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Diabetes Care Provider Perceptions on Family Challenges of Pediatric Type 1 Diabetes

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Abstract

Pediatric healthcare providers' perspectives on barriers to diabetes self-management among youth with type 1 diabetes and strategies to overcome them were explored qualitatively. Family conflict about diabetes care was viewed as a common problem, addressable by behavioral interventions to improve communication and promote family teamwork in diabetes management responsibilities.

Keywords

Type 1 diabetes; pediatrics; qualitative research; healthcare provider; family conflict; communication

Introduction

Most youth with type 1 diabetes (T1D) do not meet their glycemic targets [1], largely due to the challenges of diabetes management during childhood and as adolescents transition from their parents' care to independence [2, 3]. Positive and developmentally-appropriate engagement of the family in the youth's diabetes care is critical to optimize outcomes [4]. However, a multidisciplinary base of evidence is lacking to develop educational “best practice” guidelines.

We aimed to solicit the perspectives of stakeholders involved in the care of youth with T1D on common family-related problems around diabetes management and suggested strategies

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Conflicts of interest: None

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for overcoming these problems. Data from this research will inform the content of Family Teamwork Online [5], web-based adaptation of a proven-effective clinic-based intervention (Family Teamwork) to diminish conflict between youth with T1D and their parents around diabetes care tasks [6, 7].

Subjects, Materials and Methods

Ten out of 75 diabetes care providers at a large tertiary pediatric diabetes care center in the United States were recruited. This sample size was expected to result in theoretical saturation, the point at which no new information was attained from the qualitative interviews. Guided by purposive sampling, providers were selected to reflect the diversity of roles on the diabetes care team, ages, races/ethnicities, and to include providers with and without T1D themselves. The Institutional Review Board of this medical school waived written consent based on absence of personal information being collected (H-37245).

An interview script was developed by the investigators based on their clinical experience. Questions were open-ended and non-leading; responses were expanded and clarified with probes. Trained research staff conducted the in-person interviews, which were digitally recorded, transcribed verbatim, and reviewed for accuracy prior to analysis. Three trained staff coded and analyzed transcripts using deductive thematic analysis [8] with an a priori framework informed by the script; with new codes added during analysis. Codes were iteratively grouped into themes by the research team. Selected verbatim quotes provided support and context for the themes [9].

Results

Participants were 90% females and 70% non-Hispanic white. The sample (n=10) included an attending physician, two fellows, two nurse practitioners, a diabetes educator, a dietitian, a social worker, a nurse and a scheduler. Three participants had T1D themselves. Interview length ranged from 13 to 30 minutes.

Common Problems

Approximately 31 codes were generated and grouped into five themes: family conflict, adolescent independence, diabetes burnout, social issues and lack of access to health care. Topics included in family conflict were communication breakdown, parental under-or over-involvement, and rivalry among siblings. “Diabetes talk” replacing other topics of interest to the family exemplified communication breakdown, while parents' excessive zeal over the diabetes management plan illustrated parent over-involvement. The developmentally normal adolescent push for independence was also identified as a barrier in that it could lead to confusion about responsibility for specific diabetes care tasks. Diabetes burnout was thought to affect both patients and parents. Among social issues, life stressors were often reported. Other social concerns included lack of uniformity and quality of care provided to the child with T1D by various caregivers, and unusual schedules during vacations and holidays. Lack of access to quality health care included health insurance issues, financial constraints and difficulties scheduling clinic visits that jeopardized continuity of care.

Strategies

Approximately 25 codes were developed and further collapsed into three themes: family responsibility, communication, and resources/support. Family responsibility included managing diabetes care tasks together. Other recommended family approaches were fostering the youth's emerging independence in diabetes self-care, incorporating diabetes into daily life, seeking an agreement between parent and youth, and using positive reinforcement instead of punishment for undesirable behaviors. Effective communication was regarded as critical to coordinating diabetes management among various caregivers, e.g. across different households. Suggestions included ensuring parent communication with the youth regarding blood glucose readings was emotionally detached (i.e., factual). Constructive communication between parent and child, and understanding the others' perspectives were recommended. Role playing was a suggested method for teaching effective parent-child interactions and communication skills. Diabetes care providers advised letting adolescents safely express themselves during the clinical visit. Finally, the theme of resources/support included diabetes education for all caregivers of a child with T1D, timely referrals to social services and psychological counseling, and promoting the use of age-appropriate tools for diabetes management. There was a need for more clinic resources and increased diabetes care provider availability to improve access to care.

Discussion

Understanding the barriers to optimal diabetes care from the perspective of patients, families and providers involved in their care [10-15] is critical to developing well accepted interventions. Previous studies have sought the views of parents [12, 15] or youth living with diabetes [13]. However, to our knowledge, this is the first qualitative study with diverse diabetes care providers on the barriers they perceive in families of children with T1D and their suggested strategies for addressing them.

Many of the challenges identified by providers were related to family conflict causing lack of effective support [16-18]. To overcome them, diabetes care providers suggested improving communication and addressing diabetes care as a family responsibility. These suggestions are consistent with the targets of Family Teamwork and support maintaining this focus in the adapted version, Family Teamwork Online.

While the study sample size might be viewed as a limitation, small samples are acceptable in qualitative research [19]. The generalizability of this feasibility study may be limited to the geographic region of the United States where this study took place. Additional barriers to diabetes self-management may stem from other parties involved, such as healthcare providers.

In conclusion, diabetes care providers offered key insights into problems faced by youth with T1D and their families and strategies for overcoming them. Their suggestions can be informative when developing behavioral interventions to enhance pediatric diabetes management.

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Highlights

- Diabetes care providers identified issues of families of youth with type 1 diabetes.
- Pediatric diabetes care providers identified strategies to approach common issues.
- Reducing conflict in families of youth with type 1 diabetes must be a treatment goal.