

Helping Youth and Families with Diabetes Self-Management



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“It is hard to imagine ever doing another study where I don’t start out with patients and families first.”

- Elizabeth Cox, MD, PhD
UW-Madison, Department of Pediatrics

Overview

To prevent the long-term complications of diabetes among children, our program tailored diabetes self-management resources offered to children and their families at two pediatric diabetes centers, meeting the individual needs of over 2,200 Wisconsin children with type 1 diabetes (T1D) and their families. In addition, elements of this program were incorporated into diabetes clinics at Children’s Hospital of Wisconsin in Milwaukee. The study’s methods for engaging youth and families has inspired others like the American Diabetes Association and the Wisconsin Department of Public Health to make use of similar strategies.

The Clinical Problem

It is estimated that over 165,000 children under age 20 have T1D, and the number of cases has been increasing over time.

Due to the multi-faceted approach that is typically needed to manage diabetes, it is difficult for children and their families to adhere to their diabetes self-management regimens. Less than half of youth with diabetes have optimal glycemic control, and approximately 20% have poor glycemic control.

When youth are unable to achieve glycemic control, serious complications can result that affect the child’s quality and longevity of life, and the family may become both emotionally and financially stressed. Additionally, youth with sub-optimal glycemic control are more likely to have sub-optimal control as adults.

Our Response

T1D-SMART

The [Type 1 Diabetes Self-Management Resources Toolkit \(T1D-SMART\)](#) is a resource to help clinicians and healthcare organizations improve health outcomes and quality of life for youth with T1D and their families. The toolkit contains materials to deliver group-based family-centered self-management support by tailoring self-management resources to the needs and preferences of families of youth with T1D. The groups meet 4 times over 1 year for 75 minutes each.

Included in the toolkit are materials for planning, implementing, and evaluating the delivery of family-centered self-management resources in a group-based format integrated with routine T1D clinic visits.

This toolkit arises from Project ACE (Achieving control, Connecting resources, Empowering families), a multi-site randomized trial that evaluated the effectiveness of these resources. Project ACE's intervention was designed to improve both A1c for youth, as well as quality of life for youth and families, by addressing specific challenges that families living with T1D face every day. For details about the trial, see [Fiallo-Scharer et al., 2017](#).

“[My family’s] communication is very open now. A lot of our problem solving skills were reflected on and improved.”

- Adolescent Participant

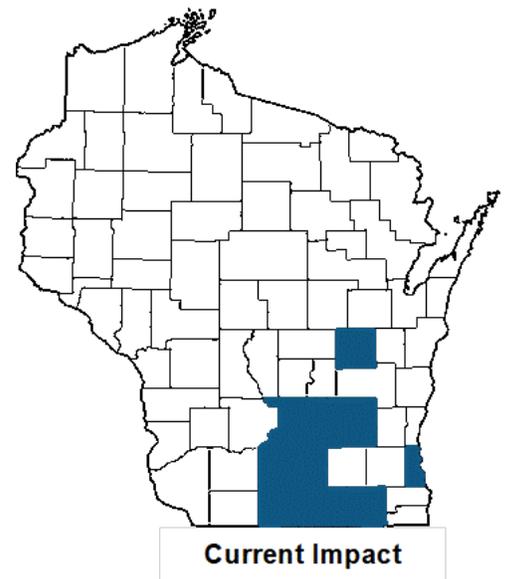
Results

In the American Family Children’s Hospital diabetes clinics, this approach significantly improved glycemic control among adolescents, a population for whom self-management is challenging to improve. The program tailored the diabetes self-management help offered to children and their families at two pediatric diabetes centers, meeting the individual needs of over 2,200 children with T1D and their families at UW Health.

Lasting Impact

The improvements in diabetes self-management seen among adolescents at American Family Children’s Hospital are expected to carry forward, improving lifelong glycemic control, and ultimately delaying complications.

Findings from the study have also prompted these clinics to undertake quality improvement efforts to ensure that needed mental health services are accessible for 600 youth with T1D who receive care at American Family Children’s Hospital diabetes clinics. Further, this work also provided the motivation for diabetes clinics at Children’s Hospital of Wisconsin to rejuvenate a group-based, family-centered approach to improving glycemic control among youth who are struggling to control their diabetes.



In addition, organizations like the American Diabetes Association and the Wisconsin Department of Public Health have used the study’s methods for engaging youth and families in their outreach work.

Resources

Toolkit

- ✓ [Type 1 Diabetes Self-Management Resources Toolkit \(T1D-SMART\)](#)