HOSPITAL ANXIETY AND DEPRESSION OF PARENTS OF CHILDREN WITH CEREBRAL PALSY WHO WERE ATTENDING OCCUPATIONAL THERAPY INTERVENTION FOR THEIR CHILDREN IN A GOVERNMENT HOSPITAL SETTING : A PROSPECTIVE STUDY

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Abstract: The purpose of this study is to determine the level of anxiety and depression in parents of children with cerebral palsy who were attending occupational therapy intervention regularly for a month in a government Hospital setting. In this prospective study 100 parents of children with cerebral palsy who were attending occupational therapy sessions daily for an hour, continuously for a month were recruited from Sir Sunderlal Hospital, Banaras Hindu University Varanasi, India. These parents both mother and father were assessed using hospital anxiety and depression scale in their first visit for occupational therapy intervention. They were asked to attended occupational therapy intervention with their child for a month .After a month they were again assessed using hospital anxiety and depression scale. From this study we conclude that occupational therapy interventions can significantly improve anxiety and depression indicators in parents of children with cerebral palsy who attended occupational therapy sessions regularly for a month with their children with cerebral palsy.

Index Terms: Anxiety, cerebral palsy, depression, occupational therapy.

INTRODUCTION

Cerebral palsy (CP) is the leading cause of physical disability, with a prevalence of 1.5 to 2.5 per 1000 live births in childhood (Apexa G et al 2002). Children with CP experience difficulties related to various motor and sensory impairments in activities of daily living. For most children with CP, the care supplied by their parents is a valuable environmental factor. Thus, if the parents are incapable to meet the challenges of providing care for their child due to psychiatric disorders, the child may not achieve his/her optimum level of functioning. In addition to the direct negative impacts of poor care giving related to parental emotional problems, parents who have psychiatric problems may subjectively view their child's functionality as negative. On the other hand, there is evidence that parents of children with poor functioning levels and quality of life show a tendency to have more psychiatric problems than parents of healthy children (Brehaut JC et al 2004). There are definite correlations between parent mental health and the psychosocial functioning and overall functional independence of their children with CP (Murphy et al 2011). Disability of a child affects the child and family members both (Gardiner E et al 2012). Disable children need more care and their parent tolerate the more stress to care for them (Yuen Shan Leung C et al 2003). Since parents of cerebral palsy children have a crucial role to provide preliminary needs and necessary treatment for these children, permanent caring is stressful for these caregivers (Zanon MA et al 2012) and causes physical and mental stress in the parents of these children (Kaya K et al 2010). Studies about depression of parents with cerebral palsy children indicated that stigma of having a disable child, leads to social isolation which again cause depression to these parents of children with cerebral palsy. There are a lot of evidences which indicates that parents who take care of disable children, experience more physical and mental disorders comparing to parents who take care of healthy children (Raina P et al 2005). Since World Health Organization (WHO) has announced, depression will become the second cause of disability after heart problem until 2020 (Horowitz A et al 2005), so investigating the effective factors on depression is very important. The Hospital Anxiety and Depression Scale (HADS) is a self assessment questionnaire that has been found to be a reliable instrument for detecting states of anxiety and depression in the setting of hospital outpatient clinic. The HADS questionnaire has seven items each for depression and anxiety subscales. Scoring for each item ranges from zero to three, with three denoting highest anxiety or depression level. The HADS questionnaire was originally developed by Zigmond and Snaith 1983. They created this outcome measure specifically to avoid reliance on aspects of these conditions that are also common somatic symptoms of illness, for example, fatigue and insomnia or hypersomnia. A total subscale score of >8 points out of a possible 21 denotes considerable symptoms of anxiety or depression. As mental health of parents plays an important role in improvement of functional level in children with CP. The aim of the study was to evaluate the depression and anxiety levels in the

parents of children with CP who were attending occupational therapy intervention for a month due to functional limitations in their children.

METHODS

In this prospective, observational study, we recruited 100 consecutive parents of children with cerebral palsy visiting occupational therapy unit of the Sir Sunderlal Hospital, Banaras Hindu University, Varanasi, Uttar Pradesh, India. In our hospital, occupational therapy services are routinely offered to children with cerebral palsy. Parents of children with cerebral palsy were referred to occupational therapy unit from Department of Pediatric And Neurology .Parents having children less than 12 years of age and those who were able to attended occupational therapy session regularly for 1 month were included for the study. Patients were enrolled from May 2016 to June 2017. We aimed at evaluating the role of occupational therapy intervention on the psychological status of the parents of children with cerebral palsy. HADS scoring was done before and after occupational therapy sessions to see whether there is a change in the baseline scores. The original HADS questionnaire in English (Fig. 1) was translated into Hindi language by an independent observer. To assess the validity of these translated versions, English back translation from Hindi was done by different individuals, i.e., other than the ones who translated the questionnaire from English to Hindi versions. Prior Institutional review board approval was sought. Each individual signed a written informed consent form agreeing to participate in the study. This study adhered to the tenets of Declaration of Helsinki. The HADS questionnaire was administered to the participants, face to face, in the occupational therapy unit of the Sir Sunderlal Hospital before and one month after the occupational therapist sessions. Except for the individual and the occupational therapist, there was no one else present during the interview. The occupational therapist confirmed that the individual understood all the questions before answering them. If the individual did not understand a question, the interviewer explained it to them. A single interview lasted for approximately 20-25 min. The participants did not have prior knowledge about the researcher or their interest in the study. None of the individuals refused to participate in the study. The questionnaire was not returned to the participants for comment or correction. The participants did not provide feedback on the findings of the study. Descriptive statistics was performed for continuous variables,

and frequency distribution was used to define the distribution of categorical variables. Independent sample *t*-test was used to find the difference in means between two groups; paired *t* test was used to find the difference in means within groups. One way analysis of variance was used to determine whether there is any significant difference in mean among various groups. Pearson correlation test was used to determine the relationship between duration of symptoms and HADS scoring. SPSS V.14.0 (IBM Corporation, 1 New Orchard Road, Armonk, New York 10504-1722, United States) was used to perform the statistical analysis and any test with P < 0.05 was considered as statistically significant.

RESULTS

We enrolled 100 parents enrolled, with 69 were father and 31 were mothers. Mean age of parents who were attending occupational therapy intervention for their children with cerebral palsy was 35.2 years (range: 18–59 years). Four parents had a family history of other children having same problems. Thirty-eight children with cerebral palsy had associated congenital disorders while the remaining had symptoms of cerebral palsy only without associated congenital problems.

The mean of GMFM score (±standard deviation [SD], range) in the children with cerebral palsy before occupational therapy intervention was 0.83 (±0.64, 4-0) and after occupational therapy intervention was 0.78 (±0.63, 4-0) (P < 0.001). The mean HADS Anxiety score was 9.6 (±4.3), which was 6.7 (±3.7) after occupational therapy intervention (P < 0.0005). Likewise, the mean HADS Depression score (±SD) was 8.4 (±3.7) and after occupational therapy intervention was 6.0 (±3.4) (P < 0.0005). The mean HADS Depression and Anxiety subscale score was calculated for varying severity of spasticity shown in table 1. There was no significant difference in the HADS Depression score between these groups (P = 0.75). There was no significant difference in the HADS Depression score between these groups (P = 0.75). There was no significant difference in the HADS Depression score between these groups (P = 0.75). There was no significant difference in the HADS Anxiety score in between groups (P = 0.58). For the sake of analysis, the parents were arbitrarily divided into 3 age groups. Group A, B and C comprised of parents having children with cerebral palsy of age >5 years, 5 and 10 years, 10 -12 years. In these groups the mean with standard deviation in HADS for Depression and Anxiety score is shown in table 2. In all groups, improvement after occupational therapy intervention is shown in table 3. When analyzed according to occupation, the anxiety and depression scores are shown in table 4. The HADS Depression subscale among students (P = 0.06) and for both

HADS Depression and Anxiety subscales among professionals individuals (P = 0.09 [HADS-D], P = 0.30 [HADS-A]) and

unemployed individuals (P = 0.09 [HADS-D], P = 0.30 [HADS-A]). Patients were also classified according to the underlying etiology Table 5. The mean HADS Depression scores (±SD) for different etiology of cerebral palsy were 9.0 (±3.5), 8.5 (±3.7), 10 (±3.6), 6.9 (±4.3), 8.6 (±2.6), 6.2 (±5.6), and 7.8 (±3.2), respectively. Following occupational therapy intervention, the improvement in scoring was statistically significant ($P \le 0.05$) for all groups. The mean HADS Anxiety score (±SD) at baseline was 10.7 (±4.6), 9 (±2.9), 7.7 (±4.7), 9.2 (±5.4), 11.2 (±2.8), 5.4 (±3.4), 10.1 (±4.1) which improved by a significantly after occupational therapy intervention in all groups. Details are presented in Table 6.Patients with acquired head injury experienced a significant decrease in the mean (±SD, P) HADS Depression and HADS Anxiety scores of 2.4 (±2.6, P < 0.0005) and 3.2 (±2.6, P < 0.0005) points, respectively. Furthermore, patients with jaundice (n = 38) had their HADS Depression and HADS Anxiety score improved significantly by a mean of 2.5 (±2.9, P < 0.0005) and 2.4 (±3.4, P < 0.0005), respectively. **DISCUSSION**

The results showed that level of depression and anxiety of parents of children with cerebral palsy decreases with proper occupational therapy interventions for these children. While little is known about the biological links between parents of children with cerebral palsy and anxiety, there is some evidence that high level of stress and impaired quality of life cause the risk of sleep disturbance, depression and anxiety (Ones et al 2005). With occupational therapy intervention parents get the hope that their child will be functionally more independent .Also during the occupational therapy intervention sessions parents get the opportunity to

share their thoughts and feelings with the parents of children with cerebral palsy and occupational therapist. It decreases their social isolation and develops the hope for future improvement of their child and themselves. The presence of high depressive symptoms may be related to multiple factors such as disability level, socio-economic status, cultural perspective and educational level. The mean score of parents for depression and anxiety scores of HADS according to age group of the child suggested that parents having children below five years shows more improvement in the level of depression and anxiety as compared to parents of children with age 5-10 years. Parents of children of age group 10-12 shows less improvement in their level of depression and anxiety this may be due to the fact that parents of small children find more improvement in functional level of child after occupational therapy intervention. These results are supported by the results of Shelly et al 2008 who find that mothers of children cerebral palsy children of age more than 10 years have poor quality of life as compared to mothers of younger cerebral palsy children. Further, depression scores of the parents were correlated with GMFCS in children with CP. There was a significant relation between GMFM scores and the level of depression and anxiety in the parents. Kaya K et al 2010 have reported that depressive symptoms observed in the parents of children with disabilities were not meaningfully related to the children's developmental status or parent-child interaction behaviors. Recently, Dagenais and co-workers 2006 investigated the correlation between parents and severity of the child's cerebral palsy. They found that caregiver stress is related with the child's disability level. It has been suggested that there were no differences between mothers with handicapped children and mothers with healthy children in regard to anxiety symptoms. According to cognitive theories, stressors play more important role in the course of depression than anxiety (Davis E, Mackinnon A 2012). It is possible that chronicity of the condition has an additive effect on depression, and depressive symptoms may relate to functional disability level. The task of caring for a child with complex disabilities at home might be somewhat daunting for parents. Brehaut JC et al 2004 reported that parents may experience the feeling of anxiety seriously at the time of diagnosis and depressive symptoms may appear with time. The mean score for anxiety and depression were not much different according to the severity of spasticity which shows that by occupational therapy intervention parents found the improvement in the mean score of GMFM post intervention. Yuen SL et al 2003 concluded that depression in these parents was associated with the severity of impairment in children with cerebral palsy. However, in our study, depression (P = 0.57) and anxiety (P = 0.34) was associated with severity of spasticity of children with cerebral palsy. This result is supported by the results of Msall ME et al 2005 who reported that children's movement ability had no significant relationship with their mother's depression and quality of life. In contrast Raina P et al 2005 reported lower independence level of CP children to be significant in mother's depression level. Long-term care giving can be devastating to parent's finances, employment, and quality of life however only a few studies have directly addressed the effects of children with disability on the parent's psychological status and their occupation. Parents worry about their children's future and acceptation in its social environment, these parental emotions can cause the risk of suffering from an anxiety disorder. Finding of study shows that parents who were more educated or professionals with good socioeconomic condition were having less improvement in their depression and anxiety score after occupational therapy intervention. This may be because of social isolation they face due to their child's disability and also loss of economy which hampers their quality of life which they expect. Zanon MA et al 2012 reported that mothers of children with cerebral palsy feel isolated in their society. If we look at mean scores according to etiology it is evidenced that improvement in score is more visible in those parents whose children were affected since birth with etiologies of hypoxic insult to brain, neonatal jaundice, and genetic conditions as compared to acquired cause of cerebral palsy of infection, head injury or miscellaneous conditions. This is because they find functional improvement in their child which they never seen before, but parents with acquired cause have already seen their children walking or sitting and can compare those postures or movement with the present condition. Anxiety and depression are the most important predictors of developing a full blown depressive or anxiety disorder according to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition. Complex limitations in self-care functions in children with CP can be detrimental to psychological well-being of their parents. Raina et al. 2005 suggested that psychological support is required for the parents of children with cerebral palsy. Our study showed that the parents of children with cerebral palsy decrease their level of depression and anxiety with hospital based occupational therapy program. In the light of these findings we thought that effective rehabilitation programs should provide sufficient opportunities for repeated follow-up interviews which offer not only information on the children's disabilities but also psychological support for the parents. CONCLUSION

The data reported by this study may allow occupational therapist to gain a better understanding of the factors associated with parent-rated level of depression and anxiety due to children with CP. This study suggests that the improvement of parent's psychiatric status occurs with hospital based occupational therapy program for their children with cerebral palsy.

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IILUSTRATION

Figure 1

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week. Don't take too long over you replies: your immediate is best.							
D	A		D	A			
	1.000	I feel tense or 'wound up':			I feel as if I am slowed down:		

3 Most of the time 3 Nearly all the time 2 A lot of the time 2 Very often 1 From time to time, occasionally 1 Sometimes 0 Not at all 0 Not at all 0 Not at all 0 Not at all 0 I still enjoy the things I used to enjoy: I get a sort of frightened feeling like 'butterflies' in the stomach: 0 Definitely as much 0 Not at all 1 Not quite so much 1 Occasionally 2 Only a little 2 Quite Often 3 Hardly at all 3 Very Often 1 I get a sort of frightened feeling as if something awful is about to happen: 1 have lost interest in my appearance:
2 A lot of the time 2 Very often 1 From time to time, occasionally 1 Sometimes 0 Not at all 0 Not at all 0 Not at all 0 Not at all 0 I still enjoy the things I used to enjoy: I get a sort of frightened feeling like 'butterflies' in the stomach: 0 Definitely as much 0 Not at all 1 Not quite so much 1 Occasionally 2 Only a little 2 Quite Often 3 Hardly at all 3 Very Often 1 I get a sort of frightened feeling as if something awful is about to happen: I have lost interest in my appearance:
1 From time to time, occasionally 1 Sometimes 0 Not at all 0 Not at all 0 I still enjoy the things I used to enjoy: I get a sort of frightened feeling like 'butterflies' in the stomach: 0 Definitely as much 0 Not at all 1 Not quite so much 1 Occasionally 2 Only a little 2 Quite Often 3 Hardly at all 3 Very Often 1 I get a sort of frightened feeling as if something awful is about to happen: I have lost interest in my appearance:
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1 Not quite so much 1 Occasionally 2 Only a little 2 Quite Often 3 Hardly at all 3 Very Often Image: Something awful is about to happen: Image: Something awful is about to happen: Image: Something awful is about to happen:
2 Only a little 2 Quite Often 3 Hardly at all 3 Very Often 4 I get a sort of frightened feeling as if something awful is about to happen: I have lost interest in my appearance:
3 Hardiy at all 3 Very Often 3 I get a sort of frightened feeling as if something awful is about to happen: I have lost interest in my appearance:
I get a sort of frightened feeling as if something awful is about to happen:
I get a sort of frightened feeling as if something awful is about to happen:
3 Very definitely and quite badly 3 Definitely
2 Yes, but not too badly 2 I don't take as much care as I should
1 A little, but it doesn't worry me 1 I may not take quite as much care
0 Not at all 0 I take just as much care as ever
I can laugh and see the funny side of things:
0 As much as I always could 3 Very much indeed
1 Not quite so much now 2 Quite a lot
2 Definitely not so much now 1 Not very much
3 Not at all 0 Not at all
Worrying thoughts go through my I look forward with enjoyment to things:
3 A great deal of the time 0 As much as I ever did
2 A lot of the time 1 Rather less than I used to
1 From time to time, but not too often 2 Definitely less than I used to
0 Only occasionally 3 Hardly at all
I get sudden feelings of panic:
3 Not at all 3 Very often indeed
2 Not often 2 Quite often
1 Sometimes 1 Not very often
0 Most of the time 0 Not at all
I can sit at ease and feel relaxed: I can enjoy a good book or radio or TV program:
0 Definitely 0 Often
1 Usually 1 Sometimes
2 Not Often 2 Not often
3 Not at all 3 Very seldom

Please check you have answered all the questions

Scoring:

Anxiety (A) _____

Total score: Depression (D) _____

0-7 = Normal

= Borderline abnormal (borderline case) 8-10

11-21 = Abnormal (case)

Table 1.Mean scores of anxiety and depression in parents in HADS according to severity of spasticity in MAS scale after occupational therapy intervention.

MAS Spasticity scale	Mean depression Score	Mean Anxiety Score	No. of parents
>2	7.9±3.9	9.0±4.4	26
1-2	8.9±3.3	9.8±3.9	50
<2	8.7±3.3	10.9±5.5	15
0	8.8±6.1	9.0±4.9	9

Table 2. Mean scores of anxiety and depression in parents in HADS according to age group of the child after occupational therapy intervention.

Group	Age of child	No. of parents	Mean of depression in HADS	P value	Mean of anxiety in HADS	P value
А	>5	22	1.6 ± 2.4	0.01	1.3±2.3	0.03
В	5-10	61	2.8 ± 2.8	< 0.0005	3.4±3.0	< 0.0005
С	10-12	17	2.0±2.5	< 0.0005	2.8±2.7	< 0.0005

Table 3.Gender wise mean scores of anxiety and depression in parents in HADS after occupational therapy intervention.

Gender	No. of	Mean of depression in	P value	Mean of anxiety in	P value
	parents	HADS		HADS	
Mother	31	$2.4{\pm}2.2$	< 0.0005	2.8 ± 2.7	< 0.0005
Father	69	2.4±2.9	< 0.0005	2.9±3.1	< 0.0005

Table 4 .Occupation wise mean scores of anxiety and depression in parents in HADS after occupational therapy intervention.

Occupation	HADS-depression, HADS-anxiety		Р	Р
Professional(3)	2.9±3.0	3.2±3.6	0.00	0.004
				1
laborer(20)	2.4±3.2	3.1±3.7	0.002	0.000
		4		
Home maker(21)	2.8±2.7	2.1±3.7	0.004	0.002
Student (7)	2.4±2.2	2.6 <u>±3.0</u>	0.004	0.002
	and all all and		Acres Acres Acres	
Farmer (27)	1.5±2.3	3.7±2.1	0.000	0.004
unemployed(4)	1.5±1.5	2.7±1.5	0.001	0.00
skilled worker	1.7±2.1	2.9 <u>±2.4</u>	0.004	0.00
				V
Business	2.7±1.5	3.2±2.7	0.004	0.001

Table 5 Etiology wise mean scores of anxiety and depression in parents in HADS after occupational therapy intervention.

Etiology	HADS-depression,	HADS-anxiety	Р	Р
Hypoxia (36)	1.9±3.2	2.2±3.0	0.002	0.00
Head injury(24)	1.4±3.2	2.1±2.7	0.001	0.004
Infections(14)	2.0±2.7	3.1±2.7	0.004	0.002
Neonatal jaundice (9)	2.1±2.2	2.8±2.0	0.004	0.004
Per ventricular hemorrhage (5)	1.8±2.3	2.7±2.3	0.001	0.002
Familiar history(4)	1.9±1.5	1.7±2.5	0.00	0.00
Miscellaneous(8)	2.7±2.1	1.9±2.3	0.002	0.00