

Case Report

Applications of Cognitive and Social Development Theory in Pediatric Type 1 Diabetes Case Management

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Introduction

Type 1 Diabetes (T1D) can occur at any age but is most commonly diagnosed between infancy and late 30s. The SEARCH for Diabetes in Youth study estimated that in 2009 about 18,436 US. Youth were newly diagnosed with T1D. Approximately 70% of these youths were non-Hispanic Whites, 17% were Hispanics, and 11% were non-Hispanic Blacks [1]. T1D is associated with an increased risk for several health problems including cardiovascular diseases [2-4], epilepsy [5], retinopathy [6], and thyroid autoimmunity [7,8]. Studies in Norway found that despite improved diabetes care, mortality remains three to four times higher among those with childhood-onset diabetes compared with the general population [9]. When looking at case management as a whole in regard to diabetes, many problems can be seen with the current management plans and limitations can be seen in the methods used to educate diabetics on their condition. When looking at future paths to take to improve diabetes case management a few can be proposed including evidence-based case management, case management methods that address low health literacy and numeracy and using various psychological behavior theories to see how this adolescent population can be best addressed.

Challenges Facing Pediatric Type 1 Diabetes Case Management Currently

When trying to address the issue of how case management can be improved in the community of pediatric diabetes, it is first important to understand what challenges or hurdles are currently faced in this field. Disease case management is a systematic and proactive approach to the prevention or treatment for chronic illnesses across the continuum of care [10]. Case management is a collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy to meet an individual's and family's

comprehensive health needs while promoting quality and cost-effective outcomes. Case management uses evidence-based clinical practice guidelines to develop individualized care plans, prioritize goals in collaboration with patients and their providers, and to assist patients with implementation of a self-management plan to improve symptoms of chronic conditions and quality of life [11]. Effective case management involves discussing medical regimens in the context of the patient's lifestyle, which may include socioeconomic status, family status, belief system and occupation. The case management care plan, a comprehensive patient care strategy, describes approaches that address the patient's needs and contains measurable goals to be achieved, a time frame for achieving them and resources available. When looking at previous studies that focused on using a care ambassador that focused on these needs that these patients and their families had, it was shown that the work of these ambassadors helped improve A1C in adolescents with suboptimal baseline glycemic control [12].

Case management for T1D poses significant challenges to parents and their children because it requires close adherence to a complex and time-consuming lifelong daily regimen. Failure to adhere to this regimen, which requires persistent monitoring of blood glucose and insulin levels, may cause acute and chronic diabetes-related complications such as seizure, coma, diabetic ketoacidosis, cardiovascular disease, retinopathy, nephropathy and neuropathy [13]. Parents typically lack the experience and skills to effectively manage their children's diabetes and face additional challenges because of the child's limited communication, less developed cognitive skills, and finicky eating patterns. Very young children may vary in their readiness to receive knowledge and willingness to be influenced, are more sensitive to variations in dosages of insulin, and are often unable to report symptoms of hypoglycemia [14].

The Limitations of Using Diabetes Education Alone

Studies have demonstrated that educating parents and their children about diabetes management without some form of follow-up outside the clinical setting does not promote effective disease management for T1D. Patients and their parents who received intensive education in diabetes self-management improved in knowledge and understanding of diabetes but did not improve significantly in glycemic control [15]. Studies from a population-based cohort of youth with T1D who received Diabetes Self-Management Education (DSME) revealed that while patients and their parents receive education on "survival skills" targeting blood glucose and what to do for low or high blood glucose there were gaps in continuing education. Patients were less likely to receive any continuing diabetes education, lacked in-depth understanding of the psychosocial issues involved with diabetes management, and were unlikely to receive any form of nutritional counseling [16].

Evidence-Based Case Management as an Alternative

Case managers serve as advocates and educators for the patient and the family, facilitating access to care through the health care delivery system and community resources, and educating the patient in self-advocacy and self-management. Primary challenges for case managers include encouraging health and wellness, promoting self-management for individuals with both the early and chronic stages of illness, and providing advocacy and support to reduce the number of acute and chronic episodes, complications, and hospitalizations [17]. Effective case managers achieve a continuity of care through titrating support and structure in response to client needs and facilitating their resourcefulness and strengths, while being flexible in implementing intervention strategies [10] such as building patient skills [17]. The Broker Model is a traditional approach that focuses on assessing needs, referring services, and coordinating and monitoring treatment.

The case manager is the coordinator of services that are provided by a variety of professionals. Clinical Case Management takes a much broader approach than the Broker model, focusing on relationships with clients that recognize the interplay between psychological and environmental domains. Interventions are holistically focused and acknowledge the interaction between biological and psychological factors and how these factors interact with a patient's physical and social environment. Case management can take many forms, depending on the patient's specific needs. It can be delivered telephonically or one-on-one by a multidisciplinary team including nurses, social workers, pharmacists, school nurses, or teachers in hospitals, homes, schools, community centers, or workplaces. Interventions involving case management can include reminders from physicians or nurses to the patient or to the patient's family, following up on patients to monitor progress, empowering the patient through counseling, education, training and advocacy [18], and ensuring compliance with medical recommendations [19]. A case manager assesses, plans, implements, coordinates, monitors, and evaluates the options and services needed by a child and family and arranges services if needed. Case management has been shown to be effective when care was coordinated among multiple health professionals. Close collaboration between nurse case managers, physicians and endocrinologist can help improve glycemic control in patients with Type 1 and Type 2 diabetes, resulting in significant reductions in fasting glucose levels and improved adherence to medical recommendations by the patients [20]. Patient outcomes also improved when nurse case managers, supervised by diabetologists and primary care physicians, made medication changes independently while still coordinating with a multiple disciplinary team providing multiple sources of input for the patient [18].

Research on the effectiveness of case management in pediatric diabetes is limited. This is due, in part to the low prevalence of type 1 diabetes as it accounts only for 5-10% of all the cases of diabetes, affecting approximately one in every 400-500 US. Children and adolescents [21,22]. Case management in pediatric diabetes is also challenged by difficulty in testing patients. However, the potential impact of case management on pediatric diabetes is illustrated by its effectiveness in symptom management of other chronic pediatric diseases such as asthma, which is also affected by

physiological, environmental, and social factors. Childhood asthma case management has been widely studied and is a good model from which to glean best practices. In the asthma literature, school-based, collaborative approaches to managing chronic diseases have been shown to be effective with pediatric patients [23]. A systematic review of 244 randomized controlled trials examined measures of self-management of asthma in children and adolescents, revealed that supported self-management can reduce hospitalizations, accident and emergency attendances and unscheduled consultations, and improve markers of control and quality of life for people with asthma across a range of cultural, demographic and healthcare settings [24]. The common characteristic of successful pediatric case management interventions with pediatric asthma patients was inclusion of disease education and self-management skills. Case management education and skill-building can also include identification of barriers to health and social support and how to overcome those barriers.

Other Important Considerations in Case Management: Improving Health Literacy and Numeracy

The primary goal of pediatric diabetes education is establishing patient/family skills related to pattern management of glucose levels at home, which require adequate health literacy [25]. Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. Health literacy is important in-patient provider encounters, during a pharmacy visit when patients are reading their prescription bottles, and at home when they are reading information concerning their own or their child's illness [26]. Poor patient health literacy has been linked with limited knowledge of their disease, lower quality self-reported and satisfaction measures and an increased risk for hospitalization (Rothman et al., 2004). Low health literacy levels can be overcome by careful case management strategies. One study investigated the impact of disease management featuring one-on-one meetings with a case manager and intensive disease management from a multidisciplinary team among patients with low literacy [27]. Compared to low literacy patients who did not receive intervention, the study demonstrated greater success in controlling blood glucose levels among low literacy patients who received one-on-one educational sessions combining counseling and medication management, treatment algorithms to manage glucose and cardiovascular risks, and strategies to address patient barriers such as telephone reminders, transportation, communication and assistance with insurance difficulties. Another study that employed a pharmacist-led diabetes management program for low-literacy patients with type 2 diabetes and poor glycemic control using hour educational sessions about glucose control, glucose monitoring and management, nutrition and exercise, proper food and eye care, and medication management requiring patients to teach back the information to assess their understanding supplemented with face-to-face or phone call follow-up every 2 to 4 weeks to assess, adherence, self-management behaviors and titrate medications if the patient needed it [28].

With pediatric patients, poor health literacy is a problem not only among the patients, but also among caregivers. Health outcomes for children with special health care needs are dependent upon their

caregiver's capacity to understand complicated medical regimens, nutritional regimens, school-system resources, and other health information [29]. Poorly controlled diabetes may occur among children because their caregivers fail to comprehend provided diabetes education. Hassan and Heptulla [25] found that the health literacy levels of caregivers significantly influenced glycemic control among children with Type 1 diabetes. Most health information is written above the tenth-grade level and chronically ill children with caregivers with low literacy, are twice as likely to use more health services as children of caregivers with adequate health literacy [30]. Adolescents and young adults are also expected to understand complex health information and make decisions regarding their own health although they frequently do not have adequate health literacy and the skills necessary to manage the symptoms of their illness. In this systematic review of 215 articles, it was found that at least one in three adolescents and young adults had low health literacy [31]. Numeracy is an important component of health literacy and has been defined as "the ability to understand and use numbers in daily life" [32].

Numeracy involves patients doing simple math for following instructions regarding how to take prescription medications or doing math to determine how much insulin is required to lower glucose levels to a normal level. Poor health literacy and numeracy skills in patients with diabetes can result in greater difficulty understanding their disease, worse glycemic control, and worse clinical outcomes as compared to patients with adequate health literacy. Low diabetes numeracy skills among adult diabetes patients were associated with worse perceived self-efficacy, fewer self-management behaviors and possibly poorer glycemic control [33]. It is important to improve numeracy skills of pediatric patients and their caregivers as studies have indicated that the level of parental diabetes-related numeracy is strongly related to the effectiveness of glycemic control among pediatric patients [34]. Current research on the role of patient and caregiver literacy and numeracy suggested that practitioners should screen both patients and their caregivers to assess numeracy and literacy skills. Mulvaney, et al., [35] have recently developed and validated a shortened version of the Diabetes Numeracy Test for Type 1 diabetes for use with adolescents. Recommendations for future studies include determining the effect of case management on numeracy skills in type 1 diabetic pediatric patients and the caregiver.

Cognitive Psychology Theory and Child Health Literacy Best-Practices

Childhood is a time of physical, cognitive, social and emotional development. Piaget studied how knowledge evolves during childhood and posited that children moved along a linear course of development that consists of different transitions between certain times in a child's life [36]. Young children's cognitive capacities to some degree limit the management of type 1 diabetes because they have difficulty in grasping complex higher-order concepts typically associated with formal, logical thought, time management, and cause and effect [13]. Most children with type 1 diabetes are diagnosed at a young age, when they may be in the pre-operational stage (two to seven years of age), the child learns to use language and represent items by images. Cognition at this age is egocentric and objects are classified by a single feature. In the concrete operational stage, which takes place between

7 to 11 years, the child can think logically and can understand the conservation of number, mass and weight. Objects are classified by several features with a single dimension. Concrete reasoning skills and limited problem-solving abilities may make adhering to diabetes treatment regimens seem like some sort of punishment to a child, leading to aggression and resistance to blood glucose checks, insulin injections, and other necessary treatment approaches.

In the formal operation stage, which occurs at 11 years of age and older, the child can think abstractly and systematically. Piaget's cognitive development theory consists of three major developmental processes: assimilation, accommodation and equilibration. Assimilation is the way children take in information and understand it according to their existing knowledge. Accommodation is the way children change their way of thinking in response to new events. Equilibration is a three-stage process that combines accommodation and assimilation. In the first stage, if the child is in a state of equilibrium or a state of cognitive balance, then information fails to assimilate or become incorporated as new information [36]. As type 1 diabetes patients enter adolescence, they assume increasing responsibility for the management of their condition at a time of decreasing parental monitoring. Unfortunately, the multifaceted demands of diabetes management require a range of competencies in executive functioning such as planning, problem solving, monitoring and ongoing regulation of behavior that are typically lacking in adolescents due to limitations related to neurobiological immaturity in areas of the brain related to executive functioning [37]. Teenagers have less decision-making competence than adults in areas related to advice seeking, evaluation process, adaptive goal setting, and learning [37]. Piaget described adolescence as a period in which personality, not cognitive thinking, was developed.

The psychologist Vygotsky broadened Piaget's cognitive psychology by incorporating ideas that social interactions and cultural factors could affect a child's cognitive development. Vygotsky's ideas included a zone of proximal development: the area between what a child can do with assistance and what a child could do without assistance (Figure 1). The zone of proximal development includes skills that are too difficult for a child to master on his or her own but can be done with assistance from a knowledgeable person [38]. If tasks are presented within the child's zone of proximal development, the child's cognitive abilities increase.

Scaffolding occurs when a task is mastered with assistance from someone else. Scaffolding involves breaking down a large, complicated task or lesson into smaller parts and then providing a tool or lesson

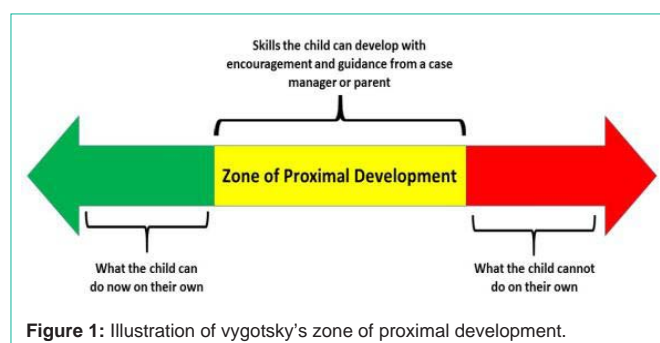


Figure 1: Illustration of vygotsky's zone of proximal development.

with each part. It would involve the instructor completing and modeling the task first, followed by the instructor and the student working together to perform the task. Lastly, the student does it on his or her own to practice and help them perform the task automatically. Once the child masters a task, the scaffolding can be removed, and the child can continue on his or her own (Figure 2). When looking at a specific example in the case of diabetes, scaffolding can be used in order to teach carb-counting to these adolescents. When looking at the case manager's instruction branch of scaffolding, this could be utilized by simplifying the task down to simple math to help the child understand as well as setting goals such as the child getting within 10 carbs of the correct carb count and possibly rewarding the child when this is achieved. When analyzing the case manager's attitude branch of scaffolding the most important thing to keep in mind when teaching the child how to carb count is to not get frustrated with the child, be very positive with them, and most importantly being patient. Vygotsky saw cognitive development as learning general and specific tasks. He also saw that learning would be more successful in social and cooperative settings because support would be provided by the environment [36]. From a Vygotskian perspective, a case manager can mediate child learning and self-care skills as they share knowledge through social interaction [39].

Scaffolding could facilitate learning how to self-manage via modeling a skill, providing hints or cues, and adapting instructions based on the child's ability [40]. Scaffolding can be performed with just about any task. Consider these guidelines, as described by Silver [41] for scaffolding instruction:

- Assess patient's knowledge and task experience
- Relate content to what patients understand or can do
- Break the skill into small, manageable tasks
- Use verbal cues and prompts (feedback) to assist the patient

A contemporary application of Vygotsky's theories is "reciprocal teaching", used to improve the learner's ability to learn from text. In this method, the instructor and learner collaborate in learning and practicing four key skills: summarizing, questioning, clarifying and predicting. The instructor's role in the process should be reduced over time as the learner's skills are developed (Figure 2). The central challenge in effective treatment of diabetes among adolescents is the effective transfer of diabetes management from the parent to the child [42]. Adolescents vary in their ability to manage different aspects of

their diabetes, achieving success in some areas while not managing other very well [43]. Adolescents may also overemphasize positive aspects of their self-management based on self-defensiveness and inconsistent awareness of the importance of their self-management of glycemic control. Curtis and Hagerty [39] suggest that to be effective, approaches to adolescents need to encourage them to verbalize personal concerns, praise them for what they are doing well, and employ nonjudgmental approaches to things that may be doing ineffectively in managing their diabetes.

Conclusion

Several studies indicate that multidisciplinary care teams provide the most effective approaches to the treatment of pediatric and adolescent diabetes. Key roles of the interdisciplinary care team involve identifying psychosocial barriers, assisting with behavioral and family issues, and adjusting care to parents and patient knowledge levels and learning styles [44]. In a review of new approaches to individualized diabetes care, Powell, et al., [45-49] propose that clinical care delivery is evolving far beyond adjustment of insulin regimes to include the integration of patient-centered strategies such as shared decision-making, motivational interviewing, shared medical appointments, and multidisciplinary team collaboration, forming a dynamic model of diabetes care delivery. This newly emerging person-centered care model holds promise for achieving glycemic targets and improving each patient's quality of life. Both cognitive psychology theories are useful in guiding when and how children can improve their health literacy. Psychologists, social workers, and nurses who function as part of the case management team can assist in the planning and implementation of developmentally appropriate interventions.

Case managers can easily provide health information to children in a format most appropriate for their age. A younger child should be given information through use of pictures while an older child should be given information in more detail. Case managers can help improve assimilation, accommodation and equilibration skills by explaining the information according to the child's stage of cognitive development. The Vygotskian approach suggests that including social support from case managers and parents could facilitate learning about type 1 diabetes management at a young age. If information and tasks are presented within the child's zone of proximal development and scaffolding, the child's cognitive abilities and skills will increase. Further, health numeracy is an essential skill for those who must carefully monitor glucose levels and balance administration of insulin with food intake and levels of physical activity. The case manager could first assist the parents and their child in building the numeracy skills necessary to manage their diabetes, such as calculating insulin dosages, and then gradually support the child to implement the skills on their own starting with simple tasks and small steps in order to experience success and consequently build self-efficacy to attempt more difficult tasks necessary for successful diabetes self-management.

Clinical care delivery for Type 1 diabetes is currently evolving far beyond adjustment of insulin regimes to include the integration of patient-centered strategies such as shared decision-making, motivational interviewing, shared medical appointments, and multidisciplinary team collaboration, forming a dynamic model of diabetes care delivery. Newly emerging person-centered care

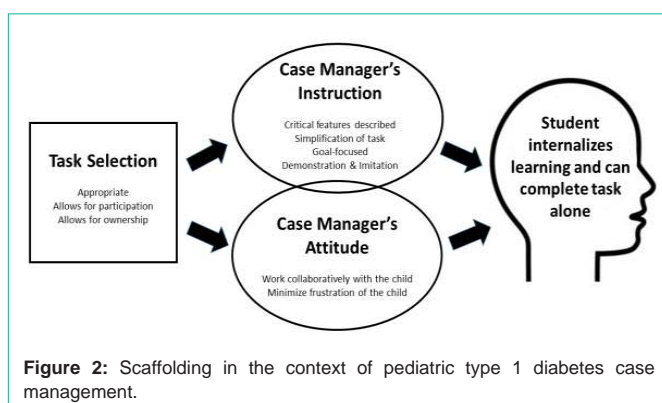


Figure 2: Scaffolding in the context of pediatric type 1 diabetes case management.

models hold the greatest promise for achieving glycemic targets and improving each patient's quality of life.

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