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Mapping the Interplay of Social Stigma, Parental Stress, Quality of Life, and Coping Mechanisms in Parents of IDC: A Correlational Study

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ABSTRACT

There are several pressures associated with raising a child with intellectual disabilities (ID), which can harm parents' physical, emotional, and mental well-being. Given that there has been limited exploration in our society of the stress level in such parents, along with associated stigmas and their life quality, there is a significant need for further investigation. The study examined the relationship between social stigma, parental stress, and quality of life. A sample of 125 parents, both mothers and fathers, of intellectually disabled children participated. Using a non-probability sampling technique, participants were chosen from both public and private mental health facilities in Rawalpindi and Islamabad. Discrimination and Stigma Scale, Parental stress scale, World Health Organization quality of life WHO-QOL BREF, and Brief – Coping Orientation to Problems Experienced Inventory were used to gather data. Results showed that social stigma is significant and positively correlated with parental stress, and has a negative significant correlation with quality of life, and is positively correlated with problem-focused coping. Social stigma also depicted a significant positive correlation with emotion-focused coping and a significant negative correlation with avoidant coping. Parental stress also showed a significant negative correlation with quality of life. It is positively related to problem-focused coping and emotion-focused coping. Quality of life shows strong positive significance with problem-focused coping and emotion-focused coping. Problem-focused coping is significantly negatively correlated with emotion-focused coping. Emotion-focused coping has a significant positive correlation with avoidant coping. The t-test results showed significant differences in social stigma and parental stress among the joint and nuclear family systems. According to one-way ANOVA results, there is a significant difference in the Social Stigma on different levels of socioeconomic status, while the type of disability also showed significant differences in Parental Stress.

Key words: *Intellectual Disability, Parental Stress, Social Stigma, Quality of Life, and Coping Mechanisms.*

INTRODUCTION

Children who have certain limitations in their cognitive functioning and many cognitive abilities like reasoning, problem-solving capability, everyday planning, abstract thoughts and judgment, learning from surroundings and experience, academic learning, social performance skills, conceptual thinking and knowledge, and practical Skills like language and self-care are referred to as having an intellectual disability (Sokolovaetal., 2017). It is estimated that 1% of people in general have intellectual disabilities, and 10% of those with intellectual disabilities also have the diagnosis of autism spectrum disorder (ASD) or exhibit autistic symptoms (Doenberg et al., 2016). Intellectual disability may result from the kind and degree of brain injury that causes cerebral palsy to impair cognitive abilities (Fennell et al., 2001). A

disorder like attention-deficit hyperactivity disorder is also linked with intellectual disability in many cases, as working memory in children and control of impulse are two main examples of executive functioning that can frequently be neglected and compromised in Attention-deficit hyperactivity disorder (Patrick et al., 2014). There can be particular difficulties for parents in raising a child with an intellectual disability that go beyond providing the assistance and short-term care required for their welfare (Sinclair et al., 2005).). Because children having intellectual deficits impact not just parents and families and the larger community, but also themselves, intellectual impairment has a profound social impact. Because of these situations, such parents whose children have intellectual deficits mostly use a range of coping mechanisms to get through the difficulties that come with being a parent of a child having a disability in intellects (Rutler et al., 2001). Feelings of loneliness might result from social stigma since parents may distance themselves from social situations to avoid criticism or judgment. The existence of children with intellectual disabilities can significantly affect the quality of life for their parents. Among the three coping mechanisms, i.e. Problem problem-focused coping mechanism, emotion-focused coping mechanism, and avoidant coping mechanism usage of effective coping skills can significantly enhance mental and emotional health. While effective coping strategies differ among parents, they typically entail asking for support from their immediate family and friends, who are their support group. Parents can improve emotional, social, and physical well-being by managing their stress more skillfully and utilizing a combination of problem-focused, emotion-focused, and support-based tactics (Sun et al., 2017).

RESEARCH GAP

Despite there being numerous studies done on the children having any intellectual disability and its influence on the life of their care giver, parents, guardians and family members, there hasn't been much focus on how the societal discrimination and social stigma towards the emotional and behavioral problems of such children effect the quality in life of these parents and mediating role of coping strategies. Previous researches indicate that Parental Stress is a significant and negative factor for Quality of Life and subjective happiness of these guardians and caregivers of the children who have these disabilities. However, there is a deficit in literature/ empirical evidence on how Social Stigma and discrimination towards these parents impacts them, specifically in Pakistan. The research on the proposed hypothesized model was conducted with the parents whose children are intellectually disabled, by using reliable and valid psychological instruments for all the study variables, to know the effects of Social Stigma and Parental Stress on the quality of life, leading to how they cope with it and how that affects the quality of their life.

OBJEVTIVES

1. To examine the relationship between social stigma, parental stress, quality of life, and coping mechanisms in parents of intellectually disabled children.
2. To investigate the differences in different demographic variables and study variables (social stigma, parental stress, quality of life, and Coping Mechanisms) in parents of intellectually disabled children.

HYPOTHESIS

1. It is hypothesized that there is a significant correlation between social stigma, parental stress, quality of life, and coping mechanisms among the parents of intellectually disabled children.
2. It is hypothesized that significant demographic differences will exist across the study variables among parents of intellectually disabled children.

LITERATURE REVIEW

Children having intellectual disabilities and their parents are among the groups that are marginalized and experience discrimination, stigma, and major barriers that limit their human rights (Kôvágó, 2005). Families with kids having impairments had a smaller network for social life than families without children, according to research comparing the two groups (Kazak et al, 1984). Parents of kids having intellectual deficits may limit themselves hence refuse to socialize and obtain public support because they feel alienated or like poor parents due to societal expectations and attitudes. Stigmatized people may be able to lessen and/or overcome the limiting effects of stigma if they can participate in meaning-making processes that lessen the threat of stigma in their lives (Crocker et al., 1989). Stress from caring for children with ID impacts all family members' physical, mental, and emotional development, especially the parents (Floyd et al., 1986). According to more recent research, parents of such children who have any intellectual deficits deal with greater stress levels in comparison to other parents who have normal children (Fernandes et al., 2005). The degree of the children having impairment has a significant factor; for example, parents whose children have reported severe stress at greater levels (Tonge et al., 2002). While a large body of literature and research highlighted that parents who have children having intellectual impairment suffer, other studies find no such consequences. For example, research revealed that 55.38% such parents thought that this particular child with impairment was the cause of better and improved dynamics of the family (Flechur et al.,1997). To raise their children, parents of these children having intellectual deficits must overcome many obstacles and need additional support. The parents' capacity for interacting with suitable coping mechanisms and support resources is a necessary component of successful adaptation. These coping mechanisms and resources assist parents in meeting their child's demands and lessening issues that affect them and their family (Hawkins, 1993). According to an earlier study, parents' and caregivers' quality of life decreases with the intensity of care or help provided to an intellectually impaired child (Akgun et al., 2001). Prior research indicates that parents devote a significant portion of their time to raising their kids, neglecting their own emotional and physical needs in the process of taking them to evaluations, therapy sessions, or medical appointments.). Other research, however, suggests that some parents can modify their circumstances by coming to terms with and accepting the disability of children, and in some situations, parents even learn to value their child's unique qualities (Gallagher et al., 1999).

METHODOLOGY

Study Design

A quantitative research design and correlational research were used for the present study. A Correlational method was used to inquire into any possible association between Social Stigma, Parental Stress, and Quality of life. Furthermore, the T-test and ANOVA analysis were utilized to measure any significant difference among different demographic variables across all four study variables.

Population and sample

The target population consists of those parents who have at least one child with intellectual disability, and participants were drawn from various public and private institutions, centers, and mental health care facilities. The locale of the population of the study was Islamabad and Rawalpindi.

Sample size

The sample included 125 parents (73 mothers, 52 fathers) of those children who were clinically diagnosed with any intellectual disability disorder.

Sampling technique

The sample was gathered using a non-probability sampling technique dedicated to children having any intellectual disabilities in Rawalpindi and Islamabad. Furthermore, both genders of parents were examined.

Inclusion criteria

1. The study involved parents (mother or father) who have one child diagnosed with intellectual disability
2. The study also ensures that the participants have direct personal experience in bringing up at least one child with intellectual disability in the age group 4 to 8 years.

Exclusion criteria

1. The study excluded parents (mother or father) whose children have disabilities other than intellectual disability.
2. Parents (mother or father) with any diagnosed mental health conditions and seeking mental health care facility will also be excluded from participation.

Research Instrument

For enhancing the reliability and precision of outcomes, participants were asked to provide demographic information encompassing key factors like age, gender, marital status, qualification, income, employment, and family structure.

Discrimination and Stigma Scale (DISC 12)

Discrimination and Stigma Scale (DISC 12) is used to assess the social stigma. It is an organized scale with a reliability of 0.7 alpha value to assess stigma and discrimination. This scale is divided into four subscales and a total of 32 questions. Responses were rated based on a four-point Likert scale with four-point (0 indicated not at all, 1 indicated a little, 2 indicated moderately, and 3 indicated very much) (Graham, 2009).

Parental Stress Scale (PSS)

To measure Parental Stress, the Parental Stress Scale developed by Berry and Jones in 1995 was used. The scale has a Cronbach's alpha reliability of 0.85. This self-reported scale comprises a total of 18 items where Respondents expressed their responses based on agreement and disagreement for every item with a 5-point scale.

World Health Organization Quality of Life -BREF

Quality of life is assessed using the World Health Organization Quality of Life-BREF, which is a self-report measurement tool with a 0.8 Cronbach's alpha reliability. The scale comprises 26 items categorized

into four sections. The response on each item of the scale is measured by a 5-point Likert scale, in which higher scores reflect a high quality of life and vice versa.

Brief – Coping Orientation to Problems Experienced Inventory

The Brief – Coping Orientation to Problems Experienced Inventory (Brief- Cope) was utilized, which has 28 items that represent specific coping strategies and are organized into 3 main coping subscales such as problem-focused coping mechanisms, emotion-focused coping mechanisms, and avoidant coping mechanisms. The Cronbach's alpha reliabilities of these subscales are 0.75, 0.91, and 0.71, respectively. Participants are asked to rate how frequently they use each coping strategy when facing stressors on a Likert scale, indicating the frequency or intensity of their use of a particular coping strategy.

Ethical Consideration

The research study adhered to specific ethical considerations. First of all, Informed consent was utilized for each participant. It was also ensured that they had a detailed and comprehensive understanding of the nature and purpose of the study. Voluntary participation was emphasized, and participants were not subjected to any form of pressure to join the study. Furthermore, participants were offered a detailed session, providing additional knowledge about the nature of the research. Sensitivity was exercised to avoid reinforcing stereotypes or inadvertently stigmatizing participants through any means.

Data Collection Procedure

Parents (mother or father) of those children who have intellectual disabilities received a detailed consent form outlining confidentiality measures and their right to exit the research at any point. Additionally, a demographic sheet was utilized to capture comprehensive personal and professional information. Clear guidance was provided to all the parents(mother or father), instructing them to thoughtfully complete the questionnaires. Data collection for all four variables, parental stress, social stigma, quality of life, and coping strategies, was conducted using four established psychological assessment tools. Subsequently, the gathered data underwent statistical analyses to draw meaningful conclusions and results.

DATA ANALYSIS

The data was analyzed using the statistical tool for social sciences (SPSS) version 26. Results and the findings of the study are presented in the form of frequency and percentages of demographic variables, descriptive statistics, and psychometrics of measures used in the study, and correlation for testing the hypothesis.

FINDINGS / RESULTS

Table 1

Descriptive analysis of demographic variables of the study participants (N=125)

Demographic variable	***f***	***%***
Type of child's disability		
Intellectual delay	34	27.2

Cerebral palsy	20	16.0
ASD	40	32.0
ADHD	31	24.8
Gender of parents		
Male	52	41.6
Female	73	58.4
Age of child:		
4	21	16.8
5	38	30.4
6	25	20.0
7	27	21.6
8	14	11.2

Note:f=frequency %= percentage

Table 1 exhibits the demographic variables and their frequency and percentage in the study sample. Considering the total participants (*f*=125) majority of the participants were female (58.4 %). The study consisted of cases of intellectual delay (*f* = 34), cerebral palsy (*f* =20), autism spectrum disorder ASD (*f* =40), and attention deficit hyperactivity disorder ADHD (*f* =31), with percentages of 27.2%, 16%, 32% and 24.8% respectively. The age of children who have intellectual disabilities that are used in the study indicated that at the age of 4 year (*f*=21), 5 years (*f*=38), 6 years *(f*=25) 7 years (*f*=27) and 8 years (*f*=14) showed the percentages of 16.8%, 30.4%, 20.0%, 21.0% and 11.2% respectively.

Table 2

Correlation between variables (N=125)

Sr. No	Variable	M	SD	1	2	3	4	5	6
1	**DISC-12**	45.08	8.20	_	.41**	-.34**	.201**	.18*	-.13*
2	**PSS**	54.5	6.21		_	-.22*	.336*	.360**	.021
3	**WHQOL-BREF**	76.6	6.72			_	.315**	.232*	-.966
4	**TPFC**	19.8	7.52				_	-.42*	.16
5	**TEFC**	27.1	11.4					_	.32*
6	**TAC**	10.7	1.20						_

*Note: M= Mean, SD= Standard Deviation, PSS= Parental stress scale, WHOQOL-BREF= World Health Organization Quality of life brief scale, DISC-12 =discrimination and stigma scale, BRIEF-COPE = Brief-coping orientation to problem experienced inventory (TPFC= problem-focused coping, EFC= emotion-focused coping, and AC= avoidant coping) *P<.05, **p<.01, significance.*

Table 3 depicts the findings of the Pearson product-moment correlation, which revealed intercorrelation among the variables of the study. The findings revealed that social stigma is significant and positively correlated with parental stress (r= +.41**). It is strongly significant and negatively correlated with quality of life (r= -.343**) and significantly positively correlated with problem-focused coping (+.201**). Social stigma also depicted a significant positive correlation with emotion-focused coping and a significant negative correlation with avoidant coping at r= +.18* and -.13* respectively. Parental stress indicated a significant negative correlation with the quality of life (r=-.22*). It is significantly positively related to problem-focused coping (r= +.336*) and significantly positively related to emotion-focused coping (r= +.360**). Quality of life shows strong positive significance with problem-focused coping (r= +.315**). It has a significantly positive relation with emotion-focused coping (r= +.232*) and it showed non-significance with the avoidant coping mechanism (r= .966). Problem-focused coping is significantly and

negatively correlated with emotion-focused coping (r=-.42*). Emotion-focused coping has a significant positive correlation with avoidant coping (r=.32*).

Table 3

One-Way Independent-Measures Analysis of Variance (ANOVA) Comparing Study Variables among types of Intellectual disabilities in children (N= 125)

Variable	ID		CP		ASD		ADHD					95%CI	
	M	SD	M	SD	M	SD	M	SD	F	P	Df	LL	UL
DISC-12	43.33	5.94	45.25	9.92	45.65	8.86	46.16	8.35	.74	.088	121	43.13	46.54
PSS	54.23	4.68	57.55	7.02	53.45	5.86	51.19	5.14	1.94	.041	121	53.44	55.64
WHQOL	77.29	9.12	76.75	6.50	75.95	6.10	74.61	4.95	.24	.102	121	75.41	77.79
TPFC	19.38	7.42	17.35	7.21	21.45	7.72	15.77	4.91	2.3	.034	121	18.48	21.14
TEFC	27.82	11.69	31.20	10.9	24.55	10.52	27.25	12.3	.58	.191	121	25.14	29.20
TAC	11.05	1.20	10.30	.923	10.72	1.37	10.70	1.07	.72	1.22	121	10.53	10.95

Note: *M= Mean, SD= Standard Deviation, P= significance, PSS= Parental stress scale, WHQOL-BREF= World Health Organization Quality of life brief scale, DISC-12 =discrimination and stigma scale, BRIEF-COPE = Brief-coping orientation to problem experienced inventory (TPFC= problem-focused coping, EFC= emotion-focused coping, and AC= avoidant coping).*

The table shows the results of One-Way Independent-Measures Analysis of Variance (ANOVA) Comparing Study Variables among the four different types of intellectual disabilities used in the study. Results are presented with means, standard deviations, and F-values, and the findings show the significant difference in the Parental Stress among different types of disabilities (F= 1.94, p<.05), where the parents of children having Cerebral Palsy scored the highest in Parental stress (M= 57.55, SD=7.02). The results also showed a significant difference among the problem-focused coping with (F= 2.3, p<.05), indicating that those parents with children having Autism Spectrum Disorder scored the highest (M= 21.45, SD=7.27) and parents of children with Attention Deficit Hyperactivity Disorder scored the lowest (M= 15.77, SD= 4.91). The remaining differences among all variables weren't significant.

Table 4

Independent Samples t-test Comparing Male and Female (N=125)

Variable	Male		Female					95% CI		
	M	SD	M	SD	t	Df	P	LL	UL	Cohen's d
DISC-12	45.98	7.99	44.45	8.35	1.02	123	.30	-.170	.542	-
PSS	55.21	6.13	54.06	6.26	.23	123	.31	-.173	.540	-
WHOQOL-BREF	76.00	6.77	77.04	6.70	.82	123	.39	-1.51	2.02	-
TPFC	19.82	7.75	19.80	7.41	.14	123	.40	-.353	.356	-
TEFC	27.00	11.5	27.30	11.4	.87	123	.85	-1.82	3.36	-
TAC	10.63	1.29	10.82	1.13	1.04	123	.39	-.511	.201	-

Note: *M= Mean, SD= Standard Deviation, P= significance, PSS= Parental stress scale, WHOQOL-BREF= World Health Organization Quality of Life Brief Scale, DISC-12 = Discrimination and stigma scale, BRIEF-COPE = Brief-coping orientation to problem experienced inventory (TPFC= problem-focused coping, EFC= emotion-focused coping, and AC= avoidant coping).*

According to the results of an independent sample t-test, there were no significant differences between the Male and Female parents of intellectually disabled children in the discrimination and stigma scale. The

parental stress scale also indicated non-significant differences across both genders. On the World Health Organization Quality of Life- Bref scale (WHOQOL-BREF), non-significant differences in quality of life were also discovered. Problem-focused coping mechanism, emotion-focused coping mechanism, and avoidant coping mechanism among the male and female parents of intellectually disabled children also had no significant differences.

DISCUSSION

The Pearson Product-Moment Correlation Analysis confirmed that there is a highly significant and negative association between variables among the parents of intellectual deficit kids. The first hypothesis is accepted, as Social Stigma and Parental Stress both showed a negative significance with the variable Quality of life. These findings are highly supported by major literature and empirical evidence, as the results and outcomes are aligned with past literature and are the same as the findings of results from this study. Previous literature also suggested that the presence of any intellectual disability among kids has been associated with increased levels of stress in their parents (Bromley et al., 2005). Another research evaluated the families of intellectual disabilities versus those without intellectual disabilities, and a high level of stress has been found for the families of disabled children (Dyson, 1996). According to past studies, parents or caregivers of those children who have intellectual impairment, if engaged in treatment that includes medical and psychological help, indicate a poorer quality in their lives (Lewallen, 2015). These findings of the results from the first hypothesis were consistent with the study, which suggested that parents who are continuously engaged in caring for their child have no time for themselves, which may affect their psychological and physical health as well (Gupta, 2012). The last hypotheses of this study speculated that there a significant differences in different demographic variables used in the study, including, gender of parents and the type of disability in experiencing social stigma, stress levels, and the quality of life in parents of intellectually disabled kids based on demographic variables. The independent T-test analysis is used for Gender (mother and father), and the one-way ANOVA analysis is used for the type of disability. According to the acquired results from the analysis of an independent sample t-test, there were no significant differences between Male and Female parents of children who are intellectually disabled among all variables studied. These results are in contradiction with some of the previous findings and research, which indicate that there is a high level of parental stress among the mothers in comparison with the fathers of such children (Baxter, 2000). According to another previous study, the frequency of stress among both parents was also found to be significant, which indicates that mothers' stress level is associated with all behavioral problems in children, while, on the other hand fathers stress was associated with their experience of social acceptance for their child's condition (Saloviita et al., 2003). Regardless of the parents' gender, both of them might face the same challenges that are related to the condition of their child. In this modern-day world, both parents share and experience equal responsibilities, caregiving hurdles, stigmatization, financial burdens, and all the other challenges that often result in similar experiences for both parents. Results from the Analysis of One-Way Independent-Measures Anova, Comparing Study Variables among the four different types of intellectual disabilities used in the study, show a significant difference in Parental Stress levels among different types of disabilities, where the parents whose children have the disorder of Cerebral Palsy depicted higher Parental stress. Evidence from past research also suggests the same, that those parents whose children have a disorder of CP mostly have greater stress levels in comparison to other parents whose children have age-appropriate development (Britner et al. 2003).

CONCLUSION

Conclusively, the present study aimed to find the relationship among social stigma, parental stress, and quality of life, and about role of coping mechanisms on parents' life quality. Results from the study demonstrated a significantly negative relationship between social stigma with quality of life. Parental stress also depicted a significant negative relation with the quality of life. The results from the study depicted no significant results in terms of the gender of both parents among the perception of Social stigma, Parental stress, Quality of parents' life, and the coping mechanism. The findings showed a significant difference in the Parental Stress among different types of disabilities, indicating parents of children having Cerebral Palsy have more Parental Stress. The results also indicated that the parents with children having Autism Spectrum Disorder are more prone to problem-focused coping mechanisms.

RECOMMENDATIONS

1. The study also highlights the need and requirement for further research into the specific coping mechanisms that can relieve and mitigate the effects of Social stigma and Parental stress, paving the way for more comprehensive models for parental support and assistance.
2. Research ought to examine how cultural variables affect parents' experiences as well as the effects of stress and social stigma, with recommendations and interventions tailored to suit various cultural situations.
3. Future studies should tend to focus on delving deeper into the function and importance of coping strategies.

LIMITATIONS

1. For constructing more thorough knowledge and a detailed understanding, future researchers will need to address and investigate these limitations as well as expand and scale up the current findings and outcomes.
2. The generalizability of the results may be impacted by a small or homogenous sample that may not accurately reflect the larger population of all such parents who have children with any intellectual deficits.
3. Because individuals may underreport or exaggerate their experiences, bias may be introduced when parental stress, societal stigma, Quality of life, and coping techniques were assessed solely through self-report measures.
4. Other factors, such as ethnicity, support networks, or pre-existing mental health disorders, may have an impact on the association between all study variables.

SUGGESTIONS

1. To offer a more thorough knowledge of the experiences of parents from diverse backgrounds, future studies must involve a bigger and diverse sample population.
2. Using longitudinal designs can make it easier to monitor changes over time and give a more dynamic picture of the interactions and effects that parental stress, coping strategies, and social stigma have on quality of life.
3. Using a variety of data sources, including observations, interviews, and third-party evaluations, can help to mitigate the bias caused by self-reporting.

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