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A STUDY OF NEEDS AND PSYCHOLOGICAL WELLBEING AMONG PARENTS OF CHILDREN WITH INTELLECTUAL DISABILITY

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ABSTRACT:

Background: Parents are the first role model to their children because they play crucial role in their children's overall development. Parenting is one of the most challenging tasks even for children with normal psychological profile, but if by chance child is intellectually disabled then they face multiple hurdles and needs in their parenting, which affects their psychological wellbeing.

Aim & Objective: The purpose of this study is to assess the overall needs & psychological wellbeing among parents of children with intellectual disability.

Material & Methods: This cross sectional research was conducted on both parents of 44 children having Intellectual Disability by using the test measures, NIMH need schedule, psychological wellbeing & DASS-42 at the Department of clinical psychology, at Santosh Medical College and Hospitals.

Result & Discussion: Significant positive correlation is seen in result of this study between psychological wellbeing & need like, facilitating interaction, marriage, personal emotional, financial, family relationships, for mother of children having intellectual disability. As for father, result reveals significant negative correlation between psychological wellbeing & needs of facilitating interaction, personal emotional, financial, family relationships.

Conclusion: This study putting light on the intricate relationship between psychological well-being, parental needs, and raising intellectually disabled children, emphasizing the need for a comprehensive strategy involving social support, healthcare, and tailored interventions.

Keywords: parents, children with intellectual disability, needs, psychological wellbeing,

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1. INTRODUCTION

Parenting is a special duty shared by both parents, who must prepare their children to seek out social adaptation. Children look up to their parents as their primary role models. Children constantly watch and imitate their parents' words, attitudes, traits, deeds, manners, and behavior. Based on their ego with intellectual disability strength and parental value system, children establish their self identity, personality traits, and strengths and acquire coping mechanisms for difficult situations, additionally they get knowledge from their parents how to be good workers, spouses, parents, and overall decent individuals when they are young Shukla, S. (2017), Aldosari, M. S. (2013). Conversely intellectually disabled children experience difficulty with the above mentioned tasks and are characterised by carrying sub-normal capacity of general functioning and as per their intellectual assessment they may be categorized according to their IQ level: i.e. mental retardation and its sub types-mild (IQ 50-69), moderate (IQ 35-49), severe (IQ 20-34), profound (IQ below 20).

Bearing a child having intellectual disability is challenging for any parent. Hodapp, R. M., & Bornstein, M. (2013). Parenting is the highly demanding task even for children with normal psychological profile, but by chance if a child is intellectually disabled, then they face multiple hurdles in their parenting. Upbringing the intellectually disabled child by the parents has been observed as a burden (personal /financial/social) on parents which every concerned parent has to bear throughout their life and such parents always visit the mental health workers with several queries & disturbances in terms of their needs & wellbeing. The parents of having children intellectual disability carries multiple curiosities and a bundle of needs like what is intellectual disturbance, types of intellectual disturbances, psychological difficulties, educational need, social development need and need to know about available intervention services, vocational services and other rehabilitation features which have already discussed in this study. Research suggest that parents refer to strong needs about information of current and future service available in society and the community which is followed by basic expenses, teaching strategies and therapy, day care services. Parents showed less expected needs towards the professional influences Sahay, et.al (2013). As far as psychological wellbeing is concerned it is described as an assessment of one's own life. In essence, it's a condition in which a person recognizes their own potential, is able to manage everyday stressors, is able to work effectively, and is able to give back to their community. World Health Organization (2004). In other words it is defined as how individuals conduct their lives physically, mentally, socially and spiritually Temiz, G. (2020). There are number of researches that says that having intellectually disabled children affect psychological wellbeing of parents. Parents having children with intellectual disability are reportedly faces high stress compare to their counterparts. Similarly, another study suggest significant level of disturbed wellbeing of every intellectually challenged children's parents Asagi, R. E. (2018). A study states that, as a result of parent's numerous duties, over half of parents do not have good psychological wellbeing Cramm, J. M., & Nieboer, A. P. (2012). Having intellectually disabled children, caregivers face discrimination, stigma and higher level of burden from the society Ebrahim, O. S., Al-Attar, G. S., Gabra, R. H., & Osman, D. M. (2020).

2. MATERIAL AND METHODS

The purpose of this research is to assess the overall needs and psychological wellbeing among parents having intellectually challenged children. Furthermore this cross sectional research was

conducted on both parents of 44 children having Intellectual Disability at the Department of clinical psychology in the collaboration with the Department of Peadiatrcis, at Santosh Medical College and Hospitals Ghaziabad, Uttar Pradesh. The study received ethical clearance from the Research Ethics Committee of Santosh Medical College & Hospitals Ghaziabad (UP). In this study, both parents of children with intellectual disability (below 18 years) participated, provided they were willing to participate with the signed consent which were obtained for this study. Parents with any neurological disorder and any psychological issues along with single, divorced and separated parents did not include in this study. Sample was selected using a purposive sampling. Data was collected using the NIMH family needs schedule, Psychological wellbeing scale, Depression anxiety and stress scale (DASS-42). Relevant statistical measures like Mean, t-test, Correlation was used to evaluate the data.

3. RESULT & DISCUSSION

Under this topic results are shown in the tables and graphical representation and findings are being discussed on the basis of statistical analysis. The tables presented in the results, for both t-test shows significant difference.

Table 1 shows Mean, Standard Deviation, t-test score on Needs among parents of children with intellectual disability.

	Variables	N	Mother Mean	Father Mean	t-test	Df
	Information condition	44	10.045 ±2.99	16.864 ±7.09	0.2	86
	Services	44	7.977 ±2.34	11.318 ±5.30	0.915	86
	Sexuality	44	1.455 ±.85	1.295 ±.794	0.135	86
	Marriage	44	1.636 ±1.240	1.455 ±.845	0.419	86
	Personal Emotional	44	5.523 ±2.172	1.25 ±1.480	0.051	86
NIMH Need Schedule for Parents	Personal –Social	44	3.045 ±1.293	5.523 ±2.172	0.262	86
	Support – Physical	44	3.636 ±1.990	3.045 ±1.293	0.998	86
	Financial	44	3.455 ±2.183	3.636 ±1.99	0.046	86
	Family Relationships	44	6.341 ±2.640	3.455 ±2.183	0.512	86
	Future Planning	44	3.182 ±1.105	6.341 ±2.64	0.407	86
	Government Benefits &	44	3.227 ±1.010	3.182 ±1.11	0.382	86

As per table 1 the following needs, that are, information condition, information condition, services, sexuality, marriage, personal–emotional, personal–social, personal–social, support–physical, financial, family relationships, future planning, government benefits & legislation, Show significant difference, between parents, out of above mentioned needs, information condition need, sexuality, marital aspect, support physical, family relationship, government benefits & legislation are higher in mother then in father & the requirement for information condition, available services, personal and social needs, financial aspects, future planning are higher in

father then in mother, these result are supported by study done in 2013 which suggest similar results that parents referred to strong needs about information of present & future service available in society and the community which is followed by basic expenses, teaching strategies and therapy, day care services. Parents showed less expected needs towards the professional influences. Another study done in 2022 suggest that 82.9 percent of the parents had high levels of cognitive needs, 65% had high levels of material needs, 75.6% had high levels of social needs, and 52.8% had high levels of intermediate needs. Noman, A. A. A., & Yasir, A. A. (2022).

Figure 1 shows mean score of various needs of both parents.

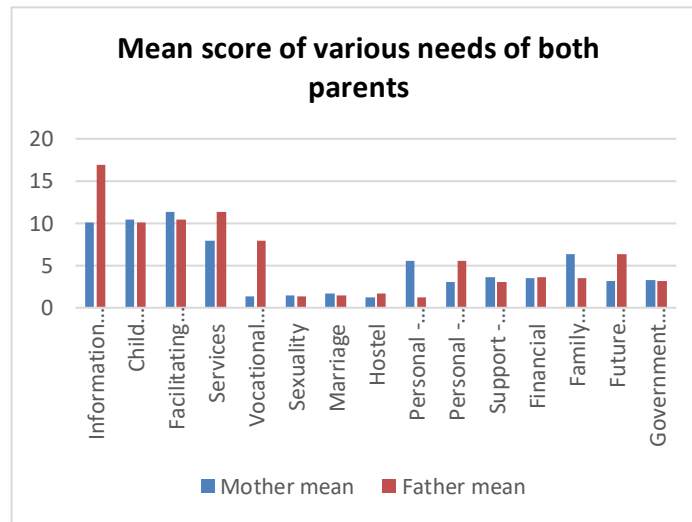


Figure no. 2 shows mean score of psychological wellbeing & depression, anxiety and stress among both parents of children with intellectual disability.

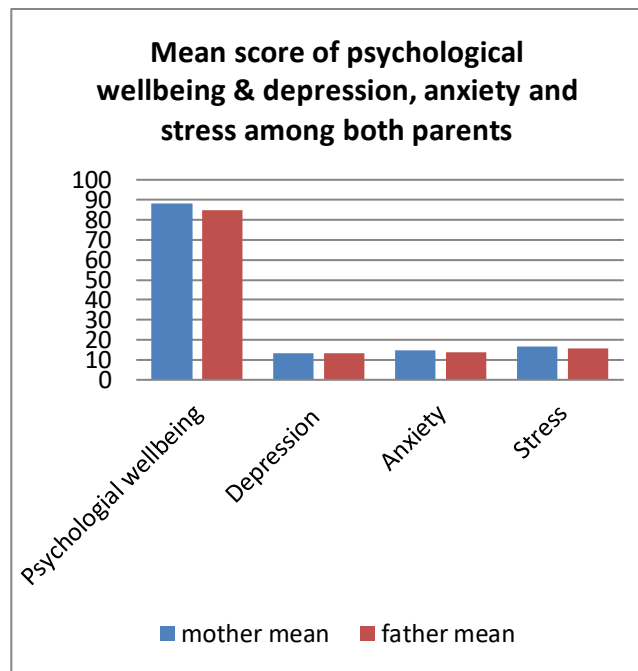


Table 2 shows correlation between psychological wellbeing & depression, anxiety, stress of mother and father of children with intellectual disability.

		MOTHER	FATHER
	Depression	-.472**	-.473**
Psychological wellbeing	Anxiety	-.431**	-.487**
	Stress	-.329*	-0.273

**At the 0.01 level, correlation is significant..(2-tailed).

*At the 0.01 level of significance the correlation. (2-tailed).

The values presented in tabular data suggest negative correlation between psychological wellbeing & depression, anxiety and stress for both the parents. These findings are in line with the research done in 2012 which states that parental stress strongly affects psychological wellbeing. Parameswari, S., & Eljo, J. O. J. G. (2016)

Table 3 shows correlation between psychological wellbeing and needs of mother and father of children with intellectual disability.

	Needs	Mother	Father
	Facilitating	.32*	-0.261
	Marriage	.305*	0.01
Psychological wellbeing	Personal-	0.097	-.358*
	Financial	.306*	-.387**
	Family Relationships	0.147	-.320*

**At the 0.01 level of significance, the correlation (2-tailed).

*Significant correlation exists at the 0.05 level (2-tailed).

Table no.3 shows significant positive correlation between psychological wellbeing & facilitating interaction, marriage, personal emotional, financial, family relationships, for child's mother of children with intellectual disability. As for father, result reveals significant negative correlation between psychological wellbeing & facilitating interaction personal emotional, financial, family relationships.

Table 4 shows correlation between depression, anxiety, stress & needs of mother and father of children with intellectual disability.

		MOTHER	FATHER
DEPRESSION	Personal-	0.229	.524**
	Financial	.304*	0.199
	Government	.316*	.321*
ANXIETY	Facilitating Interaction	0.312	.300*
	Services	0.36	.304*
	Hostel	-0.034	.598**
	Personal-	.310*	.340*
	Personal-Social	.359*	.326*
	Support-Physical	.368*	0.172
	Government Benefits & Legislation	.396**	-.487**
	Services	.364*	0.225
STRESS	Personal-Emotional	0.255	.467**
	Personal-Social	0.247	.320*
	Support-Physical	0.288	.467**
	Government Benefits & Legislation	0.275	.322*

** .At the 0.01 level of significance, the correlation (2-tailed).

*. Significant correlation exists at the 0.05 level (2-tailed).

The values presented in table no 4 suggest that, for mothers, financial & government benefits needs are correlated in positive manner with depression. Conversely, anxiety is positively correlated with personal emotional, personal social, support physical, government benefits at. Similarly, stress is positively correlated with services, at 0.05. Similarly another study implied positive association between service needs and perceived stress. Darbyshire, L. V., & Stenfert Kroese, B. (2012). As for father depression is positively correlated with personal emotional & government, anxiety is positively correlated with facilitating interaction, services, hostel, personal emotional, physical support, where as anxiety & need for government benefits are negatively correlated stress & personal emotional, support physical, government benefits, show significant positive correlation. These results are supported by study done in 2012 which suggest similar results a positive association between contentment with social support and mother's positive emotions. Mar, C. L. (1996)

4. CONCLUSION

In this study the findings convey that both the parents (mother & father) shows various needs in multiple domains due to which their psychological wellbeing is also affected poorly, but when

we compared the needs, their emotional state which is (Depression, anxiety, stress – DASS) and their psychological wellbeing, we found that mother had more needs, high DASS score that is that is their emotional state was affected more compared to father. However interestingly and unexpectedly it is observed that father's overall psychological wellbeing was affected much more compared to mothers. In order to justify this finding it is true to say that fathers are less expressive than their female counterparts (i.e mothers), which means more stressed internally hence it shows overall poor psychological wellbeing.

Additionally they have more societal pressure of multiple roles and responsibilities to take care of their children, also a financial burden on them is itself a big stressor. This stress includes multiple folds especially when they are father of intellectually challenged children.

To conclude, burden of responsibilities of intellectually disabled child is not on the shoulder of mother only, father are also seen to be having too much silent stress and depression. It is crucial for the society to pay attention on both the parents to help them, in taking responsibilities of their special children.

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