

MANAGEMENT OF CHILDREN WITH DIABETES MELLITUS — PSYCHOSOCIAL ASPECTS

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ABSTRACT

Chronic illness such as childhood diabetes places the child and family at greater emotional difficulties and stress. These may be due to the longer duration of the disease, illness being superimposed on the phase of behavior and physical development and consequences of the disease itself, in terms of life expectancy and complications. Managing diabetes in the adolescent child is difficult because other developmental demands impinge upon the child, worsening the stress. Besides, the family may be faced with additional economic and social stresses. Compliance to therapy is also difficult. The various components of compliance must be considered: behavioral, developmental, familial, knowledge and skill based, and stress related. As in adults, quality of life for the child, as well as the family, is an important aspect of diabetes management. Psychosocial interventions may be carried out in the following areas: behavioral interventions targeting self-care, compliance and skills; interventions to reduce stress levels and increase coping; family interventions for problem solving, conflict resolution; education to increase knowledge and self care etc. Childhood diabetes in India has certain cultural and economic factors, which must be considered, and future research should address these areas as well.

KEY WORDS: Type 1 diabetes; Childhood development; Family interventions; Quality of life; Stress.

INTRODUCTION

This paper focuses on the psychosocial impact a chronic illness such as type I diabetes has on the young patient and the family. It attempts to provide an overview of the various issues concerning the psychological problems as well as the interventions carried out thus far.

Attention on chronic illness has increased due to several reasons. Some of them are the sky-rocketing health care expenses and the impact on the emotional and psychological well being of the individual (1).

Chronic illness places the adolescent at a greater risk for emotional difficulties and stress. The young patient often has longer time with the illness, faces additional demands due to various phases of development and the illness itself may have far-reaching consequences in terms of life expectancy and complications.

Thus, there is a great psychological demand on the chronically ill child with diabetes mellitus. These demands often exceed their capacity to understand or cope. In addition, many children face the prospect of life long disability, medical complications, even before they are able to conceptualize their future. Often they are expected to follow rigorous regimens and restrictions, even though at times they are too young (2).

Type I diabetes is a chronic illness that is usually diagnosed in children, adolescents and young adults (3). The diabetes regimen is remarkable for its behavioral complexity and often there is no clearly identified regimen to follow (4,5). In addition to daily injections, it involves many other life style adjustments such as timing and nature of food consumption, regular exercises and blood glucose monitoring (6). The patient is required to constantly monitor and make changes in his/her behavior (7). These life style changes place unique demands on the individual as well as the family. Failure to follow any of these could lead to serious consequences in the form of hypoglycemia, ketoacidosis or micro and macrovascular complications. The long-term prognosis of type I diabetes improves with a complex, demanding and often intensive regimen and maintenance of lower blood glucose levels reduces the risk of long term complications (8).

The impact of type I diabetes is often far reaching. Managing type I diabetes is particularly difficult during adolescence, as many other developmental demands impinge upon the young diabetic making it more stressful. The changes associated with adolescence such as preoccupation with body, striving for autonomy and independence as against the restrictions imposed by the parents, need for peer

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affiliation and acceptance, all clash with the diabetes regimen (5). The course of the illness and its influence on the physiological growth of the individual, such as arrested development, delay of pubertal changes, can also have an impact on the psychological development and growth of the young diabetic. The illness could also have a positive impact. Many researchers have reported a trend towards healthy habits and patterns of living in young diabetics as compared to their normal peers (smoking, use of alcohol, exercise) (9).

In addition to these psychological sequelae of type I diabetes, the family and the patient are also faced with problems, economic and social in nature. These are often encountered in lower socio-economic group where increasing costs of insulin, blood tests and other medical expenses must be met. The social discrimination though subtle and veiled, cannot be escaped and is often seen in the form of stigma like delay in marriage or reduced job opportunities.

Among the several problems faced by the young diabetic, the most common and often most difficult to deal with is that of adherence or compliance to a regimen.

ADHERENCE IN TYPE I DIABETES

Adherence forms a central concept in most psychological research aimed at improving patients' glycemic control (3). It refers to the extent to which a person's behavior (in terms of taking medication, following diets and exercise, or executing life style changes) coincides with medical or health advice (10). While there is little agreement among researchers regarding the difference between compliance and adherence, both terms involve a comparison of patient's behavior with medical or health advice and therefore the two have been used inter-changeably.

Adherence is a multifaceted concept consisting of many behavioral, cognitive, affective and family factors (11). In addition, there is no universally agreed upon behavior in diabetes and several decisions about diet, exercise and dosage must be made. As compliance is not a unitary construct, rather there are many components to it, it is thus important to look at multiple aspects of compliance. For example, an individual could be compliant with diet and insulin but not so with exercise and foot care. Therefore, it is important to examine compliance across several behaviors.

Non-adherence is a major problem and in general diabetic patients tend to be only partially or

inconsistently compliant with their regimen (4, 12). Non compliance is not limited to younger diabetics. Although several studies have looked at the patterns of non-compliance, few have reached any conclusive findings.

Trends in Non Compliance in Type I Diabetes

Adolescents tend to be more non-compliant with their diabetes regimen than children and adults (3, 12, 13). This has been attributed to a complex interplay of many physiological as well as psychological factors. Among the physiological factors, relative insulin resistance during puberty is most often implicated. Lower adherence to regimen, family factors, health beliefs, locus of control, stress and negative emotional states, inadequate knowledge of self-care skills are some of the psychological variables.

The first episode of non-compliance usually begins after 3-4 years of diagnosis (12). This is attributed to the probable monotony with regimen seen with any chronic illness (5). The period of adolescence appears to be associated with greater non-compliance than the late teen years (17-19 years). The average age at non-compliance is around 14.8 years. Lower levels of compliance were reported during the first decade of type 1 diabetes mellitus and usually the first episode was said to occur after 3-4 years of illness. One out of every four young diabetics is non-compliant enough to warrant medical or psychological concerns.

Factors contributing to non-compliance can be categorized as following:

- Behavioral
- Developmental
- Family
- Knowledge/ skill based
- Stress-related

Behavioral Models

Behavioral models to understand non-compliance are based on the operant learning paradigm, which emphasizes the role of consequences our behaviors yield. For the young diabetic, consistent self-care is often not rewarded in the short run and also long term negative contingencies or consequences for non-compliance are not clear cut (5, 12). In addition, the short-term effects of non-compliance are often negatively rewarding for the patient and immediate consequences are often unpleasant. Consequences such as diabetic ketoacidosis (DKA) and other

complications are seen as being distant. As the novelty of the regimen wears off and becomes boring, the patient is likely to become less co-operative (5).

Behavioral models provide a sound theoretical rationale for several intervention programs planned to enhance compliance and form an important aspect of behavioral counseling for family and other significant people in the patient's life (14).

Developmental Perspective

The period of adolescence in general is viewed as being fraught with strife and conflict. The young diabetic is often striving for autonomy and independence, peer affiliation and conformity, in the wake of parental overprotection and supervision (3,5). Thus, at this period, the diabetic regimen is perceived as being an interference by the adolescent. The life style of the adolescent is also believed to be sedentary, with irregular meal times contrasting with the diabetes regimen requirement. Also seen in many families, is that the adolescent or child is handed over responsibility for diabetes care, when he/she is not prepared for it (15).

Family Variables

Family relationships undergo major changes both during illness and adolescence. Many aspects of day to day life are upset due the presence of a chronic illness. Common parental reactions that interfere with functioning include over concern, compulsive behavior, over indulgence and denial of the problem. These behaviors do little to foster compliance. Interactions between the child and the parents' family are often seen with the patient manipulating the family with threats of noncompliance.

Health Beliefs

Beliefs related to diabetes and health in general are also important determinants (15). The three key beliefs related to self-care in young diabetics are: barriers and costs of care, benefits, regimen effectiveness. Associated with health beliefs is the concept of locus of control or cognitive expectancies related to health behaviors.

Greater external locus of control was associated with negative health outcomes and lowered adherence, while greater internal locus of control was associated with better adherence and positive health outcomes (13,16). The presence of a higher powerful other locus of control was also associated with positive health outcome (17), which is particularly true in children. However, extremes of internal locus of control, commonly associated with self-blame, or

extremely powerful other locus of control, can also lead to negative health outcome (18).

Level of Knowledge or Skills

Inadequate knowledge or skills possessed by the young diabetic result in errors in diet and insulin administration (19). Lack of awareness in family members also lead to neglect and misconceptions.

Stress Negative Emotional States and Non-Compliance

Relationship between stress and non-compliance is conceptualized as being indirect (3). Stress can affect compliance and behavior through emotional states resulting in decreased activity, increased or decreased eating.

Psychiatric status can also affect regimen adherence through a general behavioral dysfunction, although by itself it has not been associated with non-compliance (12).

FAMILY AND THE YOUNG DIABETIC

Diabetes being a chronic illness may have debilitating effects on the patient as well as the family. It places unique demands because of its complex treatment. The role of the family is crucial, particularly in the adolescent with diabetes. The family's understanding and involvement, as well as support, help in the better management (6, 20, 21). It is not only important as an effective and crucial mediator of changing behavior of the diabetic youngster, but is also indispensable for the maintenance of changes once the medical or psychological treatment is withdrawn. The family may be involved in maintaining both healthy and maladaptive behaviors. There is a need to be sensitive to the multiple influences of each family member, as a direct or mediating variable in the adjustment of the young diabetic. It is thus important for the family to be a part of the management of diabetes (22).

Family stress and conflict may contribute negatively to the child's diabetic control (23, 24), that may be additionally heightened by the costs of the illness. Often, non-adherence may precipitate a crisis in the family leading to disruption. The family's contribution to the young patient's adherence is recognized as a central behavioral outcome that is directly linked to the medical outcome and glycosylated hemoglobin (9). Family support, cohesion, expressiveness, conflict and organization were related to type 1 diabetes mellitus (25).

Family support is linked to both short and long-term adherence. Family conflict adversely affects

adherence and is the strongest predictor of long term adherence. It also increases with the young and newly diagnosed diabetics. Most adolescents have reported that they expect instrumental support from their families and emotional support from their peers (6). Increased family organization and co-operation are helpful for anticipation and co-ordination of activities and responses. Studies of metabolic control and family functioning were equivocal, with conflict being most consistently associated with poor control (24). In keeping with these findings several interventions aimed at improving family communication, reducing conflict have been carried out (20, 26, 27).

ISSUES CONCERNING QUALITY OF LIFE

The impact of chronic illnesses and their treatment must be assessed in terms of their influence on quality of life, besides more traditional measures of medical outcomes such as morbidity and mortality. Type I diabetes can influence quality of life, because of the complex regimen that is required as part of the management (28). A widely accepted conceptualization of health related quality of life is that it is a multidimensional construct comprising of at least three core domains, physical, social and psychological well being. Although, adequate self-care optimizes metabolic control, it may have adverse psychosocial consequences on every day life in the short-term (17). A regular and structured life style is stressful for many diabetics. Younger diabetics, who have to deal with other developmental and environmental demands, perhaps experience this structured life style, as being more intense. Some studies have shown, good glycemic control was associated with a more negative attitude to illness, a lower quality of life and well being, and problems in social orientation (29), thus emphasizing the need for early identification and minimization of problems related to the psychosocial consequences of diabetes mellitus.

PSYCHOSOCIAL INTERVENTIONS IN THE MANAGEMENT OF TYPE I DIABETES

There are few Indian studies on psychological and behavioral intervention in diabetes, especially type I diabetes.

The existing interventions with type I diabetics can be classified based on their focus into:

- Behavioral interventions targeting self-care, compliance and skills
- Interventions related to reducing stress levels and to increase coping

- Family interventions that target communication, problem solving, conflict.
- Educational interventions that target increasing knowledge and thereby self-care
- Other psychological therapies that target psychological problems associated with diabetes (eating disorders).

Behavioral Interventions

Research has largely focussed on self-care and adherence. These studies have targeted specific self-care behaviors such as, diet, injections, or self-monitoring of blood and urine sugar levels, rather than on many inter-related aspects affecting diabetes and its management (30-35). Further, these studies have been carried out with small samples and heterogeneous patients and problems, making it difficult to generalize the findings.

Stress Reduction and Management

The concern that stress and negative emotional states may destabilize blood glucose levels in diabetic patients has led to the use of stress management interventions. These aimed at improving blood glucose levels through reducing the autonomic nervous system activity, by relaxation techniques (36-38). Attempts were made to improve metabolic control through stress management programs, targeted at reducing diabetes specific stress (39).

Educational Interventions

Educational interventions form a large portion of the research carried out in this area. These were done independent of other psychological or behavioral interventions, aiming at improving self-care skills and metabolic control through enhancing knowledge (40-42). However, a majority of these studies have been carried out with older type 2 diabetics. Younger diabetics and their families must also be involved in educational programmes.

Family Interventions

Family interventions have recently focused on the involvement of parents in diabetes management (43). Considering that reducing family conflict and enhanced family support is conducive to better diabetes management, studies were done on these aspects (20, 26, 27). They were shown to change family related variables, but not adherence measures.

Physical health is not separable from emotional health. In addition to knowing the facts, the patient

also needs to increase motivation, learn skills and have healthy behavioral habits positively reinforced. Further, with young diabetics, the family must form an integral part of the management. An integrated programme must take into consideration all these factors. It is important to identify both short-term goals such as: minimizing symptoms, maintaining social role function; as well as long term goals such as: quality of life, maximizing emotional health, delaying complications, while designing a treatment programme. Recent emphasis has been to integrate both educational and behavioral strategies rather than any one intervention (44). It is necessary to target younger populations who seem to be at risk for greater number of psychosocial and behavioral problems.

A recent meta-analysis of behavioral interventions revealed that skills training formed almost 45.7% of all the interventions, followed by family related interventions (25.7%) and dietary modifications (20%). Although a variety of outcome measures were studied, the glycosylated hemoglobin was the most common (71.4%), while diabetes self-management related measures such as adherence, was the least (11.4%). In general, programs with a theoretical rationale were more effective (45).

THE INDIAN SCENARIO

In India the current prevalence rate of type 1 diabetes is 0.01/100,000 (46). Despite this low prevalence rate, the clinician faces enormous problems while treating the young diabetic. Issues related to compliance, other behavioral problems and emotional problems such as anger and depression are often coloured by issues unique to our culture; problems with food, over involvement of parents and criticality with regard to food and exercise patterns, economic problems, social discrimination and stigma, are some of these (46).

There is a need to plan and implement treatment programs for diabetics in our clinics and to first be sensitized to existing problems. In keeping with the needs of young diabetics and their families, an intervention programme was planned and implemented (47). This study included 40 type 1 diabetics in their late adolescence. The experimental group which consisted of 20 adolescents, underwent a 15 session individually tailored behavioral programme in addition to routine medical care. The behavioral intervention included carefully selected therapeutic procedures aimed at improving compliance, reducing symptoms and negative emotional states, and also included a detailed

diabetes education package (46). Results of this study supported the efficacy of a behavioral management programme in enhancing compliance in young type I diabetics. These treatment gains were maintained at a three month follow-up. In addition, the study addressed the issue of quality of life among these young diabetics and considered the contribution of the family in diabetes management (46).

FUTURE DIRECTIONS

Research in the area of psychosocial aspects of type I diabetes is gathering pace. Sensitizing physician and general health care personnel is necessary. This is not only to detect and treat psychological/behavioral problems, but also to prevent problems through counseling and education.

In the Indian context, the economic burden on the family is a crucial determinant of health care utilization. Such problems cannot be tackled without the help of other professions and at times liaison between professionals treating the patient is necessary.

The role of the family is important in maintaining either health or maladaptive behaviors. Research must be planned to understand family roles and its functioning.

The design of studies must be refined, with more theoretically based interventions. When developing new interventions, multiple baselines, quasi-experimental or even single case designs can be used (49).

Lastly, the cognitive maturity of the child must be considered as children respond differently to stressors at different stages of development, as also the timing of interventions for them to be most effective.

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