

# Education and Multidisciplinary Team Approach in Childhood Diabetes

*Stuart J. Brink, Francesco G. Chiarelli\**

Tufts University School of Medicine, Department of Pediatrics, Boston MA, USA

\* University of Chieti, Department of Pediatrics, Chieti, Italy

**Abstract.** Type 1 diabetes is one of the most frequent chronic diseases in childhood. As in other chronic diseases (asthma, cystic fibrosis, rheumatoid arthritis, epilepsy) children and their families become the focus of self-treatment and the directors of their own care; thus, the health care team should be the guides who set the stage, provided advice and oversight and helped to re-focus efforts when goals were not being met all centered around the patient and family. Rather than the diabetes health care team being the only ones to initiate treatment, patient and parents have to be empowered to analyze their own data, identify patterns, problem solve with food and activity and do so based upon actual blood glucose results. Home record keeping and memory meters facilitate such analysis just as the algorithms currently in use attempt to mimic the basal-bolus pattern of endogenous insulin secretion previously provided by a working pancreas. In the past, often disaster control was the *modus operandi* for the person with diabetes. Parents and health care providers were involved with criticism and accusations about “cheating” rather than learning how better to supervise and provide oversight. Nowadays, better knowledge of physiopathology of diabetes, availability of new insulins and devices, as well as different education of health providers pave the way for ameliorating self-care in children and adolescents with diabetes, with the aim of improving metabolic control and quality of life of children and their family, with the ultimate aim of preventing macrovascular and microvascular complications.

**Key words:** Type 1 diabetes mellitus, self-management, empowerment, multidisciplinary team approach

## Establishing philosophy of treatment based on DCCT

The DCCT established the basis for treatment of type 1 diabetes around the world. While there were many previous proponents of “strict” or “tight” control, there was no scientifically validated research studies to support these concepts and many scientific battles occurred between the two groups for many decades. The results of the DCCT were announced and published in 1993 (1) and 1994 (2) setting a standard for near-normalization of blood glucose as well as hemoglobin A1c and utilizing a multidisciplinary team approach (3), frequent blood glucose monitoring and patient-

centered adjustments of food and insulin based upon blood glucose data generated by the patient (4).

While there were no pre-teenagers recruited in the DCCT, the standard for youngsters with type 1 diabetes was also established with some modifications (5-7) to take into account the risks of hypoglycemia as well as the difficulties of dealing with growing children. DCCT follow-up studies (8) as well as Belgian (9) and Swedish studies (10) involving pediatric and adolescent cohorts followed for many years confirm the benefits of this approach as well as the safety of this treatment philosophy. Initial studies from Pittsburgh (11) suggested that the prepubertal years “did not count” when assessing long term complications ri-

sk, these were refuted from studies in Berlin (12), Leicester (13) and Sydney (14). Pediatric diabetologists no longer believe that it is prudent to allow higher blood glucose levels in prepubertal children than is necessary to minimize serious and recurrent episodes of hypoglycemia. Many studies (15-18) suggest that it is possible to achieve "tight control" akin to the levels obtained in the DCCT in adolescents and young adults as well as in the very young as long as there is adequate education about and attention to prevention of such serious hypoglycemic episodes. While there are individual children as well as teenagers and adults who are at high risk for severe hypoglycemic episodes, an overall policy applied to all children to keep glycemic levels "safe and high" is no longer warranted. The Hvidore (19) multicentered pediatric diabetes study showed wide ranges in glycemic control in different diabetes centers around the world and suggests that philosophy of care may well be the hallmark of health care professionals' as well as patients and family's ability to achieve near-normal hemoglobin A1c values.

The DCCT was not a study of multiple insulin doses or insulin pump treatment. The DCCT was a prospective, randomized multi-centered clinical trial whose focus was targeted blood glucose levels. It succeeded not because of any single treatment strategy but with individualized treatment determined by an extraordinarily close working relationship between highly trained diabetes nurses, educators and dieticians with the patient as the focus of self-care decisions. The physician role in the DCCT was critical in establishing a *philosophy of care* and keeping the treatment focused on blood glucose targets. The nurses and dieticians translated this treatment philosophy as part of the study using frequent telephone contact between visits, frequent outpatient visits and a general atmosphere of positive problem solving behaviors to sustain these efforts.

## Empowerment

Patients and their families became the focus of self-treatment and the directors of their own care. The health care team became the guides who set the stage, provided advice and oversight and helped to re-focus

efforts when goals were not being met all centered around the patient and family (Fig. 1). Rather than the diabetes health care team being the only ones to initiate treatment, patient and parents were empowered to analyze their own data, identify patterns, problem solve with food and activity and do so based upon actual blood glucose results. Home record keeping and memory meters facilitate such analysis just as the algorithms currently in use attempt to mimic the basal-bolus pattern of endogenous insulin secretion previously provided by a working pancreas. In the past, often disaster control was the modus operandi for the person with diabetes. Parents and health care providers were involved with criticism and accusations about "cheating" rather than learning how better to supervise and provide oversight.

Work by Andersen et al (20) as well as Andersen and Funnel et al (21) highlight this changing paradigm in diabetes care not only for children and adolescents but also for adults with diabetes. Instead of blaming the victim (i.e. the person with diabetes), the empowerment paradigm shifts the responsibility for self-care to the patient with support by the family and significant others at home. When this is successfully taught and established, frustrations about care decisions often are decreased and actual glucose control improves. The paradigm shift removes the onus of decisions from the health care team and so they no longer must be frustrated when errors occur, alternative choices are made or other problems arise.

Health care professionals, in order to use the empowerment model of chronic illness, must elicit and explore the emotional content of a diabetes problem that the patient or parent has identified. Health care professionals must resist the tendency to make specific recommendations and solve problems. Instead, they must help patients and parents of patients to problem solve, make small steps towards resolution of a bigger problem and tease apart a particular problem into its component parts in an effort to then resolve the dilemma. The job of the health care professional is to create an environment in which the patient and parent's emotional experience of diabetes is validated and can be expressed freely. This will usually involve some strong and often negative feelings. When technical information is missing or faulty, then the health-

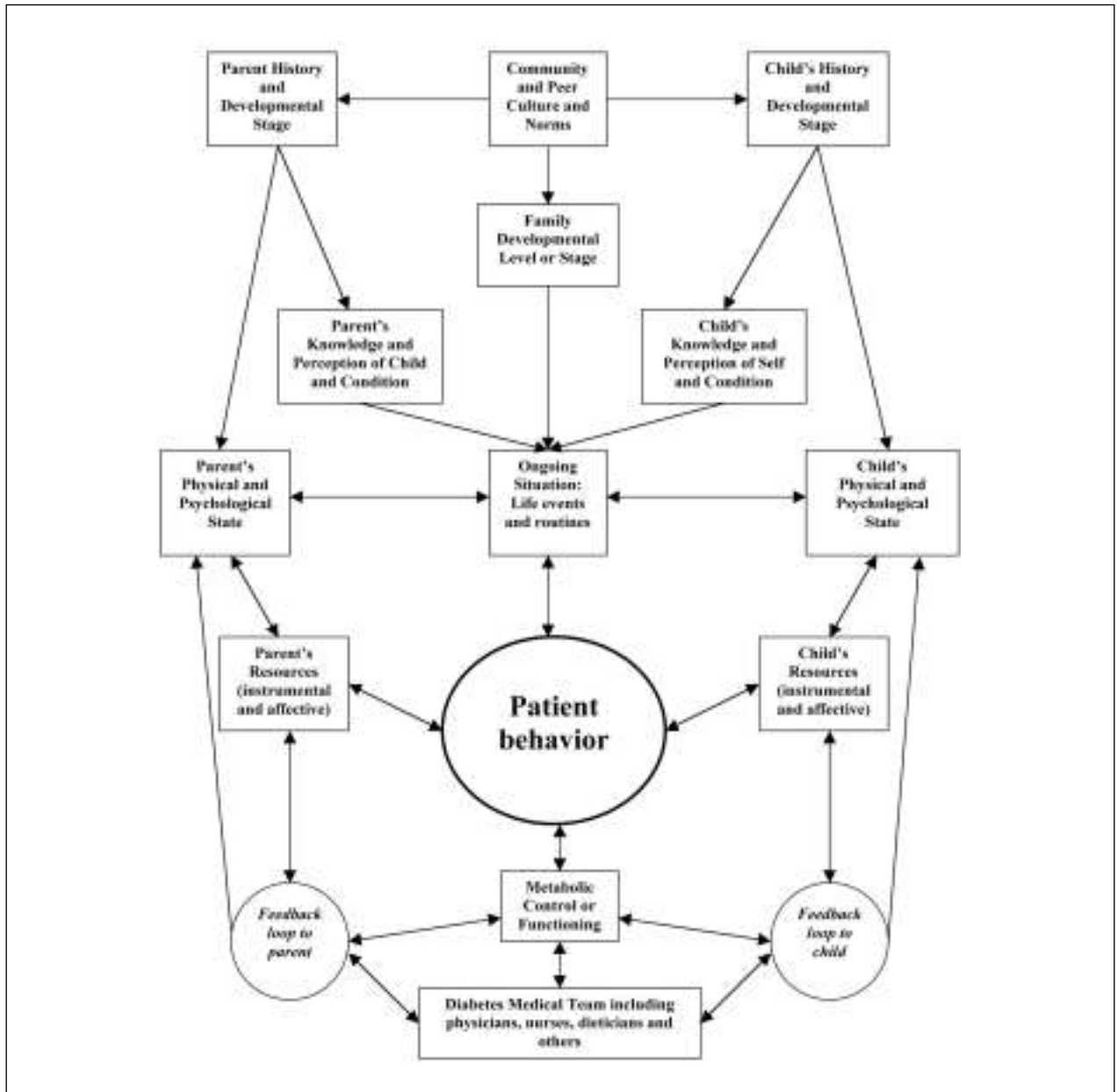


Figure 1. Patient Centered Care Model of Newbrough et al (29)

care professionals should, of course, supply such information or provide resources to bring to bear on the particular problem at hand.

Many particular barriers will involve psychological solutions. For instance, how to engage a father to help a mother care for a child with diabetes? How to facilitate school nurses in helping to care for a child's needs while at school? How to stop overeating and

follow a meal plan at school or when a parent is not at home after school? How to not feel guilty about frequent blood glucose monitoring? How to prevent a child from manipulating a parent? How to set up a positive behavior modification program rather than a negative one to change a teenager's behavior? Stop smoking? Monitor more frequently? Keep a written logbook? Actually use carbohydrate counting to help

plan an insulin dose? Call to set up a retinal evaluation? The list is very long and almost always presents as a behavior block to initiate a specified activity rather than a piece of information that is missing.

Helping patients or family member to solve such problems on their own reinforces their self-efficacy and personal responsibility for treatment decisions. As a consequence, similar decisions in the future are likely to be promoted and empowered so that self-care is enhanced. Patients have barriers to implement such empowerment just as health care professionals need assistance in retraining themselves as to how they might respond. These are based upon societal roles and previous health-care experiences in acute care models. The paradigm shift can be defined as a mutually acceptable approach to problem solve and change those behaviors which the patient and family identify as needing change. Ultimately, if the patient or family does not acknowledge the need for change, any change is unlikely to occur or be sustained. With a newly diagnosed patient and family, the focus will be on acquisition of new information and the skills necessary to make informed choices about diabetes care. With an already diagnosed patient, the focus will be on what is being done and what might be done in an improved fashion to improve overall health functioning at present and into the future.

Initial education is really survival education. What must the patient and his or her family learn in order to leave the hospital, clinic or office ready to take on the tasks of diabetes management. Too much information too soon is likely to be just as frustrating as too little information in the years to come after diagnosis. Behavioral goals should be acknowledged and incorporated into educational goals for without appropriate behaviors, applying knowledge is likely not possible. The patient and his or her family should be at the center of educational goals so that assessment is a key component of education. Being ready to learn may occur at diagnosis or later and involves a multitude of factors including ability to read, process information, accept abstract concepts and apply them in practical day to day living situations, having supportive friends and relatives and understanding why obtaining such information is likely to be helpful. When feelings such as denial, anger, nihilism, depression,

frustration and low self-esteem get in the way of learning, barriers can be enormous. The actual treatment of diabetes is predominantly an educational process that is ongoing, changes with new scientific and medical information, new medications and new mechanisms for achieving the goals of treatment. Initial education must include ways for coping with the diagnosis and its management for the child, the teenager and the family. If these goals are not met, then it will be unlikely that more in-depth training and application of knowledge can occur.

After survival education, reassessment for gaps in knowledge or attitudes must take place in an effort to maximize information transfer, make such rules and regulations specific for the individual circumstances of one patient and promote adaptation rather than frustration and noncompliance. Grief resolution must be addressed and issues of anger and denial acknowledged and placed into proper perspective; sometimes this has never been addressed and often such emotional barriers become the main barriers to advancing self-treatment. Diabetes, far from any other chronic illness, requires ongoing behavioral changes, abstract thought and processing information many times each day to try to achieve metabolic balance. The tools at hand, although far improved over the decades since insulin was introduced, are still imprecise and basically insufficient without application of how food and activity interact with insulin, what needs to be done based upon blood glucose monitoring results and how to be reactive in a given situation (correcting a high or low blood sugar right now instead of waiting, for example) as well as proactive (anticipating blood glucose changes with a change in food or activity and compensating in advance of the event, for example).

While there are no conclusive scientific studies validating the importance of a multi-disciplinary team approach to care there is much anecdotal information, including how the DCCT was run, to believe that utilizing nurses, nurse educators, dieticians, mental health professionals trained in with diabetes and chronic illness and coupling such members of a diabetes team with the patient and his or her family is helpful. When such individual disciplines do not work together as a team, however, their mere existence in the

life of the child or adolescent with diabetes is not likely to add much. Only when such members interact with each other, function in a cohesive fashion and provide a consistent educational and management philosophy does the multidisciplinary team add value to the patient with diabetes. Sharing information means meeting on a regular basis, documenting educational and treatment sessions so that other members of the team are aware of what has been discussed and ultimately increasing the patient and his or her family's fund of knowledge.

Follow-up sessions with educators and dieticians should promote honest interchange to promote flexibility with meal planning as well as insulin administration. Fewer insulin injections (i.e. twice a day insulin schedules) often work quite well when there is high consistency of meal portions, time of meals and snacks are held relatively constant and there is little change in activity duration or intensity from day to day. Multidose insulin regimens offer greater flexibility especially when combined with frequent blood glucose monitoring, pattern control and carbohydrate counting. This allows insulin to be adapted against food and activity changes rather than forcing food to counterbalance specific insulin kinetic effects (9). Especially when using the newer very rapid insulin analogs, lispro and aspart insulins, greater flexibility exists while improved post-prandial coverage and decreased hypoglycemia can be demonstrated (22) .

Follow-up educational assessment has similar goals in identifying gaps of knowledge or gaps of applying such knowledge, determining barriers to behavioral change and promoting improved glycemic control as the end result. A checklist approach often facilitates such assessment as it standardizes minimum information to be evaluated as well as actual use of such information in an age-appropriate and family-appropriate setting. Energy diverting issues such as concomitant co-morbidities, family functioning, financial resources, health system resources are important to learn about and overcome when they introduce further barriers to improved care.

Learning style (23) of the patient as well as significant others is also key to determining how one should approach a particular barrier. Dogmatic determination on the part of the health care professional

usually backfires and either the patient no longer returns for follow-up care or a system of dishonesty is established which further complicates patient-family-health care team relationships. Having finite and small goals may help prevent being overwhelmed just as working to improve targeted goals keep them in focus or reminds patient and health care provider together that the end result is about glycemic control within the construct of the patient and the family in society. A behavioral approach to education and the use of different health care disciplines working together as a team should foster application of new knowledge. Ideally, decisions should be more proactive and less reactive but both will always be needed. All such decisions will always be imprecise because how insulin works and how food is absorbed coupled with activity and stress effects are always estimates within the confines of current treatment options. Repetition without being boring also keeps positive problem solving at the forefront of useful behaviors for the patients at home, school or at work. Incorporating video games, computers, written information, oral presentations and handouts/books/manuals for home review and reference all play a role in modern diabetes education assuming that such resources not only are available but also age-appropriate, language-appropriate etc.

Styles of learning as adapted from *Diabetes Youth Curriculum: A Toolbox for Educators* (24) suggest that there are four major types: concrete sequential learners, abstract sequential learners, abstract random learners and concrete random learners. Determining style of learning can help decrease frustration and increase retention of complex information. **Concrete sequential learners** learn by doing. They tend to be very orderly and move from one basic step and build on this knowledge base. Diabetes can be frustrating for people who learn in this fashion because of the vagaries of carbohydrate absorption, differences in glycemic index of foods and food-food interactions, inconsistencies of insulin absorption and changing needs with growth and development. They tend to be perfectionists so that frustration of diabetes management on a day-to-day basis must be placed into the context of the impossibility of the task outcome always being perfect. Helping them make lists is useful since it helps create some order out of chaos. Understanding and

living with the limits of current diabetes management is very important for preventing burnout and frustrations from mounting. **Abstract sequential learners** like to think and debate about new concepts before they can be accepted and applied. They are also logical and systematic, eager to learn but like to debate with their teachers. They may overintellectualize problems and not move towards applying these principles until they are comfortable with new situations. In our modern world, such learners may be argumentative, may seek out several alternative sources (manuals, internet, other physicians, nurses and dieticians, other patients) and need some help coming to terms with alternative approaches to similar problems. **Abstract random learners** are emotion-based learners. Without acknowledging this emotionality, new concepts may not be so easily incorporated into their repertoire. They may not do well when presented information in a logical, step-by-step fashion but needs to understand the final goals in order to get each step. Using alternative teaching styles and tools such as art, drawings, cartoons and video games may be extremely valuable compared to written manuals and handouts just as focusing on themes and ideas allows them to bring their own individual ways of understanding to be utilized. **Concrete random learners** are experimenters. They like to learn on their own without so many rules and regulations. They like to problem solve and thrive on their own intellectual abilities to incorporate new information into their treatment plans. In diabetes terms, teaching them to utilize blood glucose measurements and letting them learn for themselves the difference between fast and slow acting carbohydrates, fast and slow acting insulin may be very powerful. Using their own color-coded logbooks to assess patterns of glycemic control may be more helpful than having the computer generate the same data since it utilizes their own creative problem solving approaches.

Three models used frequently from the educator's perspective include the Health Belief Model (25), Locus of Control (26) and the Self-Efficacy model (27). The **Health Belief Model** explains the failure of people to prevent or detect diseases and suggests that readiness to take action and perception that the benefits of such action outweigh the costs is the core of this model. Value expectancy theories of social psychology

are incorporated into the Health Belief Model. With very little children, such concepts may be too abstract since they may developmentally think the whole world controls them and their bodies. As children get older and become more abstract in their own thought processes, they learn that they have some control over what they do and the outcomes that are generated. A teenager must believe that they can control their food intake in an effort to control their weight and their glucose levels in order to have a chance of following a meal plan – or learn how to take extra insulin to compensate for extra food. **Locus of control** is another theoretical framework for controlling one's behavior. If one has an internal locus of control, one's diabetes health is determined by one's own behaviors. If one is doing more blood glucose checks, then this information will be helpful (learning about patterns, adjusting insulin, changing food choices, changing activity for example). If one has an external locus of control, one's diabetes health is determined by outside forces. Young children, by definition, start with an external locus of control (their parents, doctors, nurses choices) and then learn, over time, to have more say in what they do and what their choices might be. Too much external locus of control often translates into therapeutic nihilism, anger, depression, noncompliance, insulin omission, lack of blood glucose testing and/or lack of keeping followup appointments since there is not much use, in the patient's view, of doing all such work when no benefits are possible. Those with low self-esteem or severe depression may fall into this category for other reasons as well. Those with internally oriented locus of control may need greater emphasis on individual responsibility while those with external locus of control may need greater importance places upon social support systems. **Self-efficacy theory** suggests that how one perceives one's own capabilities affects not only behavior but also thoughts, motivation and emotional reactions to stress. If one has confidence and feels capable of doing something, it is more likely that such behaviors actually will be done. Because so much self-care behavior is part of diabetes self-care, having self-efficacy should help incorporate these behaviors in a useful fashion (28). Being able to communicate about new behaviors, why they should be done and how they should actually be used is complicated by communica-

tion skills of health care providers, having sufficient time to teach such skills and also to practice them and, finally, also being able to support sustained use of diabetes-related behaviors that influence overall glycemic control in a positive fashion. Individualizing such teaching approaches and knowing something about the personal styles – emotional, learning, concrete vs abstract thinking processes, etc – will be able to facilitate such changes as children and their parents grow and mature, adapt to changing life-style requirements and new treatment strategies that work for them.

### **Team membership roles**

Patient, parent, spouse or significant other takes on different roles in diabetes self-care depending upon age, learning style, personality traits, fears and interests. An important issue in diabetes care for children and adolescents is never to force too much self-care and independence since this may backfire and result in total lack of adult supervision, omitted insulin and major eating difficulties as well as lack of monitoring. Parent and many health care providers mistake independent diabetes care behavior as a primary goal when it really should be independent self-care responsibility expressed through self monitoring, meal planning, use of blood glucose data, insulin adjustments and problem solving. Most youngsters are really not able to take on such responsibility without frequent adult responsibility without making major errors or getting overwhelmed and giving up. Restitution of glycemic control then does not occur until a responsible adult resumes such care. Exactly when a child or adolescent is capable of full self-care does not take place at an exact age but at an age of maturity that does not occur until late adolescence. Many adults, in fact, never reach such a pinnacle and are forever bogged down in being dishonest not only to health care providers and family members – but also to themselves – because of the vicissitudes of insulin administration, food choices and imperfections in diabetes treatment even with today's modern technologies. When honest problem solving and realistic goals are established or re-established, then such patient and families not only function better but function in a healthier emotional as well as medical model.

Grandparents need to be involved with diabetes childcare as do school teachers and school nurses since children must be cared for by others besides their parents at times. Both mother and fathers should not only be educated but also directly involved with children's diabetes needs. In societies where divorce exists and the two parent home does not always continue, such difficulties with communication of very subtle care needs is further compromised. Fathers who view their roles as workers while mothers, even when they also work out of the home, assume the role of nurse and dietician as well as mother provide a message to the child with diabetes that may be at odds vis a vis the importance of diabetes treatment. For children and teenagers, there are further issues that occur because age and developmental changes that make the child or teenagers not only need repetition of previously available information but also changes in how such information is provided and processed intellectually as well as emotionally. Addressing the issue of honesty, imperfect treatment and frustrations of estimations that are such a major part of diabetes treatment removes the concepts of "good" and "bad" BG readings, "test results" and other similarly emotionally charged word descriptions that slip into our vocabulary so often.

The health care team must communicate with each other as well as with the patient and family, coordinate treatment with school officials and keep the door open to provide optimum and individualized care. Frequent ambulatory visits, telephone consultation, fax and e-mail via the internet can all be utilized to promote such communication and to emphasize problem solving. While the dietician may focus initially on food exchanges and label reading, progress to carbohydrate counting and address sick day and activity management issues, the dietician must be well versed in insulin kinetics as well as medical issues involving diabetes care at home to highlight the interchangeability of such treatment. Other dietary concepts are outlined in Table 1.

### **Exercise specialist**

Some teams have the luxury of a separate professional whose main responsibilities are to focus on

**Table 1.** Open Ended Diabetes Questions using the Empowerment Model 22 of Anderson and Funnell

1. What part of living with diabetes is the most difficult or the most unsatisfying for you?
2. How does this make you feel?
3. How would this have to change for you to feel better about it?
4. Are you willing to take action to improve the situation or yourself?
5. What are some steps that *you* could take to bring you closer to where you want to be? Is there anyone else who can help you? Is there one key barrier to start the process?
6. Is there *one* thing that *you* will do when you leave here?

idealizing activity, promoting future cardiovascular health and preventing obesity. Other teams have such topics incorporated into the activity of the physician, nurse educator and/or dietician. However this works for an individual diabetes health care team, it is important to not only recognize the issues of daily activity needs, how insulin and food must be adjusted and how such changes develop but also the ways in which exercise and activity specifically can be utilized to gain more enjoyment out of life while also helping – not interfering – with diabetes management. Inadequate insulin availability whether from inappropriate low insulin prescriptions, omitted insulin or unavailable insulin interferes with proper cardiac and other muscle activity since insulin is required for cellular energy metabolism. During exercise or other types of activity, hyperglycemia may reflect overeating because of fears of hypoglycemia during or after activity but also may reflect under-insulinization as well. Blood glucose monitoring and problem solving allows one to identify such problems and try out different solutions so that they may be overcome.

### Psychosocial issues

Some teams have psychologists, counselors, therapist and psychiatrists available for ongoing consultation while other team members may take on such roles and responsibilities as well. Periodic assessment of such problems as major barriers to glucose control particularly come to one's attention when there is recurrent ketoacidosis, recurrent hypoglycemia or goals

are not being met. Many of the barriers to improved glycemia are psychosocial barriers that are very difficult to change. Nevertheless, identifying such problems in and of itself may allow some resolution and respite if for no other reason than they are less powerful when less secretive. Re-involvement of parents and other adults in a child or adolescent's life can be life-saving. Some energy-diverting family issues as well as patient issues are listed in Table 2 and Table 3.

Diabetes, as a chronic disease, involves major psychological issues at diagnosis and throughout the course of diabetes. Adaptation experiences at diagnosis are based upon previous experience with the health care system and with health as well as illness issues. Are/were both parents available and involved at diagnosis? Are there or were there other family issues at the time of diagnosis? How sick was the person with diabetes? Was death a possibility and did the family understand the seriousness of the diabetes at the point of diabetes diagnosis? Are/were there sibling and how did they experience the diagnosis of diabetes? What about other family members? Grandparents?

Cognitive stage of parents as well as the child or adolescent with diabetes matters a great deal and helps to explain how information may be presented and how such information may be processed. Individual concrete thinking precedes abstract thought so that information must be provided in a manner appropriate for the stage of logic and thinking. Understanding the need for painful procedures (venipuncture, fingersticks, insulin injections) may be difficult to explain so that the health care team should strategize with parents to help them complete such tasks with minimal angst on their part. Allowing young children to act out their own fears and anxieties with play – coloring, puppets, stuffed animals, dolls – can be very powerful and very rewarding. Special attention at recognizing and preventing as well as treating severe episodes of hypoglycemia is important. Hypoglycemia fears can become a major barrier to achieving overall glycemic control particularly once a convulsive or unconscious reaction has occurred.

Family functioning also plays a role in how diabetes is handled in a young person just as personality styles of all family members matter and interact with day to day as well as long term handling of the many

**Table 2.** Education Principles (33). Childhood & Adolescent Diabetes Mellitus: NEDEC Educational Checklist

	At diagnosis	Within 1-2 months after diagnosis	Yearly
Survival education:	x		
– how to administer insulin, how and what to monitor, who and when to call, beginning meal planning			
In-depth assessment and review:		x	
– insulin kinetics and administration, monitoring and use of SMBG data, meal planning, activity changes, sick day guidelines and DKA prevention/treatment, hypoglycemia identification, recognition, prevention and treatment			
– short term and long term treatment goals			
– identification of barriers to improvement including school, learning and psychosocial and family issues			
– establishment of followup guidelines and goals and responsibilities			
In-depth assessment and re-education:			x
– all of the above plus additional needs including age-appropriate peer pressure, alcohol, sexual education, smoking prevention, eating disorders including bulimia, anorexia and obesity, diabetes associated complications assessment and ongoing barriers to control			

Adapted from Brink, New England Diabetes and Endocrinology Center (NEDEC)

needs of a person with diabetes (29). Excess guilt, excess anxiety or fear as well as excess anger all are common feelings that can, at times, become excessive enough or sustained for long enough time so that they interfere with needs of the child with diabetes.

**Table 3.** Type 1 Diabetes Dietary Concepts (from Brink (33))

1. Dietary consistency of meals and snacks
2. Timing and portion control
3. Satiety and individual idiosyncratic likes/dislikes
4. Culturally appropriate foods
5. Financially acceptable foods
6. Label reading
7. Carbohydrate counting
8. Insulin to carbohydrate ratios
9. Sick day adjustments
10. Activity adjustments
11. Growth and development tracking.
12. Obesity prevention
13. Lowering saturated animal fats to decrease cardiovascular problems
14. Lowering animal-source protein to decrease renal problems
15. Healthy nutrition for entire family
16. School lunch issues
17. Hypoglycemia treatment, prevention of overtreatment and prevention of nocturnal hypoglycemia with appropriate bedtime snacks

For infants and toddlers, parents who should be protecting them are now hurting them with blood testing and insulin injections. Food must be limited instead of being freely available. Parental guilt about how long they waited to get medical assistance, how sick is their child, why did they wait so long, why me and why us are common. Both mother and father, if possible, should share care of the very young child with diabetes so that respite can be offered by the other parent and so that decision making can be shared frequently. Older siblings may participate just as close relatives (aunts, uncles, grandparents) and close adult family friends can learn diabetes care skills. Having parents meet other parents and other families either via group activities or through the internet ([www.childrenwithdiabetes.org](http://www.childrenwithdiabetes.org), [www.jdf.org](http://www.jdf.org) or [www.diabetes.org](http://www.diabetes.org)) can help provide information and support in addition to that provided by the diabetes health care team.

As children grow and develop, they have different needs educationally just as they have different needs medically. As they move towards being independent, there is a concern of providing too much independence from adult supervision. This can occur when parents desperately want their own breathing space and

give up insulin injections and blood glucose monitoring just as it can occur when parents abrogate their responsibility to supervise meal choices and snack choices. Going to school offers a new set of dilemmas for parents of children with diabetes: who will supervise the child when away from the home, make decisions about insulin and testing results, actually give an insulin injection correctly, decide how much food should be changed to counterbalance unexpected school or sport activities etc. All these became big concerns and a source of fear and frustration particularly if the school system is not perceived as a helpful and safe environment by the family for their child with diabetes. Parents should meet with school educational as well as administrative and health personnel in advance of each school year and remain available to problem solve throughout the year. Parents assume primary responsibility for education of school personnel and to ensure that their child has diabetes incorporated into an educational plan in a safe and forthright fashion. The diabetes health care team should review such plans and also be available for school personnel to deal with school and after-school activities and maximize each child's individual strengths while ensuring safety.

For children, the fears of injections, blood testing and how parents respond to such fears, who provides comfort and the approach of the diabetes team to such questions set the stage for immediate future potential problems or solutions. Peer problems for school age and teen-age children must be handled because of many myths about diabetes. Is it contagious? Did it happen because of too much candy? How to tell friends? How do the school authorities respond? What about after-school programs? Group learning such as weekend retreats, day camps and residential winter and summer camp programs can be of tremendous assistance for school age children in dealing with the daily pressures of school, peers and general activities since they provide a safe haven to learn and explore the child's independent self-care.

For adolescents, fear and concerns of being different are magnified and coupled with loss of health, injections themselves and blood testing worries. Peer pressures mount during adolescence and issues concerning independence from parents increase in rela-

tion to health matters. Sleeping late, partying, food issues, sports, driving, alcohol and drug use, smoking are big issues and all have an impact on diabetes care either directly or indirectly. Future career and education planning may also be impacted by having to weave diabetes into such plans. The trials and tribulations of adolescence are well known and frequently compounded by the demands of living with a chronic disease like diabetes which involves so many decisions without any vacations each day. The transition from child to teenager to adult need not be an impossible task even when diabetes needs must be addressed. When parents have mistakenly given too much responsibility to a child too early, the chaos of adolescence can be the final straw that produces recurrent ketoacidosis from omitting insulin, refusing to check blood glucose levels or refusing to follow a meal plan or counterbalance food choices with appropriate insulin choices. Eating disorders such as overt anorexia nervosa or omitting insulin (diabulimia) require major psychosocial interventions just as severely out of control glycemia requires recognition of such problems and thorough planning on the part of the parents as well as the diabetes health care team. Recurrent ketoacidosis is psychological in origin until proven otherwise (30) (Brink DKA ref). An initial solution to all these major psychosocial events is identifying a responsible adult to actually prepare and inject insulin and actually do all blood glucose testing. This allows the adolescent some "breathing room" to begin therapy, know that they will be safe and address their real underlying concerns. Dysfunctional families or families with a single parents pose separate problems since they may not have the individual emotional resources or energy to also address acting out expressed vis-à-vis diabetes. Teen support groups as well as parent support groups whether provided on the internet or via weekend retreats or winter/summer camp programs not only for teenagers but also for entire families hold much promise to address these issues with role modeling, discussion formats and positive peer pressure. Adolescence is also a time for normal experimentation with sexuality as well as with nicotine, alcohol and drug use. Issues of contraception and discussions of preventing fetal malformations must take place in a sensitive yet didactic fashion in order to have any

chance of being adopted by teenagers. The normal adolescent sense of invincibility must be overcome in a manner that does not frighten or coerce yet empowers the adolescent to become aware of the risks and make decisions, hopefully, to decrease those risks that are possible to be decreased.

### The Diabetologist

Common sense would suggest that children and teenager should receive diabetes supervisory care from a pediatrician trained as an endocrinologist/diabetologist. In many parts of the world, including the richest countries of the world, this is not always available. So, while this may be an ideal to have someone trained to work with families and children in developmentally appropriate fashion, the most important factor would likely be an interest in and knowledge about diabetes issues for children and adolescents as they grow and evolve from infants to children, adolescents to young adults. Paying particular attention to the physiologic changes of young and how they may interact with insulin and food needs is important just as paying attention to the emotional needs of family members and of the child him or herself. In places where entire diabetes treatment teams do not exist, the physician must then assume responsibility for all aspects of diabetes treatment. In places where physicians trained in internal medicine and diabetes/endocrinology assume care of the children with diabetes and endocrine problems as well, cooperative consultation with family physicians, general practitioners and/or general pediatricians will be most helpful. The physicians should set the tone of the diabetes care philosophy and aim for the best possible glucose control while always minimizing and avoiding severe or recurrent episodes of hypoglycemia. Long distant consultation may be available by internet or through large university/academic programs at some distance from primary care settings and these should be utilized based on individual patient needs, hemoglobin A1c results, complications assessment etc. The needs of the adolescent in transition between pediatric and internal medicine systems of care is an especially difficult time when patients can be lost to follow-up when the transition is not facili-

**Table 4.** Type 1 Diabetes Mellitus: Energy diverting family issues (from Brink (33))

---

Alcoholism
Drug abuse
Parents or siblings who are smokers
Parent or sibling obesity
Poverty
Low education status/illiteracy
Parent with chronic illness: diabetes or other time/emotion consuming illness
Sibling with chronic illness: diabetes or other time/emotion consuming illness
Single parent home, parents who are separating or divorced; multiple parent homes with remarriages
Inadequate parenting responsibility, unequal parenting
Parental or grandparental sabotage
Mental illness of parent or sibling

---

tated. Efforts to coordinate such transitional care should acknowledge the systemic problems inherent in many health care systems and creatively promote ways to facilitate improvement<sup>31</sup>.

### Retina evaluations (7, 32)

Because most physicians are not skilled in idealized retinal examination nor do they have the tools for indirect ophthalmoscopy, retinal photography or fluorescein angiography, consultation should take place with a bona fide retinal specialist periodically. The American Diabetes Association as well as ISPAD recommend that this be done at diagnosis, annually after five years of diagnosis and/or entry into puberty

**Table 5.** Energy diverting patient issues (from Brink (33))

---

Mental retardation such as Down Syndrome
Emotional or mental illness: depression, schizophrenia, Asperger's syndrome, obsessive-compulsive disorders
Learning disabilities and attention deficit disorders
Alcohol, nicotine, drug abuse
Concomitant severe chronic medical illness: celiac disease, hypothyroidism or hyperthyroidism, Addison's, severe asthma, severe allergies, pancreatitis, enuresis or diabetes insipidus, cancer, cystic fibrosis, eating disorders, obesity, epilepsy
Associated severe clinical diabetes complications: retinopathy, cataracts, hypertension, gastroparesis, painful neuritis, nephropathy

---

since retinopathy research suggests that these are critical times for assessment of early and still reversible retinopathy, allow for interventions that might reverse severe cases of retinopathy likely to lead to blindness and promote optimum eye assessment strategies.

### Kidney and blood pressure monitoring (7, 33)

Blood pressure abnormalities often start in adolescence and reflect degree of glycemic control as well as

family history/predisposition. Because the combination of hypertension and hyperglycemia adds so much additional risk, and because of the ability to modify the risk of hypertension with well tolerated and efficacious anti-hypertensive agents (diuretics, ACE inhibitors or calcium channel blockers, for example), early identification of hypertension is extremely helpful. Similarly, monitoring the presence or absence of microalbuminuria with relatively inexpensive screening methodologies that are not labor intensive nor heavily technique dependent, allows identification of early

**Table 6.** long term treatment goals for children and adolescent with IDDM (from Brink (4))

- 
1. Normal growth without obesity
  2. Normal sexual maturation and age-appropriate function
  3. Normal psychosocial development
  4. No hyperglycemia symptoms
  5. Ideally no hypoglycemic symptoms but at least no severe or recurring hypoglycemia requiring assistance of others for treatment and no unconscious episodes or convulsions
  6. No ketoacidosis requiring emergency room treatment or hospitalization
  7. No interference with schooling
  8. No interference with age-appropriate activities; normal quality of life
  9. Age-appropriate knowledge about diabetes treatment
  10. Age-appropriate acceptance of living with diabetes as a chronic illness
  11. Ability to ask for assistance as age-appropriate and to wear/carry emergency identification
  12. Age-appropriate responsibility for self-care
  13. Family-appropriate sharing of care
  14. Appropriate followup and monitoring of diabetes regimen
    - a. height and weight plotted
    - b. sexual maturation
    - c. A1c
  15. Appropriate followup and monitoring of diabetes-associated complications
    - a. lipids
    - b. microalbuminuria/proteinuria
    - c. BP
    - d. ophthalmologic status
    - e. neurologic status
    - f. LJM
    - g. thyroid functioning
    - h. awareness of and early identification and treatment of diabetes-associated illnesses such as Addison's disease, celiac disease
  16. Appropriate transfer of care after adolescence/young adulthood
  17. Near-normalization of blood glucose as produced in DCCT or other pediatric studies or documented improvement with sequential followups
  18. Near-normalization of A1c or documented improvement with sequential followups
  19. Ideally prevention of significant retinopathy; if not, then no blindness or diabetes-related cataracts
  20. No or minimal hypertension or hypertension treated and normalized with appropriate medication
  21. No diabetic nephropathy
  22. No diabetic neuropathy
  23. No limited joint mobility
  21. No premature cardiovascular events: heart attacks, strokes, amputations
-

**Table 7.** NEDEC followup checklist for childhood & teenagers with IDDM (from Brink (4))

	At diagnosis	Within 1-2 months	6 months after diagnosis	1 year after diagnosis	18-24 months after diagnosis	Annually if normal; very 6 months if abnormal
<b>History and Physical exam</b>						
<b>Family History</b>	X		X	X	X	X
Cardiovascular risks	X			X	X	X
Smokers	X		X	X	X	X
Diabetes	X			X	X	X
Other endocrinopathies	X		X	X	X	X
Seizures	X		X	X	X	X
<b>Systems review</b>	X	X	X	X	X	X
<b>Psychosocial and school evaluation</b>	X	X	X	X	X	X
<b>Physical exam</b>	X		X	X	X	X
Plotted Ht & Wt	X	X	every 3 months			
BP	X	X	X	X	X	X
Thyroid evaluation	X		X	X	X	X
LJM evaluation	X	X	X	X	X	X
Injection Sites	X	X	every visit at least every 3 months			
Lens & dilated funduscopy	X		X	X	X	X
<b>Ophthalmologist</b>				X		X
<b>Laboratory</b>						
A1c	X	X	and at least every 3 months thereafter indefinitely and <i>with the same laboratory</i>			
Fasting lipids	X	X	X	X	X	
Urine protein	X	X	X	X	X	X
If > Tanner II or if abnormal proteinuria or BP, urine microalbumin	X	X	X	X	X	X
Creatinine	X		X	X	X	
T4, sTSH	X		X	X	X	X
Thyroid antibodies	X		X	X	X	X
Celiac screen: transglutaminase antibody	X		X	X	X	X
Adrenal and gastroparietal cell antibodies	If thyroid antibodies positive, abnormal thyroid function tests or positive family history					
ICA , GAD65 or HLA testing	Only if part of scientific research protocol					

(adapted from Brink, New England Diabetes and Endocrinology Center (NEDEC))

kidney abnormalities that would eventually lead to more devastating kidney failure or be associated with other microvascular or macrovascular angiopathies. Evidence suggested that such early identification of either mild hypertension or microalbuminuria or both will decrease morbidity and mortality very significantly.

### Record keeping

Ideally, computers which download memory meters can be utilized at home and also by all members of the diabetes health care team to share information. Written daily logbooks promote problem solving when used in an open-ended and positive system which focuses on looking for patterns of glucose levels, identify sick day issues early to avoid emergency room/hospitalization and also identifying potential problems with excessive or severe hypoglycemia so that these may be avoided. Keeping records, however, is a difficult task, often extremely abstract and frustrating for many patients as well as parents. The benefit of keeping records can be overshadowed by the hassles of keeping records. This may be very evident when patients do not feel empowered to make changes in insulin, food or activity on their own so that the records merely reflect their day to day difficulties without giving them any ability to respond. Educational efforts to teach the rationale for record keeping and self-assessment not only should focus on communication between family members responsible for diabetes care supervision but become crucial when children move between divorced or separated parents homes, from school to home, camp to home or from home to office. Home computers can be used to download information from memory meters and used in the same fashion as they are with the health care team. Summary of such information can be shared with primary physicians as well.

Health care professionals should develop, document and track a series of medical parameters in a prospective and longitudinal fashion. This is not merely a research endeavor but rather allows the identification of trends that may lend themselves to inexpensive interventions rather than wait for blindness, kid-

ney or other angiopathic abnormalities. Simple plotting of weight and height should be obvious but is not always accomplished. Growth deceleration or frank growth failure should be a "red flag" to identify possible contribution of hyperglycemia to such pubertal or growth problems. Sequential thyroid functioning, lipid analysis, blood pressure and microalbuminuria assessment all need to be done at regular intervals and repeated at regular intervals to detect trends and changes. Guidelines by ISPAD (7) as well as many other organizations (American Diabetes Association, International Diabetes Federation, British Diabetes Association, Canadian Diabetes Association, for example) all stress such longitudinal assessment with the hopes that more aggressive identification will decrease further morbidity and mortality.

Table 6 and 7 list the type of routine evaluations and testing that should be considered for patients with type 1 diabetes mellitus (4).

### References

1. DCCT Research Group. The effect of intensive treatment of diabetes on the development and progression of long-term complications: the perspective of the Diabetes Control and Complications Trial. *New England Journal of Medicine* 1993; 329: 977-86.
2. DCCT Research Group. Effect of intensive diabetes treatment on the development and progression of long-term complications in adolescents with insulin-dependent diabetes mellitus: Diabetes Control and Complications Trial. *Journal of Pediatrics* 1994; 125: 177-88.
3. DCCT Research Group. The impact of the trial coordinator in the Diabetes Control and Complications Trial (DCCT). *Diabetes Educator* 1993; 19: 509-12.
4. Brink SJ. How to apply the Diabetes Control and Complications Trial experience to children and adolescents. *Annals of Medicine* 1997; 29: 425-38.
5. Brink SJ, Moltz KC. The message of the DCCT for children and adolescents. *Diabetes Spectrum* 1997; 10: 259-67.
6. Malone JJ. Lessons for pediatricians from the Diabetes Control and Complications Trial. *Pediatric Annals* 1994; 23: 295-9.
7. Swift PGF (ed). International Society for Pediatric and Adolescent Diabetes (ISPAD): Consensus guidelines 2000. Medical Forum International, Zeist, Netherlands
8. DCCT/Epidemiology of Diabetes Interventions and Complications Research Group. Retinopathy and nephropathy inpatients with type 1 diabetes four years after a trial of intensive therapy: The Diabetes Control and Complications Trial/Epidemiology of Diabetes Intervention and Compli-

- cations Research Group. *New England Journal of Medicine* 2000; 342: 381-9.
9. Dorchy H. Insulin regimens and insulin adjustments in diabetic children, adolescents and young adults: personal experience. *Diabetes & Metabolism* (Paris) 2000; 26: 500-7.
  10. Nordfeldt S and Ludvigsson J. Adverse events in intensively treated children and adolescents with type 1 diabetes. *Acta Paediatrica* 1999; 88: 1184-93.
  11. Kostraba JN, Dorman JS, Orchard TJ, et al. Contribution of diabetes duration before puberty to development of microvascular complications in IDDM subjects. *Diabetes Care* 1989; 12: 686-93.
  12. Danne T, Kordonouri O, Enders I, Havana G, Weber B. Factors modifying the effect of hyperglycemia on the development of retinopathy in adolescents with diabetes. *Hormone Research* 1998; 40 (suppl 1): 28-32.
  13. McNally PC, Raymond NT, Swift PGF, Hearnshaw JR, Burden. Does the prepubertal duration of diabetes influence the onset of microvascular complications? *Diabetes Medicine* 1993; 10: 906-8.
  14. Donaghue KC, Fung ATW, Hing S, et al. The effect of prepubertal diabetes duration on diabetes. *Diabetes Care* 1997; 20: 77-80.
  15. Bojestig M, Arnqvist HJ, Hermansson G, Ludvigsson J. Declining incidence of nephropathy in insulin dependent diabetes mellitus. *New England Journal of Medicine* 1994; 330: 15-8.
  16. Dorchy H. What glycaemic control can be obtained in young diabetics without residual endogenous insulin secretion? What is the frequency of severe hypoglycemia and subclinical complications? *Archives of Pediatrics* 1994; 1: 970-81.
  17. Chiarelli F, Verrotti A, diRicco L, de Martino M, Morgese G. Approaches to quality of control in diabetes care. *Hormone Research* 1998; 50/S1: 41-7.
  18. Daneman D, Perlman K. Diabetes mellitus in childhood and adolescence. In Rakel H (ed): *Conn's Current Therapy*. Philadelphia: WB Saunders Company, 1999.
  19. Mortensen H, Hougaard P, the Hvidore Study Group on Childhood Diabetes. Insulin management and metabolic control of type 1 diabetes mellitus in childhood and adolescence in 18 countries. *Diabetic Medicine* 1998; 15: 752-9.
  20. Anderson BJ, Miller JP, Auslander WF, Santiago JV. Family characteristics of diabetic adolescents: relationship to metabolic control. *Diabetes Care* 1981; 4: 586-94.
  21. Anderson RM, Funnell MM. Compliance and Adherence are Dysfunctional Concepts in Diabetes Care. *Diabetes Care* 2000; 26: 597-604.
  22. Brink SJ. Insulin treatment and home monitoring for type 1 diabetes mellitus. In LeRoith D Taylor S and Olefsky J (eds): *Diabetes Mellitus. A Fundamental and Clinical Text*. Second Edition. Philadelphia: Lippincott Williams & Wilkins, 2000: 488-500.
  23. Brink, S, Siminerio, L, Hinnen-Hentzen D, et al. *Diabetes Education Goals*. Alexandria VA USA: American Diabetes Association, 1995.
  24. Moynihan P, Balik, B, Eliason S, Haig B. *Diabetes Youth Curriculum: A Toolbox for Educators*. Wayzata MN USA: International Diabetes Center, 1988.
  25. Maiman L, Becker M. Scales for measuring health belief model dimensions: a test of predictive value, internal consistency and relationships among beliefs. *Health Education Monographs* 1977; 5: 215-31.
  26. Edelstein J, Linn MW. Locus of control and the control of diabetes. *Diabetes Educator* 1987; 13: 51-4.
  27. Bandar A. *Social foundations of thought and action. A social cognitive theory*. Englewood Cliffs NJ, USA: Prentice Hall, 1986.
  28. Grossman HY, Brink SJ, Hauser ST. Self-Efficacy in adolescent girls and boys with insulin-dependent diabetes mellitus. *Diabetes Care* 1987; 10: 324-9.
  29. Newbrough JR, Simpkins CG, Maurer H. A family developmental approach to studying factors in the management and control of childhood diabetes. *Diabetes Care* 1985; 8: 83-92.
  30. Brink SJ. Diabetic ketoacidosis: Prevention, treatment and complications in children and adolescents. *Diabetes, Nutrition & Metabolism* 1999; 12: 122-35.
  31. Newton RW, Greene SA. Diabetes in the adolescent. In Kelnar CJH (ed): *Childhood and adolescent diabetes*. Chapman & Hall, 1995: 367-74.
  32. Brink SJ. Complications of pediatric and adolescent type 1 diabetes mellitus. *Current Diabetes Reports* 2001; 1: 47-55.
  33. Brink SJ. *Pediatric and Adolescent Diabetes Mellitus*. Chicago: Yearbook Medical Publishers, 1987.

---

Received: 13 December 2003

Accepted in original form: 27 March 2004

Correspondence: Prof. Francesco G. Chiarelli

Department of Pediatrics

University of Chieti

Ospedale Policlinico

Via dei Vestini 5

66013 Chieti, Italy

E-mail: chiarelli@unich.it