PSYCHOSOCIAL ASPECTS OF TYPE 1 DIABETES MELLITUS

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ABSTRACT

Psychological factors play a crucial role in the management of children with type 1 diabetes mellitus. They are important for the child as well as the family and are related to the reactions at the time of diagnosis and when complications occur, cognitive consequences and psychological factors that influence the management of diabetes. Children may face psychological problems such as temporary adjustment disorder with somatic complaints, social withdrawal, anxiety or depression. Mild impairment of cognition such as visuospatial or verbal defects may also occur. Factors in the family, such as cohesiveness and conflicts in the family, influence the psychological and self-care behavior of the child. In conclusion, it is important to treat the child rather than just the blood glucose values and give the child a sense of complete well being.

KEY WORDS: Childhood diabetes; Diagnosis; Family cohesion; Withdrawal; Depression; Compliance.

INTRODUCTION

Type 1 diabetes mellitus is a chronic condition affecting nearly 300,000 children and adults in the United States each year (1). In India, the prevalence varies from about 10.1 per hundred thousand (2) to 1.6 per hundred thousand (3).

THE CHALLENGES OF GROWING UP WITH DIABETES

The gradual attainment of independence from adults and an increasing sense of body integrity and identity characterize childhood and adolescence. Additionally other factors such as adjustment to and acceptance of the emotional and physical changes of puberty, the development of intimate and personal relationships, the establishment of personal values and the choice of future educational and vocational directions also come into play (4). These developmental changes required for normal growth and maturation may be negatively affected by diabetes because of the regimen required for diabetes care, the feeling of being "different" from one's peers, and parental supervision of the self-care treatment plan. A child's sense of independence, body image, identity, sexuality, relationships and self-esteem may thus be adversely affected by the development and treatment needs of type 1 diabetes.

Diabetes and psychology have long been linked. There are many points of interaction between diabetes and psychology

- Psychological reactions to the development of diabetes and its complications
- The neuropsychological or cognitive consequences of diabetes
- Psychological factors that influence or are influenced by the management of diabetes.

THE PSYCHOLOGICAL IMPACT OF DIABETES

Diabetes requires the patient to take responsibility of managing their health with daily injections, careful monitoring of diet, exercise and blood glucose levels for the rest of their lives. Chronic illness marks the children as different from their peers. It also burdens the family with demanding health care responsibilities that they may be unwilling to meet. It is therefore not surprising that many children with diabetes have many problems both emotional and behavioral (Table 1).

Psychological Stress Shortly after Diagnosis

Kovac studied 95 children aged 8-13 years and followed them up for 6-10 years (4). 14% of the children had psychiatric disorder at diagnosis, with anxiety disorder being the most common (8%). Within three months of diagnosis, 36% of the children had psychological disorders. Most of them had an adjustment disorder that can be defined as a transient reaction that exceeds the normal and expectable response to a specific stress which develops within three months of the onset of the stress and lasts no more than six months (5). This occurrence signals that the child is beginning to come to terms with the diagnosis of diabetes (6).It has been stated that major depression is common in diabetic children. However only 4% met the criteria for major depression shortly after diagnosis (7). Children show low rates of psychological disorder that were comparable to non-diabetic children from the community or children with

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Table1: Psychological problems in children

Diabetic group	Psychological problem
Children and adolescents at onset of diabetes (little known about adults with recent-onset diabetes)	Temporary adjustment disorder, somatic complaints, social withdrawal, sleeping disorder, anxiety, depression
Older children with established diabetes, when hospitalized	Higher frequency of depression (comparable to other chronic illness)
Patients with proliferative retinopathy	Depression, poor quality of life, psychological distress
Children with repeated hypoglycemia	Mild impairment of cognitive functioning – visuospatial /verbal defects
Later onset diabetes in children/adolescents	Verbal IQ and academic achievement lowered

recent acute medical illness (8,9). Younger preschool children show a similar psychological reaction to diabetes . Within two years of diagnosis, children under five years of age had high rates of internalizing behavior like somatic complaints, social withdrawal, sleep disturbances, symptoms of depression and anxiety, but not externalizing symptoms like destructive aggressiveness. Like school age children, their degree of true psychopathology was low and not considered clinically significant.

Psychological Reactions Emerging in the Course of Diabetes in Children and Adolescents

Most cross sectional surveys and all prospective studies have found no evidence of severe behavioral or psychological problems in diabetic children and adolescents. In a three-year follow up study, Ahnsjo studied diabetic children and demonstrated normal patterns of physical and ego development with only mild tendencies toward anxiety and depression that do not meet the diagnostic criteria for psychological distress (8). The level of psychological distress shortly after the onset of diabetes was the best predictor of symptomatology six years later. Glycosylated hemoglobin had no predictive value in most studies (10-12).

Psychological Reactions to Chronic Diabetic Complications

Diabetic complications disrupt the individual's life style and interfere with self care activities. They remind the person that even with the best of effort, they have failed to manage their diabetes adequately. Patients with proliferative diabetic retinopathy are particularly more prone for the development of psychopathology. They have higher rates of depression and poorer quality of life. Both the duration of visual problems and level of visual activity appear to affect mental health. Wulsen et al (13) followed such patients and found that greater impairment in visual activity was associated with increased psychological distress and poorer coping efforts. Duration of diabetes, quality of metabolic control and overall time of depressive disorder could predict the severity of diabetic retinopathy. Depression may therefore be a factor not only for the development of psychological problems but also of future complications.

Quality of Life

Quality of life includes an understanding of how health related variables affect physical, social and mental functioning, as well as the individual's overall feeling of well being and general satisfaction with life. Healthy, type 1 diabetic children report being satisfied overall with their life and indicate that diabetes has little impact on their lives (14). The quality of life tends to decline as the number and severity of complications increase (15,16) . A study has found that marital satisfaction is more in children who were diagnosed as diabetics before the age of nine years and that they were more likely to have children, than the children diagnosed after that age (17).

THE NEUROPSYCHOLOGICAL IMPACT OF DIABETES

Diabetes does not invariably cause neuropsychological dysfunction. Nevertheless, a subset of individuals manifest mild impairments that are not intellectually disabling, but render them less efficient mentally than would have been expected had they not developed diabetes. The psychosocial risk factors vary at different stages of life. Hypoglycemia has a particularly deleterious effect in children.

Early Onset Diabetes, Cognitive Dysfunction and Hypoglycemia

The cognitive dysfunction can be attributed to two different risk factors as shown in Table 2.

Table 2: Cognitive Dysfunction in Diabetes

Mild to moderate hypoglycemia affects the developing nervous system

Psychosocial and educational disruption associated with management of diabetes

The child who develops diabetes in the first four or five years of life is particularly vulnerable to the effects of repeated hypoglycemia. The specific pattern of impairment depends on the age at the time of assessment. Younger children with early onset of diabetes are more likely to show performance decrements that are largely limited to visuospatial tasks (18). By adolescence, impairments may be evident on a wider range of measures, both verbal and visuospatial, with girls and boys being equally affected on tests of learning, memory, problem solving, intelligence and eye hand coordination (19). This impairment may be largely due to inability to concentrate effectively and use optimal learning strategies to organize and encode information (20). As many as 24% of children with an early onset of diabetes showed neuropsychological deficits, compared with only 6% of later onset diabetic children and 6% of non diabetic comparison group (19).

Indirect evidence suggests that hypoglycemia may be the cause of neuropsychological deficit in children with early onset diabetes. Children and adolescents who develop diabetes below the age of five years, have a significantly more rate of hypoglycemia than children who develop diabetes after that age. Repeated hypoglycemia early in life may lead to relatively subtle neuropsychological dysfunction with visuospatial skills being most affected. Higher rates of hypoglycemia in children may occur because the counter regulatory mechanisms are less well developed in young children (21,22). Sufficiently, severe hypoglycemia can produce severe brain damage at any age (23). In young children the brain appears to be particularly vulnerable to traumatic or neurotoxic insult (24,25). The frequency of hypoglycemia can be reduced in young children if monitored carefully and frequently by their parents (26).

Later Onset Diabetes in Childhood and Adolescence

Role of psychosocial risk factors

There is a marked difference in children and adolescents who developed diabetes after the age of four or five years. Children with later onset diabetes perform well as their non-diabetic colleagues but on closer evaluation they have minor deficits in psychomotor efficiency, general intelligence and academic achievement (26,27). Later onset diabetics tend to perform more slowly but no less accurately on psychomotor tests that require eye-hand coordination or rapid translation of numbers into symbols according to a prearranged code (26). Performance based on measures of verbal intelligence and academic achievements with later onset diabetic adolescents earning verbal IQ scores may be lower on average by 10 points than their non-diabetic peers. Children and adolescents followed during the first five years of life showed significant performance decrements with girls showed the decline in verbal intelligence and boys showed drop in school grades (28). Verbal intelligence is a measure of knowledge base acquired in the classroom and may be poorer in children who have missed class (29). Diabetes affects intellectual and academic performance because it interferes with education. This may be mediated in part by the psychosocial problems that often develop within the families of diabetic children and perhaps by transient episodes of asymptomatic hypoglycemia.

Cognitive Dysfunction and Poor Metabolic Control in Adults with Type 1 Diabetes

Hyperglycemia, rather than hypoglycemia may be a more potent risk factor. Tasks requiring psychomotor speed and / or spatial information processing are most likely to be disrupted but other cognitive functions including attention, learning and memory are often affected in the poorly controlled adult. The mechanism for this is poorly understood. It may be a mechanism which affects the neuronal metabolism of the brain, affecting the Na^+/K^+ ATP activity and polyol metabolism. This is supported by the demonstration that adults with diabetes of long duration show slower brain transmission times during electrophysiological recordings of brain stem auditory evoked potentials (30-32).

Repeated Episodes of Severe Hypoglycemia and Cognitive Dysfunction

Mild to moderate hypoglycemia induces significant cognitive impairment in children whose brain is still developing (32). Longitudinal studies (33,34) have not found any connection between repeated hypoglycemia and brain damage, while cross sectional studies have consistently supported a link (35-38).

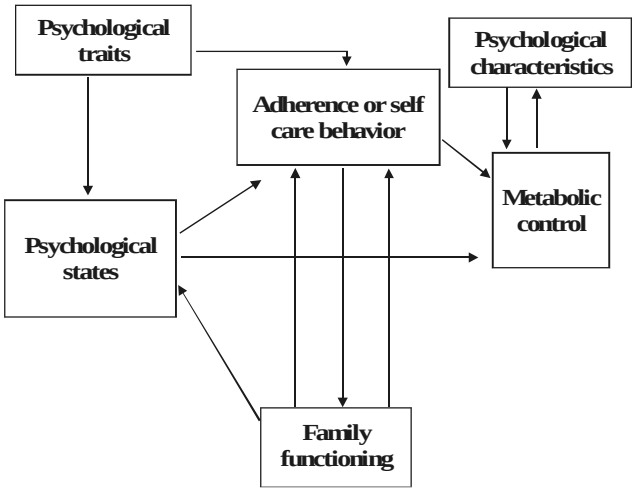
DIABETES MANAGEMENT AND PSYCHOLOGICAL PROCESSES

Certain traits of coping styles that are intrinsic to the individual's psychological make up may determine

the ability to deal with various barriers like adherence, including missed meals or tests, peer pressure, disruptive interpersonal conflicts and the normal stresses of everyday life.

There is no simple direct relationship between any single psychological variable and metabolic control (39). Figure 1 shows one such model

Fig 1: A system Model of the Relationship Between Psychological and Metabolic Variables



Psychological traits are relatively enduring characteristics that include temperament or personality and coping style. These may have a direct impact on self- care behavior (adherence) and on emotional state. Psychological states are more transitory and reflect emotions or feeling at a given point of time. Both family interactions and self-care behavior may affect and be affected by the individual's mood. Theoretically at least, certain emotional states especially stress, may influence metabolic control directly via the autonomic nervous system or indirectly by interfering with the patient's ability to manage his or her diabetes. This psychological link may be reciprocal i.e. changes in the mood may occur as a psychological reaction to an inability to maintain reasonable diabetic control. Family functioning, including conflicts and degree of family cohesiveness, can affect psychological state and influence self care behavior.

Psychological Trait

These encompass psychological concepts that include temperament, personality, coping style, locus of control, self efficacy, type A behavior and health beliefs. Each of these variables predicts metabolic control. Temperament predicts glycosylated haemoglobin in diabetic children (39). Good metabolic control is more common in children with normal activity and display milder responses to external stimuli (40). Personality characteristics also predict metabolic control. Individuals having a strong need for achievement and a high level of responsibility enjoy better metabolic control (41). Control tends to be poorer with patients with dramatic, dependent personality (42).

Locus of control is another psychological trait that may affect glycemic control. Individuals who have an internal locus of control believe that they are responsible for their health whereas, those who have an external locus believe that they are at the mercy of chance. Individuals who have an internal locus are more likely to have a better control and a better adherence to treatment (43, 44).

Psychological States

Poor glycemic control is associated with higher levels of stress in both adolescents and adults. Stress may affect metabolic control indirectly by disrupting the individual's ability to manage diabetes effectively. Stress could directly affect metabolic control by stimulating the autonomic nervous system to induce hyperglycemia (45, 46). Depression and anxiety are usually but not invariably associated with poor metabolic control (47-53).

Family Characteristics

Diabetes can disrupt the entire family. Shortly after a child's diagnosis the mother may manifest a mild increase in overall psychological distress but this usually resolves within 6-12 months (53). Children, especially younger ones, enjoy better control when their parents take an active role in managing their diabetes (54). Adolescents have better control when parents share management responsibilities with them (55). Within the family, low level of conflict (56), better communication (57) and a stronger family orientation towards achievement, are all associated with better control (58). The relationship between family characteristics and glycemic control may be mediated either via an affective route or a purely behavioral route (59,60).

Adherence and Self Care

Self-care behavior may be a good indicator of diabetic management (61). However, not all self-care activities are equally predictive of glycemic control for children (62). Younger diabetic children tend to show better adherence. Mood state is also a predictor

of adherence.

Lernmark et al (63), examined whether affective reactions and the adolescent belonged to a minority or an immigrant group. While the overall satisfaction was not different, the impact of diabetes was greater and diabetes control was worse in the ethnic minority adolescents. Quality of life was positively related to social status. Adolescents in two-parent household tended to have better quality of life and blood glucose control than in a house where only one parent worked. The psychological factors identified during the first year following the onset of diabetes could predict psychological adjustment and metabolic control five years later. In a longitudinal study on 67 children, early affective reactions, locus of control and adjustment to diabetes were shown to predict psychological adjustment to diabetes five years later. Attempts should be made to therefore evaluate early adaptation to diabetes in order to identify and treat children at risk for future problems with psychological adjustment to the condition.

For most children with diabetes, achieving blood glucose control involves adherence to a complex system of self-care behaviors. They have to pay close attention to diet, insulin administration, frequent monitoring of blood glucose levels, regular exercise and routine medical care. Through repeated education programs, children learn how to use information from blood glucose monitoring to determine insulin needs, balance food intake, and obtain regular exercise. However, the family ultimately shares some of the responsibility for the management. For many individuals, effective self-management behaviors are difficult to achieve and maintain (62, 63). Poor personal decisions about the need for lifestyle changes and inadequate confrontation of the emotional and psychological issues that accompany the diagnosis of diabetes, are barriers to effective therapy. Feelings of anger, guilt, resentment and fear often interfere with the individual's ability or desire for successful self-care.

The very nature of diabetes, its chronicity, the constant attention demanded by the disease and treatment program, the strong commitment necessary for adherence to the self-directed treatment plan and the consequences of long-term self-care, constantly pose as a challenge to the individual. Frequent problems encountered are lack of family support, excessive stress, lack of insurance reimbursement and frustration with the results of treatment. These are looked upon as barriers to effective self-management.

Physicians have traditionally focused on the medical aspects of diabetes care. However, a psychosocial approach is necessary to overcome potential barriers to self-care, so that effective self-management is successful. Towards this aim, emotions need to be explored, expressed, experienced and ultimately accepted by the individual with diabetes as well as by his healthcare team (64). Strategies for identifying and overcoming potential barriers need to be explored. Personal choices need to be clarified, targeted changes in lifestyle and behavior appropriately implemented.

Dr. Van der Ven and colleagues (65), evaluated the efficacy of cognitive group training in 24 individuals with poorly controlled type 1 diabetes. Self-care behavior, diabetes-related distress, emotional well being, and glycemic control were evaluated prospectively at baseline, three months and six months after completion of the educational program. Glycosylated hemoglobin levels decreased from 9.6% at baseline to 8.8% at three months and to 8.5% at six months. Diabetes-related distress decreased and positive well-being increased following cognitive behavioral therapy. Patients were more likely to perform blood glucose monitoring and increase their compliance with diet after the four-week course, although the number of omitted insulin doses remained unchanged. Although cognitive therapy had little effect on emotional distress, most subjects appreciated the increased attention they received from the staff. The most important effect of the four-week course was that subjects sensed that someone was genuinely interested in the outcome of their treatment.

Fear of self-monitoring of blood glucose values and self-injecting of insulin is frequently a barrier to the self-management of diabetes. Mollema et al [66] evaluated potential psychosocial co-morbidities in insulin treated subjects with diabetes. The individuals identified as fearful of self-testing and self-injecting were noted to have a greater incidence of depression and fear of blood, when compared with other children who were not fearful. These indicate that psychological co-morbidities are frequent in patients who are fearful of self-testing and self-injecting insulin. The co-morbidities may explain in part, this fearful behavior and may need to be adequately treated if this fear is to be overcome.

In an attempt to identify potential factors that may determine the quality of life of patients with type 1 diabetes, Sengül et al (67), evaluated overall quality of life and its relationship to sociodemographic, diabetes-related control parameters and presence

of diabetes complications. Approximately 300 subjects including 156 men with type 1 diabetes mellitus of 12.6 ± 4.8 years duration and an average age of 24.4 + 9.6 years were recruited. Four sub scales: satisfaction, impact, social/vocational worry and diabetes worry were evaluated. Diabetes quality of life scores averaged approximately 73% in both male and female subjects. Higher educational level, greater exercise frequency, and improved overall compliance with diabetes treatment positively affected scores. They were negatively affected by diabetes duration, greater number of hypoglycemic reactions, higher HbA_{1c} levels, and greater incidence of complications. Of interest, there were no differences between adolescents and adults with the condition.

Behaviors related to enhanced self-management are thus associated with better diabetes control and improved quality of life. It is tempting to speculate that greater compliance with diabetes treatment is associated with a increased awareness of oneself, higher sense of self-control and improved feelings of self-worth, all of which have a positive effect on the quality of life.

ETHNIC MINORITIES AND DIABETES : QUALITY OF LIFE

Dr. Danne and coworkers (68), examined the association between metabolic control and quality of life with social status and origin of ethnic minorities in adolescents with type 1 diabetes. They evaluated 2077 adolescents from 17 countries including Japan, Europe and the North American countries. Social status was determined by whether one or two parents were at home and whether one or both were employed. The health professional responsible for the adolescent's care study, concluded that ethnic minority adolescents have a poorer quality of life and have poorer blood glucose control than their native counterparts.

CONCLUSION

Diabetes in children is a serious condition, which has to be managed by both medical professionals and the social support system. The social support system could be organizations of nonmedical personnel or patients themselves who organize themselves into groups to discuss their problems. These children also need family support both emotional and financial. The psychology of the child has to be understood and each child managed individually. The adolescent period is by itself a turbulent one and when diabetes intervenes it could be very tumultuous. Medical and para medical personnel should rise and be care givers than just pill providers. It is indeed important to treat the person rather than just his blood glucose and complications and give the patient a sense of complete well being.

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