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Outcomes That Matter to Teens With Type 1 Diabetes

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Abstract

Purpose—The purpose of the study was to describe outcomes that matter to teens with type 1 diabetes. Understanding outcomes that matter to teens could support successful interventions to improve diabetes self-management.

Methods—Fifty publicly available posts published in the “teen” sections of 2 major diabetes online forums between 2011 and 2013 were analyzed using qualitative research methods. From each post, content and descriptive data (eg, duration of diabetes and age) were collected. Two members of the research team independently used open coding techniques to identify outcomes (defined as impacts or consequences of type 1 diabetes) and organized them into themes and subthemes. A codebook was jointly developed to facilitate the identification of meaningful outcomes from the posts.

Results—Teens’ average age was 15.7 years, and the average time since diabetes diagnosis was 6.3 years. The 3 most commonly mentioned outcomes were (1) interactions with peers (“I want to talk to someone who understands”), (2) emotional well-being (“Diabetes makes me want to cry”), and (3) blood glucose management (“My blood sugar never goes down”). Other identified outcomes included (4) physical well-being, (5) education and motivation of others, (6) family interactions, (7) academic achievement, and (8) interactions with important others such as teachers.

Conclusions—While teens are concerned about control of their blood glucose, there are many other outcomes that matter to them. Health care providers and diabetes educators may want to consider these other outcomes when motivating teens with type 1 diabetes to improve blood glucose control.

Introduction

Type 1 diabetes has become an increasingly prevalent illness in children and teens.¹ Approximately 175 000 youth live with type 1 diabetes in the United States, with 13 000 new cases being diagnosed each year.^{2,3} Having poor diabetes self-management affects A1C and quality of life (QOL).^{3–6} In particular, teens with type 1 diabetes have the highest rates of nonadherence and highest mean A1Cs of any youth age group,^{7,8} which has prompted the

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National Institutes of Health to issue a call for research focused specifically on improving self-management in this age group.⁹ Among teens, more than 70% do not have optimal control of their disease.^{10–12} Given the negative impact of uncontrolled diabetes on long-term health, the high rates of inadequate control among teens is a crisis in need of solutions.

Many teens with type 1 diabetes struggle to achieve adequate self-management. Self-management “includes developing knowledge of the condition and treatment; medication management and adherence; self-monitoring of the disease and symptoms; managing the effects of illness on physical, emotional and social role function; reducing health risks; preventative maintenance; and working collaboratively with health professionals.”¹³ The challenge of diabetes management during adolescence arises in part from normal developmental processes around establishing autonomy and taking on more responsibilities.¹⁴ Teens must manage many psychosocial challenges, such as stress, relationships with their peers, and family conflict.^{15,16} These new challenges require teens to work differently with their families and peers while managing their diabetes. Teens who do not achieve glycemic control via self-management face short-term consequences such as hypoglycemia or hyperglycemia as well as severe long-term consequences such as nephropathy, retinopathy, neuropathy, and heart disease.^{17,18} Therefore, adolescence is a crucial time for health care providers and diabetes educators to support patients in maintaining good control of their disease.

To help maintain motivation for diabetes self-management, providers need to understand the outcomes that matter to teens. While health care providers and diabetes educators are often focused on A1C and perhaps to a lesser degree QOL, teens with diabetes may view other outcomes as more meaningful. Furthermore, some of these other outcomes may be seen as conflicting with achieving glycemic control. For instance, teens may miss classes and leisure activities as they manage their diabetes or recover from common illnesses.^{19,20} Understanding the outcomes that matter to teens with type 1 diabetes could support successful interventions to optimize their health care and also improve their engagement in managing their diabetes.

Online health communities on the Internet can serve as unique sources of data on outcomes that matter to teens with chronic diseases. In the past decade, Internet access has become almost ubiquitous, with a 93% reported usage rate among teens.²¹ Of those with access to the Internet, 73% of teens aged 12 to 17 years old report using social networking websites, with the majority using such services daily.²² Teens often seek out the web and social media to share personal information and find disease-specific or emotional support.^{23,24} Online forums provide a virtual environment that offers the ability to use pseudonyms, potentially creating a sense of anonymity for individuals to discuss topics that may be uncomfortable or sensitive, such as health concerns, sexuality, alcohol use, or bullying.^{25–28} Teens may discuss and post information on the Internet that they might not otherwise share. As a result, content in posts by teens with diabetes can provide a rather unfiltered window into their experiences, hopes, and challenges. Therefore, the purpose of the study was to describe outcomes that matter to teens with type 1 diabetes by analyzing the content of posts of 2 popular diabetes forums. Analyzing publicly available posts on type 1 diabetes online health

communities could improve the understanding of outcomes that matter to teens with type 1 diabetes.

Methods

Research Design

This study used a 3-stage design, similar to other qualitative studies analyzing online communities of individuals with chronic conditions.²⁹ First, researchers identified diabetes forums providing suitable source materials for analysis. Once identified, researchers then collected posts that matched eligibility criteria, de-identified the posts, and collected descriptive data about the posts and their authors. In a final step, the collected posts were inductively coded into larger thematic concepts (subthemes). Through multiple coding sessions and revisions, these concepts were then grouped into general categories (outcome themes) that described outcomes that matter to teens with type 1 diabetes.

Data Sources

The research team searched the Internet to identify potential diabetes forums with a focus on type 1 diabetes. Forums were selected for review based on 3 criteria: (1) Forum posts were publicly available, (2) the forum included a section specifically for teens, and (3) the forum included an adequate volume of posts to support the analysis. Of the 5 potential online forums identified, 2 met these criteria. Of the 2 forums that were chosen, 1 was hosted in the United States, while the other was hosted in the United Kingdom.

Data Collection

Eligible posts were those within the sections for teens and posted between the years 2011 and 2013. A total of 198 posts met those criteria. Among those posts, the research team eliminated posts due to (1) the poster acknowledging they were not 13 to 17 years of age ($n = 13$) or (2) the post containing only irrelevant content (eg, spam messages or advertisements) ($n = 9$), leaving 176 posts for analysis.

The content of the posts as well as descriptive data (eg, gender, age, and duration of diabetes in years, if available) were exported as text files. To protect the privacy of posters, all potentially identifiable information was removed before analysis. Further, at the Institutional Review Board's request, descriptions of actual post content in this publication are paraphrases rather than direct quotes. This prevents the possibility of tracing back quotes to the forum where they were posted and protects the privacy of the posts' authors. With these safeguards in place, the University of Wisconsin-Madison Health Sciences Institutional Review Board deemed the study exempt from review.

Data Analysis

Three trained coders used open coding techniques to analyze the content of the posts and identify outcome themes that the authors included in their posts. When posts contained multiple outcome themes of the same type, it was counted only once. Outcome themes were defined as results or consequences of type 1 diabetes. Open coding is content analysis of data with an inductive, constant comparison approach.³⁰ Initially, the researchers

independently immersed themselves in the posts, reading and noting outcome themes mentioned. The team then met to discuss their coded data, sharing perspectives and reflections on the outcome themes identified in the post. Through an iterative and simultaneous process of coding, analysis, and categorization among the research team, outcome themes and subthemes were defined, with subthemes merged and classified into overarching themes. Definitions for outcome themes and subthemes were proposed and iteratively refined throughout the process of coding. Differences in coding between coders were resolved through discussion. A codebook was jointly developed and iteratively revised to facilitate the identification of outcome themes from the posts. After analyzing a total of 50 posts, theoretical saturation was reached, that is, no further outcome themes or subthemes emerged from the data.³⁰

Results

Characteristics of Teens Who Posted to the Forums

The 50 coded posts were written under 36 unique pseudonyms, with an average length of 91 words per forum post. The number of outcomes mentioned per post ranged from 0 to 7, with a median of 1 outcome per post. Most teens (67%) who posted to the forums disclosed their age. Of the teens who disclosed their age, the median was 15.5 years. Half of them (50%) also included how long they had been living with type 1 diabetes. The median duration of type 1 diabetes was 5.0 years, but a wide range of diabetes duration was included, from newly diagnosed (2 had been diagnosed for <2 months) to those who have had type 1 diabetes nearly all their lives (17 years). Further, 44% (n = 16) of the teens who posted on the forums stated their gender. Of those, a majority identified as female (n = 11), while 5 teens identified as male (Table 1).

Outcome Themes

From the collected posts, 8 outcome themes were identified (Table 2). The most commonly mentioned outcome themes included: (1) interactions with peers, (2) emotional well-being, and (3) blood glucose management. Other outcome themes included (4) physical well-being, (5) education and motivation of others, (6) family interactions, (7) academic achievements, and (8) interactions with important others such as teachers and health care providers.

Interactions with peers, defined as communication with other teens, was the most commonly mentioned of the 8 unique outcome themes identified within the sample (72% of all posts). The major subtheme within this outcome was advice seeking from peers (39% of references to interactions with peers). An example includes asking for advice on obtaining a new insulin pump and whether or not it is painful (Table 3). Other subthemes included seeking peers with similar experiences (33% of references to interactions with peers), improving peer interactions (14%), negative interactions with peers (8%), and sharing life-threatening experiences (6%) such as episodes of hyperglycemia or hospitalizations.

Emotional well-being included outcome themes related to a state of being content, happy, and carefree (Table 4). Among the 50 collected posts, 56% referred to emotional well-being. Almost one-third of these references were about depressed mood (29% of references to

emotional wellbeing), defined as loss of interest and enjoyment in usual activities or reduced energy and decreased activity.³¹ For instance, a teen shared how any mention of diabetes had made her feel like crying (Table 4). Teens also wrote about the desire to be “normal” (29% of references to emotional well-being), to just live a normal life like their peers do. Other subthemes within emotional well-being included anxiety from diabetes, emotional distress caused by others’ reactions to their diabetes management regimen, denial, feeling isolated from others, and emotional bother from their diabetes regimen, such as being bothered by the numerous insulin shots and pokes for blood glucose.

Blood glucose management was defined as maintaining optimal blood glucose levels and improving adherence to their regimen. This outcome theme was mentioned frequently, with 20 (40%) of the total collected posts describing efforts to manage blood glucose (Table 5). Within the outcome theme of blood glucose management, some teens expressed concern with high (35% of total mentions of blood glucose management) or even uncontrollable blood glucose levels (20%) or suboptimal A1C (15%). Posts regarding low blood glucose were also noted (20%), including fear of hypoglycemia as well as descriptions of hypoglycemia’s physical manifestations such as shakiness or sweating (10%).

Other, less frequent outcome themes were mentioned in 31 of the 50 collected posts (Table 6). *Physical well-being* outcomes were concerned with being physically healthy and pain free. Outcomes regarding physical well-being were mentioned in a fifth (20%) of the collected posts. Among the posts that mention physical well-being as a concern, the desire to achieve general physical well-being in the face of diabetes, such as not wanting to put their physical health in danger, was the most frequently raised topic (60%). The specific physical manifestations of diabetes closely followed (40%) the desire to be healthy. Examples of this included experiences with diabetic ketoacidosis and hearing loss due to suboptimal diabetes management.

Education and motivation of others was defined as providing information and encouragement with regard to diabetes. Compared to other identified outcomes that mattered to teens, this particular outcome occurred less frequently in the coded posts (14%). Teens’ posts about this topic commonly included the desire to motivate each other to achieve better diabetes management and also to increase diabetes awareness in among others.

Family interactions outcomes described the impact of diabetes on parent-child or sibling relationships (10% of total references to outcomes). Within this outcome theme, teens posted about experiencing negative interactions with family members. Examples included struggles with their parents’ constant worry about their diabetes as well as family members being embarrassed by the teen’s diabetes.

Academic achievement outcomes described concerns about current and future educational performance. This outcome was discussed in 10% of the posts collected for analysis. The common subtheme was a general concern about how diabetes can affect teens’ performance in school, such as how diabetes should be managed when taking standardized exams for long periods of time.

Lastly, outcomes regarding *interactions with important others* are described as communication with persons other than peers and family members, such as health care providers and teachers. This outcome was discussed in 8% of the total coded posts. A common subtheme included wanting greater understanding from teachers and health care providers regarding the challenges type 1 diabetes presents for the teen.

Discussion

The results from this study describe outcomes that are meaningful to teens with type 1 diabetes. One finding is that adequate blood glucose management is indeed important to teens and they do very much value their own physical well-being. At the same time, they also want to live a normal teen life and avoid embarrassment and stress related to managing diabetes. Further, emotional well-being is also an important outcome that many teens value. By enhancing understanding of the outcomes that matter to teens, diabetes educators and other health care providers can leverage this information to help teens address their concerns and lead them to achieve adequate self-management of their disease.

The findings of this study suggest that blood glucose control is an outcome that many teens are not only concerned with but also recognize their difficulties in achieving. Teens in the study frequently referenced their efforts to maintain normal blood glucose levels. Despite these efforts, many express concern that their blood glucose and A1C are still too high. Maintaining optimal blood glucose during adolescence is especially difficult. Biologically, studies have shown that there is an increase in insulin resistance during puberty.³² As teens gain more autonomy and transition to independently managing their diabetes, many fail to maintain blood glucose control. This transition is made more difficult by peer pressure, stigma, and stress typical in teenage life.^{15,33} Within the forum posts, many teens shared their desire to be normal and free of distress from social stigma associated with their diabetes treatment regimen. Whereas the typical challenges of teenage life are taxing in their own right, teens with type 1 diabetes must learn to overcome both biologic and emotional challenges and integrate their evolving chronic disease management into their already hectic lives.

Further, emotional well-being related to type 1 diabetes showed to be also inherently important to teens. In the forum posts, teens described feeling embarrassed when injecting insulin in public and how some teens perceived that their families were embarrassed about the teen's diabetes. These findings are consistent with a recent study that asked teens about barriers to self-care. One-third of those surveyed in that study reported being embarrassed about blood glucose monitoring and insulin injections in public.³⁴ In addition, references to depressed mood occurred in almost one-third of the posts that mentioned emotional well-being as an outcome theme. Teens expressed feelings of helplessness because of their diabetes and wanting to cry whenever the topic is brought up. Studies have shown that teens with type 1 diabetes are almost twice as likely to experience depressed mood compared to unaffected peers.^{35,36} In addition, depressed mood is negatively correlated with metabolic control in teens.³⁷ The obstacles of overcoming embarrassment that comes with their diabetes regimen as well as issues with mental health could be contributing factors to the poor adherence and disease control that is often seen in teens with type 1 diabetes.^{7,8}

Recently, the American Diabetes Association (ADA) has recommended psychosocial assessment to be a component of diabetes visits, with a focus on diabetes-related distress.³⁸ Given this study's findings, the ADA recommendation seems particularly on target, and promptly addressing emotional well-being with screening and referrals to appropriate care is crucially important as depressed mood may be affecting a large proportion of teens with type 1 diabetes.

This study also finds that almost one-third of teens who posted on the forums expressed their desire to achieve feeling normal or living a typical life, suggesting that they feel different from their peers. The findings are consistent with a recent study in which teens documented their daily struggles through photography in which the majority noted that diabetes management and survival can sometimes occupy an overwhelming part of their lives.³⁹ Results of a recent study found that despite having more knowledge about diabetes than their younger counterparts, teens are less adherent to their regimen due to their desire to fit in and be normal.⁴⁰ Consequently, health care providers such as diabetes educators might specifically address the possibility that the teen's desire to simply fit in and be normal may be a profound deterrent to optimal self-management for teens.

Limitations

First, since the posts included in the study sample were open for viewing to the general public, teens may be less likely to talk about sensitive information compared to posts on a private forum. However, studies have shown that the majority of teens who use social media resources often choose to post more personal information online than in real life.^{23,24} Second, teens who chose to post on the forums may not be representative of teens with type 1 diabetes broadly. Specifically, there is limited data on the gender distributions of the posters, with less than half of the teens in the study sample stating their gender. The majority of those teens also identified as female. Therefore, the outcomes identified may not be as representative of the views of teenage males. Lastly, although only the posts from forums designated for teens were included in the study sample, some posters did not include their age. Consequently, some messages not authored by teens may have been included in the analysis.

Conclusions: Implications for Treatment and Counseling

The majority of teens consider blood glucose management and achieving control of their A1C as important outcomes, creating common ground with parents and health care providers. However, other concerns such as interacting with peers that have similar experiences and achieving emotional well-being are also relevant for teens. In clinical care as well as research and intervention development, A1C has been the primary outcome sought by providers and researchers.⁴¹ The results presented suggest that providers and researchers might also consider other outcomes of importance to teens with type 1 diabetes. For example, the Patient-Reported Outcomes Measurement Information System offers a validated suite of measures to assess outcomes such as stigma, emotional well-being, and peer relationships.⁴² Further, in adolescence, when optimal control of diabetes can be especially challenging, parents and health care providers can leverage these other outcomes

that matter to the teens when attempting to engage teens with type 1 diabetes to improve their self-management skills.

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Table 1Demographics of Teens (n = 36)^a

Age (n = 24) ^a	
Median (range), y	15.5 (13–17)
Duration of diabetes (n = 18) ^b	
Median (range), y	5.0 (0.1–17)
Gender	
Female	11
Male	5
Unknown	20

^aSome teens posted more than once.

^bTeens were not required to provide this information.

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Table 2

Frequency of Outcome Themes (n = 50)

Theme	% (n)
Interactions with peers	72 (36)
Communication with other teens	
Emotional well-being	56 (28)
State of being content, happy, and carefree	
Blood glucose management	40 (20)
Maintaining optimal blood glucose levels and improving adherence to regimen	
Physical well-being	20 (10)
State of being physically healthy and pain free	
Education and motivation of others	14 (7)
Providing information and encouragement with regards to diabetes	
Family interactions	10 (5)
Impact of diabetes on parent-child or sibling relationships	
Academic achievement	10 (5)
Managing current and future educational performance	
Interactions with important others	8 (4)
Communication with persons other than peers and family, such as teachers and health care providers	

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Table 3

Interaction With Peers (n = 36)

Subtheme	Frequency, % (n)	Example Post
Seeking advice from peers	39 (14)	I am afraid of operations and would like some advice on whether getting the pump hurts.
Seeking peers with similar experiences	33 (12)	Due to the lack of control of my diabetes, I have lost the majority of my hearing. Does anyone else have similar experiences?
Improving peer interactions	14 (5)	Are there any 15–17 years olds here? I would love to talk to someone my own age.
Negative interactions with peers	8 (3)	People would make fun of me because I was different and scare me when I was doing my injections.
Sharing life-threatening experiences	6 (2)	I've been in ketoacidosis more than once and nearly died from it.

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Table 4

Emotional Well-being (n = 28)

Subtheme	Frequency, % (n)	Example Post
Depressed mood	29 (8)	Whenever I hear anything somewhat related to diabetes, I feel like crying.
Desire to be normal	29 (8)	I'm sick of the sympathy and just want to live a normal life, but it's so hard to adjust.
Anxiety from diabetes	14 (4)	This is driving me crazy! I feel like diabetes is always on my mind.
Emotional distress caused by others' reactions to regimen	14 (4)	Am I the only one that hates doing injections publicly because of all the strange looks everyone gives me?
Denial	7 (2)	My friends accept my diabetes, but I don't. The hospital's letters just make me mad so I hide them.
Feeling isolated from others	7 (2)	I feel like I have to keep everything to myself so I never spoke to anyone my own age. I feel like I can't talk to other people that have diabetes.
Emotional bother from regimen	7 (2)	So much poking, so many shots.

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Table 5

Blood Glucose Management (n = 20)

Subtheme	Frequency, % (n)	Example Post
High blood glucose	35 (7)	My blood sugar is always high. It seems like it never goes down.
Low blood glucose	20 (4)	I was sweating, crying, shaking, eating Skittles, and drinking juice when I was low today.
Controlling blood glucose	20 (4)	A few months ago it was so hard to stay dedicated to controlling my diabetes.
A1C	15 (3)	I have a 10.1 A1C right now. So terrifying!
Fear of hypoglycemia	10 (2)	Going low is one of my biggest fears and gives me severe anxiety.

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Table 6

Other Outcome Themes (n = 50)

Outcome Theme	Frequency, % (n)	Example Post
Physical well-being	20 (10)	I have lost the majority of my hearing due to poor blood glucose control.
Education and motivation of others	14 (7)	I just want everyone to know that diabetes is a small obstacle and we can all get through any challenges that this illness puts in front of us.
Family interactions	10 (5)	The worst is that after the initial sympathy was gone, my family seemed to be embarrassed about my diabetes.
Academic achievement	10 (5)	I want to repeat my last year of school to get better grades but my school is worried because I am a diabetic and run the risk of being hypoglycemic. Any advice on this?
Interactions with important others	8 (4)	I get upset when a doctor who does not know how to live with diabetes tells me how I should be living my life.

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