Family Practice Grand Rounds

Management Problems in Dealing With an Adolescent Diabetic

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DR. ROBERT B. GWINN *(Second-year resident in Family Practice)*: Today we will discuss the problem of adherence to a treatment plan in a 21-year-old woman with insulin-dependent diabetes mellitus. There is evidence that good control of serum glucose levels is significant in reducing the sequelae of diabetes.[1] It is also clear that the quality of life at any given time, in terms of sense of well-being and such complications as vaginal candidiasis, can also be improved. Adequate control of diabetes is, therefore, important for both the immediate well-being and the future of the patient. The difficulty in accomplishing this goal has been a source of frustration to many clinicians. Today we shall present a multidisciplinary approach to such a patient.

Our discussion will be presented by the patient's three primary care providers: a physician, a social worker, and a dietitian. We have also asked Peggy Crawford, a nurse clinician from the Endocrine and Metabolic Diseases Unit, to discuss her experiences with her practice group of young diabetics.

At the age of 16 years, this previously healthy woman presented to the Family Practice Center complaining of vaginal discharge. During the visit, symptoms of polydipsia, polyphagia, and nocturia were elicited. A serum glucose was found to be 532 mg/dL. There were no allergies, and she was taking no medications. A review of symptoms was unremarkable. She was a student in high school living at home with her parents and a younger sister who had a suspected learning disability. Figure 1 displays her family tree.

The patient was admitted to the hospital for control of diabetes mellitus. Physical examination at the time was unremarkable except for erythema and satellite lesions around the external genitalia. Ophthalmologic consultation confirmed no retinopathy. She was discharged on 10 U of isophane purified beef insulin suspension (NPH) and 7 U of regular insulin each day and a 2,400-calorie American Diabetic Association (ADA) diet. She was followed as an outpatient with urine self-testing. Over the next three years, her urine glucose was maintained at 1 to 2+ with an occasional 3+. Her insulin was increased to 15 units of NPH and 5 units of regular insulin each morning and 5 units of NPH in the afternoon. During the next year, she developed four episodes of vaginal candidiasis but no ketoacidosis.

One and one-half years after diagnosis, she developed an abscessed pilonidal cyst, which was treated on an outpatient basis. This treatment was unsuccessful, and she was admitted to the hospital for surgical drainage. A random glucose level after drainage was 490 mg/dL. She was discharged on

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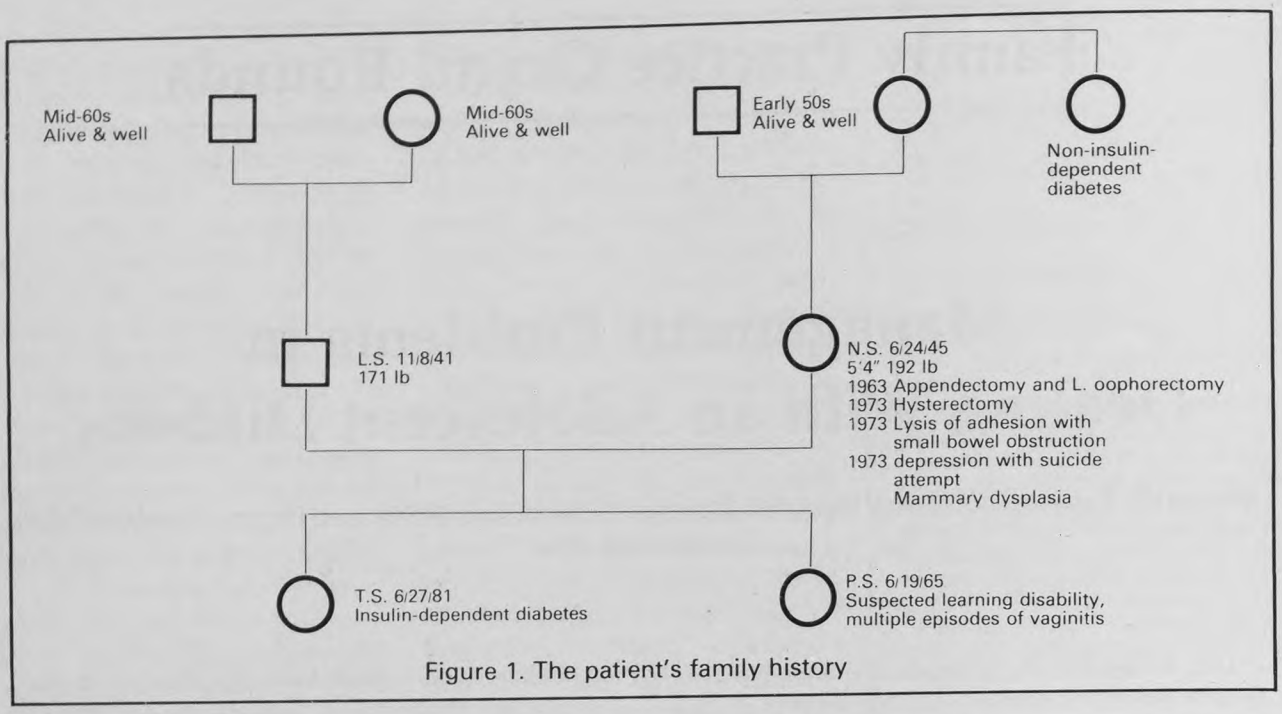

Figure 1. The patient's family history

50 units of NPH and 10 units of regular insulin in the morning and 15 units of regular insulin each afternoon. A 2,100-calorie ADA diet was prescribed. She was 5 ft 7 in tall and weighed 156 lb. At this time her problem list included (1) insulin-dependent diabetes mellitus, (2) poor dietary adherence, (3) dysfunctional family dynamics, and (4) exogenous depression.

After discharge, she began counseling with the Family Practice Center social worker and registered dietitian. Over the next three months adherence was poor. The patient gained 22 lb during this time, and her serum glucose was poorly controlled. As the patient reacted to increases in insulin doses with hostility and depression, the team decided to concentrate more on behavioral changes directed at dietary control than on insulin manipulation. Over the next three months, the patient developed strong ties with all members of our team. She made great strides in her ability to communicate and gained an understanding of the disease and her dietary requirements. She has since maintained a stable weight and reasonably stable glucose and has had no episodes of vaginitis. Her most recent fasting serum glucose was 220 mg/dL and her two-hour postprandial glucose was 293 mg/dL. Attempts are still being made for better adherence and lower glucose levels.

NANCY OLEX *(Registered dietitian, Department of Family Practice)*: Dietary counseling involved the use of food records for diet histories, food models for portion size-illustrations, label-reading activities, meal-timing manipulations, emotional support, and acceptance. The diet histories revealed continued excessive intake of simple sugar foods as snacks. The availability of these foods was assured, as the patient's mother did the grocery shopping and bought many sweets for the family. In addition, the patient frequently purchased candy for herself at work. Upon finding a boyfriend who showed interest in helping her manage her diabetes, she became more responsive to her dietary adherence. Over 10 weeks, she steadily lost 5.5 lb and became much more interested in learning about the role of diet in diabetes management. During periods of strife with her boyfriend, the overeating became pronounced and weight gain occurred. Through behavioral and dietary counseling, the patient began to gain insight into the relationship between her emotional state and her dietary intake.

CAROLYN WHITMAN *(Social worker, Department of Family Practice)*: The importance of a supportive family in the management of a diabetic adolescent cannot be underestimated. The patient

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we are presenting was not so fortunate, and we believe that her unstable diabetes, depression, and steady weight gain were, in part, brought about by lack of parental support and the family's dysfunction.

According to Teresa, her relationship with her mother had never been satisfactory and had been blighted by her mother's bad temper, physical abuse, occasional bouts of heavy drinking, and involvement with other men. Teresa believed that her mother favored her younger sister, who attended special classes in the public schools.

The parent's relationship was described as poor, with chronic conflict and lack of financial planning and security. The mother frequently accused the father of being an inadequate provider but did very little herself to add to the family finances through either employment or more-prudent management. The father was an understanding, affectionate man, but Teresa recognized his ineffectiveness. He made no effort, apparently, to confront or contain his wife. They functioned poorly as a couple and as parents. Their relationship was characterized by passive-aggressive behavior, generally low compatibility, and rare attempts to resolve issues or problems as they arose.

This family, beleaguered by so many problems, had difficulty accommodating to the additional responsibility of managing a serious health problem. It is for this reason that Teresa preferred the emotional supports offered to her by the health team over the uncertain and reluctant interest of her family. Her wishes not to contact her family were respected.

During her care, Teresa continued to seek her mother's acceptance through appeasement or avoidance, neither of which was conducive to her good health or personal growth. Teresa's tolerance for frustration and rejection was impressive. She was obliged to pay for all her medical expenses, recent hospitalizations, office visits, and medications, even though she was unable to do so. Theresa also paid her tuition and contributed to household costs. Contributing to the cost of foods purchased, however, did not give Teresa any influence over what items were selected at the grocery store. Avoiding favorite foods was difficult for Teresa, as eating was a source of comfort as well as a denial of her diabetes. It was suspected that her lack of dietary adherence supported her family's desire to deny her diabetes and maintain its familiar equilibrium. Her preoccupation about the consequences of her diabetes—loss of eyesight or the possibility of amputation—made it increasingly difficult for Teresa to resist food; her consumption increased during her months of depression. Her preoccupation with disease consequences also interfered with her ability to concentrate on studying, leading to failing work at school. Teresa did not rebel against her mother's temper and physical abuse; instead, she felt drawn into concealing her mother's drinking bouts and transient involvements with other men from her father and other family members.

According to research by Greg et al,[2] the maternal qualities of self-esteem and a sense of personal worth are the chief determinants of a diabetic child's adaptation to his or her disease. Lacking qualities of self-esteem and personal worth, the mother's reaction of guilt by commission or omission will prevail. Without confidence in herself and lacking the support of her husband in the child-rearing, the mother will be unable to model these qualities for her children or carry out the executive function of parenting with her spouse. Without confidence in herself, the mother will have little tolerance for change and be easily threatened by it. This deficit will be marked during a crisis and further strain family relationships. As a result, family function suffers and becomes skewed, in the direction either of enmeshment, permitting little autonomy, or of disengagement, providing little sense of rapport. We observed a similar situation in Teresa's family. Her mother lacked the self-esteem to accept and deal effectively with her daughter's diabetes, and her father was passive with respect to parenting. This situation contributed to the already chaotic state of this family and hence to Teresa's poor adherence to her treatment plan.

Adolescent development imposes such demands on parents. The challenge lies in keeping pace with the young adult's bid for independence while conveying a sense of belonging. Parental understanding and support during this time will lay the groundwork for the adolescent's sense of self-worth and development in initiative.

This family had functioned erratically for years. It is suspected that Teresa kept the family intact on numerous occasions through appeasement of her mother and concealment of her mother's be-

havior, while drawing just enough support from her father to survive. These activities sacrificed her development in the areas of self-confidence and career goal determination. She also lacked strong peer ties and the ability to develop heterosexual relationships. For Teresa, these tasks would have been delayed or abandoned even without the diabetes or without professional support and direction.

Treatment goals were guided by her own emotional needs as she presented them: (1) provide unconditional acceptance, recognition, and patience, (2) improve her relationship with her mother, (3) improve social skills to enhance her friendships with young men, and (4) present alternative career goals.

PEGGY CRAWFORD *(Nurse clinician, Diabetes and Endocrine Metabolism Unit)*: There are few disorders of childhood that affect the child, his family, his peers, teachers, and health care professionals as does diabetes. The therapeutic procedures focus daily attention upon the details of bodily reactions that, for most of us, go unheeded. All tasks require daily repetition on a schedule that to some extent limits the activity and freedom of the child and his family. Numerous judgments must be made, often on a daily basis, regarding types and amounts of foods, timing of meals and snacks, interpretation of urine results, and doses of insulin.

The procedures are unusual in that they are placed in the hands of the parents and eventually in the hands of the child himself. In a very real sense, we are asking families to become their own providers of health care.

As in other chronic conditions, there are both short-term and long-term goals of treatment. It is crucial to maintain the clinical control of the diabetes at the highest level possible. While the balance among food, insulin, and exercise is critical, so is the balance between ignoring the chronic condition on one hand and making it the focal point of one's entire existence on the other. A second goal, then, is to assist the child and family in developing and maintaining a comfortable attitude toward the condition so that the child can achieve his full potential for social and emotional development. An equally important goal is the shifting of responsibility for care from professionals to parents and child and ultimately to the young adult.

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For young people with diabetes, this assumption of responsibility is a task that extends over a period of many years and requires much patience, cooperation, and support from parents and professionals. Primarily a learning task, this is complicated by the unique fears, anxieties, and attitudes developed around the condition by each child and his family. Success in acquiring independence in self-care depends on many factors, such as readiness on the child's part to take on new responsibility and on the parent's to give it up, ongoing educational programs, and positive consequences to learning. Successful assumption of responsibility often leads to the development of feelings of adequacy and competence of achievement. The young person begins to feel as though he can manage and control the diabetes instead of the diabetes managing and controlling him. It is during this period of adolescence, with its special physiologic changes, social demands, and emphasis on independence, that the impact of diabetes upon developmental progress is probably strongest. It is well known that the adolescent with diabetes has a tendency to experiment with his therapy, to reject his diet, falsify his urine records, and even omit his insulin in an effort to assume control over his own life. This attitude of experimentation, rebellion, or independence is a necessary part of the adolescent development of all young people as they work toward defining their own identily.

Adolescence is a time when periods of poor control seem to occur capriciously, without apparent causes of diet, insulin, or emotional events. It has been suggested that emotional stress, factors associated with maturation, changing exercise patterns, and rebellion against restrictions may contribute to variability in control. Especially during these times of poor control parents are more likely to be aware of the possibility of complications, more aware than are their children, although parental anxiety is easily communicated to the child. The responsibility for maintaining low levels of sugar in the blood and urine is placed in the hands of the child and his parents. With regular monitoring of urine and blood sugar, they are provided concrete evidence and reminders of the success or failure in accomplishing this task. During periods of poor control, parents search anx-

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iously for factors that may have contributed to the poor control and, in their haste and anxiety, may blame the child, the physician, or each other unjustly. Friction between parents and teenagers is normal, but it is very difficult to restrict their conflicts to the usual adolescent issues without allowing them to spill over into arguments about diabetes management.

As professionals, we are reasonably well acquainted with *how* adolescent diabetics are noncompliant, but often we are not aware of the various factors contributing to *why*. Sometimes treatment plans are too complicated or too rigid. Diet, for example, is an area of diabetes management with great potential for conflict. Inflexibility in prohibiting certain foods is likely to be disregarded because it overlooks eating and drinking as forms of social intercourse and friendship. Double-voided urine sampling, of debatable value, is an example of the complicated treatment expectations usually ignored by adolescents. Noncompliance can be a way to prove or test one's normality. Many adolescents with diabetes either omit components of their care or ignore symptoms, thereby placing themselves in jeopardy. Adolescents often choose this option in the company of peers for fear they will otherwise be identified as diabetic. Many parents, in fact, have not acknowledged their child's diabetes to others and over the years have encouraged their child also to withhold this information. It is not uncommon for adolescent diabetics to display various risk-taking behaviors such as not eating before physical activity, not carrying any source of sugar for treatment of low blood sugar, or not telling their coach they have diabetes.

Noncompliance with a treatment plan is sometimes related to conflicting, incorrect, or lacking information. For example, the concept of good control is very confusing to professionals, let alone families. To many adolescents and parents alike, good control means avoiding extremes of low blood sugar and diabetic ketoacidosis. Because of this, we often see resistance, especially to changes in the insulin dose, when our goal is to reduce urinary glucose. It is important to remember that many diabetes professionals as well as educational materials expound the virtue of spilling a little sugar in the urine to avoid insulin reactions. Not only is this information incorrect, it

is misleading. Once families have been indoctrinated with information, even incorrect information, it is difficult to alter their behavior.

It is not uncommon to find adolescents who test their urines but then falsify their record, especially when they get high readings. This behavior may be a search for perfection or approval, or it may be an expression of denial, anger, or avoidance of confrontation. Children quickly realize that both professionals and parents prefer low readings to high readings, so they tell us what we want to hear.

Another form of reinforcement for this poor compliance is the way we feed diabetic children in response to their urinary glucose levels. For example, children are given sweets for negative tests but less desired foods for high readings.

Insulin and diet are sometimes deliberately manipulated, resulting in illness and hospitalization. This behavior may reflect attention seeking, dependency needs, school avoidance, or escape from less than adequate living situations.

Adolescents are quite honest about being noncompliant; in fact, many can explain why they are. For example, one older adolescent who rarely tested his urine explained that when he did test and got high readings, he felt obligated to adjust his insulin but hesitated to do so for fear of making the wrong decision. Not testing prevented him from having to make any decision. Feelings of helplessness and frustration often result in the abandonment of the diabetes regimen. When diabetes is out of control and various changes do not bring quick results, adolescents fear that nothing will help their situation, and that, indeed, control is not attainable.

One ingredient in noncompliance seems to be inconsistent health care. Often in large medical settings, care is provided by multiple caretakers, each with his own expectations and treatment approach. Visits are often brief, with little time available for questions or ongoing education about diabetes, certainly not the appropriate environment for developing a trusting relationship between adolescent and caregiver. As we become more familiar with the factors involved in poor compliance among adolescents with diabetes, it seems logical that we could make changes in the way we deliver care to this group.

DR. JACK MEDALIE *(Chairman, Department of Family Medicine, Case Western Reserve University, School of Medicine)*: I am concerned that the family was not treated along with this patient. Would anyone here care to comment on that?

DR. TOM METTE *(Director, Family Practice Residency, Cleveland and Metropolitan General Hospital)*: This situation could be viewed as a disruption within the family or, more likely, as a disrupted family that lacks the ability to deal with this disease. I would think it better to involve the whole family in counseling to improve their dealing with the problem.

DR. GWINN: This problem was discussed at length when we began treating the patient. At that time we agreed to respect the patient's wishes not to involve her parents for the time being. This decision was made in light of her financial independence and our belief that she would soon move out of her parents' home. We also felt that involving the patient's mother might lead to conflict before we had gained our patient's trust and confidence, thus impairing our relationship with the patient. Now that the patient has developed more skill in verbalizing her feelings, we expect to start working with the family with her cooperation.

DR. MEDALIE: Dr. Dickman, would you comment on the control of this young woman's diabetes?

DR. ROBERT DICKMAN *(Director, Family Practice Residency, Mount Sinai Hospital)*: I would say that given the most recent fasting and two-hour postprandial glucose levels, control is still suboptimal.

DR. GWINN: I agree; we are working for better control. We have made a significant improvement in our relationship with this patient that will allow for better control in the future.

In caring for this patient, we were able to observe the dynamics of her family in relationship to the adaptations she made to her disease. The patient's family of origin both directly and indirectly played a major role in the patient's difficulty with adherence. Directly, the parents had lost interest as the patient's adherence waned, which they demonstrated by maintaining an abundance of simple sugar foods in the home available to the patient. This family is tightly enmeshed around the mother, and there was little opportunity for the patient to develop from adolescence to a point at which she could make a good separation from the family as a mature adult responsible for her own care. The patient and her father formed a dyad

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within the family that was submissive to and dominated by the mother's will.

We were impressed by the improvement in this patient as she was encouraged and supported in developing her self-identity. The feeling of being out of control in face of a chronic disease emphasizes the need for involving patients in the control of their disease.

Addendum

Six months following Grand Rounds presentation, the patient had undergone a number of changes. She separated from the boyfriend mentioned in this presentation and within three months married another she had met since. Her most recent fasting serum glucose was 110 mg/dL and a two-hour postprandial glucose was 250 mg/dL. A hemoglobin A_1C was 8.30 (upper limit, 8.50). Her insulin dose has been decreased 10 units, and her weight has remained stable. Counseling was begun with her mother and immediate family but was discontinued at their request when the patient left home. Most recently, she became pregnant and was referred to a tertiary center for her obstetric care and constant infusion insulin (insulin pump).

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Suggested Reading

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