

## Adherence to Treatment in Children and Adolescents with Type One Diabetes Mellitus

a report by

**Susana R Patton, PhD**

*Division of Child Behavioral Health, Department of Pediatrics and Communicable Diseases,  
CS Mott Children's Hospital, University of Michigan*

Type one diabetes mellitus (T1DM) is the most common chronic metabolic disorder of childhood.<sup>1,2</sup> The etiology of T1DM is not completely known, but may result from autoimmune destruction of the pancreatic islet cells.<sup>3</sup> This, in turn, results in a permanent absence of insulin production and an inability to metabolize glucose.<sup>3,4</sup> Patients with T1DM are treated with insulin replacement, which can be delivered via multiple daily injections or by an insulin pump, which delivers a basal stream of insulin to the patient between meals and can be programmed to deliver bolus doses of insulin at meals. Other important components of diabetes care include daily self-monitoring of blood glucose levels, carbohydrate counting, and exercise.<sup>4</sup>

Current prevalence estimates suggest that T1DM occurs in one in 600 children in the United States.<sup>2</sup> T1DM appears to be most commonly diagnosed during early childhood (less than seven years old) and middle childhood (between eleven and twelve years old).<sup>2,4</sup> It can be diagnosed at any age. Longitudinal studies conducted with adolescents and adults with T1DM suggest that rigorous adherence to diabetes treatment recommendations can result in better long-term outcomes and a reduced risk of diabetes-related complications, including heart and kidney disease, stroke, blindness, neuropathy, and skin and limb complications.<sup>5,6</sup> In addition, for young children with T1DM, frequent episodes of hyper- and hypoglycemia, which may result from poor adherence, can have immediate health consequences, potentially affecting the child's growth and neuro-cognitive development.<sup>7,8</sup> Because of these potentially serious complications of poor blood glucose control, rigorous study has been made of children's adherence to diabetes treatment, predictors of poor adherence to treatment, and the development of interventions to optimize the adherence of children with T1DM and their families.

### Definition and Measurement of Adherence

Adherence is defined as 'the extent to which a person's behavior (in terms of taking medications, following

diets, or executing lifestyle changes) coincides with medical or health advice'.<sup>9</sup> To measure adherence rates, researchers must apply a standard, which may be patient-specific (i.e. an individual diet plan) or based on general practice guidelines for a specific medical condition (i.e. the American Diabetes Association guidelines). How researchers have conceptualized adherence has changed.<sup>10</sup> Previously, researchers commonly adopted a conceptualization of adherence that was trait-like and static.<sup>10</sup> Patients were either adherent or non-adherent to treatment and their adherence status did not change with time. Recently, researchers have begun to adopt a more dynamic conceptualization of adherence.<sup>10</sup> Many researchers now understand that patients' rates of adherence may differ depending on the treatment task (e.g. self monitoring of blood glucose versus diet) and that patients' adherence rates may change in response to their environment, behavior, or personal beliefs.

There are many different methods of measuring adherence in T1DM. The gold standard for measuring adherence is electronic measurement, which in T1DM may include self-monitoring of blood glucose via a blood glucose meter and insulin usage via an insulin pump. These electronic devices can record the date, time, and behavior performed (e.g. register a blood glucose value, report the amount of insulin dispensed), thus allowing for unobtrusive tracking of patient behavior. Other measures include patient self-report (e.g. blood glucose logs, diet diaries), structured interviews (e.g. 24-hour recall interview),<sup>11</sup> and patient questionnaires (e.g. self-care inventory).<sup>12</sup> In all methods, researchers acknowledge the possibility of measurement error. It is typically recommended that multiple methods be employed to obtain an accurate measure of adherence.

### Adherence Rates in Children with T1DM

Despite advances in our understanding of T1DM and diabetes treatment, the regimen remains complex and time-consuming, which can make adherence to treatment difficult. Several cross-sectional studies have revealed relatively high rates of non-adherence in children and



Susana R Patton, PhD, is an Assistant Professor of Pediatrics at the University of Michigan Medical School and a pediatric psychologist at the CS Mott Children's Hospital. Dr Patton's research is in the adherence behaviors of families of young children with type I diabetes and the potential obstacles to optimal metabolic control for these children. Dr Patton has received grant support from the National Institutes of Health (NIH) to study dietary adherence and mealtime behaviors in young children with type I diabetes. She has also received support from the University of Michigan for pilot studies investigating barriers to optimal glycemic control in preschoolers using insulin pumps. Dr Patton has published over 15 peer-reviewed articles in scientific journals and has presented her research at the Scientific Sessions of the American Diabetes Association. She has reviewed abstract and manuscript submissions for the American Psychological Association (APA) and for several prominent psychology and medical journals.

adolescents with T1DM. In a study of 74 children ages 11–16 ( $M = 13.6 + 1.7$  years), researchers found 49% of children did not adhere to their insulin and diet recommendations, 75% of youths failed to complete prescribed blood glucose tests, and 64% did not follow through with exercise recommendations.<sup>13</sup> Greening and colleagues reported non-adherence rates of about 50% for insulin, blood-glucose testing, diet, and exercise among their sample of 111 children ( $M = 12.3 + 3.7$  years).<sup>14</sup> Stewart et al.<sup>15</sup> described self-reported non-adherence rates of about 50% for diet, blood glucose testing, and exercise and slightly lower rates of non-adherence to insulin in a sample of Hong Kong youths with T1DM.<sup>15</sup>

When studies have concentrated on specific aspects of the diabetes regimen (e.g. blood glucose testing or diet), many reported rates of non-adherence have been similarly poor. Using electronic measurement to examine self-monitoring of blood glucose testing, Miller and colleagues reported that adolescents performed a mean of  $2.66 + 0.78$  blood glucose checks per day, which is approximately half the number of daily tests typically recommended for patients.<sup>16</sup> With respect to insulin, omission may be common among adolescent girls with T1DM who may use this as a weight management strategy. In one study of 143 adolescents with T1DM, ten-point-three per cent of girls reported skipping insulin and seven-point-four per cent of girls reported taking less insulin than recommended as a method of weight control.<sup>17</sup> Finally, when examining adherence to dietary recommendations, dietary adherence rates have been found to range between 21–56% among school-age children and adolescents, while among children less than eight years old, dietary adherence rates to daily carbohydrate recommendations were higher (about 75%).<sup>18</sup>

In summary, the research examining the adherence of children and adolescents with T1DM has revealed different rates of adherence depending on the specific diabetes task, patients' age, and the method of measuring adherence. Overall, the research is remarkable for moderate to low adherence rates, which underscores the need to examine patient barriers to adherence and to develop interventions to improve patient adherence.

#### **Predictors of Adherence in Children with Type One Diabetes Mellitus**

Research has uncovered a number of barriers to treatment (lifestyle or personal beliefs that may prevent or inhibit treatment adherence) in adolescents with T1DM, including behavioral factors (e.g. poor planning, not having the needed supplies), cognitive factors (e.g. discomfort or embarrassment, poor problem solving,

limited knowledge, fear), and environmental factors (e.g. limited time, no one to assist or supervise diabetes management, insurance problems).<sup>19</sup> Researchers have also endeavored to identify consistent demographic and behavioral correlates of diabetes adherence. Among demographic correlates, research suggests poorer adherence rates among older children and adolescents,<sup>10,20</sup> children living in single-parent families,<sup>4,10</sup> and children living in families of lower socio-economic status.<sup>21</sup> Behaviorally, greater knowledge about diabetes has been found to weakly predict better treatment adherence for many patients.<sup>4</sup> This association is intuitive as it would seem accurate knowledge of treatment would be required for patients to adequately adhere to their regimen. Knowledge is not sufficient for optimal adherence rates in all children if environmental and behaviors foil the parent and child's ability to perform treatment tasks. Additional behavioral factors which have been found to predict lower adherence rates include high levels of family stress,<sup>10</sup> poor social coping and problem-solving,<sup>12</sup> and inappropriate levels of child responsibility for diabetes management.<sup>22,23</sup>

#### **Interventions to Improve Adherence in Children and Adolescents with Type I Diabetes Mellitus**

Research that has measured patients' adherence rates and identified patient-specific predictors of adherence has played an important role in shaping the development of intervention programs. The interventions that have received the most attention have included components that target adherence, patients' social and coping skills, problem solving, and family communication. For the purpose of this review, two behavioral interventions that incorporate a multiple component design will be described.

The first intervention sought to modify 'Robin and Foster's Behavioral Family Systems Therapy' (BFST) to target adherence in adolescents with T1DM.<sup>24</sup> BFST is a comprehensive intervention program that targets problem solving and family communication. Originally developed for adolescents with conduct disorder, Wysocki et al. adapted BFST to make it specific to T1DM.<sup>25,26</sup> Among the changes, the new diabetes specific BFST (BFST-D) focused on diabetes-specific problem solving, increasing family knowledge about diabetes treatment, and helping families to recruit teachers, friends, and other important persons to assist with diabetes care.<sup>26</sup> Using this approach, BFST-D was found to improve adolescents' adherence rates and decrease family conflict related to diabetes post-treatment, especially among adolescents with very poor metabolic control.<sup>26</sup> Adolescents who participated in BFST-D also experienced an improvement in their

hemoglobin A1c levels, although the change was not significant.<sup>26</sup> The long-term impact of BFST-D on adherence has yet to be determined. The short-term improvements are promising and suggest that this intervention may be effective in improving adherence in adolescents with T1DM.

The second intervention is a trial of 'Multisystemic Therapy' (MST) with adolescents with T1DM.<sup>27</sup> Similar to BFST, MST was originally developed to treat youths with behavior and conduct disorders. This intensive intervention uses a home-based treatment model that targets behavioral changes in the adolescent, the family, and changes in the community systems available to support families (e.g. school and health care system). For diabetes, the target of intervention is patients' adherence to treatment and behavioral interventions to minimize barriers to adherence.<sup>27</sup> Findings of a randomized control trial using MST, revealed that compared to adolescents who did not complete MST treatment, adolescents who participated in the treatment had better adherence rates to blood glucose monitoring as assessed by electronic measurement and 24-hour recall. These patients also had a lower rate of hospitalization than adolescents who did not complete MST. When examining hemoglobin A1c levels, no difference was found between adolescents who completed MST and adolescents who did not.

BFST and MST are two intervention programs that have demonstrated short-term improvements in adherence among adolescents with T1DM. Both interventions target multiple barriers to adherence, including patient knowledge, problem solving and social skills, and family communication. To determine their long-term impact on adherence behaviors, prospective follow-up studies are needed among participants.

### Summary

Type one diabetes mellitus (T1DM) is a serious chronic illness of childhood. Longitudinal studies in adolescents

and adults have demonstrated that strict adherence to diabetes recommendations can lower the risk of diabetes-related complications, including heart and kidney disease, stroke, blindness, neuropathy, and skin and limb complications. Despite this information and medical advances that have simplified the diabetes regimen, the adherence rates of children and adolescents with T1DM tend to range from moderate to low. Many children and adolescents with T1DM do not self-test their blood glucose according to standard medical recommendations. Likewise, many children and adolescents fail to follow the dietary recommendations for T1DM and/or fail to administer insulin appropriately for the carbohydrates they consume. In an effort to predict patient variables that may affect adherence rates, researchers have identified a number of modifiable factors including patient/family knowledge, social and coping skills, problem-solving skills, and family communication.

Researchers have designed and tested multiple behavioral interventions to improve the adherence rates of children and adolescents with T1DM. This review highlighted two family-based interventions that have demonstrated short-term improvements in adherence. There remains a need for future research to examine the long-term effectiveness of these interventions as well as conduct a dismantling of the interventions to discover the specific components of treatment that led to improvements in adherence.

Physicians working with children and adolescents with T1DM are encouraged to use multiple measures to assess patients' adherence to treatment and the varied personal, behavioral, environmental barriers that could impact patients' adherence rates based on existing literature. In situations where children and adolescents are struggling to complete all aspects of their diabetes regimen, a referral to a behavioral-specialist may be needed to address adherence problems promptly versus waiting for diabetes-related complications to develop. ■

### References

1. Amos AF, McCarty DJ, Zimmet P, "The rising global burden of diabetes and its complications: estimates and projections to the year 2010", *Diabet Med* (1997);14(5): S1-85.
2. LaPorte R, Matsushima M, Chang Y, "Prevalence and incidence of insulin dependent diabetes", in Harris MI, Cowie CC, Stern PP, et al., (eds), *Diabetes in America, 2nd ed* Bethesda, MD (1995): pp. 3745.
3. Sperling M, "Diabetes Mellitus", in Sperling M, (ed.), *Pediatric Endocrinology, Philadelphia, PA: WB Saunders* (1996): pp. 229-264.
4. Wysocki T, Greco P, Buckloh L, "Childhood diabetes in psychological context", in Roberts M (ed.), *Handbook of Pediatric Psychology, 3rd ed.* New York, NY: The Guilford Press (2003): pp. 304-320.
5. *The Diabetes Control and Complications Trial*, "The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus", *N Engl J Med* (1993);329(14): pp. 977-986.

6. *The Diabetes Control and Complications Trial*, "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", *J Pediatr* (1994);125(2): pp. 177–188.
7. Brown M, Ahmed ML, Clayton KL, et al., "Growth during childhood and final height in type 1 diabetes", *Diabet Med* (1994);11(2): pp. 182–187.
8. Franzese A, Valerio G, Spagnuolo MI, "Management of diabetes in childhood: are children small adults?", *Clin Nutr* (2004);23(3): pp. 293–305.
9. Haynes R, "Introduction", in Haynes R, Taylor D, Sackett D, (eds), *Compliance in Health Care*, Baltimore: Johns Hopkins University Press (1979): pp. 2–3.
10. Johnson SB, "Insulin-dependent diabetes mellitus in childhood", in Roberts MC (ed.), *Handbook of Pediatric Psychology*, 2nd ed, New York: Guilford (1995): pp. 263–285.
11. Johnson SB, Silverstein J, Rosenbloom A, et al., "Assessing daily management in childhood diabetes", *Health Psychol* (1986);5(6): pp. 545–564.
12. La Greca AM, Auslander WF, Greco P, et al., "I get by with a little help from my family and friends: adolescents' support for diabetes care", *J Pediatr Psychol* (1995);20(4): pp. 449–476.
13. Patino AM, Sanchez J, Eidson M, et al., "Health beliefs and regimen adherence in minority adolescents with type 1 diabetes", *J Pediatr Psychol* (2005);30(6): pp. 503–512.
14. Greening L, Stoppelbein L, Konishi C, et al., "Child Routines and Youths' Adherence to Treatment for Type 1 Diabetes", *J Pediatr Psychol* (2006).
15. Stewart SM, Lee PW, Waller D, et al., "A follow-up study of adherence and glycemic control among Hong Kong youths with diabetes", *J Pediatr Psychol* (2003);28(1): pp. 67–79.
16. Miller VA, Drotar D, "Discrepancies between mother and adolescent perceptions of diabetes-related decision-making autonomy and their relationship to diabetes-related conflict and adherence to treatment", *J Pediatr Psychol* (2003);28(4): pp. 265–274.
17. Neumark-Sztainer D, Patterson J, et al., "Weight control practices and disordered eating behaviors among adolescent females and males with type 1 diabetes: associations with sociodemographics, weight concerns, familial factors, and metabolic outcomes", *Diabetes Care* (2002);25(8): pp. 1289–1296.
18. Patton S, Dolan L, Powers S, "Dietary adherence and associated glycemic control in families of young children with type 1 diabetes", *J AM Diet Assoc* (in press).
19. Wysocki T, "Behavioral assessment and intervention in pediatric diabetes", *Behav Modif* (2006);30(1): pp. 72–92.
20. Mackner LM, McGrath AM, Stark LJ, "Dietary recommendations to prevent and manage chronic pediatric health conditions: adherence, intervention, and future directions", *J Dev Behav Pediatr* (2001);22(2): pp. 130–143.
21. Glasgow AM, Weissberg-Benchell J, Tynan WD, et al., "Readmissions of children with diabetes mellitus to a children's hospital", *Pediatrics* (1991);88(1): pp. 98–104.
22. Wysocki T, Taylor A, Hough BS, et al., "Deviation from developmentally appropriate self-care autonomy. Association with diabetes outcomes", *Diabetes Care* (1996);19(2): pp. 119–125.
23. Wiebe DJ, Berg CA, Korbel C, et al., "Children's appraisals of maternal involvement in coping with diabetes: enhancing our understanding of adherence, metabolic control, and quality of life across adolescence", *J Pediatr Psychol* (2005);30(2): pp. 167–178.
24. Robin A, Foster S, *Negotiating parent-adolescent conflict: A behavioral family systems approach*, New York: Guilford (1989).
25. Wysocki T, Harris MA, Greco P, et al., "Randomized, controlled trial of behavior therapy for families of adolescents with insulin-dependent diabetes mellitus", *J Pediatr Psychol* (2000);25(1): pp. 23–33.
26. Wysocki T, Harris MA, Buckloh LM, et al., "Effects of behavioral family systems therapy for diabetes on adolescents' family relationships, treatment adherence, and metabolic control", *J Pediatr Psychol* (2006);31(9): pp. 928–938.
27. Ellis DA, Frey MA, Naar-King S, et al., "Use of multisystemic therapy to improve regimen adherence among adolescents with type 1 diabetes in chronic poor metabolic control: a randomized controlled trial", *Diabetes Care* (2005);28(7): pp. 1604–1610.