

Psychological Adjustment in Juvenile Diabetics

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The aim of the study was to understand psychological adjustment in juvenile diabetics. A sample of 30 children in the age range of 6 to 15 years, diagnosed as Insulin Dependent Diabetes Mellitus (IDDM) and their mothers were selected for the study. The tools used were the Culture Free Self-Esteem Inventory, Functional Disability Inventory and Impact of Childhood Illness Scale. The results revealed that only on general self-esteem, IDDM children scored significantly lower than controls. They however scored higher on the lie scale, indicating defensiveness. Functional Disability, Self Esteem and Impact of Illness were significantly correlated. The illness had a significant impact on both the child and his family. Authors emphasize that associated psychological problems of IDDM children need to be handled by mental health professionals.

Key Words: Chronic Illness; Juvenile Diabetes; Psychological adjustment.

Diabetes Mellitus is an endocrine disorder, characterized by hyperglycemia, that is, high blood sugar levels. Type I diabetes is typically diagnosed at childhood, with peak incidence at puberty. The treatment of Type I diabetes is often complex. In addition to daily injections, it involves many other life style adjustments such as timing and nature of food consumption, regular exercise and blood glucose monitoring. These lifestyle changes place unique demands on the individual as well as the family, as failure to follow any of these could lead to serious short and long-term consequences. Compared to children in the general population, IDDM children are likely to have difficulties in learning (Gath, Smith & Baum, 1980). Cognitive impairment is related in childhood, though not in adulthood, to the length of time since the onset of the condition. Ryan, Vega and Drash (1985) found no

differences on a range of cognitive tasks, between later onset adolescents with IDDM and matched sibling controls. However, children diagnosed prior to 5 years of age had significant deficits on predominantly visuospatial and memory tasks, as well as on tests of educational attainment, such as reading. The most marked effects on right hemisphere functioning was found in very early onset diabetes (before 5 years) for example, on visual constructional problem solving and recall of visual information and more specific effects on left hemisphere functions, in later onset IDDM as assessed, for example, by verbal concept information, reading and spelling skills. Rovet, Erlich and Hoppe (1987) reported that compared to boys, affected girls tend to show the above cognitive problems more consistently.

The psychological adjustment and coping of juvenile diabetics and their families is an interesting area of research. Anderson, Miller, Auslander and Santiago (1981) have described and compared the family environment of diabetic adolescents with varying degrees of metabolic control. Fifty-eight adolescents and their parents (mothers) were independently assessed with structured interviews. As compared with adolescents with poor control, those with good control reported less diabetes-related symptoms, less anxiety and more positive self-concept. Well-controlled diabetic adolescents also report more cohesion and less conflict among family members. More parents of well-controlled youth stated that family members were encouraged to act independently. In addition, more parents of poorly controlled adolescents believed that diabetes had affected their child's personality, physical well being, schooling and participation in activities away from home.

The findings of this study suggest a complex inter-play between the diabetic adolescent's psychological and physical, functioning, metabolic control and family environment. Marteau, Bloch and Baum (1987) studied 72 children with diabetes and their parents, to examine the relationship between the family functioning and diabetes control. Children and families characterized by cohesion, emotional expressiveness, lack of conflict and satisfactory marital relations had better diabetic control than children living in disturbed families. Children living with both biological parents or with a single parent had significantly better diabetic control than those living with a step parent or adoptive parents. Therefore, both behavioural and physiological pathways mediate the relationship. A longitudinal study was conducted by Worrall, Owens, Holland and Haigh (2002) to see the effect of parental expressed emotion on glycaemic control in children with Type I Diabetes. The sample consisted of parents of 47 children aged 6-14 yrs attending a

Paediatric Diabetes clinic. Results showed that parental emotional over-involvement or criticism did not predict glycaemic control. Presence of paternal hostility was more important than maternal hostility. Adverse life events, in particular disappointments, which lead to negative cognitions, were found to lead to subsequent poor glycaemic control in children. Hanstead (1989) examined how Type I diabetics experienced their quality of life and whether sex, age, social status, education, disease duration, HbA1c regimen and complications had any effect on quality of life. The study included 247 Type I diabetics and results indicated that 80% of them reported adequate quality of life. The author thus concluded that a majority of the patients experienced a satisfactory quality of life despite having to live with a chronic illness such as diabetes.

Grey, Whittemore and Tamborlane (2002) studied the natural history and correlates of depression in Type I diabetes in children. They highlight the importance of the combination of diabetes and depression in children and especially adolescents. It is associated with 10-fold increase in suicide and suicidal ideation. Depression tends to be more severe, and takes longer to resolve in youth with diabetes. Depression may also be associated with poorer metabolic control in diabetes, which may lead to complications and poorer outcomes. Youth with diabetes and depression are likely to have other comorbid conditions, such as eating disorders, adjustment disorders or anxiety disorders. Mollema, Snock, Ader, Heine and Ploeg (2001) reported that diabetic patients who suffered from extreme fear of self-injecting (FSI) or fear of self-testing (FST) report significantly worse psychological functioning, higher levels of diabetes related emotional distress and poorer general well-being. Hence, the above studies emphasize the role psychological factors play in the control of juvenile diabetes. As there is a dearth of Indian studies, the present

investigation aimed to study psychological adjustment in a group of Indian juvenile diabetics. The objectives were

1. To study the self esteem of juvenile diabetic patients.
2. To assess the extent of any physical disability and its relation to self-esteem.
3. To examine parent's perception of how the illness had an impact on their life in various spheres.

Psychological adjustment in this study refers to Self-esteem, extent of Functional Disability and the Impact of illness on the child and his/her family. The study was exploratory in nature. Scores on the scales were compared with available norms.

Method

Sample

The sample consisted of 30 children, boys and girls in the age range of 6 to 15 years diagnosed as IDDM and their mothers, attending the department of Endocrinology of the following hospitals – Mallya Hospital, Ramaiah Hospital, Samaja Seva Sangha (Disha Connection), Santosh Hospital and Jain Hospital. The purpose of the study was explained to the parents and children and their consent to participate in the study was sought. The first 30 children who gave consent to participate in the study were selected. The child and parent were interviewed separately in the out patient department (OPD) of the hospitals. Approximately one hour was spent with each child and mother. A pilot study on 5 children was carried out to assess the availability of the sample and to familiarize the investigator with the tools. A data sheet was designed to gather information about socio-demographic variables like education, age, sex, age at diagnosis, number of hospitalizations, side effects of the treatment, days of school missed, academic performance and family history of Diabetes Mellitus.

Inclusion Criteria

1. Children registered in a diabetics clinic
2. School going

Tools

1. Culture Free Self Esteem Inventory for Children Form A (CFSEI), developed by Battle (1981), is a 60-item questionnaire categorized into 5 sub scales.

- a. General self-esteem
- b. Social/peer related self-esteem
- c. Academic/School related self-esteem
- d. Parents/Home related self-esteem
- e. Lie scale

The sub scales were derived using factor analysis. The highest score is 50 on the first four sub scales combined and on the lie scale, 10. Higher score indicates higher self-esteem. The total score is obtained by summing the item scores. A high score on the lie scale indicates defensiveness. Vinutha, Rajini and Nagalakshmi (1989) standardized this test in India on 9th class children – 184 boys and 184 girls studying in English medium schools.

2. The Functional Disability Inventory (FDI) was developed by Walker and Greene, (1991). It is a global measure of functional disability assessing the impact of illness on the child's physical and psychosocial functioning in every day social roles. It is a 15-item inventory. Responses to each item of difficulty associated with various tasks such as reading or doing homework can range from "0" no trouble; "1" little trouble; "2" some trouble; "3" a lot of trouble; and "4" impossible. The scores can range from 0 to 60. Either the parents or the affected children can answer the questions.

3. Impact of Childhood Illness Scale (ICIS) developed by Hoare and Russell (1995) is a 30 – item questionnaire to be filled by parents of children with long standing illness. It requires the parents to make a rating along

2 dimensions of frequency and concern along a three-point scale for each item. The items are along the frequency dimension and are in response to statements like-

"Because of my child's illness he may stop breathing".

"0" – if it is never true

"1" – if it is sometimes true and

"2" – if it is always true

Along the dimensions of concern to the statement "because of my child's illness his heart may stop beating", parents respond.

"A" – if there is a lot of concern (score 2)

"B" – if there is a bit of concern (score 1) and

"C" – if there is not much concern (score 0)

The total scores along the frequency and concerns dimension can range from 0 to 60.

Results

The aim of the present investigation was to study the psychological adjustment in juvenile diabetics. Data was collected from 30 respondents aged 6-15 yrs. The self-esteem of the children was measured and parents reported on their child's level of disability and impact (frequency and concern) of the illness they felt.

The investigation attempted to answer the following questions:

- a) Does functional disability correlate with self esteem scores
- b) How do parents feel the illness has impacted their lives
- c) Is there a significant correlation between the variables of impact and childhood illness, self-esteem and functional disability.

The socio-demographic data collected was analyzed using percentages and frequencies. Majority of the children (63%) belonged to the 12-15 years age range. 83% of the children in the sample were females and 17% were

males. All the children were school going. 22 children were attending school regularly and 18 were reported to be doing well academically. Majority of the children were in the 12-15 years age range when diagnosed as IDDM. 53% of the mothers in the sample belonged to the age range of 20-40 yrs and 47% in the age range of 41-60 yrs. 57% of IDDM patient's mothers had secondary education, 3% had primary education and 4% were collegiates. 60% of the IDDM patients family income was Rs.3001 and above. 7% of the mothers were government employees, 27% private or self-employed, and 66% were housewives. 70% respondents were Hindu's, 10% Christians and 20% Muslims. 90% of the respondents belonged to nuclear families and only 10% of the respondents belonged to joint families.

All families were intact with both parents living together. 66% of the sample had family history of Diabetes Mellitus. All the children were on insulin therapy with no reported side effects. Table 1 depicts the differences in sub-scale and total scores of self-esteem between the IDDM children and a control group with mean age of 13 years (taken from Bhola, P. 2000). Significant differences were found in the areas of general self-esteem and lie scale.

Comparing self-esteem with functional disability, high negative correlations were found on all sub-scales indicating that when functional disability was high self-esteem was low (Table 2). The Impact of Illness Scale gave information on the Impact of the illness on different areas. Comparing self-esteem with impact, significant correlations were found (Table 3). Comparing functional disability with impact, significant correlation was found (Table 4). More the functional disability, the more distressing for the family it was.

Table 1 Scores on the Culture Free Self Esteem Inventory

Variables	Groups	Mean	SD	t- value
Sub-scale of self-esteem	Study	13.00	4.03	t=2.78**
	Control	15.30	1.68	df=41
Social	Study	6.17	1.84	t=1.15
	Control	6.75	1.61	df=48
Academic	Study	7.63	2.67	t=0.57
	Control	7.95	1.21	df=43
Parental	Study	8.20	1.49	t=0.7236
	Control	8.45	0.97	df=47
Lie Score	Study	5.10	2.31	t=5.36***
	Control	2.25	1.45	df=47
Total Self Esteem	Study	35.00	8.94	t=1.89
	Control	38.35	3.14	df=38

** p < 0.01; *** p < 0.001

Table 2 Comparison of Self Esteem with Functional Disability

Variables	Mean	SD	r
Functional Disability	6.53	8.44	-0.702
General SE	13.00	4.03	
Functional Disability	6.53	8.44	-0.583
Social SE	6.17	1.84	
Functional Disability	6.53	8.44	0.635
Academic SE	7.63	2.67	
Functional Disability	6.53	8.44	-0.454
Parental SE	8.20	1.49	
Functional Disability	6.53	8.44	-0.702
Total SE	35.00	8.94	
Lie Scale	5.10	2.31	-0.162

On the Functional Disability Scale, 13 children reported no disability.
The mean score was 6.53 (SD=8.44)

Table 3 Comparison of Self-Esteem with Impact

Variables	Mean	SD	r
Impact	28.57	19.65	-0.52**
General SE	13.00	4.03	
Impact	28.57	19.65	-.66**
Social SE	6.17	1.84	
Impact	28.57	19.65	-.49**
Academic SE	7.63	2.67	
Impact	28.57	19.65	-.38*
Parental SE	8.20	1.49	
Impact	28.57	19.65	-.58**
Total Score	35.00	8.94	

** p < 0.01; *** p < 0.001

Table 4 Comparison of Functional Disability with Impact

Variables	Mean	SD	r
Impact	28.57	19.65	
Functional Disability	6.53	8.44	-0.48**

Discussion

On the general self-esteem sub-scale the IDDM children scored significantly lower than the control group. However, on the lie scale, the IDDM children scored significantly higher. This could indicate that the IDDM children are defensive and do not report honestly about self-esteem issues. Gross, Johnson, Wildman and Mullett (1981) also found diabetic children to be embarrassed, ashamed and uncomfortable about their disease. They suggest that these children will benefit from psycho education and social skills training. This would help them cope more effectively in

social situations. Thanki, Bilwani and Vankar (1999) in their study on 30 IDDM children, report behavioural disorders in 20% and psychiatric disorders in 40% of their parents. On the Functional Disability Scale scores ranged from 1 to 41 (out of a total possible score of 60). Only one child had a high score of 41, with a low self-esteem score of 17 (mean – 35.00). Apart from 4 other children who scored in the 15-21 range, all others scored below 8. We thus see that majority of the children did not have any physical disability and were able to attend school and carry out activities of their daily living. Most parents were concerned that their children would injure themselves while playing and found them moody because of their illness. Mothers were also concerned about their child's academic performance and child's future (life long medication and marriage). Mothers also reported difficulty in talking about their child's illness both to the child and to others. It is important for both the child and his/her family to have adequate knowledge about the illness and its complications.

Another area of increased concern was the child needing to be closely watched at all times, because of the unpredictable course of the illness. We thus find that the impact of diabetes on the family is enormous. It is often viewed as a source of significant and chronic stress on the family structure, often necessitating unwelcome changes in family routines and life style. Other diabetes-related stresses include financial strain, anxieties about complications, reduced life expectancy, and frequent medical crisis, such as hypoglycemic or hyperglycemic episodes. Diabetes has been found to affect the lives of the parents in several areas. Functional Disability, Self-esteem and Impact of illness have been found to be significantly correlated. The study has thrown light on the psychological adjustment of Juvenile Diabetics. Coping behaviour in children with this chronic illness can be enhanced by pediatric management

involving early and repeated explanations of the condition and its implications. Bhatawdekar (1999) emphasized the need for psychosocial intervention in Juvenile Diabetes. Children need help to accept that they have a chronic illness and thus may not be able to achieve as high as other children both in academics and in extra-curricular activities. Parents and the treating team need to be sensitive to identify presence of associated psychological problems like low self-esteem, depression and anxiety. Juvenile Diabetics could be encouraged to talk about their emotions and illness related worries.

Conclusions

- 1) Children on treatment for IDDM were performing well academically and had minimal functional disability.
- 2) On general self-esteem scores IDDM children scored significantly lower than controls however scored higher on the lie scale indicating defensiveness.
- 3) The illness had significant impact on both the child and his family.
- 4) Functional Disability, Self-esteem and Impact of illness were significantly correlated.
- 5) Associated psychological problems of IDDM children need to be handled by mental health professional.

One limitation of the study is absence of a control group. However, scores of the clinic group have been compared with control group scores from a previous study, done at NIMHANS, which used the CFSEI.

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