

SUBOPTIMAL GLYCEMIC CONTROL AND FAMILY CONFLICT IN
ADOLESCENTS WITH INTENSIVELY MANAGED DIABETES MELLITUS
TYPE 1: AN EDUCATIONAL MODULE FOR HEALTH CARE PROVIDERS

By

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ABSTRACT

Diabetes mellitus type 1 is increasingly treated with intensive insulin regimens, to maximize glycemic control and ultimately minimize micro- and macrovascular complications. A diagnosis of diabetes mellitus is associated with medical expenditures approximately 2.3 times higher per capita than expenditures in the absence of diabetes. A large portion of these expenditures are attributable to the cost of treating complications. Strict glycemic control in adolescents with diabetes mellitus type 1 may result in fewer, less costly complications later in life, and better overall quality of life. Such control in adolescence is often an elusive goal, due to multiple biological, behavioral, social, developmental, psychological and physiological factors impacting glycemic control.

The purpose of this project is to review the literature regarding intensively managed adolescents with diabetes mellitus type 1, factors that negatively impact on glycemic control, and ways for the general practitioner to identify and address dysfunctional diabetes-related family dynamics. Diabetes-related family conflict is an especially critical aspect of psychosocial functioning. Generalist practices without access to resources and specialists that specialist practices utilize to address this conflict are at a disadvantage, yet increasingly are being faced with the need to effectively manage adolescents with diabetes mellitus type 1 with intensive treatment regimens. The Diabetes-Related Family Conflict Scale is an easily administered and interpreted tool that the generalist can use to quickly identify dysfunctional family conflict. This educational module for general practitioners was developed to maximize the use of this tool, and propose some initial interventions.

CHAPTER 1

Introduction

The importance of good glycemic control in preventing long-term complications of diabetes mellitus type 1 is a major tenet in the management of diabetes (American Diabetes Association, 2008a; Levine, Anderson, Butler, Antisdel, Brackett and Laffel, 2001; Pickup and Keen, 2002; Plotnick, Clark, Brancati and Erlinger, 2003). Advances in diabetes mellitus management over the last 15 years have allowed attainment of strict glycemic control, even in populations commonly recognized as “difficult to manage”. Intensive insulin therapy, especially those using continuous subcutaneous insulin infusion treatment has greatly increased the potential for tight glycemic control (Ahern, Boland, Doane, Ahern, Rose, Vincent and Tamborlane, 2002; Bode, Tamborlane and Davidson, 2002; Danne and Tamborlane, 2006; Weissberg-Benchell, Antisdel-Lomaglio and Seshadri, 2003).

Among all age groups with diabetes, adolescents are recognized as an especially challenging population in which to establish or maintain good glycemic control (Danne and Tamborlane, 2006; Faulkner and Chang, 2007; Jack, 2003; Phillip, Battelino, Rodriguez, Danne and Kaufman, 2007; Roberts, 2004). Use of continuous subcutaneous insulin infusion in the adolescent population has burgeoned in the last 5 to 10 years, fueled by the development of new, short-acting insulin analogs, more user-friendly pump technology, and the growing awareness of the relationship between tight glycemic control and the delay / diminution of long-term complications of diabetes mellitus later in life (Pickup and Keen, 2002; American Diabetes Association, 2008a; Danne and Tamborlane,

2006; Hoogma, 2001; Nabhan, Rardin, Meier, Eugster and DiMeglio, 2006). Initiation of continuous subcutaneous insulin infusion in adolescents most commonly occurs in the context of a specialty practice, with access to resources for multidisciplinary patient and family evaluation, education and training, and follow-up/ continuing care (Ahern et al, 2002; Cogan, Streisan and Sarin, 2002; Skyler, Ponder, Kruger, Matheson and Parkin, 2007).

As continuous subcutaneous insulin infusion treatment of adolescents with diabetes mellitus becomes more main-stream, there is a growing realization that glycemic control in this population is greatly influenced by psychosocial factors, as much as or more than purely physiologic aspects of diabetes mellitus type 1 (Berlin, Davies, Jastrowki, Hains, Parton and Alemzadeh, 2006; Cogan et al, 2002; Jack, 2003; Lloyd, 2001; Wysocki, Harris, Buckloh, Wilkinson, Sadler, Mauras and White, 2006). There exists a “perfect storm” for many of these adolescents and their families, engaged in the normal tasks of growth and development (i.e., stress and learning to cope with stress, peer pressure, emerging self-identity, changing physical appearance and renegotiation of family roles – Jack, 2003; Palmer, Berg, Wiebe, Beveridge, Korbel, Upchurch, Swinyard, Lindsay and Donaldson, 2004) and simultaneously attempting successful glycemic control via adherence to a rigorous daily intensive management regimen, while navigating the transition from parental oversight of care to effective self-care. This trifecta often results in increased levels of family conflict around issues of diabetes mellitus type 1 management, and inconsistent adherence to treatment with less than optimal glycemic control as the result. Increased rates of long-term complications of

diabetes mellitus type 1 and increased healthcare costs may result if this process of transition is not successfully negotiated.

These problems are exacerbated by treatment delays due to a significant national shortage of pediatric endocrinologists, pediatric diabetes specialists and diabetes specialty practices, particularly in rural areas (Rizza, Vigersky, Rodbard, Labenson, Young, Surks, Kahn, and Hogan, 2003; Malasanos, Burlingame, Sloyer, and Muir, 2004). Increasingly, general practitioners are being called on to fill this treatment gap. Many are prepared to address the issues presented in physiological management of diabetes mellitus type 1, but most do not have the training or resources to identify and treat many of the psychosocial issues that influence glycemic control, particularly in this age group (Skyler et al, 2007).

Statement of Problem

Generalists increasingly are faced with the need to make timely treatment decisions for their adolescent diabetic population. When adolescents are physiologically poor candidates for continuous subcutaneous insulin infusion initiation or continuation, a clearer set of parameters to evaluate fitness for continuous subcutaneous insulin infusion is available. Similarly, adolescents with major psychiatric disorders are easier to identify as not being appropriate continuous subcutaneous insulin infusion candidates (Lloyd, 2001; Jack, 2003; Dann, von Schutz, Lange, Nestoris, Datz and Kordonouri, 2006). Adolescents currently receiving continuous subcutaneous insulin infusion treatment, but who are struggling with glycemic control due to psychosocial issues consistent with normal, age-appropriate growth and development tasks may be more challenging for the generalist (Jack, 2003).

Statement of Purpose

Current research underscores the integrative nature of effective diabetes mellitus type 1 management, incorporating biological, psychological, behavioral and sociocultural factors (Jack, 2003). Family-specific factors (i.e., number of caregiving parents in the family, caregivers' level of formal education, family literacy, family income, language and cultural barriers), diabetes-specific conflict, and developmental issues of adolescence must be considered when planning interventions for glycemic control and diabetes management issues (Hood, Butler, Anderson and Laffel, 2007). The feasibility of such an integrative approach in a generalist setting may depend on the ability of the practitioner to realistically administer, assess and interpret evaluative tools within a "typical office visit" time frame, especially when specialist psychosocial resource personnel are not readily available for routine diagnostic and follow up referral (Peyrot and Rubin, 2007, p. 2433).

Family conflict is an especially critical aspect of psychosocial functioning that can impact glycemic control, even if all other physiologic and psychosocial factors are ideal for continuous subcutaneous insulin infusion therapy (Hood et al, 2007). Family conflict may be difficult to identify and address as a source of poor glycemic control in the context of a typical generalist's office visit. The Diabetes-Related Family Conflict Scale "is a tool that can be easily administered during routine clinic visits to identify a potentially modifiable and potent area of family functioning" (Hood et al, 2007, p. 1768). If significant conflict is identified as a real or potential cause of glycemic dysfunction, timely and appropriate intervention can be arranged, while avoiding non-productive,

costly, circuitous attempts to identify and address reasons for poor glycemic control and diabetes-related family conflict.

Significance of Intervention

Avoidance of long-term complications of diabetes mellitus results in improved long-term quality of life, better health and decreases the financial burden of care. Interventions aimed at the early identification and treatment of diabetes-related family conflict are advantageous to families under stress, who are often at greater risk for conflict and constraints regarding diabetes mellitus management (Hood et al, 2007; Berlin et al, 2006; Jack, 2003).

There are financial costs associated with unaddressed or ineffectually addressed psychosocial issues in the diabetic population; in the short term, there are costs related to more intensive health service usage to treat diabetic ketoacidosis and hypoglycemia, and the direct and indirect expenditure of clinician time on these issues at subsequent visits (Peyrot and Rubin, 2007; American Diabetes Association, 2008b). Short-term costs also include the cost of training, education, support and start-up equipment costs. The average cost for an insulin pump is \$6000, and monthly costs for continuous subcutaneous insulin infusion and blood glucose monitoring supplies alone can be greater than \$450; some of these costs may be covered by 3rd party payers, but many are not (Bradley, 2006).

Long-term costs are those associated with treatment of complications of diabetes mellitus (neuropathy, peripheral vascular disease, cardiovascular disease, nephropathy, and retinopathy). Health care expenditures in the United States attributed to medical conditions associated with diabetes mellitus during 2007 totaled approximately 58

million dollars. A diagnosis of diabetes mellitus is associated with medical expenditures approximately 2.3 times higher per capita than expenditures in the absence of diabetes (American Diabetes Association, 2008).

Short term expenses are justified if continuous subcutaneous insulin infusion-related improvements in glycemic control result in decreased long-term complications and their associated costs, and in improved life-long productivity in those with diabetes. Data to conclusively support these associations are lacking. The most recently available estimate of cost-effectiveness of continuous subcutaneous insulin infusion therapy in all age groups indicates that it may take 9 years for treatment to become more cost-beneficial than conventional therapy (Turkelson and Coates, 1995; Nuboer and Bruining, 2006). This suggests that premature termination of continuous subcutaneous insulin infusion may result in greater long and short-term treatment costs without the benefit of cost savings on fewer, less intense long-term complications. Interventions that contribute to long-term continuous subcutaneous insulin infusion therapy success are thus cost-effective, for individuals, families, health care practitioners, health care payors, and the nation as a whole.

Summary

Glycemic control is critical for effective diabetes management. Adolescents present a dual challenge for the practitioner, in the modification of complication development through early, strict glycemic control, and the widely acknowledged difficulty in achieving glycemic control, due to physiologic, behavioral, developmental and psychosocial issues. Family conflict is an especially crucial psychosocial issue

impacting glycemic control. The current national shortage of pediatric endocrinologist and diabetes specialists compounds these problems.

Generalists are increasingly filling this provider vacuum by default, despite inadequate access to specialty support personnel to maximize effectiveness of interventions. There is a need to explore the use of other resources and assessment / evaluation tools to make the most of support specialists that may only be available for limited intervention solely by formal referral (Goldberg, Cooke, and Hackman, 2007). Short and long term costs for associated complications can be avoided or ameliorated early in the disease course if conflict is addressed. These costs impact on many levels:

- for patients, the financial outlay for complication treatment and diminished quality of life,
- for practitioners, costs associated with increased acuity and required interventions,
- for families, deteriorating relationships, increased conflict and diminished quality of life, and to
- for the nation, increased long-term healthcare costs.

This project aims to provide generalists with an understanding of the importance of glycemic control in adolescents with diabetes mellitus type 1, an overview of intensive diabetes mellitus type 1 management with an emphasis on continuous subcutaneous insulin infusion, an understanding of the multifactorial issues related to deteriorating glycemic control in adolescents, and access to an evaluation tool useful in identifying a

common etiology for poor glycemic control that is compatible with a busy practice in terms of time constraints, validity and ease of interpretation.

Chapter 2

Introduction

In this chapter, the Double ABCX Model of Family Stress will be presented as the theoretical framework for this project. Joan Patterson and Hamilton McCubbin (1983) developed this model as a way of understanding families' adaptations to a child's chronic illness. This perspective frames the presentation of diabetes-related family conflict. A literature review is presented that summarizes the etiology, diagnosis, multidisciplinary nature of effective management, integrative factors of management, glycemic control and intensive management regimes, and psychosocial attributes of management of adolescents.

Theoretical framework:

The Double ABCX Model of Family Stress is a dynamic framework to understand family efforts at adaptation to multiple stressors via family resources and perceptions as components of coping to attain family balance. Family vulnerability to crisis and maladaptive coping result from the interaction of stressors (a factor), with existing resources (b factor) and family perceptions (c factor). At times, a conflict or crisis (x factor) overwhelms the family's resources, resulting in threatened family stability. The family must cope, the process of adaptation and achievement of a new level of systemic balance. Coping results from the pile-up of demands presented by chronic illness management, and the interaction of resources, perception and behavioral responses. Different family systems have differently-sized pile-ups of unresolved

stressors that contribute to undesirable family environments and conflict (Patterson and McCubbin, 1983). .

Resources are “the psychological, social, interpersonal, and material characteristics of individual family members..., of the family unit..., and of the community...which are used to meet family demands and needs” (Patterson and McCubbin, 1983, p. 29). Less conflict is found in families with member self-esteem, good communication, mutual support, problem-solving abilities, physical and emotional health, and a sense of mastery of events (Patterson and McCubbin, 1983). .

Regarding perceptions, families that are able to see stressors and crises as challenges to be met often ultimately redefine their situations and restore balance.

Family crises are an opportunity for health care providers to promote family well-being through improved problem-solving skills, and improved interpersonal relationships. This promotion does not need to be provided directly by the health care provider, but can be provided indirectly, through appropriate referral to mental health specialists (Patterson and McCubbin, 1983).

In adapting this model to diabetes-related family conflict in intensively managed adolescents with diabetes mellitus type 1, stressors can be the initial diagnosis of diabetes and the demands that management places on the family. Existing resources include those social, psychological, healthcare and financial resources that the family possesses or can access. Perceptions of diabetes and it’s management as manageable or overwhelming will greatly influence if and how a family copes with the adolescent’s diagnosis and treatment, and whether or not glycemic control is attained (bon- vs. maladaptation). A

crisis occurs when some aspect of diabetes and its treatment becomes overwhelming, either directly (i.e., management intensification) or indirectly (loss of existing resources or change in perceptions). A pile-up of stressors (i.e., an adolescent girl's weight gain and loss of self-esteem after transition to continuous subcutaneous insulin infusion) that cannot be addressed adequately with existing resources (inability to lose weight in part due to lack of physical activity) or perceptions (her perception of intensive management as causing weight gain, without consideration of the importance of glycemic control in preventing long-term complications), may result in ineffective coping (poor treatment adherence), and maladaptation (poor glycemic control and family conflict regarding deteriorating adherence and glycemic control), with the maladaptation itself becoming a self-perpetuating crisis. Diagnosis of family conflict and interventions to address it will provide the adolescent and family with new resources for adaptive coping by decreasing the pile-up of stressors and diminishing the crisis (see figure 1).

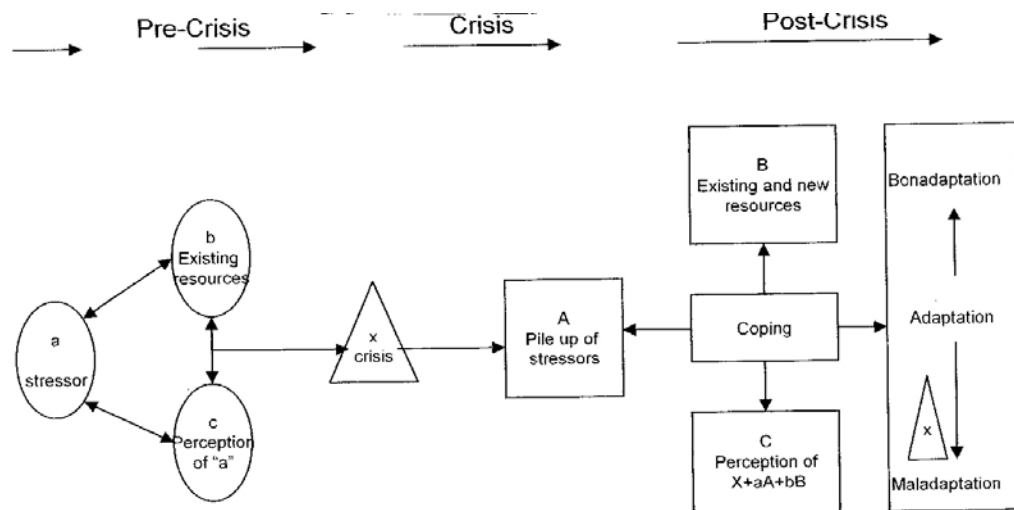


Figure 1: The Double ABCX Model, for understanding families' adaptations to a child's chronic illness (adapted from Patterson and McCubbin, 1983). Degree of family vulnerability to maladaptive coping results from interaction of stressors (a factor), with existing resources (b factor) and family perceptions (c factor). Conflict/ crisis (x factor).

Literature Review

The majority of diabetes mellitus type 1 is caused by pancreatic beta-cell destruction. An autoimmune, relatively rapid pathologic process is a common etiology for this beta-cell destruction in children and adolescents. The result is an absolute deficiency of endogenous insulin secretion with rapidly developing, severe hyperglycemia and ketoacidosis if untreated. Diabetes mellitus type 1 account for 5-10% of the overall incidence of diabetes. As of 2005, approximately one in every 400 to 600 children and adolescents under the age of 20 in the United States had diabetes mellitus type 1, slightly greater than 2 million children and adolescents (American Diabetes Association, 2008a; American Diabetes Association, 2008b; National Institute of Diabetes and Digestive and Kidney Diseases, 2005).

Diagnosis is based on a fasting plasma glucose of ≥ 126 mg/dl, a 2 hour plasma glucose reading of ≥ 200 mg/dl obtained during an oral glucose tolerance test, or the coexistence of symptoms of hyperglycemia [polydipsia, polyphagia, polyuria, unexplained weight loss] with a random plasma glucose of ≥ 200 mg/dl. In the absence of unequivocal hyperglycemia, confirmation by retesting on a subsequent day is required for diagnosis (American Diabetes Association, 2008a; American Diabetes Association, 2008b).

Once diagnosed, treatment should ideally involve multidisciplinary healthcare providers trained in caring for the physiologic, psychologic, and social needs of adolescents with diabetes mellitus type 1. Diabetes education forms the basis for all other interventions, with the ultimate goal of developing the adolescent's knowledge of diabetes mellitus and treatment modalities, along with self-care competence. Self-care begins with shared management involving parents/adults and the child, transitioning to the child/young adult as a competent self-care agent in a fashion that parallels and is complemented by the child's age-appropriate attainment of physical, psychological and emotional maturity (American Diabetes Association, 2008a; American Diabetes Association, 2008b).

Another multidisciplinary aspect of diabetes mellitus type 1 management in the adolescent is medical nutritional therapy (MNT), provided minimally at diagnosis and annually. MNT should address the usual nutritional needs for normal growth and development, along with specific topics such as meal planning and carbohydrate counting. Issues that most adolescents face such as nutritionally unbalanced or deficient

diets, excessive consumption of simple carbohydrates and sugars, eating irregularities, skipping meals, and other behavioral issues related to food should be addressed (American Diabetes Association, 2008a; American Diabetes Association, 2008b).

Adolescents with diabetes mellitus type 1 deal with the same psychological and emotional issues of growth and development that their peers without diabetes mellitus type 1 face, compounded by the experience of living with a chronic medical condition that requires close adherence to a medical and nutritional plan of care for successful treatment. Effective management requires that issues related to self-care, affect, normal tasks of adolescent growth and development, and family dynamics be addressed.

Physiologic changes in the growing adolescent with diabetes mellitus type 1 can create challenges in treatment, as outlined below:

- Insulin resistance increases in response to increases in growth hormone during puberty.
- Greater levels of estrogen and testosterone can derange blood glucose levels.
- physical growth during adolescence in this population is impaired due to the effects of insulin in both males and females, with girls being more likely to experience an increase in body fat in response to insulin therapy
- further weight gain may result from elevated growth hormone concentration and reduced concentrations of growth factor-1, a pattern seen in diabetes mellitus type 1 adolescents. (American Diabetes

Association, 2003; American Diabetes Association, 2008a; American Diabetes Association, 2008b; Jack, 2003).

Degree of desired glycemic control in adolescents is less strict than that recommended for adults with diabetes mellitus type 1; younger adolescents ≤ 12 years should ideally maintain a plasma blood glucose between 90-180 mg/dl preprandially, and 100-180 mg/dl overnight. Their desired A1c value is $< 8\%$. Older adolescents and young adults aged 13-19 years have plasma blood glucose goals of 90-130 mg/dl preprandially and 90-150 mg/dl overnight. For this group, an ideal A1c value is $< 7.5\%$. Degree of glycemic control correlates with rates of progression of microvascular and neuropathic complications; improved control is associated with decreased, decelerated rates of complication development. The most recent Diabetes Control and Complications Trial position statement relates that “the greatest number of complications will be averted by taking patients from very poor control to fair or good control...further lowering the A1c from 7 to 6% is associated with further reduction in the risk of complications” (American Diabetes Association, 2008a, p. S19). Glycemic goals must be individualized, higher when frequent hypoglycemia occurs, and lower if safe to do so while avoiding hypoglycemia. Hypoglycemia presents unique risks to the developing brain, especially in younger children, and should be avoided (American Diabetes Association, 2008a; American Diabetes Association, 2008b).

The significance of psychosocial attributes on diabetes treatment, adherence and outcomes is increasingly recognized in the research literature. The most recent standards of care issued by the American Diabetes Association recommend psychosocial screening

and follow-up to assess attitudes regarding diabetes, management and outcome expectations, quality of life, emotional well-being, psychiatric comorbidities and financial and healthcare resource availability. Adherence to treatment is a significant issue; adolescents who demonstrate poor treatment adherence should be evaluated for psychosocial problems including but not limited to depression, eating disorders, anxiety, family conflict, coping disorders, self-care deficits and cognitive impairments (Weissberg-Benchel et al, 2003; Jack, 2003). Referral to mental health specialists versed in diabetes management is warranted for any of these issues, particularly those that potentially present a danger to the patient (gross noncompliance, depression, cognitive functional impairment) (American Diabetes Association, 2008a; American Diabetes Association, 2008b).

Given the difficulty frequently encountered in achieving desired glycemic targets in adolescents, intensive insulin therapy is warranted, as it demonstrably lowers A1c levels, total daily insulin dose and the incidence of hypoglycemia.

Intensive therapy involves either multiple daily injections (MDI) of short- (lispro, aspart) and long-acting insulins (glargine), or continuous subcutaneous insulin infusion using short-acting insulins only. Both forms of therapy are associated with improvements in A1c values. In stable patients with good treatment adherence, an MDI regime using long-acting, peakless insulin analog basal doses with prandial rapid-acting insulin analog bolus doses based on blood glucose monitoring results (preprandial and as needed, at least 4 times/day) and carbohydrate counting can produce glycemic control comparable to that obtained with continuous subcutaneous insulin infusion (Liberatore

and Damiani, 2006; Ahern et al, 2002). A clear disadvantage of MDI treatment involves the number of daily injections required (3 or more), which can negatively impact on adolescents' quality of life (Bode et al, 2002). continuous subcutaneous insulin infusion may be especially useful in adolescents with diabetes refractory to other management options, or with diminished quality of life related to an inflexible treatment regimen, as complication rates are most significantly improved in those with the most deranged glycemic control prior to continuous subcutaneous insulin infusion initiation (Pickup and Keen, 2002). Ahern et al (2002) were able to demonstrate a significant improvement in A1c levels with continuous subcutaneous insulin infusion treatment of diabetes mellitus type 1 adolescents compared with results obtained with MDI therapy over 1 year. The use of continuous subcutaneous insulin infusion therapy for children and adolescents had increased 10-fold by 2002 and continues to grow, primarily in North America and Europe (Ahern et al, 2002).

Continuous subcutaneous insulin infusion therapy is accomplished using a small external pump, similar in appearance to a pager, that consistently delivers short-acting insulin via thin tubing to a soft cannula inserted subcutaneously, usually on the abdomen, legs or lower back. The pump is programmed to deliver insulin at a modifiable basal infusion rate coupled with prandial boluses to match carbohydrate intake, preprandial blood glucose monitoring results, and anticipated activity level (American Diabetes Association, 2008a; American Diabetes Association, 2008b). The infusion set is changed every 48-72 hours. The pump can be disconnected from the tubing for short periods of time, for swimming, bathing / showering, sports or intimate activities (Skyler et al, 2007).

Advantages of continuous subcutaneous insulin infusion insulin delivery include insulin pharmacokinetics that more closely resemble endogenous insulin secretion, less absorption variability with a resultant decrease in the total daily insulin dose by at least 14%, less risk of hypoglycemia and the dawn phenomenon, and more flexibility in eating/snacking patterns (Bode et al, 2002; Liberatore and Damiani, 2006; Pickup and Keen, 2002). No significant increase in rates of DKA requiring hospitalization or ER treatment is demonstrated for continuous subcutaneous insulin infusion (American Diabetes Association, 2008a). The role of continuous subcutaneous insulin infusion in weight gain is more ambiguous; some studies demonstrate no BMI elevation secondary to continuous subcutaneous insulin infusion (Bode et al, 2002), while others resulted in some associated elevation (Purnell, Hokanson, Marcovina, Steffes, Cleary and Brunzell, 1998).

There is variability in the literature regarding improvements in glycemic control and duration of that improvement. Liberatore and Daminani (2006) comment on the trend toward reversal of initial reduction in A1c values back to levels prior to continuous subcutaneous insulin infusion initiation after 6 months to 1 year. In a randomized open crossover trial comparing MDI and continuous subcutaneous insulin infusion regimes in children and young adolescents, Weintrob, Benzaquen, Galtzer, Shalitin, Lazar, Fayman, Lilos, Dickerman and Phillip (2003) found that either modality resulted in similar metabolic control and rates of adverse events, a result they attributed to compliance problems with diet and boluses in continuous subcutaneous insulin infusion therapy involving the young adolescent population. In a meta-analysis of 52 research studies,

Weissberg-Benchell et al (2003) found significant improvement in serum glucose levels of both pediatric and adult populations when treated with continuous subcutaneous insulin infusion. Other authors report decreases in A1c values anywhere from 0.2% to 0.4% using continuous subcutaneous insulin infusion therapy with adolescents (Bode et al, 2002; Pickup and Keen, 2002; DCCT Research Group, 1995).

Any improvement in glycemic control of any duration in treating adolescents with diabetes mellitus type 1 is significant in reducing or slowing complication development, some not evident until later in life. For example, the incidence of retinopathy development and progression can be decreased by 30-40% with a sustained lowering of A1c values by 0.6-0.7% (Ahern et al, 2002). Other common complications of poorly controlled diabetes mellitus include cardiovascular disease, dyslipidemia, nephropathology, and neuropathy.

A clear disadvantage of continuous subcutaneous insulin infusion therapy is cost. The annual cost of continuous subcutaneous insulin infusion in the United States is between \$2,274 and 8,500, as compared to the cost of MD using syringes (\$1,008-1,495/year). Even when factoring in the savings achieved by reducing hypoglycemia treatment by healthcare personnel and amount of insulin used, continuous subcutaneous insulin infusion therapy still increases the annual cost of treatment by \$1,250 – 7,000 over treatment using syringes (Liberatore and Damiani, 2006; Skyler et al, 2007; Nuboer and Bruining, 2006). These cost increases have put continuous subcutaneous insulin infusion out of the reach of many otherwise eligible adolescents without the financial resources to cover its costs. The average cost of total medical care over 3 years for an

adult (presumably experiencing diabetes mellitus complications in relation to degree of long-term glycemic control) is approximately 11% greater for a A1c of 10% versus an A1c of 6% (Berger, 2007). This suggests that control of maximally elevated A1c levels frequently seen in adolescence may convey very real clinical and financial benefits later in life.

Most authors are in agreement about general indicators for continuous subcutaneous insulin infusion therapy in adolescents:

- Problematic glycemic control
 - A1c elevated over 7.5-8%, or over the adolescent's target goal and/or,
 - Elevated morning fasting glucose levels (dawn phenomenon, blood glucose monitoring >140-160 mg/dL) and/or,
 - Excessive variability in daily glucose levels (Danne, von Schutz, Lange, Nestoris, Datz, and Kordonouri, 2006).
- Significant incidence of recurrent unpredictable hypoglycemia or DKA requiring care by emergency personnel or hospitalization (Pickup and Keen, 2002).
- Desire or need for flexibility around timing of meals, snacks and insulin activity peak effects (Bode et al, 2002).
- Needle phobia (Danne, von Schutz, Lange, Nestoris, Datz, and Kordonouri, 2006).

- Patient's expressed desire to transition to continuous subcutaneous insulin infusion (Bode et al, 2002).
- Patients' and families' demonstrated pattern of adherence to current diabetes self-management regime, including keeping appointments and accurate self-management records (Skyler et al, 2007).
- Positive attitude and ability regarding learning and actively applying basic and advanced diabetes management and trouble-shooting skills to daily self-care regime, (Pickup and Keen, 2002; Skyler et al, 2007).
- Physical ability to operate an insulin pump (Skyler et al, 2007).

Adolescents who would most likely be poorer choices for continuous subcutaneous insulin infusion are those with:

- Severely brittle diabetes with recurrent ketoacidosis and insulin resistance.
- Poor adherence to current diabetes mellitus management regime.
- Psychological or social issues that result in deliberate treatment sabotage.
- Major psychiatric disorders such as psychosis, severe depression or debilitating anxiety.
- Discomfort wearing a pump because it makes a diabetes mellitus diagnosis more apparent.
- No access or inconsistent access to the financial resources allowing consistent continuous subcutaneous insulin infusion treatment adherence. Such patients may be better served by MDI therapy

until cost of treatment decreases due to market forces, or are better subsidized by 3rd party payers. The assumption driving this recommendation is that consistent (albeit less optimal) glycemic control is better than an inconsistent pattern of improving and deteriorating glycemic control due to shortages of necessary supplies and equipment (Pickup and Keen, 2002).

Ultimately, decisions about treating adolescents with continuous subcutaneous insulin infusion must be made on an individual basis, incorporating the patient, family and caregivers, acknowledging the expectation of increased demands of time, effort and money in treatment intensification. Continuous subcutaneous insulin infusion initiation generally involves specialized patient and family training, to review basic concepts of diabetes self-management (detection, prevention and treatment of hypoglycemia, use of insulin to counteract hyperglycemia, prevention and treatment of ketoacidosis, sick day management, glucometer operation), followed by training in calculating carbohydrate: insulin ratios, calculating premeal bolus insulin doses based on preprandial blood glucose monitoring results coupled with carbohydrate counting, calculating basal and correction bolus doses, guidelines for pump therapy while exercising, catheter insertion and site care, tubing attachment, advanced pump features and troubleshooting (Ahern et al, 2002; Skyler et al, 2007). Patients and families should be prepared to administer insulin boluses based on increased frequency of blood glucose monitoring (4-6 times / day) in conjunction with consistent carbohydrate counting.

A review of research literature demonstrates that improved glycemic control with continuous subcutaneous insulin infusion is significantly associated with four aspects of treatment:

- Frequent (4-6 times/day) blood glucose monitoring. Each additional daily reading is associated with a 0.2% A1c reduction (Bode et al, 2002; Plotnick, Clark, Brancati and Erlinger, 2003).
- Consistent pattern of appropriate preprandial and hyperglycemia correction insulin bolus administrations (Bode et al, 2002; Skyler et al, 2007).
- Realistic expectations regarding continuous subcutaneous insulin infusion therapy as a treatment for diabetes mellitus type 1, not a cure. (Bode et al, 2002; Danne, von Schutz, Lange, Nestoris, Datz, and Kordonouri, 2006; Skyler et al, 2007).
- Positive, supportive parental involvement in continuous subcutaneous insulin infusion therapy, augmenting the adolescent's development of self-care skills with parental oversight ensuring that blood glucose monitoring and insulin boluses consistently occur (Plotnick et al, 2003).

Other aspects of continuous subcutaneous insulin infusion treatment that improve glycemic control include:

- Appropriately set basal insulin rate (neither hypo- nor hyperglycemic when a meal is skipped) (Bode et al, 2002).
- Consistent carbohydrate counting (Bode et al, 2002).

- Treatment of hypoglycemia with the correct amount of carbohydrates (Bode et al, 2002).
- Evidence of a pattern of insulin administration (reflected in the pump memory) that correlates with degree of hyperglycemia (recorded in the glucometer memory / logbook) (Bode et al, 2002).
- 24 hour access to multidisciplinary team representatives, for advice, questions and troubleshooting (Bode et al, 2002).
- Appropriate pump selection; some are programmable pumps only, while others can recommend insulin doses depending on the glucometer reading, carbohydrate count, and other factors. Depending on the adolescent's level of self-care ability, one type of pump may be more suitable than another. Other pump considerations should include customer service, training and support services (Skyler et al, 2007).

In summary, successful treatment of diabetes mellitus type 1 with continuous subcutaneous insulin infusion depends on knowledge of diabetes mellitus management using continuous subcutaneous insulin infusion and appropriate self-care attributes. Some centers clearly assess, teach and contract with patients around these concepts (Danne, von Schutz, Lange, Nestoris, Datz, and Kordonouri, 2006), while others do not (Bode et al, 2002). Many practitioners use behavioral contracts with adolescents and their families, clearly summarizing in detail a list of patient, parent and caregiver responsibilities and expectations, and consequences of not fulfilling the behavioral contract (Skyler et al, 2007).

There are few evidence-based guidelines to help navigate this process (Danne, von Schutz, Lange, Nestoris, Datz, and Kordonouri, 2006; American Diabetes Association, 2008a; Silverstein, Klingensmith, Copeland, Plotnick, Kaufman, Laffel, Deeb, Grey, Anderson, Holzmeister and Clark, 2005), with the result being less initiation and effective management of continuous subcutaneous insulin infusion in adolescents in general practices, despite clinical evidence that clearly demonstrates relatively few absolute contraindications to continuous subcutaneous insulin infusion in adolescents (Bode et al, 2002; Danne, von Schutz, Lange, Nestoris, Datz, and Kordonouri, 2006; Pickup and Keen, 2002; Plotnick et al, 2003).

One of the most difficult aspects of continuous subcutaneous insulin infusion therapy with adolescents involves maintenance of parent-adolescent teamwork without increasing diabetes related family conflict when treatment is intensified. Research literature demonstrates an association between diabetes-specific family conflict and lower adherence rates and poorer glycemic control in adolescents (Wysocki et al, 2006). This conflict may result from discrepancies in levels of autonomy and ability related to diabetes self-management, and adolescents' interpretations of parental involvement as misguided, intrusive or controlling (Hood et al, 2007). Since psychosocial measures related to continuous subcutaneous insulin infusion use are not routinely considered or reported using a standard metric in the research literature, it is difficult to incorporate assessment of diabetes-related family conflict into routine continuous subcutaneous insulin infusion care (Weissberg-Benchell et al, 2003). Most researchers and pediatric diabetes specialists are able to rely on the judgment of the diabetes multidisciplinary

treatment team in determining the specific etiology of psychosocial problems affecting treatment (Weintrob et al, 2003; Hoogma, 2001). Pediatric diabetes specialty practices, with their routine access to a range of pediatric specialists knowledgeable about adolescents and diabetes, might be less likely to use such a tool. A general practitioner, with fewer specialty resources to devote to elucidating the etiology of non-physiologically based glycemic deterioration, might welcome a quick, easily administered and interpreted questionnaire that could help identify a possibly modifiable dysfunctional relationship, and efficiently guide most appropriate intervention with potentially significant improvement in glycemic control as an outcome (Hood et al, 2007).

The revised Diabetes-Related Family Conflict Scale can be used in assessment of family conflict associated with deteriorating glycemic control. This tool would be useful to a busy general practitioner attempting appropriate intervention in an adolescent treated with continuous subcutaneous insulin infusion experiencing glycolic deterioration when family conflict regarding diabetes management is suspected. The general practitioner must be able to differentiate between patients who are physiologically refractory and those whose poor glycemic control is a direct factor of modifiable psychosocial issue. Based on results of the Diabetes Family Conflict Scale, the practitioner would be better equipped in approaching the situation, either by appropriate referral to a behavioral health specialist, diabetes educator, social worker, or within their own practice. In their meta-analysis of research studies regarding continuous subcutaneous insulin infusion, Weissberg-Benchell et al (2003) found that subjects most likely to discontinue

continuous subcutaneous insulin infusion therapy were younger, with shorter a duration of diabetes. These are both attributes of the adolescent diabetic population. Appropriate, timely intervention makes improved glycemic control more likely, ensuring that the initial financial outlay for continuous subcutaneous insulin infusion translates into decreased complication rates and better quality of life in the long term.

There are a number of acknowledged short-coming in the bulk of continuous subcutaneous insulin infusion research involving adolescents in general, and in the research literature regarding the Diabetes Family Conflict Scale. Different treatment or research centers base individualized therapy on different standardized approaches based more heavily on experience than on evidence (Danne et al, 2006). Sample sizes in many studies are small, and often were self-enrolled rather than randomly assigned, potentially introducing bias and thus diminishing the statistical strength of their conclusions. Study designs generally are either paired, parallel, or involve randomized crossover, making meta-analysis and comparative consideration more difficult when studies with dissimilar designs are considered (Weissberg-Benchell et al, 2003). The population of adolescent continuous subcutaneous insulin infusion users represented in these studies are relatively homogenous - predominantly Caucasian, living in two parent households, of middle to upper socioeconomic class, with the resources (adequate health insurance, monetary income, access to multidisciplinary practice groups maximizing success through extensive treatment and education interventions) to afford the considerable costs of initiating and maintaining continuous subcutaneous insulin infusion therapy (Ahern et al, 2002).

Summary

The majority of diabetes mellitus type 1 result from an autoimmuneological, relatively rapid process. Treatment ideally involves multidisciplinary healthcare providers who can address the physiologic, psychologic, and social needs of adolescents. Diabetes education forms the basis for all interventions, with the ultimate goal being the adolescent's self-care competence in maintaining an acceptable level of glycemic control. Attainment of this goal requires functional self-care, affect, attainment of tasks of adolescent growth and development, and family dynamics.

Glycemic control is measured by A1c levels, with desired values for adolescents generally less than 7.5-8%. Consistent maintenance of glycemic goals is associated with fewer complications and slower rates of progression. Physiologic factors (changes in and effects of growth hormone, estrogen, testosterone and insulin, weight gain) affect goal attainment, on par with psychosocial factors, primarily expressed in adherence-to-treatment patterns. Psychosocial screening and routine follow-up are significant aspects of care.

Intensive treatment modalities (multiple daily injections vs. continuous subcutaneous insulin infusion) have made significant improvements in glycemic control possible. Advantages of continuous subcutaneous insulin infusion insulin delivery include insulin pharmacokinetics that are more physiological, less risk of hypoglycemia, and greater lifestyle flexibility. Disadvantages include cost, though in the long-term, a strict degree of glycemic control may convey clinical and financial benefits later in life

Problematic glycemic control, hypoglycemia or DKA associated with a demonstrated pattern of adherence, and a need for lifestyle flexibility are general indicators for continuous subcutaneous insulin infusion therapy in adolescents. Those adolescents who are severely brittle diabetics, have poor adherence, have psychological/social issues, are diagnosed with major psychiatric disorders, or have inconsistent access to the required financial resources are considered poorer choices for consistent continuous subcutaneous insulin infusion treatment. Ultimately, however, treatment decisions must be made on an individual basis

Effective treatment with continuous subcutaneous insulin infusion is found in those who frequently monitor their blood glucose levels, administer insulin boluses as appropriate, have realistic expectations about treatment potentials, and have positive, supportive parental involvement. Without successful parent-adolescent teamwork, glycemic control is threatened.

The potential for diabetes-related family conflict when treatment is intensified is a concern. General practitioners, without resources found in specialty practices, are at a disadvantage in dealing with this conflict. The Diabetes-Related Family Conflict Scale is suggested as an easily administered and interpreted questionnaire that could help identify and address this type of conflict.

CHAPTER 3

Introduction

This project is an educational module, for general practitioners who encounter adolescents using continuous subcutaneous insulin infusion to treat their diabetes mellitus type 1. This module includes a pretest and post test to measure learning about family conflict and continuous subcutaneous insulin infusion, and explores:

- the importance of glycemic control in preventing complications of diabetes mellitus type 1.
- the challenges encountered in achieving tight glycemic control in adolescence (physiologic, behavioral and psychosocial).
- the role of continuous subcutaneous insulin infusion in achieving tight glycemic control
- the risk factors for dysfunctional family conflict related to diabetes mellitus type 1.
- continuous subcutaneous insulin infusion, general practitioners, and psychosocial issues in diabetes mellitus type 1 management.
- using the Diabetes-Related Family Conflict Scale as a valid screening instrument for dysfunctional family conflict.
- useful interventions when dysfunctional family conflict is identified.

Content expert evaluation to determine content validity, and internal consistency to ensure reliability (by computing a Cronbach alpha score) would be important to consider. Literature covering type 1 diabetes mellitus in adolescents was reviewed,

specifically etiology, diagnosis, treatment and intensive management, and family conflict, to ascertain questions that would comprise the survey instrument. This resulted in the selection of 11 questions designed to determine knowledge regarding family conflict, intensively managed type 1 diabetes mellitus, and adolescent patients with type 1 diabetes mellitus. Content-relevance would need to be determined by experts, such as university professors, pediatric endocrinologists, diabetes educators, and nurse practitioners with an area of expertise in diabetes mellitus type 1 in adolescents. Each expert would comment on the appropriateness of each of the items for a pretest to determine baseline knowledge of type 1 diabetes mellitus in intensively managed adolescents. Relevance of each item to the current study would be determined.

Reliability and internal consistency of the test could be estimated by Cronbach's alpha, with a value of 0.70 or higher considered to estimate reasonable reliability (Social Research Methods, n.d.).

Clinical Presentation to Health Care Personnel

Pretest:

Correct answers for pretest questions are bolded.

1. Short-term complications of poor glycemic control include:
 - a. Retinopathy
 - b. Diabetes ketoacidosis
 - c. Nephropathy
 - d. Hypoglycemia
 - e. **B and D**

f. A, B, and C

2. The American Diabetes Association guidelines target an A1c value of less than 7.5% for adolescents 12 years and older.

T or F.

3. Poor glycemic control is infrequently associated with a psychiatric comorbidity in adolescents with diabetes mellitus type 1. (**Half of the participants with historically poor glycemic control in a prospective longitudinal study of health outcomes in diabetes mellitus type 1 had a psychiatric comorbidity**).

T or F.

4. Adolescents with the most deranged glycemic control prior to continuous subcutaneous insulin infusion treatment initiation often experience the most significant improvement in complication rates after continuous subcutaneous insulin infusion is started.

T or F

5. Continuous subcutaneous insulin infusion treatment is indicated in adolescents with:

- a. **Recurrent unpredictable hypoglycemia.**
- b. Difficulty managing their current daily diabetes mellitus treatment regime due to gross nonadherence
- c. Schizophrenia
- d. A and B

6. Improved glycemic control with continuous subcutaneous insulin infusion is associated with realistic expectations about continuous subcutaneous insulin infusion as a treatment for diabetes mellitus, frequent blood glucose monitoring, consistent administration of correction insulin boluses, and little parental involvement in daily management. (**Improved glycemic control with continuous subcutaneous insulin infusion is associated with active parental involvement in daily management**).

T or F.

7. Poorer glycemic control in adolescents using continuous subcutaneous insulin infusion is associated with:
- parental oversight of blood glucose monitoring
 - family conflict about differing goals of diabetes management.**
 - the child's developmental need for greater autonomy
 - checking the blood glucose 4-6 times/day.
8. Increased diabetes-related family conflict correlates with poorer glycemic control as measured by A1c values.

T or F

9. When using the Diabetes-Related Family Conflict Scale, which score indicates the highest level of conflict?:
- 23
 - 19
 - 37**

d. 114

10. Routine administration of the Diabetes-Related Family Conflict Scale is not necessary, as it should only be used when significant family conflict is suspected.

T or F

(The Diabetes-Related Family Conflict Scale should be administered routinely and as needed).

11. When referring an adolescent on continuous subcutaneous insulin infusion therapy to a mental healthcare professional, that specialist's knowledge of diabetes mellitus and its management is not a significant consideration.

T or F

(Mental health providers should be knowledgeable regarding diabetes mellitus and its management).

Importance of glycemic control

Strict glycemic control is associated with the development of fewer short- and long-term complications of diabetes mellitus type 1, and slower progression of existing complications. Short-term complications of poor glycemic control may include diabetes ketoacidosis and hypoglycemia. Long-term complications associated with more liberal glycemic control over time include micro- and macrovascular changes leading to retinopathy, neuropathy, cardiovascular disease and nephropathy (Silverstein et al, 2005).

Improvement in glycemic control of any duration in adolescents with diabetes mellitus type 1 is significant in reducing or slowing irreversible complication development, some of which will not be evident until much later in life. Control of

maximally elevated A1c levels (frequently seen in adolescence) may convey very real clinical and financial benefits later in life (Berger, 2007).

Diabetes mellitus type 1 and adolescence

Recommended degree of desired glycemic control for adolescents is not as uniform as it is for adults given the tumultuous nature of adolescence, with the potential for rapid swings in blood glucose secondary to hormonal changes of puberty, and dietary, behavioral and treatment inconsistencies.

The American Diabetes Association (2008a, p. S19) makes the following recommendations for glycemic control in adolescence:

Age	Plasma glucose, preprandially	Plasma glucose, overnight	Target A1c value
< 12 years old	90-180 mg/dl	100-180 mg/dl	<8%
12-19 years old	90-130 mg/dl	90-150 mg/dl	<7.5%

Glycemic goals may need to be further individualized, to avoid hypoglycemia and the neurological risks it presents to the developing brain (American Diabetes Association, 2008a; American Diabetes Association, 2008b).

A wide range of psychological, neurological, developmental and social variables impact on glycemic control and disease management for this age group. Adolescents with diabetes mellitus type 1 are at greater risk for psychiatric disorders, especially females. A prospective longitudinal study of health outcomes in type 1 diabetes demonstrates that half of the participants with historically poor glycemic control had a psychiatric comorbidity (Northam, Matthews, Anderson, Cameron, and Werther, 2004, in

Delamater, 2007). These comorbidities include depression, behavioral problems, eating disorders, anxiety, and poor self-esteem.

Neurocognitive and neuropsychological deficits have been demonstrated in young people with diabetes; recurrent severe hypo- and hyperglycemia have been associated with decreased memory and learning capacity. Six years after diagnosis, children with diabetes have been found to have poorer performance when measuring intelligence, attention, processing speed, and long-term memory than comparable control subjects (Northam, Anderson, Jacobs, Hughes, Warne, and Werther, 2001). These deficits may impact on the adolescent's ability to effectively manage their diabetes through intensive therapies requiring a high level of self-care, integrative decision making, and intact executive functioning.

Living with diabetes mellitus type 1 can be stressful for adolescents and their families. Ineffective coping due to uneven maturation, (i.e., "learned helplessness", or a mismatch between self-care abilities and cognitive comprehension), correlates with poorer treatment adherence and glycemic control (Hanson, Cigrant, Harris, Carle, Relyea and Burghen, 1989, in Delamater, 2007). Degree of regime adherence and glycemic control are influenced by health beliefs; adolescents with diabetes mellitus type 1 often underestimate their own long-term risks from poor adherence and uneven glycemic control, though they are better able to perceive the gravity of these risks for their peers with diabetes mellitus type 1 (Patino, Sanchez, Eidson and Delamater, 2005).

Family functionality is indirectly reflected in the degree of glycemic control attained. Tight glycemic control and routine treatment adherence is more commonly

found when there is family cohesion, agreement about division of responsibility for diabetes management, and supportive relationships. Poorer control and variable adherence correlate with family and treatment conflict, and lack of agreement regarding diabetes management responsibilities (Delamater, 2007).

Continuous subcutaneous insulin infusion

Continuous subcutaneous insulin infusion may be especially useful in adolescents with diabetes refractory to other management options, or with diminished quality of life due to an inflexible treatment regimen. Complication rates are most significantly improved in those with the most deranged glycemic control prior to continuous subcutaneous insulin infusion initiation (Pickup and Keen, 2002). Ahern et al (2002) were able to demonstrate a significant improvement in A1c levels with continuous subcutaneous insulin infusion treatment of diabetes mellitus type 1 in adolescents compared to results obtained with MDI therapy over 1 year.

Since this project is directed at adolescents already established on continuous subcutaneous insulin infusion therapy, general indicators for continuous subcutaneous insulin infusion therapy will not be reviewed here. The reader is referred to the review discussion of criteria for initiation of continuous subcutaneous insulin infusion therapy, contraindications to continuous subcutaneous insulin infusion therapy, and advantage of continuous subcutaneous insulin infusion therapy in Chapter 2.

Diabetes-related family conflict

One of the most difficult aspects of continuous subcutaneous insulin infusion therapy with adolescents involves maintenance of parent-adolescent teamwork without

increasing diabetes related family conflict when treatment is intensified. Successful continuous subcutaneous insulin infusion therapy in adolescents requires greater parental involvement in self-care activities, but at a time when adolescent personal identity formation calls for increased autonomy (Weinger, O'Donnell and Ritholz, 2001). Such a situation seems almost guaranteed to result in increased family conflict. Research literature demonstrates an association between diabetes-specific family conflict, lower adherence rates and poorer glycemic control in adolescents (Wysocki et al, 2006). This conflict may stem from discrepancies in levels of autonomy and ability related to diabetes self-management, and adolescents' interpretations of parental involvement as misguided, intrusive or controlling (Hood et al, 2007). Parents must simultaneously support their child's attainment of the routine developmental tasks of adolescence (driving, peer pressure, physical changes associated with puberty, and coping with increasingly complex, less predictable schedules), while maintaining positive family support around tasks related to intensive diabetes management (reminding about, helping with and occasional performance of self-management tasks such as blood glucose monitoring, cartridge/ tubing/ catheter site changes, pump troubleshooting, and carbohydrate counting) (Weinger et al, 2001).

In an analysis of a focus group research approach involving 24 adolescents at a diabetes summer camp, Weinger, O'Donnell and Ritholz (2001) found that adolescents' perceptions of parental worry and parent's more limited understanding of diabetes mellitus type 1 and its complexities, coupled with perceived intrusive and blaming behaviors were conflict etiologies. Another common cause of family conflict in diabetes

is the discord between parents' concern about hyperglycemia and cumulative, long-term complications, and adolescents' immediate desire to avoid hypoglycemia, out of fears for safety and not fitting in socially:

“The differing fears of adolescents and their parents may manifest in differing goals of diabetes management. If adolescents are trying to avoid hypoglycemia and parents are trying to avoid hyperglycemia, conflicts will inevitably arise. Interventions that allow parents and adolescents to discuss their differing points of view...may be helpful in decreasing this source of conflict” (Weinger et al, 2001, p. 334).

When diabetes-related family conflict was targeted in a research study looking at office-based interventions to maintain family teamwork in diabetes management, parental involvement was strengthened and conflict diminished (Anderson et al, 1999; Grey, Boland, Davidson, Yu, Sullivan-Bolyai and Tamborlane, 1998).

Continuous subcutaneous insulin infusion, generalists and psychosocial issues in diabetes mellitus type 1 management:

There are a range of approaches discussed in the literature regarding psychosocial issues that impact on diabetes, both assessment and treatment. There is agreement only that a plethora of psychosocial issues may impact on glycemic control in the adolescent age group. Silverstein et al (2005) provide concrete recommendations regarding adjustment and psychiatric disorders:

- adolescents with poor glycemic control and / or inconsistent adherence or with recurrent diabetes ketoacidosis should be screened for psychiatric disorders

- routine screening for depression and family coping should be done
- those who are found to have a psychiatric disorder or difficulties with family coping should be referred promptly for treatment.

Incorporating assessment of psychosocial issues into routine continuous subcutaneous insulin infusion care is challenging due to a lack of standard reporting metrics in the research literature (Weissberg-Benchell et al, 2003). Comparing three different practice guidelines addressing diabetes mellitus type 1 management using intensive therapy illustrates this point:

Practice Guidelines	Continuous subcutaneous insulin infusion treatment	Mental health support recommendations
National Institute for Clinical Excellence, 2003	Multispecialist team involvement recommended at initiation and at follow-up routinely. No mention of mental health specialists as team members, or of the patient and family's roles.	No mention of mental health support at initiation or routine follow-up care
Silverstein et al, (2005)	Ideally, multispecialist team involvement at diagnosis and at treatment intensification; no overt mention of the patient's role	Mental health professional support at diagnosis and at treatment intensification
American Diabetes Association, (2008a)	Multispecialist team involvement at diagnosis and at treatment intensification, including patient and family as essential team members with active self-care roles	Mental health professional support at diagnosis and at treatment intensification

The American Diabetes Association (2008a) provides the most comprehensive and flexible approach to treatment, advising a physician-coordinated team composed of physicians, nurse practitioners, physician's assistants, nurses, dieticians, pharmacists and

mental health professionals with expertise and interest in diabetes. Further, they specifically recognize the patient as an essential team member who assumes an active self-care role, and the family as part of the individualized therapeutic alliance for care.

Many pediatric diabetes specialists are affiliated with diabetes multidisciplinary treatment teams and can refer patients with psychosocial issues affecting diabetes management to them for diagnosis and treatment (Weintrob et al, 2003; Hoogma, 2001). In lieu of immediate access to specialty providers for seamless response to care provision needs, general practitioners involved in the care of this patient population need readily available, easily implemented, valid and reliable evaluation tools to screen for psychosocial issues in general and diabetes-related family conflict in particular.

Screening for diabetes-related family conflict: The Diabetes-Related Family Conflict Scale:

A common scenario for family conflict genesis involves an adolescent or school-age child who has successfully transitioned to continuous subcutaneous insulin infusion with a consistent pattern of tight glycemic control for a period of time, who then experiences a non-critical deterioration in glycemic control (Ahern et al, 2002). In a busy pediatric endocrinology practice, or in an area experiencing a specialist shortage, there might be a months-long delay before an appointment can be made to address this issue. A primary care provider might be consulted by the family in the interim.

A general practitioner, with fewer resources for elucidating the etiology of glycemic deterioration could use a quick, accurate, easily administered and interpreted assessment instrument that identifies dysfunctional family conflict related to diabetes

management, and efficiently guides the most appropriate interventions (Hood et al, 2007).

The Diabetes Family Conflict Scale was first developed by Rubin, Young-Hyman, and Peyrot in 1989, prior to the introduction of intensive management regimes. The Scale was modified and revised in 2007 by Hood, Butler, Anderson and Laffel, to better address the potential for conflict presented by the requirements of intensive regimes, and to evaluate its psychometric properties (see figure 2). This scale has acceptable internal reliability for both the child and parent formats, as confirmed by Cronbach's alpha scores of 0.85 and 0.81, respectively, with each of the 19 items contributing consistently to the score as a whole. Validity assessment was accomplished by comparing child and parent responses to the age/ role-appropriate versions of the Blood Glucose Monitoring Communication Questionnaire, the Pediatric Quality of Life Inventory and the Problem Areas in Diabetes-Parent Version; child-reported conflict correlated in a statistically significant way with negative affect associated with blood glucose monitoring and diminished quality of life. Parent/caregiver conflict likewise correlated with adult reporting of negative affect associated with blood glucose monitoring, proxy reporting of diminished quality of life in the child, and the adult's greater perception of caregiver burden. Thus, this revised version of the Scale is both reliable and valid in assessing for diabetes-related family conflict (Hood et al, 2007).

The revised Scale was also found to have predictive validity, as both child and parent reports of diabetes-related family conflict correlated with glycemic control as measured by A1c values. Greater degrees of diabetes-related family conflict were

significantly associated with poorer glycemic control, and minimal conflict with more optimal control. A multivariate analysis was performed, to determine the contribution of diabetes-specific family conflict to glycemic control, when direct management task factors were considered (amount of daily insulin dosing, frequency of blood glucose monitoring, and number of injections per day). Diabetes-specific family conflict was found to have an additive, independent contribution to glycemic outcome, accounting for 6% of the variance in A1c values, in addition to that contributed by other direct management tasks (Hood et al, 2007).

The revised Scale lists 19 management tasks, rated along a 3-point Likert scale (1=never argue, 2=sometimes argue, 3=always argue), for a score range of 19 to 57, with 19 indicating no conflict, and 57 indicating maximal conflict. The questionnaire is designed to be completed in less than 5 minutes, with only a few extra minutes required for scoring (Hood et al, 2007). Scores can be calculated by assistive personnel. Interpretation of results should be the purview of the healthcare professional.

An effective use of this score would be its relative value in tracking trends in conflict over time by routinely administering the survey in conjunction with A1c measurements, quarterly in most stable patients, and as needed for those with glycemic control issues. Establishing a benchmark ratio of preexisting degree of conflict to degree of glycemic control would be useful in comparison with later ratios, especially those obtained during situations of glycemic deterioration, when significant family conflict is suspected.

Figure 2: Diabetes Family Conflict Survey (Revised), child version (Reprinted with permission of Dr. K Hood, 2008).

Diabetes Family Conflict Survey

Think about your diabetes care over the past month. For each of the following parts of your diabetes care, **decide how much you argued or hassled with your parents about it during that time.** The word "parents" refers to the adult(s)/family members involved in your diabetes care.

During the **PAST MONTH**, I have argued with my parent(s) about...

	<u>Almost Never</u> <u>Argue</u>	<u>Sometimes</u> <u>Argue</u>	<u>Almost Always</u> <u>Argue</u>
1. Remembering to give shots or to bolus (pump)	①	②	③
2. Taking more or less insulin depending on results	①	②	③
3. Remembering to check blood sugars	①	②	③
4. Remembering clinic appointments	①	②	③
5. Giving shots or boluses (pump)	①	②	③
6. Meals and snacks	①	②	③
7. Results of blood sugar monitoring	①	②	③
8. The early signs of low blood sugar	①	②	③
9. What to eat when away from home	①	②	③
10. Making appointments with dentists and doctors	①	②	③
11. Telling teachers about diabetes	①	②	③
12. Telling friends about diabetes	①	②	③
13. Carrying sugar/carbs for reactions	①	②	③
14. School absences	①	②	③
15. Supplies	①	②	③
16. Telling relatives about diabetes	①	②	③
17. Rotating injection sites or infusion sets (pump)	①	②	③
18. Changes in health (like weight or infections)	①	②	③
19. Logging blood sugar results	①	②	③

If diabetes-based family conflict does not appear to be a significant issue, other areas for the practitioner to explore would include quality of life, neuropsychological evaluation for learning disabilities, developmental adjustment and self-care efficacy, psychosocial adjustment disorders, psychiatric disorders, and eating disorders (Delamater, 2007). Quality of life and self-care assessment tools are available, to aid in the identification of problems in this arena. For many of these issues, prompt referral to mental health care providers versed in diabetes mellitus management is warranted. Any

expression of suicidal ideation or concerns regarding potential harm to self or others requires emergent psychiatric evaluation. Further exploration of interventions in these areas is beyond the scope of this paper.

Evidence-based interventions for diabetes-related family conflict

Adolescents and their families should have the ability to interact with mental health professionals, for comprehensive assessment of psychosocial and neurobehavioral functioning and treatment of pathology. Given the propensity for conflict in general during adolescence between parents and children, a proactive approach to diabetes-related conflict would include educating parents about effective, nonintrusive interactions around diabetes management concerns prior to conflict development, and appointment time for more routine psychosocial “check-ins” (Weinger et al, 2001). A good example of this type of family-based behavioral intervention is Anderson et al’s office-based approach to maintain family teamwork in diabetes management (1999). Such an intervention would be feasible in a practice that deals with a number of intensively managed adolescents with diabetes mellitus type 1. If only a few were seen in the practice, it would be more effective to directly refer these patients to the psychosocial specialists affiliated with the endocrinology practice that routinely manages their continuous subcutaneous insulin infusion therapy. These professionals should also be available to the practitioner for consultation regarding “recognition and management of mental health and behavioral problems” (Delamater, 2007, p. 343). If these specialists are not available, the generalist needs to be prepared to refer to appropriately trained independent specialists, using community support resources as appropriate for adjunct

or interim support (i.e., community support groups for adolescents with diabetes mellitus type 1 and their families). Any mental health specialists involved in the care of adolescent patients with diabetes mellitus type 1 should have some understanding of diabetes and its management (Delamater, 2007).

Posttest

After the presentation is completed, the pretest is administered as a post-test. The comparison of both test results will indicate the module's effectiveness in preparing general practitioners to evaluate and manage diabetes-related family conflict in the adolescent population using the continuous subcutaneous insulin infusion modality to manage their diabetes mellitus type 1.

Evaluation of module effectiveness

Health care practitioners who attended this presentation will be asked to evaluate the impact of this training 3 to 6 months after attendance. They will be asked:

1. Did you attend the continuous subcutaneous insulin infusion and diabetes-related family conflict for the generalist presentation on _____ (date)?
 - _____ Yes
 - _____ No
2. If you attended, did you find it useful?
 - _____ Yes Comments: _____
 - _____ No Comments: _____
3. Have you administered the Diabetes-Related Family Conflict Scale since the training?

Yes

No

4. Do you routinely care for adolescents who manage their diabetes mellitus type 1 with continuous subcutaneous insulin infusion therapy?

Yes

No

5. How useful or effective do you feel the diabetes-related family conflict scale to be?

a. Of no use

b. Little use

c. Moderately useful

d. Very useful

6. Do you screen for diabetes-related family conflict in other ways?

Yes Comments _____

No Comments _____

7. When is the best time to screen for diabetes-related family conflict? Circle all that apply:

a. routinely with A1c evaluation

b. only as needed, when conflict is apparent

c. when glycemic control deteriorates.

d. Other _____

8. Should all adolescents with diabetes mellitus type 1 managed with continuous subcutaneous insulin infusion be screened for diabetes-related family conflict?

___ Yes

___ No

If no, who should be

screened? _____

Summary

An educational module was presented, focusing on the roles of glycemic derangement in complication generation, challenges to adolescents' attainment of glycemic control, the role of continuous subcutaneous insulin infusion in that attainment, role of and risk factors for dysfunctional family conflict in glycemic derangement, and the role of generalists in mitigating the effects of psychosocial issues. The Diabetes-Related Family Conflict Scale was introduced, along with suggestions for administration, scoring and interventions. This presentation was designed for general practice health care providers who interact with adolescents with diabetes mellitus type 1 treated with continuous subcutaneous insulin infusion therapy. This patient population is susceptible to glycemic repercussions of diabetes-related family conflict.

Module evaluation is suggested, 3 to 6 months after module presentation, to determine changes in practice around recognition and treatment of diabetes-related family conflict in adolescents.

CHAPTER 4

Discussion of project

Patterson and McCubbin's Double ABCX Model of Family Stress (1983) provides an effective theoretical model for use in assessing the generation and significance of family conflict in diabetes mellitus type 1 management of adolescents. This model of shifting adaptation and balance over time complements the multifactorial nature of adolescent growth and development coupled with the demands of managing an evolving chronic illness.

The significance of the contribution of psychosocial aspects to glycemic control has been recognized more recently in the research literature and new methods of assessing their presence and impact are being developed. The prevalence of psychiatric comorbidities with a diabetes mellitus type 1 diagnosis is high, approaching 50% in those with poor glycemic control (Northam et al, 2004, Delamater, 2007; Jack, 2003). Normal adolescent growth and development coupled with chronic disease management intensification encourages added stress and conflict, often to the point of dysfunction (Delamater, 2007; Wysocki et al, 2006; Weinger et al, 2001; Jack, 2003). The Diabetes-Related Family Conflict Scale (Rubin et al, 1989; Hood et al, 2007) was developed and revised in response to this dynamic, as were office-based interventions (Anderson et al, 1999). With these new methods and assessment tools, the potential for increased participation of general practitioners in complex management regimes is more likely. Ever-increasing cost-containment forces and shortages of specialist providers are further accelerating this development. The potential for continuous subcutaneous insulin

infusion regimes to revolutionize long-term outcomes for people with diabetes mellitus type 1 is considerable. Improved long-term quality of life and overall health, with significant savings on healthcare expenditures these gains represent are within our reach with intensive management. The uneven development of knowledge of and techniques for treating psychosocial aspects of intensive management regimes threatens this development. Assessing for and addressing treatment-related family conflict in intensive management will help realize this potential.

Time is of the essence when glycemic control is impacted in adolescence, as lack of control translates into acceleration of complication development and exacerbation in later life (Ahern et al, 2002; Bode et al, 2002; Pickup and Keen, 2002; Liberatore and Daminani, 2006; Weissberg-Benchell et al, 2003). There is no “catching up” later. Use of the DRFC Scale is a reasonable, responsive approach in such situations.

Strengths of project:

Use of the Diabetes-Related Family Conflict Scale can resolve conflicting realities generalists face, of professional responsibility to patients and families to act on issues that the practitioner may have little familiarity with, when the financial reality of managed care practice demands a rapid ascent of steep learning curves, with little time for in-depth intervention. The Scale allows accurate and rapid identification of family dysfunction related to diabetes management by general practitioners.

Another strength of this project is its approach to diabetes mellitus type 1 management, linking characteristics of growth and development with technological advances. In successful intensive diabetes mellitus management, the adolescent patient’s

willingness and ability to consciously oversee CSII therapy via insulin pump is as critical to success as was the development of rapid acting insulin analogs, yet till recently, this aspect of care was given little attention. Even today this aspect is often unevenly addressed outside of specialty practices. Given specialist shortages, and long waits for appointments, is imperative that this information be made readily available to general care practitioners (Skyler et al, 2007).

Limitations

There are a lack of mental health specialists knowledgeable about DM and its management. In a recent study of 201 adults with diabetes mellitus type 2 and serious mental illness, only 14% of participants reported that their mental healthcare provider asked to speak with their diabetes care provider. Integration of mental and physical health care for those with diabetes is generally lacking (Goldberg et al, 2007). Without access to such specialists, or integrative healthcare, projects like these are difficult to operationalize.

Reimbursement for primary care provider office visits with a mental health diagnosis code is often lacking, especially in managed care plans. Clearly, this does not encourage generalists to screen extensively for mental health issues, nor does it encourage the development and implementation of office-based interventions to address diabetes-related family conflict (American Academy of Family Physicians, 2001).

In today's "paper heavy" practices, competing demands for attention to documentation, billing, and regulatory compliance make it increasingly difficult to

introduce new assessment tools into routine practice, even ones that are relatively easy to implement (American Academy of Family Physicians, 2001).

Generalizability of study conclusions, screening effectiveness and screening accuracy are limited due to the homogeneity of most research participant populations (white, middle to upper class, educated, predominantly stable two parent households, with adequate financial resources and access to consistent healthcare) (Ahern et al, 2002). Those who could most benefit from the improvements made possible by continuous subcutaneous insulin infusion therapy are ironically those who are least likely to be encouraged to pursue it, due to barriers of cost, access, culture and outreach.

Conclusions

Adequate treatment of diabetes mellitus type 1 over the long term requires strict attention to glycemic control over the short term. Use of intensive insulin regimes, especially continuous subcutaneous insulin infusion pumps with rapid acting insulin, has made the potential for strict glycemic control more of a reality than ever before. Treatment intensification, especially in adolescent populations, comes with a new set of adaptive issues. Among these issues, diabetes-related family conflict looms large, and its full impact on glycemic control is often overlooked, especially in the primary care practice. Use of the Diabetes-Related Family Conflict Scale for assessment and tracking purposes can help in identifying problem areas of management, and aids in effective treatment intervention.

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