Missed Medical Appointments and Disease Control in Children With Type 1 Diabetes

Kristine Fortin, MD, MPH, Elizabeth Pries, BSN, MSN, PNP, APN, & Soyang Kwon, PhD

ABSTRACT

The need exists to identify children with type 1 diabetes who are at risk for poor outcomes, and we hypothesized that missed appointments could be a useful indicator. We aimed to describe the frequency of missed medical appointments in children with type 1 diabetes and evaluate the relationship between missed appointments and poor disease control. Medical records of 1,002 children aged 0-17 years with type 1 diabetes and two or more scheduled appointments during a 43-month period were reviewed. Sixty-eight percent of patients missed no appointments, 17% missed one appointment, and 15% missed two or more appointments. Compared with patients who missed no appointments, patients who missed two or more appointments were three times more likely to have a diabetic ketoacidosis episode and three times more likely to have a hemoglobin A1c level equal to or greater than 8.5%. They were also more likely to be a member of a racial/ethnic minority group and be publicly insured. Missed appointments may be an important indicator of poor treatment adherence, requiring targeted interventions. J Pediatr Health Care. (2016) *30*, 381-389.

KEY WORDS

Adherence, medical care, medical neglect, outcomes, type 1 diabetes mellitus

Kristine Fortin, Assistant Professor, Division of General Pediatrics, Children's Hospital of Philadelphia, Philadelphia, PA, and Assistant Professor, Department of Pediatrics, Perlman School of Medicine at the University of Pennsylvania, Philadelphia, PA.

Elizabeth Pries, Advanced Practice Nurse, Division of Endocrinology, Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL.

Soyang Kwon, Research Assistant Professor, Stanley Manne Children's Research Institute, Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL.

Conflicts of interest: None to report.

Correspondence: Kristine Fortin, MD, MPH, Division of General Pediatrics, Children's Hospital of Philadelphia, 34th Street and Civic Center Blvd, Philadelphia, PA 19104-4399; e-mail: fortink@email.chop.edu.

0891-5245/$36.00

Published online November 7, 2015.

http://dx.doi.org/10.1016/j.pedhc.2015.09.012

Diabetes mellitus (DM) is one of the most common chronic childhood diseases, affecting 1 in 433 U.S. youth (Pettitt et al., 2014). The prevalence of type 1 DM has increased over time (Dabelea et al., 2014), and the number of U.S. youth with type 1 DM could almost triple by 2050 (Imperatore et al., 2012). Recommended diabetes care includes ongoing insulin therapy, medical visits every 3 months, repetitive home glucose testing, and dietary monitoring (Silverstein et al., 2005). Nonadherence with these intensive treatment demands engenders life-threatening complications. In the short term, lack of treatment is associated with diabetic ketoacidosis. Well-established long-term consequences of inadequate care include nephropathy, cardiovascular disease, and retinopathy (Nathan & DCCT/EDIC Research Group, 2014; The Writing Team for the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Research Group, 2014).

Given the significant short- and long-term consequences of inadequate DM management, early identification of nonadherent patients and targeted

intervention is important. Recognizing children at risk for poor care may ultimately reduce both short- and long-term morbidity in pediatric patients. Additionally, children rely on their parents to supervise and participate in their medical care (Silverstein et al., 2005). Medical neglect is a consideration when poor adherence is ongoing in pediatric patients. Identification of easily recognized markers that may indicate medical neglect could be useful in intervening with families prior to the development of medical consequences of the disease. Indicators of poor disease control are also relevant to health care costs. Diabetes accounts for an estimated 14% of U.S. health care expenditures (Zhang et al., 2010). Poor disease control is associated with increased health care costs (American Diabetes Association, 2003). Health care resources are limited, and clinical indicators of poor disease control could help target prevention efforts for patients at highest risk for complications.

Missed appointments have the potential to be a useful indicator of poor adherence and control. Prior research supports a relationship between appointment attendance and disease control. Adult studies, predominately of persons with type 2 diabetes, found that missed appointments were associated with poor disease control and with other nonadherent behaviors, such as home blood glucose testing and medication adherence (Ciechanowski et al., 2006; Karter et al., 2004; Schectman, Schorling, & Voss, 2008). Similar relationships between appointment attendance and disease control have been found in studies that include children with type 1 diabetes. A United Kingdom study of patients with type 1 diabetes ranging in age from 0.9 to 75 years found that clinic nonattendance was associated with increased risk for recurrent diabetic ketoacidosis (DKA; Wright et al., 2009). A New England study of patients with diabetes (mostly type 1) who were younger than 30 years found that patients with two or more cancelled or missed appointments had higher hemoglobin A1c (HbA1c) levels (Markowitz, Volkening, & Laffel, 2014). An Oregon study found that clinic attendance was associated with elevated HbA1c level in a sample of 155 patients with type 1 diabetes aged 2 to 18 years (Urbach et al., 2005). Compared with a referent group with three to four visits per year, patients with more frequent visits and patients with fewer visits had poorer disease control. This study focuses on the relationship between missed appointments, defined as appointments that were not kept or canceled, and poor disease control among patients with type 1 diabetes who were younger than 18 years. Data about missed appointments are easily accessible to clinicians. If missed appointments are associated with poor disease control, they could serve as a signal that further assessment of adherence and targeted interventions are needed.

Missed appointments have the potential to be a useful indicator of poor adherence and control.

The goal of this study is to describe the frequency of missed appointments in a sample of children with type 1 DM and evaluate the relationship between missed appointments and poor disease control.

METHODS

This medical record review of patients receiving outpatient care for type 1 DM was approved by the Institutional Review Board of Ann & Robert H. Lurie Children's Hospital of Chicago, IL (formerly Children's Memorial Hospital).

Setting and Study Population

The study was conducted among 1,002 patients receiving care for type 1 DM at a large urban children's hospital and affiliated satellite clinic. At these sites, outpatient care of children with type 1 DM is provided by a multidisciplinary team of endocrinologists, advanced practice nurses, nutritionists, social workers, and medical psychologists. During the study period, frequency of clinic visits was generally every 3 to 4 months. Families are encouraged to make return appointments at the end of each clinic visit and are provided with a written schedule of future appointments. Patients also receive appointment reminders in the form of recorded messages from the hospital, live phone calls from the diabetes clinic office, and letters 1 week prior to all scheduled appointments. Telephone prescription refills are not routinely provided for patients who have not been seen in more than 12 months. Patients who miss more than one clinic appointment receive a letter outlining clinic policy and asking them to call for an appointment.

Patients were identified through an International Classification of Diseases, Ninth Revision (ICD-9) code search in EpicCare electronic medical record (EMR). Persons with type 1 diabetes and at least two appointments scheduled for diabetes care from July 1, 2007, to January 31, 2011, were included. The start point coincided with EMR implementation. Because this study focused on children with type 1 DM, patients with a diagnosis of type 2 diabetes, type 1 and type 2 diabetes in combination, maturity-onset diabetes of the young, transient neonatal diabetes, secondary diabetes (as a result of cystic fibrosis or a pancreatectomy), diabetes related to medication, or type not yet diagnosed were excluded. Patients 18 years of age or older on July 1, 2007, also were excluded. Patients were not excluded on the basis of the duration of follow-up because this would have favored exclusion of newly diagnosed patients and patients transitioning to adult care and would have been less reflective of clinical practice.