



A STUDY ON PSYCHOLOGICAL STATUS AND WELL-BEING AMONG PARENTS OF CHILDREN WITH INTELLECTUAL DISABILITY

Mental Health Nursing

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ABSTRACT

Intellectual disability is a permanent condition, unlike many other diseases. It is a highly disabling condition. Parents having child with ID experience its impacts on their psychology and may develop depression, anxiety & stress. They also have more fear about their future and their child's future, which may adversely affect their wellbeing. The present study aimed to assess the Psychological status and well-being among parents of children with intellectual disability. The conceptual framework was based on Sister Callista Roy's Adaptation model. A non-experimental, descriptive design was used, and the sample was selected using purposive sampling. The sample consisted of 125 parents of children with intellectual disability. The tools used were a semi-structured questionnaire to assess the socio-personal and clinical variables of parents and children with intellectual disability, the DASS-21 scale to assess psychological status and Ryff's Psychological Well-being Scale (RPWS) to assess psychological well-being among parents of children with intellectual disability. There was a significant association between depression and occupation, IQ and other medical illnesses of child. There was a significant association between stress and occupation duration of stay with the child. There is a negative correlation between psychological status and well-being among parents of children with intellectual disability. These findings have implications for nursing practice, education, administration and research.

KEYWORDS

Psychological status, well-being, parents of children with intellectual disability

INTRODUCTION

Parents play a very significant and vital role in one's life; they are genuine well-wishers, caretakers and custodians of the interests of their children. Parents always plan for a perfect, healthy and normal child. They never expect or think about children with any abnormality or disability. Parenting is a complex, exhausting, responsible and, at times, unrewarding job, yet it is accomplished by most humanity with dedication, pleasure, and love. In general, parenting is a challenging task. It can be further complicated by child or parent difficulties, such as mental disorders in children and their parents.¹

The World Health Organization defines mental health as "a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively, and can make a contribution to his or her community" There are two distinct dimensions in mental health: a positive dimension, corresponding to psychological well-being, and a negative dimension, including psychological distress and mental disorders. Parents of children with Intellectual disability facing lots of negative emotions like stress, anxiety, and depression, and they also have more fear about their future and their child's future, which will have an adverse effect on their well-being.³

The prevalence of intellectual disability among children in developing countries is estimated to be exceptionally high. In stark contrast to the 1–3% prevalence of intellectual disability in children globally (reported by WHO).⁴ According to the Disability Census Report of 2015, there are 1,30,798 differently-abled children under the age of 19 in Kerala. Of them, 21,533 are intellectually disabled, 8,697 suffer from speech and language disabilities, and 6,833 have learning disabilities. Parents of children with Intellectual disability are facing lots of negative emotions like stress, anxiety, depression, and they also have more fear about their future and their child's future, which will have an adverse effect on their well-being. Despite that, some parents accept the reality and tend to lead a positive life, developing their coping skills and self-esteem. It also develops the confidence to help their child consider their future.⁵

OBJECTIVES

- Assess the psychological status among parents of children with intellectual disability.
- Assess the psychological well-being among parents of children with intellectual disability.
- Find out the correlation between psychological status and well-being among parents of children with intellectual disability.
- Find out the association between psychological status among parents of children with intellectual disability and selected variables.

- Find out the relationship between psychological well-being among parents of children with intellectual disability and selected variables.

Hypotheses

- H₁: There is a significant correlation between psychological status and well-being among parents of children with intellectual disability.
- H₂: There is a significant association between psychological status among parents of children with intellectual disability and selected variables
- H₃: There is a significant association between psychological well-being among parents of children with intellectual disability and selected variables

Conceptual Frame Work:

The study is based on the concepts of Sister Callista Roy's Adaptation Model.

Methodology

A quantitative non-experimental research approach was used for the study, and it is considered appropriate for the present study. The research design adopted for the present study is a descriptive survey design. The sample comprises of 120 parents of children with intellectual disability attending outpatient department of Child Development Services (CDS) IMHANS, Kozhikode and Composite Regional Centre (CRC)-for skill development rehabilitation and empowerment of persons with disability Kozhikode, who fulfills the inclusion criteria.

Tool And Technique

Tool 1: Semi-structured interview schedule to assess socio-personal data of parents and child, clinical data among children with intellectual disability

It includes three sections IA, IB, IC respectively.

- **Section IA:** Socio-personal variable of parents of children with intellectual disability
- **Section IB:** Socio-personal variable of children with intellectual disability
- **Section IC:** Clinical variable of children with intellectual disability

Tool 2: The Depression, Anxiety and Stress Scale – (DASS-21)

Tool 3: Ryff's Psychological well-being scale

Technique: self-reporting

RESULTS**Sample Characteristics**

Out of 125 parents 50.4% were belonged to the age group of 31-40 years .21.6 % of parents were males and 78.4 % were females.Regarding the education 48.8% of parents attained higher secondary education, 72.8% of the subjects were home makers and 50.4% of the subjects were under above poverty line category.Regarding the type of family 60% parents belonged to nuclear family. 93.6% of the subjects were married and 84.8% of the subjects marriage were non consanguineous marriage.56.8% of the subjects have two children. The study revealed that 58.4% parents were living in panchayath.53.6% of subjects were getting social supportscheme.The study revealed that 84.8% children of the subjects belonged to the age group of 5-10 years.52.8% of the children of the subjects were male and 54.4% of the children were born as first child to their parents. The study revealed that 71.2% children of the subjects were studied state/aided school and.78.4% of the children of the subjects were regularly going to school .The study showed that 68.8% of the children of the subjects were intreset not identified.13.6% of the children of the subjects had behavioural problems. 79.2% of the children of the subjects emotionally attached with their mother.The study revealed that 87.2% of the children of the subjects belong 50-70 IQ level.11.2% of the children of the subjects belong to 35 to <50 IQ category and % 1.6of the children of the subject belong to 20 to <35 IQ category.

The study revealed that 39.2% Of children had age at the time of diagnosis 4 years.60% of children duration of diagnosis less than six months.68.8% of children duration of treatment more than one year.19.2% of the children had other diseases.The mean score of depression was 10.05 (SD±5.53), mean score of anxiety was 7.68 (SD±3.81) and stress score was 13.84(SD±5.16) .Analysis shows that 44% of parents level of depression is normal and very severe level of depression seen in 1.6% of subjects.45.6% of parents level of anxiety is normal and very severe level of anxiety seen in 1.6% of subjects. 56.8% of parents level of stress is normal and very severe level of stress seen in 0.8% subjects. The mean score of RPWBS is 51.18 with standard deviation 7.49. Lowest score obtained in positive relation and autonomy subscale and highest score obtained in personal growth self-acceptance subscales.

Correlation Between Psychological Status And Well-being Among Parents Of Children With Intellectual Disability (n=125)

Variables	correlation Coefficient	p -value
Depression and well-being	-.567	.001***
Anxiety and well-being	-.651	.001***
Stress and well-being	-.468	.001***

***Significant at the 0.001 level (2- tailed)

Result showed that computed spearman's correlation coefficient value for the relationship between psychological status (Depression, Anxiety Stress Score) and well-being (RPWBS score) among parents of children with intellectual disability are -.567,-.651,-.468 and p value 0.001, .001 and .001 respectively. Hence the null hypothesis is not accepted. It is concluded that there is a negative correlation between psychological status and well-being among parents of children with intellectual disability.

Association between psychological status among parents of children with intellectual disability and selected variables**A) Association between depression and selected variables among parents of children with intellectual disability**

It is evident that there is a statistically significant association between depression and educational status ($\chi^2(12) = 25.99, p < 0.05$) and depression and IQ of child ($\chi^2(8) = 32.57, p < 0.05$), depression and other medical illness of child ($\chi^2(4) = 10.44, p < 0.05$).Hence the null hypothesis not accepted and null hypothesis accepted for other variables. There is a significant association between level of depression of parents and educational status. The parents attained primary/secondary education experienced very severe level of depression. There is a significant association between level of depression of parents and IQ of child. The parents of children IQ 50-70 experienced very severe level of depression.. There is a significant association between level of depression of parents and other medical illness of child. The parents of children with other medical illness experienced very severe level of depression.

B)association Between Anxiety And Selected Variables Among Parents Of Children With Intellectual Disability (n=125)

Variables	Df	χ^2	p-value
Age	8	4.54	0.80
Sex	4	8.88	0.06
Educational status	20	28.15	0.10
Occupational status	20	34.94	0.02*
Socio economic status	4	2.26	0.68
Monthly family income	8	11.20	0.19
Type of family	8	3.81	0.87
Marital status	12	4.94	0.96
Type of marriage	4	8.19	0.08
Number of children	12	9.80	0.63
Place of residence	8	16.35	0.03*
Duration of stay with the child	4	4.13	0.38
Frequency of school visit	16	22.62	0.12
Availability of social support scheme	4	3.86	0.42
History of medical illness	4	2.66	0.61
Family history of ID	4	9.70	0.04*
IQ of child	8	33.10	0.001**
Other medical illness of child	4	12.57	0.01**

*Significance at 0.05 level**Significance at 0.01level ***Significance at 0.001 level

There is a significant association between level of anxiety of parents and IQ of child. The parents of children IQ 20-<35 experienced severe level of anxiety. There is a significant association between level of anxiety of parents and other medical illness of child. The parents of children with other medical illness experienced severe level of anxiety

C) Association between stress and selected variables among parents of children with intellectual disability

Result showed that there is statistically significant association between stress and occupational status ($\chi^2(12) = 41.56, p < 0.05$) and stress and duration of stay with the child ($\chi^2(4) = 11.80, p < 0.05$).Hence the null hypothesis not accepted and null hypothesis accepted for other variables. There is a significant association between level of stress of parents and occupational status. The home maker experienced severe level of stress. There is a significant association between level of stress of parents and duration of stay with the child. 11 to 15 years duration of stay with child of parent experienced severe level of stress

Relationship Between Psychological Well-being Among Parents Of Children With Intellectual Disability And Selected Variables

The result showed there is a significant relationship between RPWB Score and type of family (F=2.89, p value 0.05), hence the null hypothesis was not accepted for these variables and null hypothesis accepted for the other variables .There is significant relationship between RPWB Score and type of family (F=2.89, p value 0.01). There is significant negative moderate correlation between RPWB Score and other medical illness of child.

DISCUSSION

The present study was conducted parents of children with ID. According to the findings of the study revealed that 50.4% of the sample belonged to the age group of 31-40 years.21.6 % of parents were males and 78.4 % were females. This study findings concordance with the study conducted in Malawi on prevalence of psychological distress among parents of children with intellectual disabilities (ID). The study revealed that the mean age of the participants was 34.4 years (SD: 9.5).While 79% were middle aged.The majority of participants were female (90% (n = 156)). Another study was conducted in Netherlands to assess psychological well-being of caregivers of children with intellectual disabilities support this findings. Average age of study participants was 38.6(±9.2) years old. The result showed 79% of study participants were females.

The findings of the present study revealed that 86.4% of the child have behavioural problems present.79.2% of child emotionally attached with their mother. The result is consistent with the result of the study conducted to assess Factors influencing the expectations of parents for their mentally retarded children. The study revealed that 96.4% of child primary care taker for their mother.90% of the child have behavioural problem present.

CONCLUSION

The study was aimed to assess the psychological status and well-being among parents of children with intellectual disability in IMHANS, and CRC Kozhikode. In the present study shows that significantly high proportion of parents of children with ID have stress symptoms, anxiety symptoms, depressive symptoms, or both. These symptoms appear to be associated with severity of ID and lack of social support and are more in mothers (primary care givers). Recommend that routine screening for stress, anxiety and depression, of all parents of children with ID should be carried out so that secondary prevention measures can be undertaken resulting in better outcome for both the child and the parents.

The study finding conveys that most of the parents do not have good psychological well-being due to their multiple responsibilities. To improve their psychological well-being the parents of intellectually challenged children should undergo therapies such as psychotherapy, relaxation and stress management techniques. And it also applicable to the family members of the intellectually challenged children, referral services can also be given to parents and the family members to lead their life in positive way

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