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Impact on Family Functioning, Social Support and Psychological Distress in Parents of Children with Intellectual Disability

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Abstract

The study explores the association between impact on family functioning, social support, and psychological distress in parents of children with intellectual disability. The study used a correlational research design and purposive sampling (non-probability) to collect data. 100 parents with an average age of 38 years (*SD*= 5.81*)* constituting both mothers *(n*= 50*)* and fathers *(n*= 50*)* were recruited. The results of correlation analysis revealed positive relationship of impact on family functioning and psychological distress and also negative relationship of social support with psychological distress in caregivers of individuals with intellectual disability. The results of hierarchal regression analysis indicated that psychological distress was predicted by social support in parents of intellectual disabled children. The results of independent sample t-test indicated significant differences in mother and father of children in ID, where mothers had higher mean score than fathers in the study. The study can lay the basis to set to preventive protocols and guideline for psychological distress faced by caregivers due to negative impact on family life and enhance social support in hospitals, educational institutions and primaryhealth care departments.

Keywords: family functioning, social support, psychological distress, intellectual disability

Introduction

Children diagnosed with intellectual disability have deficits in cognitive and adaptive abilities, such as restricted communication, self-help skills, and self-directed behavior. Furthermore, children with intellectual disability have a cognitive process that is characterized by simplicity, limited capacity for comprehension and retention, and deficiencies in language comprehension and numerical skills. A child is diagnosed with ID when an individual exhibits deficiency in intellectual functions, lacks adaptive functioning skills, and experiences the onset of intellectual and adaptive impairments during the developmental period (APA, 2022). As children with intellectual disability often struggle with issues related to independence and self-help skills, therefore, they are dependent on their parents or caregivers even for everyday tasks (Nurhidaya et al., 2020). The parenting of children may come with a sense of accomplishment but it can negatively influence the psychological, economic and financial functioning of family members (Bruce et al., 2014; Yoon & Kim, 2015). The parenting of children with ID places demands on parents in terms of time, effort, and finances, often resulting in caregiver burden and psychological distress in parents (Tadema & Vlaskamp. 2010). Malhotra et al. (2012)

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reported that families with ID have higher caregiver burden due to issues with independent self-care and communication. It was also reported that families with ID show poor family functioning and marital dissatisfaction (Al-Krenawi et al., 2011). These demands can make parents of children with special needs prone to psychological distress (Beckers et al., 2021). This psychological distress is caused by the ongoing demands of caregiving, uncertainty over the future, financial pressure, and social isolation (Arif et al., 2021). Furthermore, the internalization of societal stigma can result in parents experiencing emotions such as shame, remorse, and inadequacy, which intensify their psychological burden (Smith et al., 2020). The discrimination that the parents of children with intellectual disability (ID) experience are evident in several ways, including the use of derogatory labels, impolite remarks, attributing guilt to the parents for their child's condition, and outright rejection (McLean & Halstead, 2021).

In this regard, social support plays a crucial role in moderating the connection between impact on family functioning and psychological distress. Poor social support, the clinical status of the children, and sociodemographic factors can influence the psychological distress of parents (Chen et al., 2021). The absence of social support for parents with childing having ID might result in adverse outcomes, including family, emotional and behavioral difficulties (Nurhidaya et al., 2021). Social support acts as a vital protective buffer against the deleterious effects of stigma, offering emotional validation, practical assistance, and a sense of belonging (Smith et al., 2010). Therefore, parents of children with intellectual disabilities greatly require social support from various sources such as their spouses, family members, friends, peer groups, and other healthcare professionals. This support directly impacts these children's quality of life and health (Naz et al., 2020).

Recognizing the dynamic interplay among these factors underscores the need for tailored interventions that bolster support networks, reduce negative on family, and provide accessible mental health resources. Ultimately, clarifying these connections can helps in understanding what it’s like to be a parent and guides attempts to create a more accepting and helpful environment for families with children who have intellectual disabilities. The objective of this study was to analyze examine the relationship impact of ID on family functioning, social support and psychological distress in parents of children with ID. The study can help in formulating intervention strategies, support systems, and policies to enhance the well-being and overall quality of life of parents.

Hypotheses

H1: There is a likely positive association between impact on family functioning and psychological distress in parents of children with ID.

H2: There is likely to be a negative relationship between social support and psychological distress in caregivers of individuals with ID

H3: Impact on family functioning and social support are likely to predict psychological distress in caregivers of children with ID.

H4: There are likely to be gender differences in impact on family functioning, social support and psychological distress in caregivers of children with ID.

Method

Research Design

Correlational research design was used.

Sampling Strategy

A purposive sampling technique of non-probability sampling method was accustomed to select a sample of 100 parents of children with intellectual disability. With the utilization of purposive sampling technique, research included parents *(N = 100),* consisting of both mothers *(n = 50)* and fathers *(n = 50).* The sample was taken from schools having children with special needs and community. In schools, parents were given the questionnaire and asked to fill it by the other day. In community, the researcher filled the questionnaires in face-to-face interaction with the parents. Those parents that do not know how to read were explained each question and then they replied accordingly. The mean age of the participants was 38.60 (*SD*=5.81) while the mean age of the child with ID was 10.87 (*SD*=4.56). The reported number of caregivers hours was 20.49 hours (*SD* = 6.62). Parents' having at least one child with special needs (age 4 to 18 years) in a moderate to severe category were included. The study did not include caregivers who were divorced, widowed, separated and were physically ill.

Table 1

Demographic Details of the Sample (N=100)

Demographics	*n*	*%*
Mothers	50	50
Fathers	50	50
Education		
Illiterate	20	20
Primary	20	20
Matric	20	20
Intermediate	18	18
Bachelor	12	12
Masters	10	10
Partner's education		
Illiterate	9	9
Primary	11	11
Matric	22	22
Intermediate	10	10
Bachelor	33	33
Masters	15	15
Level of disability of child		
Moderate	60	60
Severe	40	40

Assessment Measures

Assessment measures or tools that researcher has used in this study were;

Demographic Data Sheet

A demographic information sheet developed by researcher was used to collect information about the mother and father, such as gender, age, household income, education level, occupation, child's age, level of disability of child, number of children, child birth order, and number of caregiving hours.

Kessler Psychological Distress Scale (Kessler et al., 2002)

The Scale KPDS had 10 items rated on 5-point Likert scale ranging from "1=none of the time and 5= all of the time". The scores were calculated after summing up the ten item and they ranged from10-50 where high values indicated high psychological distress in a pants. The scale has high Cronbach's alpha of 0.88.

The Family Impact Questionnaire (Donenberg & Baker, 1993)

The scale FIQ included 50 items that compare caregivers' assessments of their child's impact on their families to "most kids his/her age have on their folks/family" in several dimensions of family functioning. Items were rate on three-point scale "(0) not at all to (3) very lot". The scale reliabilities varied from. 83 to.92. The current sample shows a Cronbach alpha of .65.

Multidimensional Perceived Social Support Scale (Zimet et al., 1988)

The scale MSPSS has 12 items. The questionnaire assesses the perceived sufficiency of social support from three sources: family, friends, and significant others. The statements are rated on a 7-point scale "1=very strongly disagreeto 7=very strongly agree". The MSPSS questionnaire is divided into three subscales: friends, family and significant others and each of which is represented by a different item number. The Cronbach alpha of MSPSS scale was .85. The family subscale ranged from .81 to .93, friends ranged from .78 to .94, and significant other ranged from .79 to .98.

Procedure

The topic of study was chosen based on the researcher's interests and then finalized by the supervisor. After deciding on a topic, research questionnaires were used to evaluate the study variables, and the valid questionnaire for measuring variables was chosen. The researcher of the poll acquired authorization. To conduct the research, the researcher got institutional clearance letters from the department of Psychology. The letter verified the researcher's identity and the research subject. This authority letter was distributed to the various principals of special schools in order to collect data. The researcher determined the study's exclusion criteria. The sample was reached through purposive method. The researcher assures the parents that any information gathered from them will be kept secret, and parental agreement was requested. Permission was granted from the supervisor before conducting data. The research and the research subject were explained to the participants. Participants were given questionnaires, and those who checked the box for informed permission filled them out. Every statement on the surveys was explained to the participants verbally. Following brief instructions, the surveys were distributed. All questions were described in detail so that participants could select the best choice for them. As a result, participants had no problem

completing the questionnaire. The participants gave enthusiastic responses and were able to comprehend and respond to the question without difficulty. It took around 25 to 30 days for the entire sample to finish all of the replies.

Ethical Considerations

Following ethical considerations were used for conducting this study:

- The author's permission to use the scales was obtained before using the scales.
- In response to the author's application, the department issued an authority letter, which was then submitted to the relevant authorities to get permission for data collection.
- Each participant received a consent document from the researcher asking for their permission.
- Data collection began when formal consent was obtained from all reliable sources, and only individuals who satisfied the requirements were allowed access to the questionnaire.
- Participants in study have the option to withdraw at any time if they feel uncomfortable.

Results

The psychometric properties of variables were checked using descriptive statistics. To determine the association between impact on family functioning, social support, and psychological distress, Pearson product moment correlation was utilized. The relation between social support and psychological distress was predicted using regression, and the mean differences among carers of children with ID was measured using an independent sample t test.

Table 2

Psychometric Properties of Impact on Family Functioning, Social Support and Psychological Distress

Variables	*M*	*SD*	Range	Cronbach's α
Impact on Family Functioning	60.80	13.74	22-72	.81
Social Support	61.20	12.91	26-72	.93
Psychological Distress	28.07	2.78	22-37	.85

Results found excellent internal consistency for impact on family functioning (α=.81), social support (α=.93) and psychological distress (α=.85) scale.

According to the hypothesis, there is a likely positive association between impact on family functioning and psychological distress in parents of children with intellectual disabilities. Also, there is likely to be a negative relationship between social support and psychologicaldistress in caregivers of individuals with Intellectual Disability. The results are given below in Table 3.

Table 3

Relationship between Impact on Family Functioning, Social Support and Psychological Distress in Parentsof Children with Intellectual Disability

Variables	*n*	*M*	*SD*	*1*	*2*	*3*
1. Impact on Family Functioning	100	60.80	13.74	-		
2. Social Support	100	61.20	12.91	-.34**	-	
3. Psychological Distress	100	28.07	2.78	.22*	-.36**	-

*p< .05, **p< .01, ***p< .001

The findings of Pearson product moment correlation showed that impact on family functioning was negatively related to social support and positively related to psychological distress in parents with childing having ID. It showed that high impact on family functioning was related to less social support and more distress in parents. Furthermore, psychological distress was positively related to impact on family functioning and inversely related to social support in parents with childing having ID. This showed that high impact on family functioning is associated with more psychological distress.

The third hypothesis social support and impact on family functioning are likely to predict psychological distress in caregivers of individuals with intellectual disability was tested using hierarchical regression analysis.

Table 4

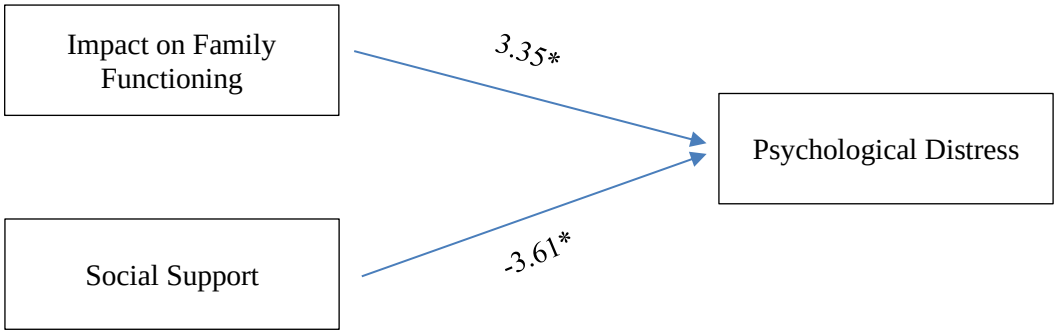
Hierarchical Regression Analysis showing Predictors of Psychological Distress

		95% CI for *B*					
Variables	*B*	*LL*	*UL*	*SE B*	*β*	R^2	ΔR^2
Step 1						.07***	.07**
Constant	31.37***	28.93	33.8	1.23			
Social Support	-.05**	-.09	-.01	.02	-.26**		
Step 2						.10***	.04**
Constant	28.35***	24.70	31.9	1.84			
Social Support	-.73*	-1.3	-.114	.31	-3.61*		
Impact on Family Functioning	.72*	.06	1.38	.33	3.35*		

In step 1, when social support was added as a predictor of psychological distress or the model was significant and social support negatively strongly predicted the psychological distress (F (1, 98) = 7.61, p= 0.007), with only 7% of the variance explained by the model. In step 2, when impact on family functioning was added along with the social support as the predictors. The model again came out as significant (F (1, 97) = 6.32, p= 0.003), and model explained 10% of the variance in model. Impact on family functioning was a positive while social support was a negative predictor of psychological distress.

Figure 1

Emerged Regression Model



Lastly, it was hypothesized that there are gender differences in perceived impact on family functioning, social support, and psychological distress among carers of people with intellectual disabilities. To determine if there will be statistical gender differences between male and female, an independent sample t-test was utilized.

Table 5

Differences between Caregivers of Individuals with Intellectual Disability

	Father		Mother				
Variables	*M*	*SD*	*M*	*SD*	*t*(98)	*p*	Cohen's *d*
Impact on Family Functioning	117.50	13.05	123.20	14.42	85.46	.26	.41
Social Support	57.63	10.01	45.89	18.27	27.48	.29	.79
Psychological Distress	21.65	7.67	23.00	8.02	28.63	.03	.17

Table 5 showed significant differences in terms of psychological distress. Mothers got a higher mean score, indicating that they had a higher proportion of psychological distress than fathers having ID children. However, no significant difference was found in perceived impact on family functioning and social support.

Discussion

The current study looked at perceived impact on family functioning, social support and psychological distress in parents of children with intellectual disability. It was hypothesized that there is a likely positive association between impact on family functioning and psychological distress in carers. Also, there is likely to be a negative relationship between social support and psychological distress in caregivers. Both of these hypotheses were approved in the present study. The findings of Pearson product moment correlation showed that impact on family functioning was positively related to psychological distress in parents with childing having ID. Research by Arif et al. (2021) also reported that parents having children with special needs experience significant changes in their family functioning and it significantly results in distress.

Furthermore, there was a negative association between social support and psychological distress in parents with childing having ID. Social support has a vital role in reducing the negative effects of parenting a child with ID and promoting the well-being of parents. According to a meta-analysis by Gerstein et al. (2009), social support is related to low psychological distress among parents of children with developmental disabilities, including ID. Duran and Ergun (2018) previously conducted research that showed similar findings. Parents of children with ID do not receive appropriate support from family members, friends, or society, particularly due to perceived stigma. Therefore, parents of children with ID are at increased risk of experiencing psychological distress due to the challenges they face in caregiving and navigating societal attitudes. Psychological distress may manifest as symptoms of depression, anxiety, or stress. Research by Eisenhower et al. (2005) indicated that parents of children with ID reported higher levels of depression and stress compared to parents of typically developing children.

It was further hypothesized that impact on family functioning and social support would predict psychological distress in caretakers ID childrem. Accordingto the results, perceived impact on family functioning positively predicts psychological distress. This is consistent with previous research. Reed et al. (2023) also reported that poor family functioning predicts lower mental health in parents of children with ID. Furthermore, social support negatively predicts psychological distress in parents of children with ID. The findings are similar to those of Song and Kim (2015), the research indicating that social support serve as an important social resource and a protective factor that reduce the distress in parents of children with ID. A study by Hastings et al. (2005) also demonstrated that social support moderated the relationship between stress and psychological well-being among parents of children with ID.

Furthermore, impact on family functioning, social support, and psychological distress were hypothesized to differ by gender among caretakers of persons with intellectual disability. The results showed that there is a statistically significant gender difference in psychological distress, according to the results of the independent sample t-test but no gender difference in perceived impact on family functioning or social support. These findings are partly consistent with those of Azeem et al. (2013). Women had a substantially higher rate of psychological distress than fathers. Caley (2012) also reported that mothers as a primary caretaker usually experience higher levels of stress then fathers. According to the data, there were no difference in impact on family functioning and social support. It means that both parents perceived same level of social support and also equal impact of child's behavior. Therefore, it can be concluded that the relationship between impact on family functioning, social support and psychological distress in parents of children with ID is complex and multifaceted. Moreover, family functioning, social support, and psychological distress are interconnected factors that significantly influence the experiences of parents of children having special needs. Addressing stigma through education and advocacy, while reinforcing social support networks, is essential for promoting the well-being of these families. Interventions aimed at enhancing social support and reducing negative impact of family life can help parents and ultimately, improve their over well-being.

Conclusion

Impact on family functioning was positive associated with psychological distress while social support was negatively related to psychological distress in children with ID. Despite the

fact that there were no significant gender differences in social support and impact on family functioning, mothers experienced greater psychological discomfort than fathers.

Limitations and Suggestions

- Limited small sample size resulted in the limited generalize ability togeneralize results to other populations.
- The research sample may have been skewed towards higher socioeconomic class participants due to underrepresentation of those with lower socioeconomic status.
- Finally, the time between the initial diagnosis and the current condition was unexpected and unpredictable. The intensity of a parent's initial sorrow and his or her present feelings may have been very different because thisresearcher only considered the first month after diagnosis. Participants who responded to the surveys soon after receiving the diagnosis and those who did sosome years later may have different perspectives.
- Further research on the risk factor of parent psychological distress may be useful.

Implications

The study highlights the need that parents must be educated about childhood disability. The study emphasized the need for mental health and psychosocial interventions for parents of children with intellectual disabilities. Parents of children with intellectual disabilities require a great deal of social support. Furthermore, social support program should also be available for parents. In order to obtain and determines a child path, parents must also be included in the treatment of their children such as they can be an active member of the Individual Education Program (IEP) team.

References

Al-Krenawi A. (2012). A study of psychological symptoms, family function, marital and life satisfactions of polygamous and monogamous women: the Palestinian case. *The International Journal of Social Psychiatry*, *58*(1), 79–86. https://doi.org/10.1177/0020764010387063

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). American Psychiatric Association Publishing.

Arif A, Ashraf F, Nusrat A. Stress and coping strategies in parents of children with special needs. *Journal of Pakistan Medical Association*, 71, 1369–72. https://doi.org/10.47391/JPMA.1069

Azeem M. W., Dogar, I. A., Cheema, M. A. Asmat, A., Akbar, M., Kousar, S., Haider, I. I. (2013). Anxiety and depression among parents of children with intellectual disability in Pakistan. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 22*(4), 290–295.

Beckers, L. W., Smeets, R. J., van Der Burg, J. J. (2021) Therapy-related stress in parents of children with a physical disability: A specific concept within the construct of parental stress. *Disabil Rehabil.*, 43, 1185–92. https://doi.org/10.1080/09638288.2019.1646815

Bruce, E., Lilja, C., & Sundin, K. (2014). Mothers' lived experiences of support when living with young children with congenital heart defects. Journal for specialists in pediatric

nursing. *JSPN, 19*(1), 54–67. https://doi.org/10.1111/jspn.12049

Caley L. M. (2012). Risk and protective factors associated with stress in mothers whose children are enrolled in early intervention services. *Journal of Paediatric Health Care: Official Publication of National Association of Paediatric Nurse Associates & Practitioners, 26*(5), 346–355. https://doi.org/10.1016/j.pedhc.2011.01.001

Chen, J., Clark, M., Liu, H., & Yu, Q. (2021). Factors influencing psychological distress in parents of children with intellectual disabilities: The roles of social support, patient clinical status, and sociodemographic variables. *Journal of Mental Health, 30*(2), 125-135.

Donenberg, G., & Baker, B. L. (1993). The impact of young children with externalizing behaviors on their families. *Journal of Abnormal Child Psychology, 21*(2), 179–198. https://doi.org/10.1007/bf00911315

Duran, S. & Ergun, S. (2018). The stigma perceived by parents of intellectual disability children: An interpretative phenomenological analysis study. *Anatolian Journal of Psychiatry, 19*(4), 390-396. http://doi.org/10.5455/apd.282536

Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). Preschool children with intellectual disability: Syndrome specificity, behavior problems, and maternal well-being. *Journal of Intellectual Disability Research, 49(*9), 657–671

Gerstein, E. D., Crnic, K. A., Blacher, J., & Baker, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(12), 981–997

Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., & Espinosa, F. D. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism, 9*(4), 377–391

Kessler, R. C., Andrews, G., Colpe, L. J., Hiripi, E., Mroczek, D. K., Normand, S.-L. T., Walters, E. E., & Zaslavsky, A. M. (2002). *Kessler psychological distress scale (K6, K10)* [Database record]. APA PsycTests. https://doi.org/10.1037/t08324-000

Malhotra, S., Khan, W. and Bhatia, M. (2012). Quality of life of parents having children with developmental disabilities. *Delhi Psychiatry Journal, 15,* 173–174.

McLean & Halstead. (2021). Resilience and stigma in mothers of children with emotional and behavioral difficulties. *Research in Developmental Disabilities, 108* (103818). https://doi.org/10.1016/j.ridd.2020.103818

Naz, S., Nawaz, S., Liaqat, S., Rasheed, T. & Fatima, S. (2020). Effects of social and psychological factors on students' learning achievements in English at intermediate level in Pakistan. *Palarch's Journal of Archaeology of Egypt/Egyptology 18*(4), 443-462.

Nurhidayah, I., Alhusniati, F. A., Rafiyah, I., & Hidayati, N. O. (2020). Social support on parents of children with intellectual disability. *Indian Journal of Public Health Research & Development, 11*(03), 2019-2022.

Reed, M., Bedard, C., Perlman, C.M., Browne, D. T., & Ferro, M. A. (2023). Family Functioning and Health-Related Quality of Life in Parents of Children with Mental Illness. *Journal of Child and Family Studies, 32,* 3366–3377. https://doi.org/10.1007/s10826-023-02556-6

Smith, A., Johnson, M., & Brown, K. (2020). Stigma and intellectual disability: A review of the literature. *Research in Developmental Disabilities*, 106, Article 103753. https://doi.org/10.1016/j.ridd.2020.103753

Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 41*(5), 567-578.

Song, H. J., & Kim, S. Y. (2015). Moderating effects of social support and disability acceptance in the relation between parenting stress and psychological well-being of parents of children with disabilities. *Journal of Special Education, 22*(2), 94-115. https://doi.org/10.34249/jse.2015.22.2.94.

Tadema, A. C., & Vlaskamp, C. (2010). The time and effort in taking care for children with profound intellectual and multiple disabilities: a study on care load and support. *British Journal of Learning Disabilities, 38*(1), 41-48. https://doi.org/10.1111/j.1468-3156.2009.00561.x

Yoon, S. O., & Kim, W. H. (2015). The effect of parenting burden on quality of life of parents of children with disabilities: Focusing on mediating effect of family resilience. *The Korean Journal of Early Childhood Special Education, 15*(2), 133–149.

Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). *The Multidimensional Scale of Perceived Social Support. Journal of Personality Assessment,* 52, 30-41