlation between parental intervention program and levels of parental stress

Variables	Social impact	Psychological impact	Educational impact	Cognitive impact	Religious impact	Intervention Program
Levels of parental stress	0.212*	0.065	-0.058	-0.067	0.101*	0.105*

Table-4: T values showing differences between psychological stress in the mother and father of Down syndrome children.

Variable	Mother (n=52)		Father (n=53)		T	P	95% confidence interval		Cohen's D
	M	SD	M	SD			LL	UL	
Psychological Stress	8.67	1.26	9.24	1.21	-2.37	0.020	-1.05	-0.09	0.46

Note: n=sample size, α=level of significance, M=Mean, SD=Standard deviation, P=probability, LL=Lower limit, UL=Upper limit, df=Degree of freedom

DISCUSSION

The findings of this study conclude that in Khyber Pakhtunkhwa, the recognized early Intervention Programs are not helping parents of children with Down syndrome. Moreover, many intervention programs were found unsuccessful in offering adequate assistance on how to deal with difficult situations or how to create a conducive environment for both parent and child. A potential reason for this lack of efficacy is that the professionals conducting these programs have a limited clutch of what constitutes an effective program for parents living with children with special needs. Furthermore, it was observed that there is sometimes limited access to these customized programs that may assist families in managing the stress associated with such parenting issues. In contrast, intervention programs offered to parents of children with Down syndrome have beneficial benefits, leading to an increase in autonomy for these persons¹⁵. The current study is an in-depth examination of the Intervention Programs (IPs) accessible to parents of children with Down syndrome. This IPs is critical for the effective rehabilitation of parents of Down syndrome children, as it helps in improving the cognitive capacities, mental health, and overall well-being of the parents. These programs further serve as possible support for parents going through difficult times and additionally, provide valuable advice on raising a kid with Down syndrome. IPs are also considered crucial since many parents don't know how to seek support or guidance. According to the findings of this study, the social impact of these programs is remarkably favourable. The IPs-social Impact ($r = 0.212$) was assessed based on its potential to enhance participant outcomes as well as its broader effect on Down syndrome child cohesiveness and development, i.e., the ability to improve social skills, communication, and behaviour. This finding is in line with the findings.¹⁶ The psychological impact ($=0.065$), educational, (-0.058) cognitive (-0.067) or religious impacts (0.101) however, shows that these programs had no appreciable benefits for the parents. The study

highlights the importance that parents of these specially abled children must be given the right to use the resources and support, including specialized treatments and educational opportunities. Nevertheless, the importance of effectively communicating with families, and giving them clear and true information about their child's development and condition by these professionals can also not be undermined. Research highlights the important advantages of early intervention programs for parents and their kids. These studies demonstrate how involvement in these programs—whether they are centred on comprehensive intervention, education, or child development—helps parents become more aware of and understand their kid's needs.¹⁷⁻¹⁹

CONCLUSION

In conclusion, the study results highlight the constraints and difficulties that Parental Intervention Programs encounter across Khyber Pakhtunkhwa regions. The limitations of the study show that these efforts fall short of their expected benefits because of low resources and inefficient policy execution, which is contrary to previous literature stressing the beneficial impact of such programs. The usefulness of these programs in the unique cultural, political, social, and religious context of the area is called into serious question by this.

Recommendation

Significant changes are required to develop these programs and assist parents in dealing with particular difficulties. Governments and communities may enhance the results by implementing a comprehensive strategy that incorporates policy reform, expanded resource accessibility, and support networks. The research sheds light on the effectiveness of these initiatives, identifies areas for development, and suggests practical methods for assisting families in adjusting to their child's diagnosis.

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AUTHORS' CONTRIBUTION

The initial literature search, conceptualization of the study design, data collection, analysis, and interpretation were conducted by Sidra Ali. The co-author, SKFH was responsible for proofreading and the final write-up

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