Knowledge, information and data: screening for social determinants of health in pediatric Type 1 diabetes

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Chronic conditions are defined as a disability which interferes with normal life and activities, requiring treatment for three months or more during a year (van der Lee et al., 2007). The Centers for Disease Control describes Type 1 diabetes (T1D) as a chronic condition that can develop in children, teens, and young adults (CDC, 2022). T1D is one of the most common chronic health conditions affecting adolescents in the United States and the recommended treatment is a significant source of stress, potentially leading to poor health outcomes (Rechenberg et al., 2017). According to the CDC National Diabetes Statistics Report (2022), some 1.45 million Americans are living with T1D, and approximately 64,000 people are diagnosed each year in the U.S. Without rapid diagnosis and appropriate treatment, T1D can result in diabetic ketoacidosis and rapid death, making awareness and education about the condition critical (International Diabetes Federation, 2022).

The identified clinical question our team was interested in exploring is whether screening for social determinants of health (SDOH) supports pediatric patients with type 1 diabetes (T1D) who are at risk for uncontrolled/emergency glycemic events?

The World Health Organization (WHO) defines SDOH as conditions or circumstances in which people are born, grow, live, work, and age and these conditions are shaped by political, social, and economic forces (WHO, 2008). SDOH carry significant value in understanding T1D, as they are the substructure of a person's health, relating genetics, behavior, environmental and physical influences, medical care, and social factors (Martinez-Cardoso et al., 2020). In a study that identified and quantified barriers to diabetes, Simmons et al. (1998), were some of the first to highlight social issues that posed significant barriers to self-management of T1D. Today, nearly 25 years after this initial research, knowledge, information and data related to SDOH and

T1D continue to influence how T1D is managed. Evidence demonstrates that SDOH accounts for between 30-55% of health outcomes (WHO, 2023). SDOH are the primary contributors to unfair and avoidable differences in health status, including risk for developing diabetes and diabetes complications (Hill-Briggs, 2020).

First Evidence Based Source of Knowledge: SDOH

Since the early 2000s, the American Academy of Pediatrics has encouraged pediatric providers to develop standardized screening tools, assessing social and behavioral risk factors that are relevant to their patient populations to identify and address risks (Sokol et al., 2019). Evidence is currently lacking on which specific SDOH factors have the largest impact on child health; therefore, the American Professional Society on the Abuse of Children encourages pediatricians to tailor SDOH screening to their patients' needs and available community resources (Sokol et al., 2019).

Recent studies have shown that integrating screening and mechanisms of data collection related to SDOH, improve patient outcomes including quality of life; however, the question remains how can the provider best address SDOH (Mayer-Davis et al., 2018, Iturralde et al., 2019, Kaushal et al., 2022 and Cummings et al., 2018)? Acquired knowledge has pointed to an association between social disadvantage and negative outcomes for children with T1D (Cummings et al., 2018). SDOH and diabetes management has shown that when people can't manage their financial situation or housing issues, their diabetes self-management becomes a lower priority (Akhter et al., 2016). Recommendations for providers to support patient needs based on social and psychological issues are illustrated in Appendix A. Failure to collect data translates to a loss of information and a deficit of knowledge.

Relating to the importance of screening for SDOH in T1D patients, Hardy et al., (2021) found that when families answered survey data questions screening for SDOH (answering yes/no, or ranking choice options on a scale of need that related to housing, utilities, transportation, and food), 12.0% of the families reported a general social need, with 28% of

those needs identified as urgent. Patients with food and transportation needs were more likely to have an ED or inpatient visit at 6 months pre-screening and 6 months post-screening compared with those without needs. Hardy et al., (2021) enhance the clinical knowledge and understanding that screening for SDOH, specifically things like housing, utilities, transportation, and food, better supports that patient's success with T1D care management.

Second Evidence Based Source of Knowledge: Diabetes Standards of Care

Diabetes self-management and control demands complex and frequent monitoring of multiple components including blood sugar monitoring, carbohydrate counting, insulin administration, lifestyle management, and treatment of hypo and hyperglycemia (Chao et al., 2016). Since 1978, "Standards of Care in Diabetes" has been published yearly by the prestigious American Diabetes Association (ADA) with the goal of promoting better patient care for those diagnosed with T1D (ADA, n.d.).

In the most recent ADA edition (2023), the editors address plans to, "concentrate on the themes of justice, equity, diversity and inclusion" (p. 4), focusing on discrepancies in care, prioritizing future research and dispatching tools that focus on health inequities in T1D. Recent studies have provided that African American patients with T1D have a much lower use of technologies to control their chronic condition than equivalent Caucasian patients diagnosed with T1D (ADA, 2023). The ADA editors (2023) relay the importance of other data points for providers to collect, like notes that document neighborhood conditions, lack of adequate insurance, marital and employment status, as well as implicit racial bias (ADA, 2023).

Adolescent patients diagnosed with T1D face multiple challenges managing this chronic health condition, facing both long-term health difficulties, as well as the threat for emergency events in adolescent years and adult years (Jin et al., 2017). Exploring data and the associated information can provide a form of understanding as to the challenges adolescent T1D patients face. Harnessing this information, together with clinical expertise and adolescent patient experiences, offers the opportunity to transform information into knowledge, bridging

understanding to causes that might preclude emergency events and long-term poor health outcomes. The Institute of Medicine (2013) states that clinical decision support tools have become a staple for providers, ensuring clinical guidelines are upheld and evidence-based care leads to improved patient care.

The 2023 Standards of Care for Diabetes published by the American Diabetes Association addresses the unique components to adolescent diabetic care and how critical it is for providers to understand the management of adolescents with T1D. Unlike adults, pediatric and adolescent diabetic care is less likely to be based on clinical trial evidence and have more of an emphasis on both expert opinion and a review of relevant experimental data (ADA, 2023).

Information: 3 examples

Information on SDOH like food security, access to technology, access to mobile devices and transportation, lends providers a connection with how to best manage T1D. Information can be drawn from structured data (i.e. yes/no) and unstructured data (free text narratives) and is instrumental in generating positive health outcomes. Information like BG target ranges and sliding scale insulin dosing are all important ways of connecting to supported care practices.

Research has shown that at least 88% of adolescents own a cell phone and that over 50% of adolescents use devices for data input (Kaushal et al., 2019). Utilizing the ubiquity of cell phones, health care teams can cultivate information from the data patients enter in their devices. Providers can access information based on a patient's or family's responses to survey questions that offer information on social needs outside of their T1D care, providing a more comprehensive and holistic plan of care (see Appendix A).

In a randomized trial study that examined information feedback to patients with T1D, Skrøvseth et al., (2015), explored how a mobile phone-based application can be useful for providing patients with information that relates to better health outcomes. Information displayed

on mobile devices can allow a patient to see blood glucose trends, carbohydrate counting and guide insulin administration.

Data: 6 elements

Compiling data for T1D patients involves multiple structured data points as well as various unstructured data metrics. The structured data measured and collected by the provider includes: A1C measurements, multiple daily glucose readings, basal and bolus insulin administration and corresponding orders, and carbohydrate counts. In addition to these structured data points, providers need to manage T1D adolescent patients with unstructured data points which include, quality of life and activities the patient engages in, involvement of parent or guardian in both understanding as well as management of their child's diabetes, and an understanding of how diabetes related distress or emotional needs relate to their diagnosis. Together, these structured and unstructured data points serve as directives for both the patient's treatment as well as their future health outcomes.

Decision support tools

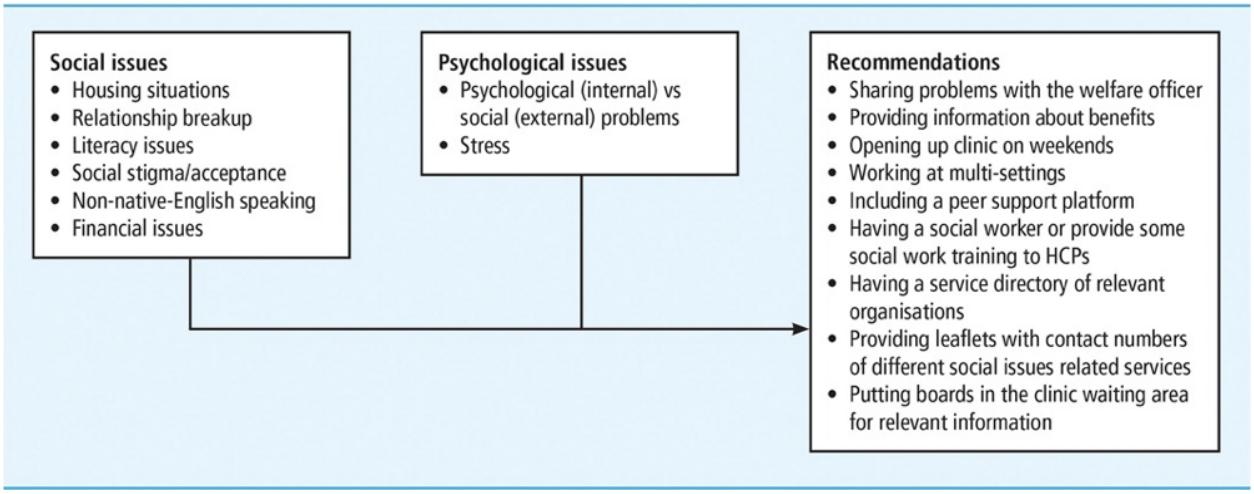
In a study by Buitron de la Vega et al., (2019), an EHR-based SDOH screening and referral system was implemented in clinical practice. The study found that integrating a systematic clinical strategy using EHR workflows to address SDOH is feasible and streamlined the provision of resources to patients requesting additional information. Incorporating such a screening tool for T1D patients could offer both patients and providers better outcomes through streamlining referrals to patients in order to better manage their T1D. Historically, some providers and clinics have collected data on SDOH but this collection has been done manually and "ad hoc" (Gold et al., 2017). Using the EHR to gather the data, disseminate the information and apply the knowledge on SDOH presents an opportunity for better care coordination as well as better health outcomes (Gold et al., 2017).

Conclusion

Pediatric patients can be a vulnerable population. As T1D cases represent millions of individuals in the U.S., this information necessitates the need for a timely diagnosis, applying knowledge for treatment, and ongoing support for aspects that relate to SDOH. In order to care for pediatric patients with T1D, care teams and individuals can use data, information and knowledge related to SDOH and T1D to support positive care outcomes.

Understanding the patient and family dynamics involves an in-depth understanding of the family's language, culture, education, social and economic status. In many cases, for both providers and patients, medical advancements in EHRs and clinical documentation systems are being created to offer tools that relate to better screening and management for T1D. New opportunities in research and practice meet the patient "where they are", instilling a foundation that offers more relationships with the whole patient, ensuring they have what they need to live a long and healthy life.

Appendix A



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