

IMPACT OF INTELLECTUAL DISABILITIES OF CHILDREN ON MENTAL HEALTH OF PARENTS

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ABSTRACT

Parents of disabled children face unique challenges in their daily lives resulting in stress. This study was conducted focusing on the parents of children living with intellectual disability to evaluate the rate of anxiety and depression. This cross-sectional study included the parents of children who attend the Health and Wellness Physiotherapy Rehabilitation center and Physiotherapy rehabilitation center of NCS University. There were 290 parents who consented and participated in the study. The participants were given a questionnaire with pre-designed questions about the socio-demographic characteristics of the family. Furthermore, the Beck's Depression Inventory (BDI) scale and State trait Anxiety Inventory were used to assess the level of depression and anxiety in our study population. Data was analyzed through Statistical Package for Social Sciences (SPSS- version 22.0). Out of 290 participants, 179 (61.7%) were males and 111 (38.7%) were females. With respect to BDI the number of mild mood disturbance was reported in 20 (6.9%), borderline clinical depression in 50 (17.2%), moderate depression in 82 (28.3%), severe depression were 113 (39%) and extreme depression was seen in 25 (8.6%). Likewise, 21 (7.2%) participants denied any anxiety, 32 (11%) were in mild anxiety level, 114 (39.3%) were in somewhat anxiety level but 123 (42.4%) were in high anxiety level of state trait anxiety inventory scale. According to the study's findings, parents of disabled children were considerably affected by anxiety and depression.

Key Words: BDI Scale, Birth Disables, Depression, District Mardan, STAI Scale

INTRODUCTION

Intellectual disabilities are extremely common in children around the world, and rates are expected to rise in the upcoming years due to advanced medical facilities and improved infant survival rate (1, 2). The rate of intellectual disability in children is reported to be particularly high in developing countries and late diagnosis is reported from less developed regions of the world. In Kenyan children, rates of neurological disability are estimated to be as high as 9.3%, which also includes intellectual disability (3). Raising a child with such a disability is a challenge for parents at times giving them anxiety and depression. The association of caring for a child with intellectual disability and development of anxiety and depression in parents has been explored mostly in the developed-countries with social support systems (4). According to the studies conducted in less developed countries such as Kenya, Kuwait, Qatar, Pakistan, and India, the parents of such children have shown 47% to 50% prevalence of psychological disorders (5-7). Raising and caring for a child having intellectual disability may result in challenges in family bonding, stress, and warrant a need to adopt a different

parenting style as compared to parenting a normal child(8). Stress has been linked to negative couple attributions about marital satisfaction, as well as the impact of stress on family functioning (9). There are reports suggesting that these challenges can also result in divorce and financial constraints (10). The experts in the field believe that the stress level which arises from a situation; comes with caring a disabled child due to lack of the knowledge and experience of dealing with the situation and understanding the child's needs. There are a number of studies looking at factors influencing parents of intellectually disabled children and causing psychological distress. These factors include but not limited to lower socioeconomic status with compromised financial support(11), single parent(mostly mother)(12, 13), feminine gender(14), perceived burden of care(13), lack of psychosocial support system(15) and inadequate knowledge of the child's disability(16). In case of familial problems when there are multiple disabled children in the family, it also raises the risk of depression in parents. In situations when the younger child is having disability and certain disorders, such as autism, are reportedly associated with high stress levels in parents (11).

Most of the literature focusing on the subject is reported from developed countries, while there is limited literature available from under-developed countries. On the other hand, less developed area estimates are relatively higher and limited services are available. It is therefore crucial to explore the level of the problem in less developed countries with limited social support. Thus, this study was designed to explore anxiety and depression levels among parents of disabled children living in Mardan District of Pakistan.

METHODS

This was a prospective cross-sectional study approved by institutional review board, and ethical committee of NCS University Swabi Campus. This was a questionnaire-based survey and data was collected on a pre-designed questionnaire to find out the rate of depression and anxiety among parents of children with Intellectual disabilities. A non-probability convenient sampling technique was adopted in the study. Both parents of children with intellectual disabilities, attending services at Health and Wellness Physiotherapy Rehabilitation Center, NCS Physiotherapy Rehabilitation Center and Private Clinic of District Mardan Pakistan, were invited to take part in the study. A total of 290 parents consented to participate in this study. The data was collected for a period of 6 months, from 1st February 2021 till 30th August of 2021. Beck's depression inventory (BDI) questionnaires, STAI and written informed consent were provided to Parents of children with Intellectual disabilities. Those parents who agreed to provide the information and signed the consent form were invited to provide information in the questionnaire. The parents with limited literacy were provided assistance in filling up the responses.

Beck et al. (1) created and revised the BDI; the test-retest reliability of BDI was 0.86. This mental health tool consists of 21 items, each of which describes depressive symptoms and asks the respondent to rate their relevance to the symptom and how much it bothered them in the previous week. The response was recorded on a four-point scale. The sum of the total responses ranging from 0 to 63. The higher scores suggest a higher level of depression. Spielberger et al. created the STAI inventory, which is used to assess predisposition to anxiety (trait) and existing levels of apprehension in the respondents. It has 40 items that need to be reported by the respondent where 20 items assess state anxiety and 20 items evaluate anxiety predisposition. The score for each item rated from one to four. The response score of each item is added together to get the total score. The higher the score, the higher the level of anxiety.

All the parents of children with intellectual disabilities were briefed about the study along with harms and benefits and were explained about the confidentiality of the data they will be providing. They were also assured that they are free to leave the study if they wanted to leave the study at any time without any legal bonding.

Statistical analysis

Data was analyzed using Statistical Package for Social Sciences (SPSS version 22.0). The responses were recorded and presented in the scores. Frequency distribution was presented in graphs.

RESULTS

The total participants were 290; including 179 (61.7%), males and female participants were 111 (38.7%). Age was distributed in three categories; the participants between the age of 21 to 30 years were 28.3 % (n=82), between the age of 31 to 40 years were 44.1 % (n=128) and above the age of 40 years were 80 (27.6%). Around 31 (10.7%) single parents were living without a partner (i.e. divorced). Majority of the families belonged to the middle socio-economic class (n=93, 32.1), while 66 families were poor (i.e. 22.8%) and 50 parents reported to be from a strong financial background. Majority of the participants had 1 child (n=270, 93.1%) in their families and while 6.9% had 2 children in their families.

The mean and SD in BDI was 3.97± 0.99; the mean and SD of BDI in male was 4.38 ±1.19 and in female was 4.03 ±0.76, but the mean and SD of BDI in participants living with partner was 4.17± 1.08 and in divorced participant living without partner was 4.87± 0.42. Although, the mean and SD was in STAI was 3.16±0.89; the mean and SD of STAI in male was 3.49± 0.50 and in females was 2.64±1.11 but the mean and SD of STAI in participants living with partner was 3.15±0.93 and participant living without partner (divorced) was 3.25± 0.44. (Figure1 and 2)

With respect to BDI the number of mild mood disturbance were n=20 (6.9%), borderline clinical depression were 50 (17.2%), moderate depression were n=82 (28.3%), severe depression were n=113 (39%) and extreme depression were n=25 (8.6%). Therefore, the majority of participants were in a severe depression level of the BDI scale. Likewise, the n=21 (7.2%) were in Not At All Anxiety level, n=32 (11%) were in little anxiety level, n=114 (39.3%) were in somewhat anxiety level but n=123 (42.4%) were in very much anxiety level of state trail anxiety inventory scale.

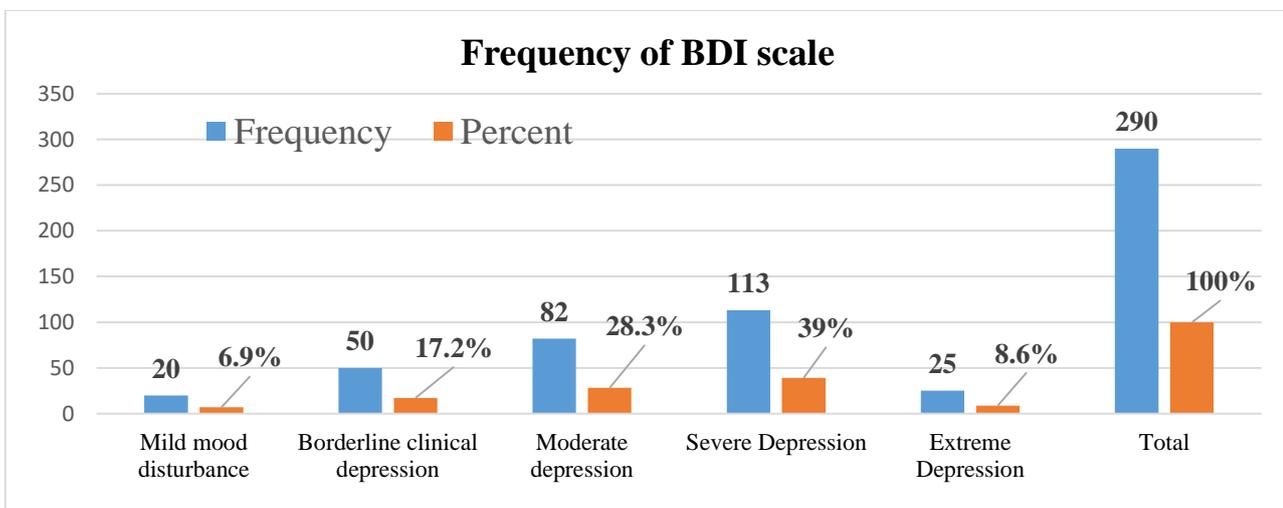


Figure 1: Showing the Frequency of Beck's Depression Inventory Scale

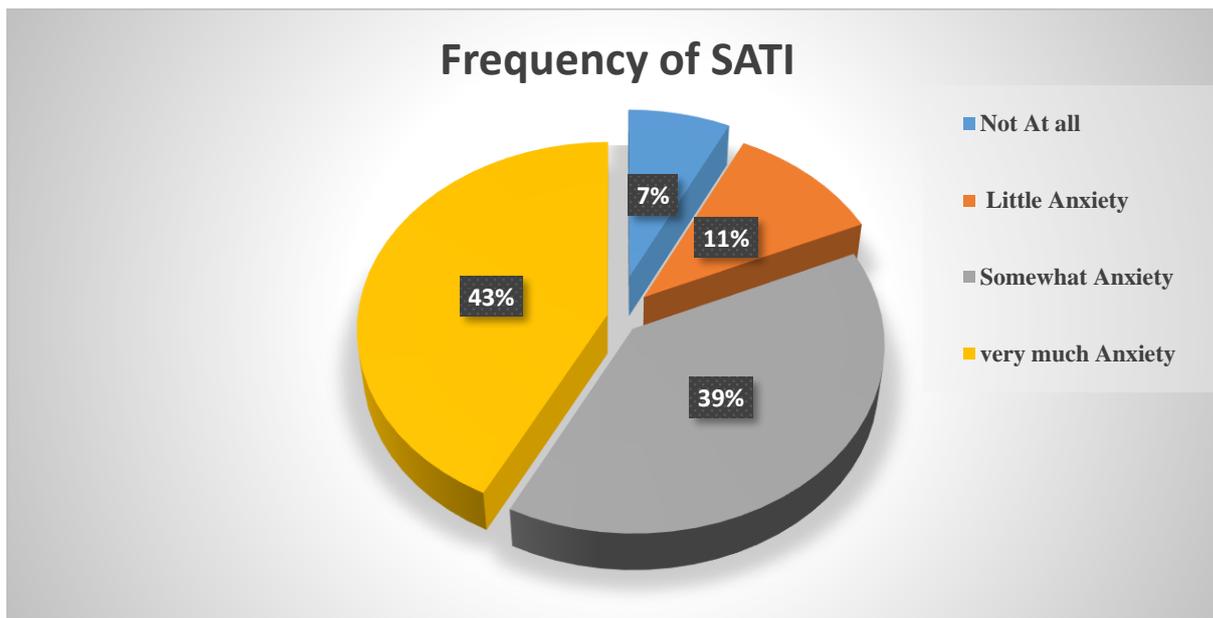


Figure 2: Showing the frequency of SATI Scale

DISCUSSION

The results of our study showed a considerable level of anxiety and depression in parents raising children with intellectual disability and more than 40% showed a level of distress higher than the normal level. The results of the study demonstrates that a considerable number of parents of such children suffer from undiagnosed and untreated mental illnesses. According to previous research, the rate of mental health issues among disabled children's parents range from 32 to 89 percent (18, 19). Our study's high prevalence rate is consistent with the previously reported undiagnosed distress and mental health issues of parents. The situation gets even worse due to the lack of emotional and technical support provided by health facilities in Pakistan. Especially given the scarcity of trained mental health care providers in this country. The importance of health care providers addressing mental health issues of parents having intellectually compromised children is highlighted by this finding. The high prevalence found in this study is consistent with existing literature. Our findings are lower than those reported in Kenya, where a prevalence rate of 79 percent has been reported (20). Differences in data collection instruments could be a reason for this discrepancy. The BDI was used in our study, which is a self-report proforma with a chance of misinterpretation of the feelings and a risk of reporting bias. In terms of social demographics, many of the study participants were in their thirties. This is primarily due to the family system in our country where people normally get married in their twenties or early thirties and have children during the respective age range; similar findings in relation to age have been previously reported (17, 21). There were far more women in this study than men. It is again related to the family unit design in our country where women generally take a role as primary caregivers for children and in case of separation and divorce mothers continue to take charge of the growing child(22). Husbands may distance themselves from the disabled child in some cases, and in certain situations mothers may be blamed for having the disabled child (23). Even if other caregivers from the extended family support in child care, the mother is the one with highest responsibility. It is unquestionably critical to implement programs that benefit women in particular and train them to care for their children appropriately. Designing

and facilitating psychological interventions that address issues focusing mothers of such children particularly.

A considerable number of participants in this study were jobless, and a high proportion belonged to a low socioeconomic class. There has been a well-established association reported between a child's disability and social status of the parents (24). It is also seen in our sample too. This said relationship has multiple factors in relation to joblessness and poverty. This can jeopardize mothers' health and also related to late provision of perinatal services. The poverty has association with low birth weight and birth asphyxia, which in turn have established causal relationships with intellectual disability in children. Among families living with a disabled child, up to 88 percent of caregivers find it difficult to meet the basic needs of their disabled child (25). Families in Mardan who were from a higher socioeconomic class, with educated parents, and received social support had less psychological distress, according to our research. These factors are associated with the economic situation of parents included in our study. Despite being somewhat rural, the population of Mardan is more educated, and as a result, people in Mardan will have better livelihoods because of better employment. People with a higher socioeconomic status and educated parents are more likely to seek and receive better material and psychological support, according to studies (26, 27). In this study, a high perceived responsibility of care for the child was linked to a higher level of stress and anxiety, most likely as a result of being a single parent. This may be due to reduced informal sources of support (i.e., friends, relatives and social support groups), which have shown to reduce stress in caregivers of disabled children (28-31). High stress level has been shown to be inversely proportional to the level of confidence in managing such a child. This is in line with previous reported literature, which has found that less confidence level reduces parental self-efficacy in child management, putting parents and their families under stress (32, 33).

CONCLUSION

Parents raising intellectually disabled children in Mardan face a significant psychological burden. Residence in Mardan city, low socioeconomic status, understanding of a child's disability, lack of confidence and training, burden of care, and limited social and psychological support are all associated with this high stress level. In Mardan, parents of children with intellectual disabilities require contextualized psychosocial interventions. Financial difficulties had an effect on the level of depression and anxiety as well. Depression and anxiety levels were found to be higher in facing negative societal attitudes.

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