



Research Article

HEALTH COPING AMONG PARENTS OF CHILDREN AND ADOLESCENTS WITH INTELLECTUAL DISABILITY AND FUNCTIONAL PSYCHOSIS

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ARTICLE INFO

Article History:

Received 15th February, 2023

Received in revised form 7th

March, 2023

Accepted 13th April, 2023

Published online 28th May, 2023

Key words:

Coping, Psychosis, Intellectual Disability

ABSTRACT

Background: Parents of medical and psychiatric conditions such as intellectual disability and functional psychosis have to cope with greater demands when caring for their child in comparison to those with healthy children. They have to adjust their family life to accommodate the frequent medical visits, the multi-component treatment regimen and their child's unpredictable illness course. It is important to underline that the child's quality of life can also influence the way in which a parent cares for their child and may affect the way they cope. Parental coping refers to a specific effort by which the parent attempts to handle or reduce a demand on the family system.

Aim & Objective: The purpose of this study was to assess and compare the behavior problems and health coping strategies among parents children with intellectual disability and functional psychosis.

Participants and Methods: This study was a cross-sectional hospital based study. The study samples were selected through purposive sampling technique. The sample size was 40 parents among which 20 parents of children and adolescent with intellectual disability and 20 parents of children and adolescent with functional psychosis taken from Erna Hoch Child and Adolescent Psychiatry Unit and Charak Outpatient Department, of the Central Institute of Psychiatry, Kanke, Ranchi. "Coping Health Inventory for Parents (CHIP)" (McCubbin HI. *et al.*, 1983) scale was used for the data collection. Data were analyzed by Statistical Package for Social Sciences (SPSS- 21 version).

Result & Conclusion: Results indicated no significant group differences in ratings of "Coping Health Inventory".

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INTRODUCTION

Coping: Coping is a complex phenomenon that is difficult to understand (Tak & McCubbin, 2002; Beutler, Moose, 2003). The study of coping started in the 1940's and 50's during World War II and the Korean War (Lazarus & Folkman, 1984). Although a 37 consensus has not yet been reached on a specific definition of coping, there is general agreement (Lazarus & Folkman, 1984; Pearlin & Schooler, 1978) that coping is defined as the constantly changing cognitive or intrapsychic and behavioral or action-oriented efforts developed to manage and minimize specific internal and external demands that are found to exceed the resources of the person. In the view of Friedman *et al.* (2003) coping is restricted to the actual behaviors or cognitions people utilize, not to the resources they might use. Folkman and Lazarus (1984); Monat & Lazarus (1991) explained that coping requires both thought and action, and an individual first appraises the stressor by identifying it and deciding whether it is threatening or challenging (primary appraisal). Following this interpretation, the individual decides whether the coping resources and options available are adequate to cope with the

situation (secondary appraisal). McCubbin & McCubbin (1993) define family coping as an active process where the family utilizes existing family resources and develops new behaviors, responses and resources to strengthen the family and to decrease the influence of stressful life events. When shifting from the individual level of coping, family coping becomes hard to explain. Because of the difficulty in assessing family coping efforts, most family coping research describes a combination of individual and family coping responses utilized by the family members.

The function of coping as described by McCubbin *et al.* (1996) and Danielson, Hamel-Bissell & Winstead-Fry (1993) is to maintain and restore the balance between demands and resources, and at the same time to eliminate or decrease the intensity of the chronic and/or critical illness and its associated hardships. Positive family coping occurs 38 when the family succeeds in maintaining family equilibrium following an illness stressor. Coping is necessary for survival, and it determines how successfully the person will reduce the effects of stressors. McCubbin *et al.* (1984, 1996) stated that the family can use available resources from both the family and

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community to regulate the stressful situation. The family can use resources from within the family itself such as changing roles, sharing problems, and also from the community (e.g., social support from relatives and friends, neighbors, extended family, professional interventions). In addition, in order for families to have positive coping, families have to use their ability to redefine stressful events so they become more manageable; they must also accept problems and think how to deal with it, thereby minimizing their effects (McCubbin, 1985).

Intellectual Disability: Intellectual Disability, formerly known as "Mental Retardation," is a disorder with onset during the developmental period. It includes intellectual deficits and difficulty functioning in daily life in areas such as communication, self-care, home living, social/interpersonal skills, self-direction, academics, work, leisure, health, and safety.

According to American Association on Mental Retardation (AAMR), "Mental Retardation refers to significantly sub average general Intellectual functioning, resulting in or associated with concurrent impairments in adaptive behavior, and manifested during the developmental period. According to ICD-10(WHO, 1992) Mental Retardation or Intellectual Disability is a condition of arrested or in complete development of mind, which is especially characterized by impairment of skills manifested during the development period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities.

Psychosis: It is not easy to define psychosis; therefore, sometimes we have to specify whether we are referring to the psychodynamic or psychiatric definition, or to the perspective of a given author. There are a wide series of definitions: "loss of affective contact with reality," "temporary or permanent withdrawal from objective reality," "a severe psychic disturbance that eventually leads to the deterioration of personality structures," "a pathological exacerbation of constitutional tendencies," "an extensive personality disorganization," "a severe mental disorder or pathological reactions, which vary and involve all forms of adaptation," "the final outcome of the confluence of several nociceptive factors on the psychic apparatus" or "fragmented personality."

Aim of the Study: This study was planned to explore and compare health coping patterns among parent of children with intellectual disability and functional psychosis.

Objective of the Study

- To explore and compare the health coping among parents of the children and adolescents with intellectual disability and functional psychosis.

Hypotheses

- There will be no significant difference between coping strategies among parents of children and adolescents with intellectual disability and functional psychosis.

METHOD AND MATERIALS

This study was conducted at the Erna Hoch Child and Adolescent Psychiatry Unit and Charaka outpatient department of the Central Institute of Psychiatry, Kanke,

Ranchi. The present study was a hospital-based, cross-sectional study. The study samples were selected through purposive sampling technique. The sample size was 40 parents among whom 20 parents of children and adolescent diagnosed with intellectual disability and 20 parents of children and adolescent diagnosed with functional psychosis taken from Erna Hoch Child and Adolescent Psychiatry Unit and Charak Outpatient Department, of the Central Institute of Psychiatry, Kanke, Ranchi. In this study 32 children and adolescents with intellectual disability were screened on DST and VSMS and 29 children and adolescents with functional psychosis were screened on BPRS-C after considering inclusion and exclusion criteria 20 children and adolescents were selected in each group. Selected children's and adolescent's parents were assigned to two study groups.

Inclusion and Exclusion Criteria

In intellectual disability group, children and adolescents belonging to the age range of 6-17 years who diagnosed with Moderate to Profound Mental Retardation as per ICD-10-DCR were included. Children and adolescents age below 6 years and more than 17 years, diagnosed with severe physical disability, addiction (except nicotine and caffeine) and problems in addition to mental retardation were excluded from the study. And in functional psychosis group, children and adolescents belonging to the age range of 6-17 years who diagnosed with schizophrenia/bipolar disorder/acute and transient psychosis as per ICD-10-DCR were included. Children and adolescents age below 6 years and more than 17 years, diagnosed with co-morbid psychiatric diagnosis and mental retardation, severe physical disability, substance addiction (except nicotine and caffeine) and problems in addition to their primary diagnosis (psychosis).

Similarly, parents belonging to the age range of 30-55 years and educated up to at least Class-8 and above who gave written informed consent for the study were included. Parents aged <30 or >55 years, education level less than Class-8 and not giving written informed consent for the study were excluded from the study in both groups.

Tools used for data collection

1. Socio-demographic & clinical data sheet"
2. "Development Screening Test (DST)"(Bharat Raj. J., 1983)
3. "Vineland Social Maturity Scale (VSMS)" (Bharat Raj. J Indian adaptation by A. J. Malin, 1992)
4. "Brief Psychiatric Rating Scale for Children (BPRS-C)" (Overall JE. Pfefferbaum B, 1982))
5. "Coping Health Inventory for Parents (CHIP)" (McCubbin HI. *et al.*, 1983)

Descriptions of Tools

1. **Socio-Demographic & Clinical Data Sheet:** This data sheet was used to obtain information about various socio-demographic and clinical variables of the selected children and their parents like age, gender of children, education of children and parents, religion, ethnicity, domicile, psychopathology and behavioral problems, family history, etc.
2. **Development Screening Test (DST):** Developmental Screening Test developed by Bharath Raj (1977, 1983)

was designed for the purpose of measuring the developmental sequences of children from birth to 15 years of age. It consists of 88 items which represent the behavioral characteristics of respective age levels. At each age level, items are drawn from behavioral areas, like motor development, speech, language, and personal-social development. Appraisal of a child can be done in semi-structured interview with a parent or a person well acquainted with the child. Scores obtained on these items with IQ calculator are used to assess the level of development in the child.

3. **Vineland Social Maturity Scale (VSMS):** This scale consist 89 items. The Vineland social maturity scale was originally devised by E. A .Doll in 1935 and Indian adaptation was developed by A. J. Malin in 1992, since then this test is being used in many parts of the country. This scale is not only providing social age and social quotient measures but also indicate the social deficits and social assets in a growing child. It is for age level from 0 to 15 years. It is good to locate mentally retarded.
4. **The Psychiatric Rating Scale for Children:** The Brief Psychiatric Rating Scale for Children commonly abbreviated BPRS-C scale), is a 21-items clinician-based rating scale designed for use in evaluating psychiatric problems of children and adolescents. It was developed to provide a descriptive profile of symptoms applicable to a broad range of child and adolescent psychiatric disorders and is increasingly used as an outcome measure in research, managed care, and public-sector child/adolescent clinical settings. Ratings are based on a 7point Likert scale, from "Not Present" (scores 0) to "Extremely Severe" (scores 6 points).
5. **Coping Health Inventory for Parents (CHIP)**
The CHIP is a 45-item parent questionnaire used to assess a parent's perception of how he or she manages family life with a child with a chronic illness. This instrument can be used to develop intervention strategies and measure change in parents' ability to cope when faced with parenting a child with chronic illness. It has three subscales:

- Maintaining family integration, cooperation, and an optimistic definition of the situation;
- Maintaining social support, self-esteem, and psychological stability
- Understanding the medical situation through communication with other parents and consultation with medical staff. These three factors were validated against criterion measures of improvements in the child's health and adaptive family-life dimensions of cohesiveness, expressiveness, conflict reduction, organization, and control. The findings have implications for present strategies of health-care delivery and for health-care professionals seeking to facilitate family adaptation to the stresses of chronic illness.

Procedure

Parents of the children and adolescents with diagnosis of Intellectual Disability and Functional Psychosis as per ICD-10 (DCR) criteria included in accordance with the inclusion and exclusion criteria taken for the study. At first, written informed consent were taken from each parent who was willing to participate in the study. After that socio-demographic profile was filled and later on Development Screening Test (DST) and Vineland Social Maturity Scale (VSMS) had been applied on children with intellectual disability and Brief Psychiatric Rating Scale for Children (BPRS-C) was applied on children with Functional Psychosis. Subsequently, Coping Health Inventory for Parents (CHIP) was administered on parents of children with intellectual disability and functional psychosis.

Statistical Analysis: The raw data was analyzed statistically with aid of the computer program-SPSS (Statistical Package for Social Sciences)-21. Descriptive statistics was used to describe various sample characteristics. Chi square test was used for describing and comparing categorical data. Mann Whitney U Test was used for describing and comparing continuous data. Spearman’s correlation and point bi serial correlation coefficient were computed to study the relationship for continuous and categorical variables, respectively.

Table 1 Comparison of socio-demographic variables of patients and parents with Intellectual disability and Functional Psychosis

Variables	Groups N=40		χ^2 /Fisher's Exact Test#	df	p	
	Intellectual Disability N=20, n (%)	Functional Psychosis N=20, n (%)				
Sex of the patients	Male	11(45.8)	13(54.2)	.417	1	.519
	Female	9(56.2)	7(43.8)			
Religion	Hindu	17(48.6)	18(51.4)	.230#	-	1.000
	Other	3(60)	2(40)			
	Farmer	5 (35.7)	9 (64.3)			
Father Occupation	Labourer	6 (75)	2 (25)	8.744#	-	.090
	Business	2 (28.6)	5 (71.4)			
	Private Job	5 (83.3)	1 (16.7)			
	Gov. Job	0 (0)	2 (100)			
	Unemployed	2 (66.7)	1 (33.3)			
Mother Occupation	Employed	0 (0)	1 (100)	1.412#	-	1.000
	Unemployed	20 (51.3)	19 (48.7)			
Parental Status	Both parents	18 (48.6)	19 (51.4)	1.204#	-	1.000
	Single parent	1 (50)	1(50)			
Family Type	Separated	1 (100)	0 (0)	2.553#	-	.301
	Nuclear	12 (44.4)	15 (55.6)			
	Joint	8 (66.7)	4 (33.3)			
Socio-economic Status	Extended	0 (0)	1 (100)	.476	1	.490
	Lower	15 (53.6)	13 (46.4)			
	Middle	5 (41.7)	7 (58.3)			

Table 1 Shows comparison of socio-demographic variables of patients and parents of children and adolescents with Intellectual Disability and Functional Psychosis. Most of the patents were male and Hindu by religion in both groups. It was found that majority of the fathers were farmer by profession in functional psychosis group. Results also shows that most of the mothers were unemployed (51.3% & 48.7%) in the both groups respectively. It was also found that majority of the families with children and adolescent with intellectual disability, and functional psychosis were belonging to lower socio-economic status and nuclear family. There was no significance difference with regards to sex, religion, father’s occupation, mother’s occupation, marital status, family type and socioeconomic status in both the groups.

Table 2 Comparison of clinical variables of parents with Intellectual Disability and Functional Psychosis.

		Groups N=40		χ^2 /Fisher's Exact Test#	df	p
Variables		Intellectual Disability N=20, n (%)	Functional Psychosis N=20, n (%)			
Past History	Present	0 (0)	12 (100)	21.949#	-	.000
	Absent	20 (71.4)	8 (28.6)			
Family History	Present	5 (33.3)	10(66.7)	2.667	1	.102
	Absent	15(60)	10 (40)			

***p<.001

Table 2 shows clinical profile of the children and adolescent with Intellectual Disability and functional psychosis. There was a significance difference in the past history of mental illness of children and adolescents of intellectual disability and functional psychosis. No significance difference was found in the family history between intellectual disability and functional psychosis.

Table 3 Comparison of patient’s age, education, age of onset, duration of illness, number of hospitalization and duration of pharmacological treatment in patients with Intellectual Disability and Functional Psychosis.

		Groups N=40		Mann Whitney U Test	P
Variable		Intellectual disability (Mean Rank) N=20	Functional Psychosis (Mean Rank) N=20		
Age		13.12	27.88	52.500	.000
Education		11.30	29.70	16.000	.000
Age of onset		10.50	30.50	00.000	.000
Duration of illness		29.98	11.02	10.500	.000
Number of hospitalizations		12.60	28.40	42.000	.000
Duration of pharmacological treatment		18.82	22.18	166.500	.340

***p<.001

Table 3 shows the socio demographic and clinical profile in patients with Intellectual Disability and Functional Psychosis. There was significantly higher in age (***p<.000), education (***p<.000), age of onset (***p<.000), and number of hospitalizations (***p<.000) in Functional Psychosis as compared to Intellectual Disability. Results also found duration of illness (***p<.000) was significantly higher in Intellectual Disability as compared to Functional Psychosis.

Table 4 shows socio demographic profile of parents and families of children and adolescents with Intellectual Disability and Functional Psychosis. There was significantly higher in father’s age (.002**) and mother’s age (***p<.000), fathers’ education (.035*) and mothers’ education (.000***) Functional Psychosis as compared to Intellectual disability.

No significant difference was found in the number of family member in Intellectual Disability as compared to Functional Psychosis.

Table 4 Characteristics of father age, mother age and number of family members in families with Intellectual Disability and Functional Psychosis

Variable	Groups N=40		Mann Whitney U Test	P
	Intellectual Disability (Mean Rank) N=20	Functional Psychosis (Mean Rank) N=20		
Fathers age	14.85	26.15	87.000	.002**
Fathers education (in years)	16.70	24.30	124.000	.035*
Mothers age	12.82	18.18	46.500	.000***
Mothers education (in years)	11.40	29.60	18.000	.000***
Number of family member	18.30	22.70	156.000	.229

Table 5 shows the comparison of domains of health coping of parents of children and adolescents with intellectual disability and functional psychosis. This indicated that there was no significant difference found in the domains of health coping i. e. maintaining family integration, cooperation and optimistic definition of the situation, maintaining social support, self-esteem and psychological stability and understanding the medical situation through communication with other parents and consultation with medical staff in Parents of children and adolescents with intellectual disability and functional psychosis.

Table 5 Comparison on Health Coping in Parents of children and adolescents with intellectual disability and functional psychosis.

Variable	Intellectual Disability (Mean Rank) N=20	Functional Psychosis (Mean Rank) N=20	Mann Whitney U Test	p
Maintaining family integration, cooperation, and an optimistic definition of the situation	20.38	20.62	197.500	.946
Maintaining social support, self-esteem and psychological stability	19.30	21.70	176.000	.515
Understanding the medical situation through communication with other parents and consultation with medical staff.	19.38	21.62	177.500	.540

DISCUSSION

The present study was a hospital based cross sectional single contact study and it was conducted at the Central Institute of Psychiatry, Ranchi. The purpose of this study was to assess and compare the health coping among parent of children with intellectual disability and functional psychosis.

In the present study, Parents were asked to record how helpful each coping strategy was in their family situation. As stated earlier, the instrument measures three coping patterns via three subscales. In the first subscale, Parents of children and adolescents with functional psychosis reported (20.62) higher mean score in this domain that focuses they have better strengthening family life and relationships and the parents’ outlook on life with a psychologically challenged child (e.g. ‘trusting my spouse to help support me and my child’ as compare to parents of children and adolescents with intellectual disability.

In the second subscale parents of children and adolescents with functional psychosis scored higher (21.70) mean than parents of children and adolescents with intellectual disability” that focuses in this group of parents’ efforts more to develop relationships with others, engage in activities that enhance feelings of individual identity and self-worth plus strategies to manage psychological tensions and pressures (e.g. ‘engaging in relationships and friendships which help me feel important and appreciated’).

In the third subscale parents of children and adolescents with functional psychosis reported higher mean score in comparison to parents of children and adolescents with intellectual disability that directed at the parents’ relationships with healthcare professionals and other parents of psychologically challenged children (e.g. ‘talking with the medical staff when we visit the medical clinic’).

However, no significant difference was seen in the subscales of the health coping inventory measuring scale in either group. Reason could be parents of children and adolescents with either condition feel that they have to deal with lots of chronic or perennial problems, which cannot be cleared by interventions rapidly. Therefore, they have to learn the skill to live with this situation.

Asarnow and Horton (1990) compared the coping and disruption in parents of children with depressive and schizophrenia spectrum disorders. Parents described disruption in their family lives, relationships, leisure time, and work functioning. High maternal disruption was associated with the absence of intimate relationships and child chronicity. Parents most frequently reported using active cognitive coping strategies, but with the advantage of hindsight, advised seeking community resources for helping their children. In either condition, parents have to put lots of efforts to cope with the situation. Clinicians have categorized childhood schizophrenia on the basis of the age of onset: early onset schizophrenia (EOS), when the psychotic symptoms are present after the age of 13 years, and very early onset schizophrenia (VEOS), when the onset is at or before the age of 13 years (Werry, 1992; Russel, 1994). EOS and VEOS show atypical features when compared with adult-onset schizophrenia (AOS): insidious onset; more severe premorbid neurodevelopmental abnormalities; more frequent terrifying visual hallucinations; constant inappropriate or blunted affects; higher rate of familial psychopathology; minor response to treatment; and poorer outcome. Therefore, a significant proportion of these children and adolescents have the risk of developing chronic and recalcitrant symptoms. Supposedly, parents and caregivers of these children and adolescents have to be prepared for dealing with chronic adversities associated with the illness. Premorbid abnormalities in academic, motor, language, and affective development are considered to be a neurodevelopmental marker unique to schizophrenia, social deterioration being a more general premorbid feature of severe affective and other psychotic illness (Alaghband-Rad *et al.*, 1995; Allen *et al.*, 2005). In addition, several studies suggest that more pronounced early developmental premorbid abnormalities are usually associated with a poor outcome (Alaghband-Rad *et al.*, 1995). So, early onset schizophrenia is as damaging as intellectual subnormality in children in many aspects. Probably, because of this reason, no significant difference was noted between the parents of the children with intellectual

subnormality and psychosis in present study. It is already well established that parents of children with developmental and psychiatric difficulties are at risk for experiencing greater distress than parents of typically developing children (Baker *et al.*, 2002; Dumas *et al.*, 1991; Hauser-Cram *et al.*, 2001; Hodapp *et al.*, 2003; Johnston *et al.*, 2003; Rodrigue *et al.*, 1990). Several studies also showed that parents of children with autism spectrum disorders (ASD) may have higher levels of distress than mothers of children with other disabilities (Gallagher & Bristol, 1989; Abbeduto *et al.*, 2004; Blacher & McIntyre, 2006; Eisenhower *et al.*, 2005; Kasari & Sigman, 1997) and their condition is much akin to the parents of the children with chronic and debilitating psychiatric disorders. This way this particular finding of the present study (i.e. no difference in coping) is consistent with previous studies.

LIMITATION & CONCLUSION

It was a hospital based study with small sample size which was the main limitation of this study as hospital based study, which dealt with referred patients which might not have been truly representative of the general population. Nevertheless, it has given us numerous insights into the problems of the patients who reach us but due to less sample size generalization of results could not possible. Future research with larger, less selective samples and longitudinal designs may provide a clearer picture of the multiple factors associated with health coping of parents of children with Intellectual Disability and Functional Psychosis.

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How to cite this article:

Jagritee Singh¹ and Haque Nizamie S (2023) 'Health Coping Among Parents of Children And Adolescents With Intellectual Disability And Functional Psychosis', *International Journal of Current Advanced Research*, 12(05), pp. 2037-2042.
DOI: <http://dx.doi.org/10.24327/ijcar.2023.2042.1446>
