



Literature Review

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# EL PASO DIABETES ASSESSMENT/PLAN

El Paso Diabetes Leadership Council  
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**PASO DEL NORTE  
HEALTH FOUNDATION**

Paso del Norte Health Foundation in partnership with  
University of Texas at El Paso and Health Resources in Action

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## **Intervention Opportunities Across the Diabetes Continuum: Review of the Literature**

### **Objectives**

In 2019, Paso del Norte Health Foundation partnered with Health Resources in Action (HRiA) and the University of Texas at El Paso (UTEP) to conduct an assessment of diabetes services in El Paso to identify challenges, service gaps, and potential opportunities to increase screening for and manage diabetes (including prediabetes, Type 1, Type 2, and gestational diabetes) for persons residing in El Paso. This multi-phase process will result in the development of an action plan that will be presented to the El Paso Diabetes Leadership Council in the Spring of 2020 to support efforts in developing a set of strategies for improving the continuum of care for diabetes in the region. As a first step in the process, Health Resources in Action conducted a review of the available peer-reviewed literature and one Congressional report to better understand three key topics:

1. The landscape of current evidence-based interventions and recommendations to screen for and diagnose type 2 diabetes, prevent type 2 diabetes, and manage type 2 diabetes;
2. Responses to and coping with type 1 diabetes diagnoses for young children and health care seeking practices for caregivers of young children with type 1 diabetes; and
3. Experiences with and interventions focused on gestational diabetes.

When possible, this literature review highlights research that includes Hispanic/Latino populations and/or focuses on the US border region. Each topic closes with a summary of recommendations that emerged from this review.

### **Topic 1.1: Pre-Diabetes and Type 2 Diabetes Screening and Diagnosis**

The American Diabetes Association (ADA), US Preventive Services Task Force, and Medicare Part B each identify several health status and sociodemographic risk factors that guide diabetes screening practices. The ADA recommends screening overweight or obese adults with at least one risk factor for pre-diabetes and type 2 diabetes for persons >45 years of age every three years (Martinez et al., 2019). By comparison, the US Preventive Services Task Force recommends screening overweight or obese adults 40-70 years of age and screening at earlier ages or lower body mass index (BMI) for individuals with family history of diabetes or personal history of gestational diabetes, as well as members of high-risk racial/ethnic groups (Martinez et al., 2019). Finally, Medicare Part B eligibility criteria for type 2 diabetes screening include the following risk factors: hypertension, dyslipidemia, BMI  $\geq 30$ , or previous identification of an elevated impaired fasting glucose or glucose tolerance (Koller et al., 2013). Medicare Part B also permits diabetes screening for recipients with two or more of the following: BMI >25 but

<30; family history of diabetes; aged 65+ years, or history of gestational diabetes or delivery of a baby weighing >9 lbs (Koller et al. 2013).

In terms of screening tests, the ADA recommends screening that involves fasting glucose and/or 2-hour glucose tests. The American Association of Clinical Endocrinologists (AACE) recommends that a diagnosis of pre-diabetes be confirmed on a different day with a repeat test and confirmation of a diagnosis of pre-diabetes with a test of fasting plasma glucose levels (Martinez et al., 2019). The oral glucose tolerance test was characterized as a simple screening methodology used to screen participants into the Diabetes Prevention Project (Ockene et al., 2012). Barry and colleagues (2017) examined the efficacy of pre-diabetes tests and found that HbA1c was not sensitive or specific for detecting pre-diabetes, whereas fasting glucose was specific, but not sensitive.

In a recent assessment of diabetes screening practices following the 2010 ADA diabetes screening guidelines, Evron and colleagues (2019) found that 78% of age-eligible patients were screened for diabetes in a three-year period; the majority of tests conducted were glucose tests (86%). While HbA1c tests were performed less frequently (14%), they were more common among high risk patients (e.g., overweight or obese individuals with hypertension, dyslipidemia, and/or hypoglycemia).

Hafez and colleagues (2017a) conducted chart-stimulated recall interviews with primary care providers (PCPs) in an academic health system to better understand factors that influenced diabetes screening practices and provider communication of findings with patients. When asked about reasons for not screening for type 2 diabetes, PCPs cited a previously normal screening test (49%) and a visit for a non-health maintenance examination (48%). The most common reasons PCPs provided for screening patients for type 2 diabetes were knowledge of a previously abnormal screening test (49%), patients' weight (42%), and patients' age (38%). PCPs reported 95% of test results to patients. When patients were found to have pre-diabetes, in 58% of cases PCPs recommended weight loss and increased physical activity, while they did not recommend participation in a Diabetes Prevention Program or metformin.

As part of a Centers for Medicare and Medicaid Innovation demonstration project, the American Medical Association worked with the YMCA of the USA to evaluate a quality improvement strategy to increase screening, testing, and referral of Medicare patients with pre-diabetes to Diabetes Prevention Programs (DPPs) at local YMCAs (Holliday et al., 2019). Use of the modified version of the American Medical Association's Clinician Diabetes Prevention Toolkit for Identifying Patients with Prediabetes, coupled with systems changes (e.g., workflow changes and process maps to identify and refer patients to YMCA Diabetes Prevention Programs; training; technical assistance; standardized referral forms) were associated with increased screening and referrals to Diabetes Prevention Programs for Medicare

patients with pre-diabetes (Holliday et al., 2019). Holliday and colleagues (2019) found that the highest referrals for the Diabetes Prevention Program were among practices that created a pre-diabetes register using their electronic medical records.

#### *Limitations of and Considerations Regarding Literature Reviewed*

There are several limitations of the screening and diagnosis literature reviewed above. First, pre-diabetes and type 2 diabetes screening is not framed as a public health intervention. Second, diabetes screening and diagnosis recommendations largely focus on older age and history of health-related risk factors for diabetes, with limited attention to differential risk of diabetes by subgroup (e.g., race/ethnicity, socioeconomic status). Third, assessments of pre-diabetes and type 2 diabetes varied across studies.

#### *Recommendations*

Several studies recommended screening high-risk individuals for pre-diabetes and type 2 diabetes (Crawford 2017; Martinez et al., 2019). The literature review elicited mixed recommendations regarding type 2 diabetes assessments, with some studies recommending an initial screening with fasting or random glucose tests and confirmation with HbA1c (Evron et al., 2019, Martinez et al., 2019), while Meyerowitz and colleagues (2019) recommend HbA1c testing in hospital and general practice settings.

Best practices for screening patients for pre-diabetes and type 2 diabetes identified in this review include: locating diabetes screening services in areas with a high prevalence of diabetes (Wright et al., 2019); creating a pre-diabetes registry based on electronic medical records to identify cases eligible for screening that may be missed during medical visits (Holliday et al., 2019); and framing screening and referral for diabetes as a quality improvement strategy (rather than a requirement) to gain buy-in from the health care team (Holliday et al., 2019).

#### **Topic 1.2: Interventions to Prevent Type 2 Diabetes**

Currently, public health approaches to diabetes prevention are focused on lifestyle and weight loss interventions. The Diabetes Prevention Program (DPP) was the most common diabetes prevention intervention identified in this literature review, with a strong evidence base that includes several randomized controlled trials, systematic reviews, and studies of the translation of the DPP to community-based settings. The DPP is a structured lifestyle intervention designed to improve nutrition, physical activity, and behavior change strategies related to diabetes prevention.

In a systematic review and meta-analysis, Sumamo and colleagues (2013) identified seven lifestyle interventions that demonstrated a decrease in the risk of diabetes up to 10 years after the

intervention – the longest assessment of long-term outcomes identified in this review. In a comparative effectiveness study of lifestyle interventions relative to metformin treatment for participants at risk of diabetes, O'Brien and colleagues (2015) found that for both intervention arms participants with a college education experienced a greater reduction in risk of diabetes incidence than participants with lower educational attainment.

Adaptations to the Diabetes Prevention Program include translating the individual-based design to group-based sessions implemented in community settings (e.g., parks, recreation centers, African American churches) (Katula et al., 2011; Katula et al., 2013; Kramer et al., 2009; Boltri et al., 2011; Ockene et al., 2012), culturally tailoring the DPP intervention (Boltri et al., 2011; Ockene et al., 2012); creating a literacy-sensitive DPP curriculum (Ockene et al., 2012); facilitation of the DPP intervention by community health workers (Katula et al., 2011 and Katula et al., 2013); and collaborating with multiple community partners (Ockene et al., 2012).

Participation in the DPP was associated with significant decreases in blood glucose (Katula et al., 2011; Boltri et al., 2011), insulin (Katula et al., 2011; Katula et al., 2013; Ockene et al., 2012), weight (Kramer et al., 2009; Dunkley et al., 2014; Katula et al., 2011; Katula et al., 2013; Ockene et al., 2012), waist circumference (Kramer et al., 2009; Katula et al., 2011; Katula et al., 2013), body mass index (Kramer et al., 2009; Katula et al., 2011; Katula et al., 2013), total cholesterol (Kramer et al., 2009), non-HDL cholesterol (Kramer et al., 2009), systolic blood pressure (Kramer et al., 2009), and diastolic blood pressure (Kramer et al., 2009).

#### *Cross-Sector Collaborations for Diabetes Prevention and Management*

Cross-sector collaborations to support community members with or at risk of diabetes generally provide chronic disease support in community settings, often with a focus on vulnerable populations. Cross-sector collaborations may involve collaborations with the health care sector and/or public-private partnerships. Tung et al. (2018) conducted a qualitative assessment to identify factors that motivate stakeholders (e.g., business, community development, faith-based) to engage in a cross-sector diabetes collaboration with an academic medical center, with a focus on in a low-income residents in Chicago, IL. A key motivating factor that emerged across stakeholders was that collaboration provided an opportunity to promote community health among vulnerable populations. Additionally, stakeholders described collaboration as facilitating financial support, brand enhancement, access to specialized skills or knowledge, professional networking, and the involvement of health care systems in community-based activities. The following sections describe community-based diabetes prevention and management interventions identified in this review.

*Food Pantry and Food Bank Diabetes Prevention and Management Interventions*

Food insecurity, or insecure and/or inconsistent access to nutritious food disparately affects low-income individuals and households, who often turn to food pantries or food banks to meet their dietary needs. One systematic review by Long et al., (2019) identified six food pantry or food bank interventions that examined implications of health interventions in food pantry or food bank settings for the prevention or management of chronic diseases, including type 2 diabetes, overweight/obesity, cancer, and HIV. Four of the six studies delivered health education (e.g., nutrition, physical activity, diabetes self-management), along with providing healthy foods (e.g., fruits, vegetables, lean meats, whole grains). Across all six studies, the majority of participants were women, and the mean age ranged from 45.9 years to 56.6 years. Two of the identified studies involved predominantly Latina/o clients, and three out of six studies focused explicitly on diabetes, while for another study the inclusion criteria pertained to the prevalence of overweight/obesity. Information regarding food pantries and food banks was limited in the articles reviewed. Only one of the three studies focusing on type 2 diabetes demonstrated a statistically significant improvement in glycemic control. Results were mixed when examining intervention effects on BMI and waist circumference.

Seligman et al. (2018; reviewed in the Long et al., 2019 systematic review) conducted a randomized control trial at food pantries affiliated with food banks in Oakland, CA; Detroit, MI; and Houston, TX. Clients with Hba1c  $\geq 7.5\%$  were randomized to a waitlist control or 6-month intervention that involved access to healthy food, diabetes education, health care referrals, and glucose monitoring. At six months, Seligman et al. (2018) reported significant improvements in food security, food stability, fruit and vegetable intake, while the authors found no difference in diabetes self-management, diabetes distress, depressive symptoms, or HbA1c.

*School-Based Diabetes Prevention Interventions*

Based on this review, school-based interventions to prevent diabetes included diabetes screening practices and multi-level, multi-component school-based interventions. One diabetes screening study by Cottrell et al., (2013) described training personnel to screen middle school children in Appalachia for pre-diabetes using acanthosis nigricans marker, as indicated by a pigmented rash on the child's neck or axilla. The authors complemented diabetes and cardiovascular screening activities with referrals for consultation with a provider, student education regarding cardiovascular and diabetes risk, and policy changes to enhance diabetes and cardiovascular screening of students (Cottrell et al., 2013). In a separate study, a natural experiment in California examined the association of optional parental notification of mandated school-based BMI screening results with changes in student BMI from fifth

grade to seventh grade (Madsen, 2011). Findings indicated no change in BMI for students from fifth to seventh grade, nor variation in this association by race/ethnicity (Madsen, 2011).

In terms of multi-level school-based diabetes prevention interventions, the Bienestar school-based intervention focused on diabetes prevention for low-income fourth-grade Mexican American students in San Antonio, TX (Treviño et al., 2004). The 32-session multi-component intervention included a health class, physical education curriculum, family program, school cafeteria program, and afterschool health club (Treviño et al., 2004). Relative to students in the control schools, students at schools who received the Bienestar intervention demonstrated improvements in fasting capillary glucose levels, fitness scores, and dietary fiber intake. However, there was no difference in percent body fat and dietary saturated fat intake among students in intervention vs. control schools (Treviño et al., 2004).

Additionally, the NEEMA school-based diabetes prevention intervention is a 14-week intervention that was adapted from Bienestar and focused on reducing diabetes risk for African-American children in San Antonio, TX (Shaw-Perry et al., 2007). The NEEMA intervention included student health education in classroom settings, after school programs that included physical activity, home-based engagement through Family Fun Fairs, and a food service programs delivered in the cafeteria. Evaluation of the NEEMA intervention indicated improvements in student fitness laps, fasting capillary glucose, and percent body fat (Shaw-Perry et al., 2007).

A more recent study of a multi-component school-based diabetes prevention interventions focused on middle school students of racial/ethnic and socioeconomic backgrounds most vulnerable to obesity and diabetes (Foster et al., 2010). The intervention focused on nutrition, physical activity, behavioral knowledge and skills, and communications and social marketing (Foster et al., 2010). Relative to control schools, students at schools that received the intervention demonstrated improvements in BMI, waist circumference, fasting insulin levels, and prevalence of obesity (Foster et al., 2010).

#### *Worksite Wellness Interventions for Diabetes Prevention and Management*

Systematic reviews and single empirical articles regarding worksite interventions indicated a strong focus on implementing the Diabetes Prevention Program in workplace settings, while some studies focused on worksite wellness programs more broadly. A RAND review of worksite wellness programs among employers with  $\geq 50$  employees found that 56% of employers with wellness programs focused on diabetes (Mattke et al., 2013a). Another RAND review of employers with  $\geq 200$  employees found that 92% of employers reported having a wellness program that was not restricted to diabetes (Mattke et al., 2013b). Among wellness programs, exercise (63% of employers), smoking (60% of employers), and weight loss (53%) were the primary areas of focus (Mattke et al., 2013b). However,



estimates indicated that less than 20% of employees participated in wellness interventions offered at workplaces (Mattke et al., 2013b). It was unclear from this review whether wellness interventions focused on the broader workforce, or employees at particular risk of cardiometabolic conditions such as diabetes. Another systematic review of worksite interventions by Shrestha and colleagues (2017) found that worksite wellness interventions were associated with significant improvements in HbA1c and fasting glucose, with greater intervention effects seen for women relative to men and for individual-level interventions relative to environmental interventions. This latter finding may be in part influenced by the time span of the intervention assessment.

In a review of workplace diabetes prevention interventions, Hafez et al., (2017b) report that the Diabetes Prevention Program was the most common and more intensive workplace intervention identified in their review and demonstrated greater weight loss among participants than less intensive worksite interventions. Brown and colleagues (2018) reported common elements of worksite Diabetes Prevention Programs, including: group sessions (<20 employees) focused on healthy eating, physical activity, and/or monitoring and managing diabetes and cardiovascular and 1-hour sessions offered during lunch or other times during the workday for 12-24 weeks. By comparison, single empirical studies evaluating the effectiveness of the Diabetes Prevention Program when implemented at worksites (e.g., County offices, Union Pacific Railroad, manufacturing plant) demonstrated that intervention participation is associated with weight loss, declines in body mass index, increased physical activity, and reduced dietary fat intake (Barham et al., 2011; DeJoy et al., 2013; Giese and Cook, 2014).

#### *Faith-Based Interventions to Screen for Diabetes and Deliver Health Education and Referrals*

Interventions in faith-based settings offer another promising opportunity to screen community members for diabetes and to deliver diabetes prevention and management interventions. Kelly (1998) examined the effectiveness of faith-based organizations as a community setting to deliver a combined diabetes screening and health education intervention in a large city along the Texas Mexico border. Church-based screenings were most likely to identify high blood sugar in older Latinas/os living within one mile of the Roman Catholic churches that participated in the intervention. Individual health education was offered to all participants and participants with high blood glucose levels identified during screening were encouraged to speak with health educators on site and received referrals to physicians and local Diabetes Association classes. As with other studies, the majority of participants identified as Latina/o and women. Fully 95% of participants characterized places of worship as appropriate for health screening and health education, citing as facilitating factors the population (low income, older), convenience, and a strengthened sense of connection with the church. The challenges to

church-based interventions identified by participants included participants seeking the church as a refuge from their worries and preference for health care settings to address health issues.

Baig et al. (2014) conducted focus group discussions with mostly Mexican American adults who identified as Catholic to understand how diabetes self-management interventions can leverage faith-based organizations as community assets to reach Latinas/os with diabetes. Participants expressed interest in church-based interventions for diabetes management and stressed the importance of programs that emphasized information sharing, skills building, and social networking.

#### *Limitations of and Considerations Regarding Literature Reviewed*

Notably, the Diabetes Prevention Program was the most common diabetes prevention intervention identified in this literature review. While the original DPP program was individually focused and oriented towards health care settings, recent DPP interventions have focused on the translation of the DPP to community-based settings, delivering the intervention in group-based formats, and tailoring the DPP intervention to racial/ethnic minority communities. Strong national support (e.g., NIH, CDC) for the Diabetes Prevention Program may contribute to the strength of the evidence base for this intervention. While the DPP programs identified focused on middle-aged adults, an important gap in this literature review pertains to diabetes prevention initiatives focused on children, youth, and younger adults.

#### *Recommendations*

Recommendations regarding diabetes prevention interventions that emerged from this literature review include: implementing intensive, comprehensive lifestyle interventions for high-risk populations (Sumano et al., 2013; Kramer et al., 2009; Albright & Gregg 2013); translating the DPP model to community-based settings (Katula et al., 2011; Katula et al., 2013; Boltri et al., 2011; Ockene et al., 2012); delivering the DPP intervention in a primarily group-based format (Ockene et al., 2012); ensuring that community health workers lead diabetes prevention interventions (Katula et al., 2011; Katula et al., 2013); culturally tailoring interventions (Ockene et al., 2012); tailoring interventions to participants' educational attainment and literacy levels to ensure robust intervention effects across socioeconomic statuses (O'Brien et al., 2015, Ockene et al., 2012); and collaborating with multiple community partners (Ockene et al., 2012).

#### **Topic 1.3: Type 2 Diabetes Management Interventions**

Diabetes management interventions identified in this literature review were largely individual-level interventions and mostly focused on interventions based at or in collaboration with health care systems. The following section describes four type 2 diabetes management interventions: (1) integrating

psychosocial care into diabetes care; (2) Chronic Care Management; (3) other health care systems interventions; and (4) Lifestyle-Based Diabetes Education and Self-Management Interventions.

#### *Integrating Psychosocial Care into Type 2 Diabetes Care*

The American Diabetes Association emphasizes the importance of integrating psychosocial assessments and care into primary care visits for persons with type 2 diabetes (Young-Hyman et al., 2016). Recommendations include:

- Integrating psychosocial assessments and intervention into each phase of primary care delivery (e.g., initial assessment, annual visits, major life changes);
- Using validated tools to assess diabetes-related distress, depression, anxiety, disordered eating, and other stressors;
- Addressing identified psychosocial issues by making referrals to interventions or behavioral health care providers;
- Providing training regarding diabetes self-care during the initial patient visit and on an annual basis;
- Tailoring treatment plans to patient social support and self-efficacy for diabetes management;
- Referring patients to blood glucose awareness training; and
- Monitoring patients for diabetes-related distress, particularly when treatment targets are not met.

#### *Chronic Care Management*

The Chronic Care Management (CCM) model was the type 2 diabetes management intervention approach with the strongest evidence base, as indicated by several systematic reviews and meta-analyses of randomized controlled trials assessing outcomes associated with implementation of CCM models. CCM models refer to team-based diabetes care that is: integrated into primary care settings and designed to reduce barriers to care; provides diabetes self-management support; addresses health care delivery system design (e.g., coordinating care processes); and leverages clinical information systems to track progress on diabetes-related outcomes (Stellefson et al., 2013). The literature regarding CCM models often focused on middle-aged and older adults. Some, though not all CCM models identified in this review include clinic-community partnerships.

One meta-analysis found that interventions that include more than two CCM model components demonstrate modest improvements in glycemic control (Elissen et al., 2013). In a descriptive synthesis of the literature, Stellefson and colleagues (2013) report the following results of each CCM component:

- Organization of the health care system to support the implementation of a CCM model: Associated with improved quality of diabetes care, rates of eye exams, HbA1c, blood pressure, cholesterol, and weight.
- Diabetes self-management support: Associated with improvements in physical activity, and slight improvements in HbA1c, blood pressure, cholesterol, and connections with case managers.
- Decision support to primary care providers for diabetes care: In some cases, associated with improved diabetes knowledge, HbA1c, and HDL.
- Specialized decision support services for primary care providers delivering diabetes care (e.g., problem-based learning meetings, telephone and email support, telemedicine): Associated with improved communication between diabetes educators, primary care providers, and patients; HbA1c; medication management and adjustment processes; and stronger support networks.
- Clinical information systems: Linked with improved tracking of patient health outcomes and provider responses to clinical data (e.g., medication adjustment).
- Incorporate community resources and policies: Linked with provider training in CCM models for diabetes management, greater access to funding, and administrative support for CCM implementation.

*Recommendations.* The American Diabetes Association recommends incorporating CCM models into health care settings, aligning treatment plans with CCM models, implementing decision-support tools, and ensuring community involvement in model implementation (American Diabetes Association, 2017). In a systematic review, Stelfox et al. (2013) call for CCM models that leverage community-based resources and public health policies to improve diabetes outcomes.

#### *Other Health Care Systems Interventions*

Other diabetes management interventions in health care settings that emerged from this review include the implementation of a computerized clinical decision support system and broader quality improvement strategies. Jeffrey and colleagues (2013) found that the implementation of a computerized clinical decision support system into ambulatory diabetes management systems was associated with improvements in HbA1c and patient quality of life and reductions in diabetes-related hospitalizations. In a more comprehensive assessment of health systems quality improvement strategies, Tricco and colleagues (2012) described quality improvement strategies focused on health care systems and health care providers to support the communication of diabetes-related information between providers, including: case management, audits and feedback, clinician education, clinician

reminders, financial incentives, and electronic patient registries. At the patient level, quality improvement strategies included incorporating patient reminder systems, educating patients about diabetes, and promoting diabetes self-management (Tricco et al., 2012). In a meta-analysis, the Tricco and colleagues (2012) report that quality improvement strategies across multiple levels were linked with increased likelihood of patients receiving prescriptions for diabetes and diabetes-related comorbidities, screening (e.g., retinopathy, renal function, foot abnormalities). However, statin use, hypertension control, and smoking cessation did not improve (Tricco et al., 2012). Interventions focused only on health care professionals were associated with improved health and self-management outcomes only for patients with poor HbA1c control (Tricco et al., 2012).

*Recommendations.* Tricco and colleagues (2012) recommend implementing quality improvement strategies focused on health care systems and health care professionals. In an effort to improve access to diabetes-related medications, a recent report by the House of Representatives Committee on Oversight and Reform for the 16th Congressional District of Texas calls for ensuring that Medicare beneficiaries and uninsured patients pay the same prices for diabetes medications as patients in Australia, the United Kingdom and Canada.

#### *Lifestyle-Based Type 2 Diabetes Education and Self-Management Interventions*

Lifestyle interventions for adults with type 2 diabetes focused on diet modifications, increasing physical activity, and patient education regarding diabetes management. Some, though not all interventions identified in this review were delivered by community health workers.

Chen and colleagues (2015) conducted a systematic review and meta-analysis of randomized controlled trials involving lifestyle interventions – including pharmaceutical care; group counseling about diabetes self-management, education on lifestyle modifications, structured and personalized exercise prescription, supervision by a case manager, physical activity, and diet education – and found lifestyle interventions were associated with improvements in body mass index, HbA1c, systolic blood pressure, and diastolic blood pressure. Notably, Chen and colleagues (2015) found no difference in HDL and LDL between intervention and control groups. When looking more specifically at intervention components and associations with health outcomes, Huang and colleagues (2016) found that dietary modifications were associated with reduced systolic and diastolic blood pressure; physical activity was associated with reduced diastolic blood pressure, and patient education was not associated with any differences in HbA1c, blood pressure, or cholesterol for participants in the education intervention when compared to the control group.

In a systematic review of lifestyle interventions for socially disadvantaged populations, Glazier and colleagues (2006) found that cultural tailoring of interventions, interventions lead by lay persons or community educators, one-on-one interventions with individualized assessment and reassessment, a focus on behavior-related tasks, providing feedback to intervention participants, and more than 10 points of contact delivered over a long period (at least 6 months) demonstrated positive results. By comparison, interventions focused on didactic teaching or knowledge building did not demonstrate positive results (Glazier et al., 2006).

The literature review yielded several individual studies (compared to systematic reviews and meta-analyses) involving randomized controlled trials of community health worker/promotores interventions. Many community health worker interventions focused on individuals with type 2 diabetes who are low-income and/or identified as African American or Hispanic/Latino. Common elements of community health worker interventions included cultural tailoring of diabetes self-management interventions with opportunities to discuss and practice goal setting and self-management, interventions lead by community health workers, and referrals to social and support services (e.g., housing, medical insurance). Often, the intervention was delivered in multiple formats, including group sessions, one-on-one visits, telephone follow-up, and/or accompaniment to one clinic visit with the participant's primary care provider (Rothschild et al., 2014; Two Feathers et al., 2005; Palmas et al., 2014; Staten et al., 2012). One intervention involved the cultivation of leadership within the intervention group to provide participants with ongoing emotional and behavioral support after the first six months of the intervention (Spencer et al., 2018)

Community health worker interventions involving participants with type 2 diabetes demonstrated improvements in: understanding of diabetes self-management (Spencer et al., 2018); dietary knowledge (Two Feathers et al., 2005); dietary practices (Two Feathers et al., 2005; Staten et al., 2012); physical activity knowledge (Two Feathers et al., 2005); physical activity (Rothschild et al., 2014; Staten et al., 2012); HbA1c levels (Two Feathers et al., 2005; Rothschild et al., 2014; Spencer et al., 2018); body mass index (Staten et al., 2012); waist and hip circumference (Staten et al., 2012); systolic blood pressure (Staten et al., 2012); diastolic blood pressure (Staten et al., 2012); total cholesterol (Staten et al., 2012); diabetes-related distress (Spencer et al., 2018); depressive symptoms (Spencer et al., 2018); and diabetes social support (Spencer et al., 2012). In contrast, Palmas and colleagues (2014) found a non-significant trend toward HbA1C reduction. Additionally, Rothschild and colleagues (2014) found no effect of the community health worker intervention on blood pressure control, glucose self-monitoring, or adherence to medications or diet.

*Limitations of Literature Reviewed.* Several diabetes management interventions were relatively brief (e.g., 3-5 months), and few studies examined long-term outcomes of the intervention. Spencer and colleagues (2018) found that several intervention effects seen at 6 and 12 months since the start of the intervention were not sustained at 18 months, perhaps attributed to the reduced intensity of the intervention beyond 6 months.

*Recommendations.* Based on their systematic review, Glazier and colleagues (2006) recommend ensuring that community health worker interventions incorporate multiple points of contact with participants over a protracted period, with a focus on strengthening and sustaining diabetes self-management skills. Individual studies included several recommendations specific to community health worker interventions, including: tailoring community health worker interventions to the local and cultural context (Two Feathers et al., 2005; Rothschild et al., 2014; Staten et al., 2012); developing community-based interventions (Two Feathers et al., 2005); strengthening social support (Two Feathers et al., 2005); enhancing self-efficacy to adopt and sustain diabetes self-management practices and lifestyle modifications (Rothschild et al., 2014; Staten et al., 2012); delivering interventions over a longer period (e.g., 2 years) (Rothschild et al., 2014); strengthening intervention fidelity (Palmas et al., 2014); and sustaining intervention effects with volunteer peer-leader models (Spencer et al., 2018).

### **Topic 2.1: Factors Influencing Delayed Diagnosis of Type 1 Diabetes in Young Children**

The literature regarding type 1 diabetes diagnoses in children, and responses and coping amongst children and family members pertained to diagnoses in young children, predominantly children 2 to 12 years of age. These studies involved surveys of parents or caregivers, interviews with parents, and/or a review of medical record information.

Smith-Jackson and colleagues (2018) estimate that 34% of children with type 1 diabetes experience a delayed diagnosis. When compared to children without a delayed diagnosis, children with a delayed diagnosis were more likely to be: diagnosed in the emergency room; transported by ambulance or life flight; hospitalized; admitted to Intensive Care; and experience diabetic ketoacidosis (Smith-Jackson 2018). According to Muñoz and colleagues (2019), 68% of children with a missed type 1 diabetes diagnosis experienced diabetic ketoacidosis. Smith-Jackson and colleagues (2018) found that younger children were at greater risk for a missed type 1 diabetes diagnosis. Moreover, parents recounted frustration in receiving a prompt diagnosis for their child, which they linked with challenges in scheduling an appointment with a primary care provider, glucose testing, and the dismissal of concerns by providers (Smith-Jackson 2018).

In interviews with parents of young children with type 1 diabetes, health care providers, and teachers, Townson and colleagues (2018) report that parents of children diagnosed with type 1 diabetes sought support from other sources (e.g., family members, internet) before consulting health care providers. Providers highlighted the rarity of type 1 diabetes diagnoses and the importance of considering type 1 diabetes when examining sick children (Townson et al. 2018).

Based on interviews with parents of young children with type 1 diabetes, Rankin and colleagues (2014) identified two pathways to type 1 diabetes diagnoses in young children. The prompt pathway to diagnosis involved parents who had knowledge of diabetes (had type 1 diabetes themselves, had gestational diabetes, health care professionals, or knew someone who had the disease) (Rankin et al., 2014). Parents with no knowledge of type 1 diabetes and its symptoms described delayed pathways to diagnosis (Rankin et al., 2014). Several parents in the delayed group noted that type 1 diabetes symptoms (e.g., bed wetting, weight loss) were confused with normal stages of children's development and described young children's challenges in communicating symptoms. Despite making prompt appointments with health care providers, some parents reported that the doctor did not notice the signs, contributing to delayed diagnosis. Regardless of the pathway to diagnosis, parents reported high levels of distress when their child was diagnosed with type 1 diabetes. This response was exacerbated for parents in the delayed pathway, who reported feelings of guilt and blame and reflected on what they could have done to better detect and diagnose their child's condition (Rankin 2014).

#### *Limitations of Literature Reviewed*

Notable gaps in the literature regarding family-level responses to type 1 diabetes diagnoses in children include a limited focus on Latina/o families, cultural factors (e.g., stigma, the role of other care givers (e.g., older siblings, extended family members), and the role of other systems (e.g., schools) in supporting families in diagnosing and managing type 1 diabetes for young children.

#### *Recommendations*

Recommendations to facilitate earlier diagnoses of type 1 diabetes in young children include ensuring that pediatricians consider type 1 diabetes when evaluating patients with non-specific symptoms (Muñoz 2019); conducting glucose screenings (Smith-Jackson et al., 2018); educating parents to raise awareness of type 1 diabetes symptoms that warrant medical treatment (Smith-Jackson et al., 2018); community-based intervention to raise awareness about type 1 diabetes signs for stakeholders to facilitate timely diagnoses (Townson et al., 2018); screening parents for psychological distress when their child is diagnosed with type 1 diabetes and regularly thereafter (Rankin et al., 2014); and providing parents with emotional and psychological support to parents (Rankin et al., 2014).



## **Topic 2.2: Information, Sleep, and Support Needs For Families with Young Children with Type 1 Diabetes**

In interviews with parents of young children with type 1 diabetes, Rankin and colleagues (2016) identified several information and support needs for families at two critical points: (1) during hospital admissions when children are diagnosed with type 1 diabetes and (2) upon returning home shortly after their child is diagnosed. During the hospital admission, parents reported information overload when providers used clinical terminology to describe their child's diagnosis and instructions for managing type 1 diabetes. Parents also reported distress upon learning of their child's diagnosis, which impeded their ability to absorb the information providers shared. Parents in this sample identified the need for details regarding managing their child's diabetes before being released from the hospital, while also desiring more emotional support as they processed the diagnosis. Upon returning home, parents reported several challenges in managing their child's type 1 diabetes, including: explaining the condition to children; explaining the need for daily injections; administering injections; mitigating children's fear; and concerns among inflicting pain on their children when conducting injections. While parents described increased confidence to monitor their children for signs of hypoglycemia during the day, another concern that emerged pertained to nocturnal hypoglycemia. In particular, parents expressed concerns that they would not detect symptoms when their child was asleep, that their child would not wake up, and the potential for their child to die in bed due to nocturnal hypoglycemia. As a consequence, many parents described sleeping lightly, being vigilant throughout the night, and/or experiencing disrupted sleep, each of which contributed to parental exhaustion. Parents cited several reasons for not discussing these concerns with their child's provider, including perceptions that providers lack personal experience parenting a child with type 1 diabetes and concerns that parents would not receive empathetic and non-judgmental support from providers.

Resonating with findings by Rankin and colleagues (2016), in interviews with parents of children with type 1 diabetes and a survey, Macaulay and colleagues (2019) found that more than half of parents reported poor sleep quality. Parents cited glucose monitoring and fear of hypoglycemia as contributing to parental sleep disturbance. Two distinct time periods emerged that contributed to greater sleep disturbances: (1) immediately following a diagnosis of type 1 diabetes and (2) when using a new diabetes technology. Mothers described greater night-time care burden and sleep disturbance than fathers (Macaulay et al., 2019).

In a qualitative analysis of blogs of caregivers of children with type 1 diabetes, Oser and colleagues (2017) find that fear and worry were common reports among caregivers, continuing – though

evolving – beyond the point of diagnosis. Caregivers recalled persistent physical and emotional burdens of managing their child’s type 1 diabetes and described technology as helpful for managing the condition and reducing concerns about hypoglycemia, though they also characterized alarms as compounding caregiver burdens (Oser et al., 2017). Caregiver frustrations with perceived missed or delayed diagnoses were also common (Oser et al., 2017).

With respect to children’s sleep, Jaser and colleagues (2017) found that 67% of children met the criteria for poor sleep quality. Poor sleep quality was associated with severe hypoglycemia and diabetic ketoacidosis, poorer parental sleep quality, poorer parental well-being, and parental fear of hypoglycemia, though not linked with the use of diabetes technology.

When examining barriers to insulin pump use for children with type 1 diabetes, Commissariat and colleagues (2017) found that compared to non-pump users, pump users had lived with their type 1 diabetes diagnosis for longer, were more likely to have annual household incomes >\$75,000, have a parent with at least a college education, and conduct frequent blood glucose monitoring. Barriers to insulin pump use included: concerns about physical interruptions and therapeutic effectiveness. In some cases, financial burden was a concern.

### *Recommendations*

Recommendations regarding parent information and support needs as they cope with a child’s diagnosis of type 1 diabetes include: providing emotional support and practical advice to parents as they adjust to their child’s diagnosis (Rankin et al., 2016); offering support within the first few weeks following the diagnosis (e.g., home visits, phone calls) (Rankin et al., 2016); providing experiential training to providers regarding managing type 1 diabetes for young children (Rankin et al., 2016); increasing pediatric diabetes care teams’ awareness of diabetes-related factors that affect parental sleep (Macaulay et al., 2019); considering the mixed effects of diabetes technologies (Macaulay et al., 2019); tailoring parental support and education (Macaulay et al., 2019; Commissariat et al., 2017); and addressing socioeconomic barriers to insulin pump use (Commissariat et al., 2017).

### **Topic 3: Experiences with Gestational Diabetes and Interventions to Prevent or Manage Gestational Diabetes**

Carolan-Olah and colleagues (2017b) conducted interviews with Mexican-origin women in El Paso who had gestational diabetes to better understand their experiences with gestational diabetes. Findings indicated five themes regarding a path of gradual adjustment to gestational diabetes: (1) an initial stage of distress and fear as women processed their diagnosis; (2) realizing the major lifestyle changes required (e.g., diet, exercise, glucose monitoring, insulin medication); (3) learning to manage

gestational diabetes, which included carefully managing dietary intakes, which contributed to hunger, frustration, boredom, repetitive meals, and occasional low blood glucose levels until they developed strategies to manage their diabetes; (4) finding motivation to manage gestational diabetes, which was influenced by a desire to maximize their baby's health, interest in improving their own health, and interest in investing in their family's health over the long-term; and (5) following providers' instructions regarding lifestyle modifications despite limited understanding. Common misunderstandings about gestational diabetes included: (1) perceiving women had a mild case of gestational diabetes; (2) misunderstandings about food values and permitted foods; and (3) viewing that they were 'on a diet' for the rest of their pregnancy, rather than adopting modifications for the rest of their life. Several beliefs and perceptions also shaped these perceptions and experiences, including that the baby would know if the mother cheated on her diet, the baby could taste that the mother at during pregnancy, and a strong interest in managing their gestational diabetes despite these challenges. Additionally, social and family commitments shaped the timing and content of meals. Women described feelings of fear, self-blame, guilt, and failure, which attenuated as women adjusted to their diagnosis.

In a systematic review, Carolan-Olah and colleagues (2017a) identified seven intervention studies, including 2 interventions to prevent gestational diabetes among Hispanic women (1 study in the US, 1 study in Mexico) and 5 interventions to promote normal blood glucose levels among women with gestational diabetes (2 studies in the US, 3 studies in Mexico). This review suggests that intensive dietary counselling over a prolonged period, along with a low calorie, low glycemic index diet may be reduce risk of or improve management of gestational diabetes.

#### *Limitations of Literature Reviewed*

Additional interventions (e.g., Dulce Mothers, Centering Pregnancy) not included in Carolan-Olah et al., 2017a focus on preventing or managing gestational diabetes among Latina women.

#### *Recommendations*

Recommendations that emerged from this review include: developing materials written for women with low literacy levels that explain lifestyle modifications needed and are sensitive to women's food values (Carolan-Olah et al., 2017b) and develop culturally adapted interventions for pregnant Latina women (Carolan-Olah et al., 2017a).

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