

Incorporation of Quality-of-Life Considerations Into Intensive Diabetes Management Protocols in Adolescents

Two articles in this issue of *Diabetes Care* address the relationship between metabolic control and adolescents' perceptions of the impact of diabetes on their quality of life (1,2). A third describes the beneficial effect of a specific psychosocial intervention on both metabolic control and self-perceived quality of life (3). Publication of these studies emphasizes the importance the *Diabetes Care* editorial board gives to research that addresses the effects of treatment on not only the physical but also the psychological health of adolescent patients. It is, therefore, an opportune time to perform an overview of some of what is known and what needs to be known about these topics.

A major increase in interest in and research into psychosocial aspects of diabetes began about 20 years ago. This change was concurrent with the increasing sense that controlling glucose levels might do more than prevent acute life-threatening episodes and with the development of measures of glucose control more sensitive and reliable than glycosuria. It also became clear that newer therapeutic approaches would require increasing involvement by patients and their social supports, including health care teams. Whereas former treatment consisted of one, or occasionally two, injections per day, and the unpleasant but nonpainful use of urine dipsticks, treatment that meets the Diabetes Control and Complications Trial (DCCT) recommendations usually consists of three or more daily injections, multiple finger punctures, constant awareness of what one eats and how one exercises, and an increased risk for hypoglycemia (4). Much research, therefore, has focused on how to minimize the potential negative psychosocial effects of intrusive treatment while recognizing the increasing importance and hope associated with it.

These problems are particularly important and vexing for adolescents. The DCCT has shown that the link between excellent metabolic control and reduced risk for complications applies to this age-group.

However, daily activities during adolescence are typically less structured than during childhood or adulthood, making adherence to a complex regimen much more difficult. Furthermore, adolescents are still maturing cognitively and emotionally, and there is justifiable concern that long-term psychological health not be compromised by treatment.

Formal assessment of how intensive treatment of diabetes affects the emotional state of patients was initiated by the DCCT investigators, who incorporated a diabetes-specific measure of quality of life (DQOL) into their trial (5). This measure was subsequently modified by Ingersoll and Marrero (6) to reflect specific adolescent concerns, and this instrument was used in the three current studies. What is its value? Primarily, it provides a reliable assessment of how adolescents see themselves as being affected by the presence and treatment of diabetes. This outcome is as important as metabolic control in comprehensively evaluating new treatment approaches. Quality-of-life measures are increasingly incorporated into analyses of therapeutic trials in a variety of illnesses (7), and it cannot be too controversial to say that the potential negative (or positive) effects of treatment on quality of life should be known and minimized. For adolescents with diabetes, the goal is to minimize the effects of both the disease itself and of therapeutic interventions on both physical and psychological health and development.

Unfortunately, to date, we know relatively little about the relationship between DQOL and diabetes treatment in adolescents. In this issue of *Diabetes Care*, Guttman-Bauman et al. (1) report that DQOL correlates positively with metabolic control as determined by both mean HbA_{1c} and a single measurement. Grey et al. (2) (and earlier, Ingersoll and Marrero [6]) found no correlation with single measurements. The conflicting results, therefore, do not allow us to answer the most important question: What is the effect of a DCCT-type intervention on quality of life? What really needs to be known is whether we can use

currently available technology to achieve a level of control that minimizes complications and is tolerable to the patient.

Along these lines, the study by Grey et al. (3) is particularly interesting. It reports results from a randomized 3-month trial of intensive therapy (external pumps or three or more daily injections, self-monitoring of blood glucose at least four times daily, monthly outpatient visits, and intermittent telephone contacts) with and without a structured psychosocial intervention of six to eight weekly sessions. The specific intervention, coping skills training (CST), incorporates social problem-solving, social skills training, and conflict resolution. Patients role-played diabetes-specific social situations with demonstration and feedback of positive coping behaviors. Important preliminary findings show that at 3 months, intensive therapy alone improved metabolic control in a relatively unselected population to DCCT levels while DQOL and other psychosocial measures did not deteriorate. Addition of CST resulted in even lower HbA_{1c} levels and improvement in some indexes of DQOL and diabetes self-efficacy.

Although this study is limited by the 3-month follow-up period and by a potential selection bias toward more socioeconomically advantaged patients, it allows several important preliminary conclusions. First, attempts to reach excellent levels of metabolic control using an intensive regimen in adolescents are not a priori doomed to failure and, in fact, can succeed. Second, they do not necessarily increase psychological distress. Third, addition of at least one type of diabetes-specific psychoeducational (N.B.—not just educational) curriculum can further improve metabolic control and improve aspects of psychosocial functioning. Finally, for purposes of health policy planning, treatment by primary care physicians, even in conjunction with initial diabetes education, continues to be shown to be insufficient.

There are at least two direct extensions of this line of research. The first is to evaluate ways to extend the ability to success-

fully participate in intensive treatment to as many adolescents as possible. Clearly, many cannot now do so, and there is still a great deal of work needed to more fully understand how to universally implement optimal treatment. A number of psychosocial factors have been shown to be critical in determining how well patients can follow complex regimens and achieve levels of control that will improve their long-term health status. Guttman-Bauman et al. (1) in this issue of *Diabetes Care*, and I and my colleagues (8) a number of years ago, have shown how much socioeconomic disadvantages can impair diabetes treatment. Furthermore, while the theoretical models that best describe the nature of the family's contribution to diabetes management have been debated (9), the importance of supporting and involving families is clear.

Therefore, if treatment that minimizes complications is to be available to adolescents who do not live in relatively affluent, stable families, diabetes programs must be prepared to provide sophisticated, integrated social services and psychiatric treatment. Earlier studies have shown that structured stepwise programs emphasizing educational and social interventions designed to eliminate barriers to adherence to basic diabetes treatment can eliminate most acute life-threatening events such as ketoacidosis (8). However, attempts to achieve excellent metabolic control in many high-risk patients have not been successful. These patients or their parents suffer from alcoholism, drug abuse, psychiatric illness, school failure, physical and/or sexual abuse, poverty, or severe family dysfunction. They are not likely to benefit from a structured program such as that described by Grey et al. (3). In fact, they are unlikely to attend such programs. For these patients to benefit from DCCT findings, much more intensive psychosocial interventions need to be developed and evaluated.

A final concern that should be addressed in any comprehensive evaluation of diabetes treatment in adolescents is its effect on core psychological development. The DQOL primarily measures self-perceived effects of diabetes on cognitions and behaviors that, by definition, are consciously known to the adolescent. However, critical tasks of adolescence and young adulthood, including the develop-

ment of a comfortable identity, the capacity to enjoy intimate relationships, the ability to preserve previously developed senses of autonomy and productivity (10), and the acquisition of more mature defenses against adversity (11) are complex developmental tasks that are generally outside of conscious awareness. Adolescents who retain more immature defenses are at greater risk for long-term psychological impairment (11), and it has been reasonably suggested that patients with medical illnesses who maintain immature defenses are more likely to require increased structure and support in treatment (12). The use of immature defenses needs to be understood as a desperate attempt to cope with, but also to avoid, the consequences of dealing with diabetes in the present.

Concern that there is an effect of diabetes and/or its treatment on core personality development was raised by the earlier findings of Hauser et al. (13) that adolescents with diabetes demonstrate lower levels of ego development than a control sample. Ego development describes a complex set of developmental processes central to how one perceives his or her role and position in the larger world. Potential disruption of these developmental tasks, therefore, is particularly worrisome. An adolescent with diabetes ultimately needs to understand and accept a new identity, an uncertain one that includes the risk of sudden catastrophe and the possibility that long-term medical sequelae will have a definite effect on quality and perhaps length of life. Therefore, comprehensive evaluations of the psychological effects of treatment protocols should incorporate not only self-perceived DQOL but also more complex measures of development.

In sum, we have developed tools to measure and improve levels of metabolic control and reduce the long-term detrimental effects of diabetes on the physical health of adolescents. We should now use newer instruments such as the DQOL to similarly measure and improve emotional health.

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