Interventions to Promote Diabetes Self-Management in Children and Youth: A Scoping Review

Susan M. Cahill, Katie M. Polo, Brad E. Egan, Nadia Marasti

MeSH TERMS
- child health services
- diabetes mellitus, Type 1
- diabetes mellitus, Type 2
- occupational therapy
- self-care

As children and youth with diabetes grow up, they become increasingly responsible for controlling and monitoring their condition. We conducted a scoping review to explore the research literature on self-management interventions for children and youth with diabetes. Eleven studies met the inclusion criteria. Some of the studies reviewed combined the participant population so that children with Type 1 as well as children with Type 2 diabetes were included. The majority of the studies focused on children age 14 yr or older and provided self-management education, self-management support, or both. Parent involvement was a key component of the majority of the interventions, and the use of technology was evident in 3 studies. The findings highlight factors that occupational therapy practitioners should consider when working with pediatric diabetes teams to select self-management interventions.


Occupational therapy practitioners are becoming increasingly concerned with the rates of obesity in children and youth and how this condition affects health and influences occupational performance (Bazyk & Winne, 2013; Pizzi & Orloff, 2015). Childhood obesity has risen to an epidemic level in the United States, affecting almost 17% of children and adolescents (Pozzilli, Guglielmi, Caprio, & Buzzetti, 2011). Children and youth who are overweight or medically classified as obese are at risk for multiple health issues, including diabetes (Orsi, Hale, & Lynch, 2011). Diabetes is one of the most common chronic childhood diseases, and nearly 192,000 children and youth in the United States younger than age 20 yr are estimated to have a form of diabetes (Pettitt et al., 2014). Childhood diabetes and obesity are reciprocally related epidemics that are projected to reach catastrophic levels in the near future (Pozzilli et al., 2011).

Diabetes is commonly classified into two different types, Type 1 and Type 2. Connections between diet and obesity have been found to be associated with and precipitating factors for both types of diabetes in children (Pozzilli et al., 2011). In fact, distinctions between the two types have become less clear because evidence has increasingly pointed to similar and overlapping etiological, clinical, and lifestyle determinants and continues to call into question the clinical utility of a two-type classification system (Pozzilli et al., 2011). The increased prevalence of both Type 1 and Type 2 diabetes in children and youth, as well as the estimated $245 billion annual costs associated with these conditions, make childhood diabetes a major public concern (Pettitt et al., 2014) and strongly suggest the need for increased health and lifestyle management (Jackson et al., 2015).

Type 1 diabetes is an autoimmune condition characterized by irregular pancreatic functions and exacerbated by environmental factors (Pettitt et al., 2014). People with Type 1 diabetes are unable to produce the adequate amount of insulin...
necessary to control blood glucose levels (Chiang, Kirkman, Laffel, & Peters, 2014). The incidence of obesity in children with Type 1 diabetes is thought to parallel that of obesity in the general population of children (Pettitt et al., 2014). Type 2 diabetes is a metabolic disorder that is distinguished by a pattern of insulin resistance (Pettitt et al., 2014). It is highly associated with overweight status and obesity and is often diagnosed in children after the onset of puberty (Cameron & Wherrett, 2015). Over time, both Type 1 and Type 2 diabetes can lead to serious health complications.

Uncontrolled diabetes, regardless of type, has been associated with poor health outcomes in children as young as age 13 yr (Jackson et al., 2015). The primary mechanism for controlling both Type 1 and Type 2 diabetes is the attainment of glycemic control. Glycemic control can be achieved through frequent monitoring of blood glucose levels, healthy eating, physical activity, and the administration of insulin as recommended by a physician (Jackson et al., 2015). Beginning in elementary school, many children with diabetes are able to self-administer insulin and recognize the symptoms of hypoglycemia and hyperglycemia (Jackson et al., 2015). Students in middle school and high school, depending on their level of maturity and the length of time they have had their condition, may demonstrate an even greater ability to manage their own diabetes care (Jackson et al., 2015).

Self-Management

Diabetes management is complex and often requires a person to modify his or her typical habits and routines to maintain optimal health (Thompson, 2014). Policymakers have responded to the challenges of diabetes management, including the needs of children and youth, by including several important provisions in the 2010 Patient Protection and Affordable Care Act (ACA; Pub. L. 111–148). The ACA prohibits providers from denying coverage on the basis of a preexisting condition and includes coverage for several preventive services associated with diabetes, including childhood height, weight, and body mass index screenings and diabetes screenings (Burge & Schade, 2014). In addition, the ACA calls for the creation of the National Diabetes Prevention Program at the Centers for Disease Control and Prevention with the purpose of “evidence-based lifestyle change programs” (Burge & Schade, 2014, p. 403) for the treatment and prevention of diabetes.

The ACA further supports coverage provided through the Children’s Health Insurance Program Reauthorization Act of 2009 (CHIPRA; Pub. L. 111–3) and allows states to cover diabetes self-management (Bethell et al., 2011). Self-management is a key factor to effective diabetes care and is essential in the prevention of secondary complications, such as retinopathy, peripheral neuropathy, and nephropathy (Haas et al., 2012; Pyatak, 2011a, 2011b). The task force that developed the National Standards for Diabetes Self-Management Education and Support (NSDSES) identified diabetes self-management education as “the ongoing process of facilitating knowledge, skill, and ability necessary for prediabetes and diabetes self-care” (Haas et al., 2012, p. 2394) and diabetes self-management support as “activities that assist the person with prediabetes or diabetes in implementing and sustaining the behaviors needed to manage his or her condition on an ongoing basis” (Haas et al., 2012, p. 2394).

The extra occupational demands associated with caring for oneself in the presence of diabetes may be particularly difficult for children and adolescents to routinely maintain because many of the practices associated with diabetes self-care, such as adherence to blood glucose monitoring, following a healthy diet, and engaging in exercise, often fall outside of their typical performance patterns (Pyatak, 2011a; Thompson, 2014). Yet, it is critical that children and youth with diabetes develop self-management skills because they will grow and mature to become their own principal caregivers (Bodenheimer, Lorig, Holman, & Grumbach, 2002, p. 2470).

Daily activities and routines provide a framework in which a person may embed diabetes-related self-care through the application of self-management skills and behaviors (Pyatak, 2011b). Occupational therapy practitioners can promote healthy lifestyle changes through their understanding of physical and mental health chronic disease management and their sophisticated analysis of performance patterns (Cahill & Suarez-Balcazar, 2009; Pyatak, 2011a). To effectively support the development of self-management skills in children and youth with diabetes, occupational therapy practitioners need to use evidence-informed practices. The purpose of this scoping review was to explore the existing evidence related to the use of interventions to teach children and youth with diabetes self-management skills both within and outside the field of occupational therapy.

Method

Scoping reviews are gaining popularity in the field of occupational therapy as a means to identify the available research on a certain topic and to uncover gaps that could benefit from further research (McKinstry, Brown, & Gustafsson, 2014). Different from systematic reviews, scoping reviews provide an overview of the broad landscape of the
scholarly work associated with a certain topic (Arksey & O’Malley, 2005). In addition, scoping reviews include lower levels of evidence (e.g., case reports compared with randomized controlled trials) and forgo quality appraisal (Pham et al., 2014). To conduct this review, we used the methodology outlined by Arksey and O’Malley (2005). This methodology has been recommended as a model by occupational therapy scholars (McKinstry et al., 2014) and has also been used by previous occupational therapy scholars to complete scoping reviews on other topics (see, e.g., Hand, Law, & McColl, 2011). The steps involved in conducting the scoping review were as follows: (1) Identify a research question, (2) search the literature for relevant studies, (3) develop inclusion criteria, (4) select studies for inclusion on the basis of the research question and the inclusion criteria, and (5) chart and summarize the data (Arksey & O’Malley, 2005).

We completed a scoping review of peer-reviewed literature to answer the question “What interventions increase self-management skills in children and youth with diabetes?” For the purposes of this review, we defined self-management skills as those skills or behaviors necessary for monitoring diabetes or responding to its physical, behavioral, or lifestyle effects and those skills or behaviors completed by the child or adolescent independently or with adult supervision (Haas et al., 2012).

The first three authors (Cahill, Polo, and Egan) collaboratively developed a list of search terms that were relevant to the focus of the review and commonly used in each database. The list of terms was reviewed by a pediatric endocrinologist to identify additional keywords that would help capture other potential studies to include in the review. The pediatric endocrinologist was selected because of her extensive clinical expertise in working with children and youth with Type 1 and Type 2 diabetes. In addition, two librarians at an osteopathic school of medicine reviewed and approved the proposed search process.

Inclusion criteria for this review were developed after the literature search in accordance with the recommendations put forth by Arksey and O’Malley (2005). Developing the inclusion criteria post hoc allowed us to thoughtfully consider the clinical outcomes that were most relevant to the practice of occupational therapy, such as the attainment of new skills and habits, versus those relevant only to the management of diabetes as a medical condition (i.e., blood glucose level). To this end, the inclusion criteria for this scoping review were as follows:

1. The data collected through the study were focused on outcomes designed to measure gains in the child’s or adolescent’s performance related to one or more self-management skills or behaviors or the perceptions of the child or youth or adults regarding the child’s or youth’s gains in self-management skills.
2. The study included children or youth with either Type 1 or Type 2 diabetes.
3. The study was published in a peer-reviewed publication.
4. The study was published between 2005 and April 2015.
5. The study was written in English.

Studies in which a parent, clinician, or other adult completed the diabetes management tasks (i.e., performed the blood glucose reading, prepared the meal, or uploaded data to a mobile device) or in which it was not explicitly clear whether the child or youth was in any way responsible for initiating or performing any of the actual required steps of the diabetes management task were excluded from this review.

All authors were involved in the data collection process. The first author searched the key databases—PsycINFO, CINAHL, PubMed, ERIC, Cochrane Library, and OTseeker—and screened titles and abstracts to determine whether articles were appropriate for review. All four authors participated in article review and data extraction using McMaster University’s Critical Review Form for Quantitative Studies. Each article was reviewed by two authors. Disagreements regarding the quality of certain studies were resolved by a third author, and, in some cases, studies were discussed among the entire research team.

Results

The search resulted in 226 articles. Twelve articles met the established inclusion criteria; 11 of them presented findings from 11 different studies, and 1 article was a systematic review (Plante & Lobato, 2008). However, the relevant studies presented in Plante and Lobato (2008) were published before 2005; therefore, this systematic review was not included.

Type of Diabetes and Participant Age

Of the 11 studies included in this scoping review, 7 focused on children with Type 1 diabetes (Carroll, DiMeglio, Stein, & Marrero, 2011a, 2011b; Jaser, Patel, Rothman, Choi, & Whittemore, 2014; Kichler, Kaugars, Marik, Nabors, & Alemzadeh, 2013; Lasecki, Olympia, Clark, Jenson, & Heathfield, 2008; Maranda, Lau, Stewart, & Gupta, 2015; Mulvaney, Rothman, Wallston, Lybarger, & Dietrich, 2010), 1 study focused on children with Type 2 diabetes (Piven & Duran, 2014), and 3 studies focused on children with either Type 1 or Type 2 diabetes (Ellis et al., 2012; Wang, Stewart, Tuli, & White, 2008; Wysocki et al., 2006). Taken as a whole, the age of participants included in the studies ranged from 8 to 19 yr. However,
the majority of the studies focused on children between ages 14 and 18 yr, and the most frequent lower limit related to age of inclusion was 13 yr.

**Self-Management Outcome Measures**

The outcome measures used to collect data targeted at measuring gains in the child’s performance of one or more self-management skills varied throughout the 11 studies. All of the studies used more than 1 measure, and 17 different measurement tools were identified. Two of the studies (Carroll et al., 2011a; Wysocki et al., 2006) used the Diabetes Self-Management Profile (Harris et al., 2000), which was the most frequently cited measurement tool. Three studies included varying quality-of-life measures (Kichler et al., 2013; Maranda et al., 2015; Wang et al., 2008), and 2 studies used self-designed Likert measures related to perceptions of self-management skills and behaviors (Carroll et al., 2011b; Wang et al., 2008). One study (Piven & Duran, 2014) used the Canadian Occupational Performance Measure (COPM; Law et al., 2005).

**Parent Involvement**

The majority of the studies included in this review (n = 8) involved parents in the self-management intervention (Carroll et al., 2011a, 2011b; Ellis et al., 2012; Jaser et al., 2014; Kichler et al., 2013; Lasecki et al., 2008; Maranda et al., 2015; Wysocki et al., 2006). Parents in several studies supported their children in problem solving and monitored their performance with self-management tasks, such as regular blood glucose testing (Ellis et al., 2012; Kichler et al., 2013; Lasecki et al., 2008; Maranda et al., 2015; Wysocki et al., 2006). For example, Kichler et al. (2013) explored the effects of the Kicking in Diabetes Support, which consisted of a series of six semi-manualized groups for adolescents (ages 13–17 yr) and their parents that focused on the developmental aspects of diabetes management in adolescence, parent–child negotiation, and appropriate parental involvement in care. The findings from this study suggested that parent–child group interventions better supported increases in adherence and in the child’s ability to assume responsibility for diabetes care tasks than individual therapy.

Parents in 2 other studies were explicitly instructed not to nag their children to complete self-management tasks (Carroll et al., 2011a, 2011b), and 1 used formal behavioral contracts to help promote the completion of self-management tasks and reduce nagging (Carroll et al., 2011b). Finally, another study (Jaser et al., 2014) encouraged parents to provide positive affirmations to their children while the investigators provided parents with reminders to do so every 2 wk for 8 wk.

**Use of Technology**

Three studies (Carroll et al., 2011a, 2011b; Mulvaney et al., 2010) used technology to deliver a significant part of the intervention. Two studies used cell phone–based glucose recording systems (Carroll et al., 2011a, 2011b). For example, in the study conducted by Carroll et al. (2011b), adolescents were provided with a cell phone meter that was monitored remotely by a health care provider who provided daily contact based on an algorithm tied to the frequency of blood glucose monitoring and values. Parents were provided with a link to a website so they could also monitor data and were encouraged to decrease their cues for self-monitoring and self-management. Postintervention survey outcomes suggested that the majority of the adolescents (71%) felt more independent in caring for their diabetes. In addition, the majority of the adolescents (94%) also reported that their self-management habits were supported by text reminders to check their blood sugar.

One study examined the effectiveness of an Internet-based intervention designed to promote the development of diabetes-related self-management skills. Mulvaney et al. (2010) examined the effects of YourWay, an 11-wk-long self-management intervention for adolescents with Type 1 diabetes. Participants in the intervention group created their own personalized homepage and multimedia presentations related to problem solving different diabetes-related situations, participated in discussion forums, and reviewed six multimedia stories that highlighted common barriers to diabetes self-management. In addition, the intervention group participants received weekly check-in emails to encourage participation in the program. Self-management adherence improved significantly in the intervention group compared with the control group (d = 0.64, p = .02; 95% CI [.53, .79]).

**Self-Management Education or Support**

Three categories of intervention were developed for this scoping review on the basis of the aforementioned NSDSES definitions of self-management education and self-management support (Haas et al., 2012). First, separate categories were developed for education and for support. A third category was developed for interventions that included elements of both education and support.

None of the studies included in this scoping review aligned solely with the NSDSES definition of self-management education (Haas et al., 2012). However, 8 studies (Carroll et al., 2011a, 2011b; Jaser et al., 2014; Lasecki et al., 2008; Maranda et al., 2015; Mulvaney et al., 2010; Piven & Duran, 2014; Wysocki et al., 2006) aligned with the
NSDSES definition of self-management support (Haas et al., 2012). Two common features of all of the interventions that aligned with the NSDSES definition of self-management support (Haas et al., 2012) were the shift from parental management of diabetes to the child’s management of diabetes and the child’s sustainment of habits that led to the self-management of his or her medical condition.

For example, Piven and Duran (2014) examined the effects of individualized client-centered and occupation-based intervention activities that were designed to address specific self-management habits for one 19-yr-old man. Examples of some of the intervention activities included meal preparation and performing daily glucose checks. This single-participant study used the COPM (Law et al., 2005) to measure the participant’s rating of his performance and satisfaction on a Likert scale ranging from 1 to 10. The client’s baseline COPM ratings were 1 for satisfaction and performance. At the end of the intervention, his COPM ratings had increased to 10 for satisfaction and performance in all goal areas except preparation of meals and eating healthy. Ratings for this goal improved from 1 at baseline to 8 at the conclusion of the intervention.

Another study by Maranda et al. (2015) compared the association of pet care (Betta splendens fish) with daily and weekly self-management habits and routines of usual diabetes care (control condition) over the course of 3 mo. All of the study participants were asked to independently monitor their hemoglobin levels (HbA1c) 4 times a day and discuss the trends associated with levels with a parent or caregiver once a week. Participants in the intervention group were asked to take their hemoglobin levels at the time they were instructed to feed their pet fish (i.e., once on waking and again before going to bed) and to review the hemoglobin level trends with their parent or caregiver around the same time they changed a portion of the water in the fish’s bowl, or once per week. Participants in the intervention group demonstrated significantly improved hemoglobin levels compared with the control group. In addition, the intervention group demonstrated a positive change in one item on the Self-Management of Type 1 Diabetes for Adolescents (SMOD–A) questionnaire (Schilling et al., 2009). Specifically, the intervention group scored higher than the control group on the item related to reviewing blood glucose readings with parents. No other differences were reported related to the rest of the SMOD–A items.

Three studies (Ellis et al., 2012; Kichler et al., 2013; Wang et al., 2008) used a combination of interventions that included aspects of both self-management education and self-management support. For example, Wang et al. (2008) examined the effects of participation at Camp Sweeney, a 20-day-long camp for people between ages 12 and 16 yr with diabetes that includes daily medical education and discussions, repeated insulin adjustments and supervised injections, and other medical care as needed. Improvements in self-management were evaluated through self-reports of adherence and parent questionnaires. Results from the parental questionnaires suggested that the intervention group’s adherence significantly improved compared with that of the control group. The participants’ self-reports of adherence improved but were not statistically significant.

Discussion

Legislators have recognized the value of diabetes self-management for children and youth by including several important provisions in the ACA and CHIPRA. One of the primary goals of occupational therapy with regard to diabetes care is to support clients so that they are able to engage in occupations that they need and want to do. To this end, occupational therapy practitioners may support children with diabetes as they develop self-management skills such as self-monitoring their condition, self-administering medication, problem solving, and reducing the risks of further complications (Sokol-McKay, 2011). As members of a diabetes team, occupational therapy practitioners are skilled in addressing the physical, cognitive, and psychosocial aspects of diabetes-related self-care that support engagement in occupations (Sokol-McKay, 2011). The acquisition of self-management skills is foundational to optimal health in adulthood and critically influences the development of children and youth with diabetes (Bodenheimer et al., 2002). However, little intervention research has been completed in the field of occupational therapy with this specific population of children and youth. Therefore, the purpose of this scoping review was to explore the existing evidence related to the use of interventions to teach children and youth with diabetes self-management skills both within and outside the field of occupational therapy.

Type of Diabetes and Age of Participants

Type 1 and Type 2 diabetes have previously been treated as separate and distinct conditions. However, scholars have more recently determined that the clinical and lifestyle determinants associated with both conditions significantly overlap (Pozzilli et al., 2011). Although the majority of the studies in this scoping review focused on either Type 1 or Type 2 diabetes, 3 studies included participants with both types of diabetes. The inclusion of participants with both types of diabetes provides a basis for clinicians and
scholars to further question the utility of a two-type classification system, particularly when the focus is on the development of self-management skills. The relatively low number of studies included in this scoping review that focused only on children with Type 2 diabetes supports the notion that the development of Type 2 diabetes in children and youth is a fairly recent phenomenon and that standard treatment protocols are not yet well established (Protudjer, Dumontet, & McGavock, 2014). Therefore, occupational therapy practitioners and academicians interested in specifically supporting the self-management skills of children and adolescents with diabetes should consider interventions that have been evaluated in populations with either Type 1 or Type 2 diabetes.

The participants included in the studies in this scoping review ranged in age between 8 and 19 yr, with most being between ages 14 and 18 yr. This finding is consistent with the literature on childhood diabetes self-management, which has suggested that children in middle school and high school have the ability to manage their own diabetes care (Jackson et al., 2015). Before middle school, children with diabetes may be able to begin to learn the skills associated with self-management, such as the self-administration of insulin, but they may lack the executive functioning skills required to consistently manage their disease independently (Jackson et al., 2015). Therefore, occupational therapy practitioners should consider working on readiness skills for self-management (e.g., learning about diabetes and how to draw insulin and promoting a healthy and active lifestyle) with elementary school age children and then shift the focus of their intervention to self-management as the child enters adolescence.

Self-Management Outcome Measures

Successful diabetes management is often determined by the use of medical indicators, such as body mass index levels or HbA1c levels. Although medical indicators are certainly of value and speak to the improvement or decline in diabetes as a condition, they are a relatively weak metric for assessing self-management behaviors and skills (Kichler et al., 2013). This review only included intervention studies that used specific measures to identify changes in self-management behaviors or perceptions related to the use of self-management skills. However, the studies included in this scoping review lacked consistency with regard to the evaluation of self-management. This lack of consensus suggests a need to more clearly define what it means to have improved self-management skills. Moreover, a need exists for objective measurement tools that can be used by occupational therapy practitioners on diabetes teams to mark their clients’ improvements in self-management, which is a critical self-care occupation for people with diabetes.

Parent Involvement

Pediatric occupational therapy practitioners often include parents as part of the client constellation. The findings from this scoping review suggest that including parents in diabetes self-management interventions increases youths’ adherence to self-management routines, increases the use of self-management skills, and increases parents’ perceptions of their child’s ability to contribute to the effective management of diabetes. Moreover, the findings support the inclusion of parents in self-management interventions for as children become more accountable for their own diabetes care. This may be due, in part, to the renegotiation of diabetes management–related responsibilities that often occurs between parents and their children during adolescence (Leonard, Garwick, & Adwan, 2005).

Use of Technology

The use of cell phones and Internet-based platforms was featured in some of the articles included in this scoping review. This finding suggests that the use of such technology may support the development of self-management skills in children with diabetes. Occupational therapy’s use of tele-rehabilitation to treat patients with chronic conditions is regarded as a practical service delivery model and one that is supported by the ACA (Cason, 2012). Occupational therapy practitioners working on pediatric diabetes care teams should consider using technology to creatively address diabetes self-management within the context of a primary or augmentative service delivery model. Moreover, occupational therapy researchers should investigate the efficacy of such approaches to determine whether they are as, or more, effective than current interventions.

This review was limited by our search strategy as well as the possible exclusion of articles that might have been related to the development of self-management skill, as well as to the practice of occupational therapy. The review included only intervention studies that used specific measures to identify changes in self-management behaviors or perceptions related to the use of self-management skills rather than focusing on other, more medically focused indicators of diabetes management (e.g., body mass index levels or HbA1c levels). Therefore, we established strict criteria so that the review included only studies explicitly noting self-management measures closely aligned with outcomes more proximal to occupational therapy intervention (i.e., change in behavior or perceptions about skills), which may have limited the total number and types of studies reviewed.
Implications for Occupational Therapy Practice

Pediatric occupational therapy practitioners can support clients with childhood diabetes to develop self-management skills as part of a coordinated team (Cason, 2012; Sokol-McKay, 2011). Occupational therapy practitioners can add value to diabetes teams by evaluating the child’s motor, process, communication, and interaction skills and making recommendations regarding the selection of a self-management intervention that best matches the child’s strengths and needs. Occupational therapy practitioners may also analyze how features of the environment support or inhibit self-management participation. In addition, occupational therapy practitioners may collaborate with teams to implement an intervention designed to promote the development of self-management skills. The results of this scoping review suggest that occupational therapy practitioners should take the following steps:

- Consider interventions that are designed to promote the development of self-management skills in children with Type 1 or Type 2 diabetes.
- Address self-management readiness skills of children with diabetes younger than age 14 yr.
- Provide self-management education and self-management support to children who are age 14 yr or older.
- Involve parents or primary caregivers in self-management education and self-management support interventions.
- Consider integrating the use of technology in the self-management intervention. ▲

Acknowledgments

We thank Claudia Boucher-Berry, director of the Pediatric Endocrinology Fellowship Program and assistant professor of pediatrics, Section of Pediatric Endocrinology, Children’s Hospital of the University of Illinois, for reviewing our search terms and Catherine Lencioni and Sarah Schmidt, health sciences librarians at Midwestern University, for their helpful feedback regarding our search process. In addition, we thank Marian Arbesman for her support and guidance during the inception of this project.

References


*Indicates article included in the scoping review.


