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Effective Use of Diabetes Management Videos Among Young Adults

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About NEHI

NEHI is a national nonprofit, nonpartisan organization composed of stakeholders from across all key sectors of health and health care. Our mission is to solve complex problems and achieve value in health care by fostering interdisciplinary collaboration and innovation.

NEHI brings together expert stakeholder perspectives with relevant research to devise policies that speed the adoption of innovations.

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Executive Summary

Purpose and Methods

This project gathered information from young adults with diabetes and from clinicians who work with them to learn more about how online videos can best support diabetes management among young adults and how this population currently uses and assesses web-based patient education and information. The cornerstones of this analysis comprise both primary and secondary research, with the former featuring an online survey of 140 young adults and a focus group with this same population. Additionally, a focus group with diabetes clinicians was conducted to obtain their perspectives.

Key Findings

Patient Survey

An online survey asked young adults with diabetes about their experiences with videos about diabetes management – what topics interested them; their preferred information, presenters, and presentation formats; and their feelings about using various social media platforms for finding and viewing videos. The final section of the survey asked respondents to view four sample videos and respond to a series of questions about them. Respondents said they were interested in a variety of topics related to diabetes management. They were less in need of basic information, such as monitoring glucose levels, but were interested in learning about technology for managing diabetes. In addition, they reported:

- Turning to the internet for information, ahead of talking to professionals and their peers
- Seeking written materials and videos with equal frequency
- Having watched an online video on diabetes management
- Accessing social media platforms for videos more often than professional websites, despite rating professional sites highest for credibility
- Rating YouTube and Instagram highest for the ease of finding relevant information and that they used these two platforms most frequently (ahead of TikTok and Facebook).
- Having the most interest in “how to” demonstrations
- Preferring videos in which a person with diabetes spoke to the viewer or in which there was a conversation among people with diabetes
- Being less interested in text information on the screen with accompanying voiceover and in diabetes “experts” speaking directly to viewers

Patient Focus Group

We recruited participants for a patient focus group from the survey participants and through an advertisement in the College Diabetes Network (CDN) newsletter. Focus group participants had had their diabetes diagnosis for many years, so the information they tended to seek went beyond basic facts and advice. Overall, their opinions supported the survey findings (though there were some discrepancies) and elaborated on some of them. We elicited content in four areas:

Useful content. Participants reported seeking videos about using devices and about specific topics related to diet and exercise. They added that they look for someone with lived experience with diabetes and described vlogs (video blogs) as useful. They expressed an interest in “authentic experience” and could tell when they were being “sold” something. Participants also found helpful videos that presented complex information, such as how to use health insurance, in a digestible, interesting way. One participant thought videos were also useful in covering more sensitive subjects, such as alcohol and navigating romantic relationships.

Finding relevant information. Participants reported that they usually do not actively search for videos; more often they choose whether to watch videos that appear in their TikTok feed. When they need specific information, they may start with a general Google search and then turn to a video search. Participants described YouTube as the easiest to navigate when searching for specific content. They said that when they are seeking information on a very specific topic, they might turn to a non-video platform such as Reddit, rather than look for a video.

Effective characteristics of a good video. Participants identified several characteristics that make videos interesting and engaging: the use of humor, variety in presentation, brevity, and the “relatability” of the presenter.

Assessing credibility. Participants believed that individuals with diabetes presenting information in a video were as credible as professionals. The quality of a video (including being grammatically correct) enhances its credibility, and self-promotion and advertising diminish it. Most participants did not think the platform a video appeared on affected its credibility. One participant felt videos on YouTube were more credible than those on TikTok, but added that official channels of respected groups like the College Diabetes Network lend credibility to videos regardless of the platform.

Clinician Focus Group

We conducted a focus group with clinicians to understand their perspectives on their patients' use of videos in managing their diabetes, how they might use videos themselves in working with young adults, and how they balance patient preferences in video content with the reliability of the information. The focus group participants were supportive of young adults using videos to inform themselves about diabetes management. Several themes emerged.

What makes a good patient video:

- *“Relatability” matters to patients.* Participants specified that their patients respond to “relatable” videos, which means videos that are clear, concise, and engaging. They also reported that young adults prefer content that is presented by other young adults.
- *Length and platform.* Clinicians' understanding of their young adult patients is that they prefer shorter videos. Focus group participants said that many patients use TikTok for videos because they can view what appears in their feeds rather than having to search. Participants thought a young adult would more likely view a video produced by an organization such as Beyond Type 1 if they were directed to its TikTok channel rather than to the Beyond Type 1 website.

The role of the clinician:

- *Video recommendations by clinicians.* The participants said they prefer not to recommend videos unless specifically requested, such as for demonstrations of device use. They are generally more reactive concerning their patient's use of videos and see their role as helping patients sort through the veracity and applicability of what they see. They caution patients about videos posted by individuals, whose accuracy may be inconsistent and who may be rewarded for the number of views rather than quality of the information. They are skeptical of designations such as the “From Health Sources” tag on YouTube because, even if the information is accurate, it may not be right for a particular patient. This point led directly to the focus group's final theme.
- *Relationships between patients and their clinicians are critical.* All focus group participants stressed the primacy of a strong patient-clinician relationship. Social media is ubiquitous and around the clock. Physicians and educators need to have their patients' trust so patients feel safe discussing video content with them. Credible and engaging information needs to be matched to the right patient and it is difficult for videos to customize advice. Providing clear information about the identity and affiliations of the video presenter or the circumstances in which the video advice is

provided is important. A video that prompts further inquiry with a trusted advisor is also one that is more likely to advance an individual's knowledge and health.

Conclusions

This project shed some new light on how young adults with diabetes use information from the internet, and particularly from online videos, to help them manage their illness. The patients and clinicians who participated in the survey and focus groups agree that videos can be a useful tool for young adults. Videos with certain characteristics are more likely to engage a young adult's attention, and particular topics lend themselves more to video presentation. Young adults are aware of the varying quality of videos and apply discriminating criteria to assess credibility. At the same time, clinicians want to be able to assist their patients in making the best use of videos, less by making specific recommendations than by helping patients curate the content they encounter and understand what information is relevant to their situations. Finding ways to encourage this dialogue may be helpful.

Introduction

Diabetes is a chronic illness that affects more than 1 in every 500 children in the United States and requires diligent self-monitoring and management (Majumder et al., 2017). As children with diabetes grow into adults, the period of transition can be challenging, as they shift to adult health care and take on primary responsibility for managing their diabetes. This transition often occurs alongside many other environmental and social changes, such as moving out of their parents' home, starting college, and forming new relationships. These changes can disrupt routines and lead to poor diabetes management (Garvey et al., 2012; Ramchandani et al., 2019; Majumder et al., 2017).

Several factors contribute to young adults' (aged 18-25 years) lapses in diabetes management. Many may be leaving their parents, a major support system in their diabetes care, for the first time (Garvey et al., 2012). For those going to college, irregular schedules and limited on-campus dining options can interfere with their typical diabetes care routines (Ramchandani et al., 2019). Further, academic pressures can cause young adults to neglect their condition (Ramchandani et al., 2019). Inadequate sleep can affect their insulin resistance. Among those who do not attend college, work obligations can greatly detract from their care (Peters & Laffel, 2011; Pyatak et al., 2014). Social pressures to "be normal" can also significantly affect young adults' diabetes care (Pyatak et al., 2014; Ramchandani et al., 2019). Alcohol is often a part of young adults' social life, but alcohol consumption worsens glycemic control (Ramchandani et al., 2019). And experimentation with substance use can interfere with vigilance in monitoring glucose levels (Saylor & Calamaro, 2016).

In addition to leaving home and balancing work, school, and social priorities, many young adults face challenges in maintaining contact with a healthcare professional. Young adults with diabetes have been found to be at greater risk of poor glycemic control (Garvey et al., 2012), and at greater risk of going to the emergency room (Thind et al., 2022) and hospitalization (Butalia et al., 2019). The challenges are even more pronounced for young adults who are Black or Hispanic — people who are less likely to use diabetes management technology such as insulin pumps and continuous glucose monitors (Agarwal et al., 2020) — resulting in poorer glycemic control and more adverse outcomes (Butler et al., 2017; Nip & Lodish, 2021).

Facing this unique set of circumstances, people in this age group need better-targeted health education to equip them with the knowledge and skills to properly care for themselves. The internet has become the first source of information for patients actively seeking medical information (Fernandez-Llatas et al., 2017). Videos available on platforms such as YouTube are an especially popular medium among young adults (Madathil et al., 2015). Indeed, research has shown that text-only educational formats are not the most effective way to engage this age group, and can result in low patient attention, comprehension, and adherence (Banbury & McCloud, 2021; Liu et al., 2020). Other studies suggest that informational videos lead to better knowledge retention and self-efficacy for diabetes management (Paragas Jr. & Barcelo, 2019). Online videos, therefore, are an important tool for young adults as they navigate diabetes management alongside other life changes. We do not know enough, however, about how this tool can be most effective.

While the internet allows patients to be active information seekers (Kong et al., 2021), it can also be overwhelming, time-consuming, and confusing to find the most relevant information among the numerous search results (Battineni et al., 2020). One strategy that people appear to use to manage this challenge is to navigate only to the first few results of a search to look for relevant content, which may limit their findings (Fergie et al., 2016). To support young adults in finding relevant content, it is important to know what attracts them – what information and characteristics of delivery are most resonant. For example, social and emotional connection to peers appears to be a key aspect of online information-seeking for young adults; finding information from people with similar conditions helps them feel validated and less isolated in their own experiences (Fergie et al., 2016).

There is more to know about the unique information needs of young adults. While YouTube is one of the most popular social media platforms for video content among young adults (Gaus et al., 2021), a number of other platforms, such as TikTok, are gaining in popularity. Given the growing number of platforms and their variety of video content from individuals with diabetes, health professionals, healthcare companies, and others, knowing how young adult patients choose platforms and how they seek and assess information is important to ensuring they receive high-quality, reliable information. Some data suggest that the most popular health care videos feature patient presenters, are shot at home, and involve interviews (Zhang et al., 2016). However, there is not much literature focusing on health video use specifically among young adults, or specifically about diabetes.

The aim of this project was to gather patient and clinician input to inform how videos can best support diabetes management among young adults. We sought to understand the information young adults want from online videos, how they assess and use the video content, what factors are important in accessing videos, and the characteristics that make videos engaging and impactful. Additionally, we solicited clinician perspectives on the role of online videos in diabetes management for their young adult patients. The project had three components: an online survey of young adults with diabetes; a focus group with the same target population; and a focus group with clinicians who work with young adults with diabetes. We describe each of these in the sections that follow.

Patient Survey

Overview

We conducted an online survey of young adults with diabetes, aged 18 to 25 years, about their information needs related to diabetes management, their experience with videos about diabetes management, and their perspectives on four sample videos on different diabetes-related topics. The video topics included managing college life, navigating insurance, managing sexual relationships, and dealing with “bad days” in terms of diabetes control. The videos are described in further detail below.

Participants

We recruited participants for the survey through advertisements on NEHI’s website and social media pages and through advertisements in the College Diabetes Network (CDN) newsletter and social media posts. We received 140 valid responses from young adults with the following characteristics:

Diabetes Type: 82.86% of the participants reported having Type 1 diabetes, 16.43% had Type 2 diabetes, and 0.71% (one individual) had MODY (Maturity-Onset Diabetes of the Young, a rare form of diabetes caused by a single gene mutation).

Age: The average age at diagnosis was 10.81 years (SD= 5.18 years). The average age of participants was 20.96 (SD= 1.95 years).

Gender: 61.43% of participants were female, 36.43% male, 1.43% non-binary, and 0.71% preferred not to answer.

Race/Ethnicity: Participants were 48.57% White, 11.43% Black, 15% Asian, 4.29% American Indian or Alaskan Native, 4.29% Native Hawaiian or Pacific Islander, 2.86% Hispanic or Latinx, 12.14% multiracial/ ethnic, and 1.42% did not answer.

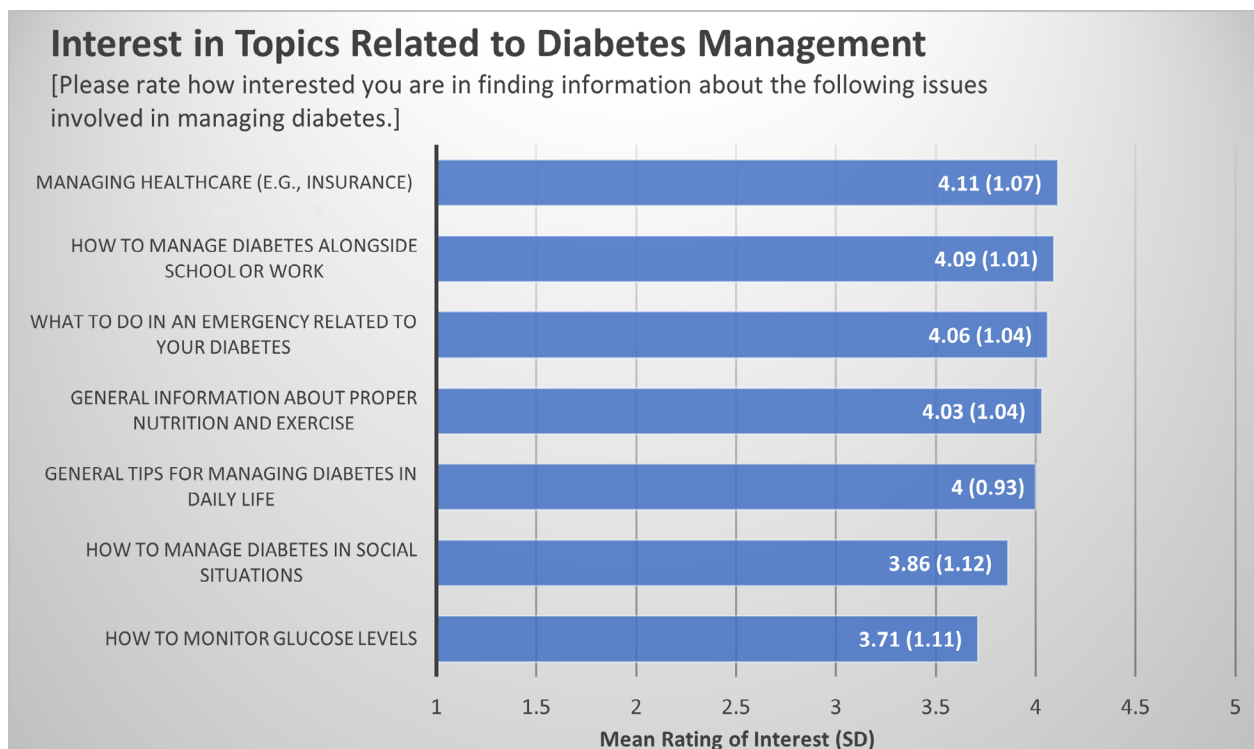
Geographic Distribution: Participants were from across the United States. Only a small percentage of the participants were from south-central (5%) and mountain states (4.3%).

Education and Work Status: Over 80% of the participants were full-time (67.86%) or part-time (15.71%) students, nearly 60% had a high school degree or some college, 28.57% had bachelor’s degrees and 8.57% had graduate or professional degrees. Most of the participants were also working for pay, 27.14% part-time and 47.14% full-time.

Findings

Self-efficacy. We asked participants to rate on a 10-point scale (10 being the most confident) how confident they are that they can manage their diabetes before asking about information preferences and video use. On average participants reported confidence/self-efficacy ratings of 7.37 (SD= 2.12).

Topics of Interest. We asked participants to rate on a five-point scale (1=not at all interested to 5=very interested), their interest in information on seven topics related to diabetes management. On average, participants were at least “somewhat interested” in all of the topics, indicated by an average rating of over three. Graph 1 below is a rank-ordered list of topics based on participants’ average ratings. In addition to these options, participants indicated an interest in content related to diabetes management technology in the space for comments about other topics of interest following the rating scale.



Graph 1

Effective Use of Diabetes Management Videos Among Young Adults
NEHI (Network for Excellence in Health Innovation)

Sources of Information. We asked participants to rate on a five-point scale (1=never to 5=very often) how often they sought information about managing their diabetes by: using the internet, talking to a professional, talking to peers or others with diabetes, and talking to friends or family.

Participants reported using the internet the most, with a mean rating of 4.02 (SD= 1.02), followed by talking to professionals (3.81, SD= 0.94) and talking to peers (3.79, SD= 1.23). Talking to friends or family members was the least used method, with a mean rating of 3.57 (SD= 1.06).

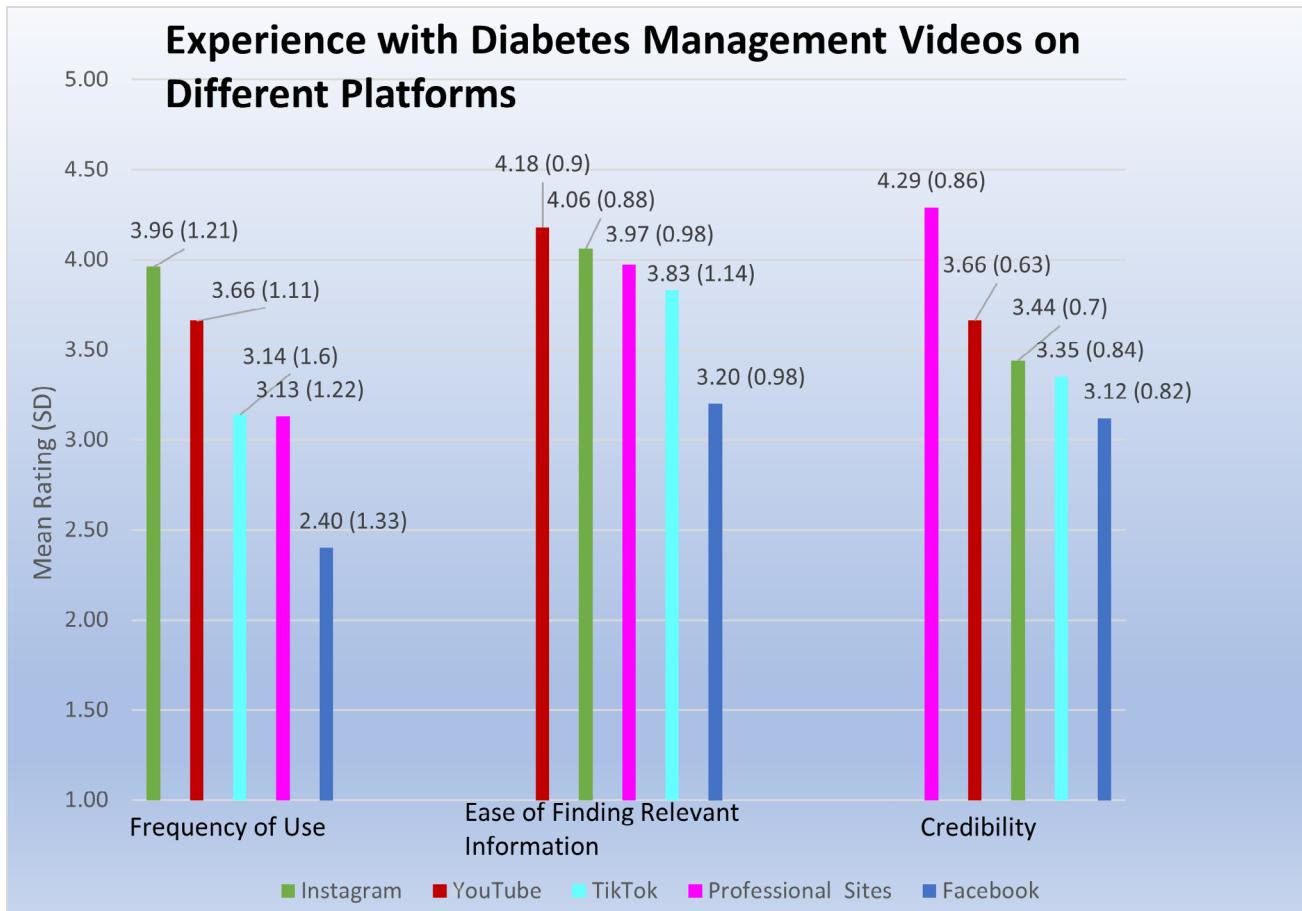
Information format. We asked participants to rate on a five-point scale (1=never to 5=very often), how often they sought information through written materials and videos. There was no difference in the frequency of use, with mean ratings of 3.56 (SD= 1.23) for written materials and 3.54 (SD= 1.19) for videos.

We asked participants to rate the usefulness to them of interactive videos, presented in a game format, for example, which present content tailored to their needs. The average rating was 3.83 (SD= 0.86) on a 5-point scale (1=not at all useful to 5=extremely useful).

Experience with videos. Approximately, 60% of participants had watched an online video on diabetes management.

Platforms. We asked participants who had watched diabetes management videos about their experiences with videos available on different platforms including professional websites and commonly used social media sites: Instagram, TikTok, YouTube, and Facebook. Participants were asked to rate how often they used each platform, how easily they could find the information they were looking for on the platform, and how credible they found the information. Ratings were on a 5-point scale, 5 being the most favorable rating. The ratings of each platform are displayed in Graph 2 below.

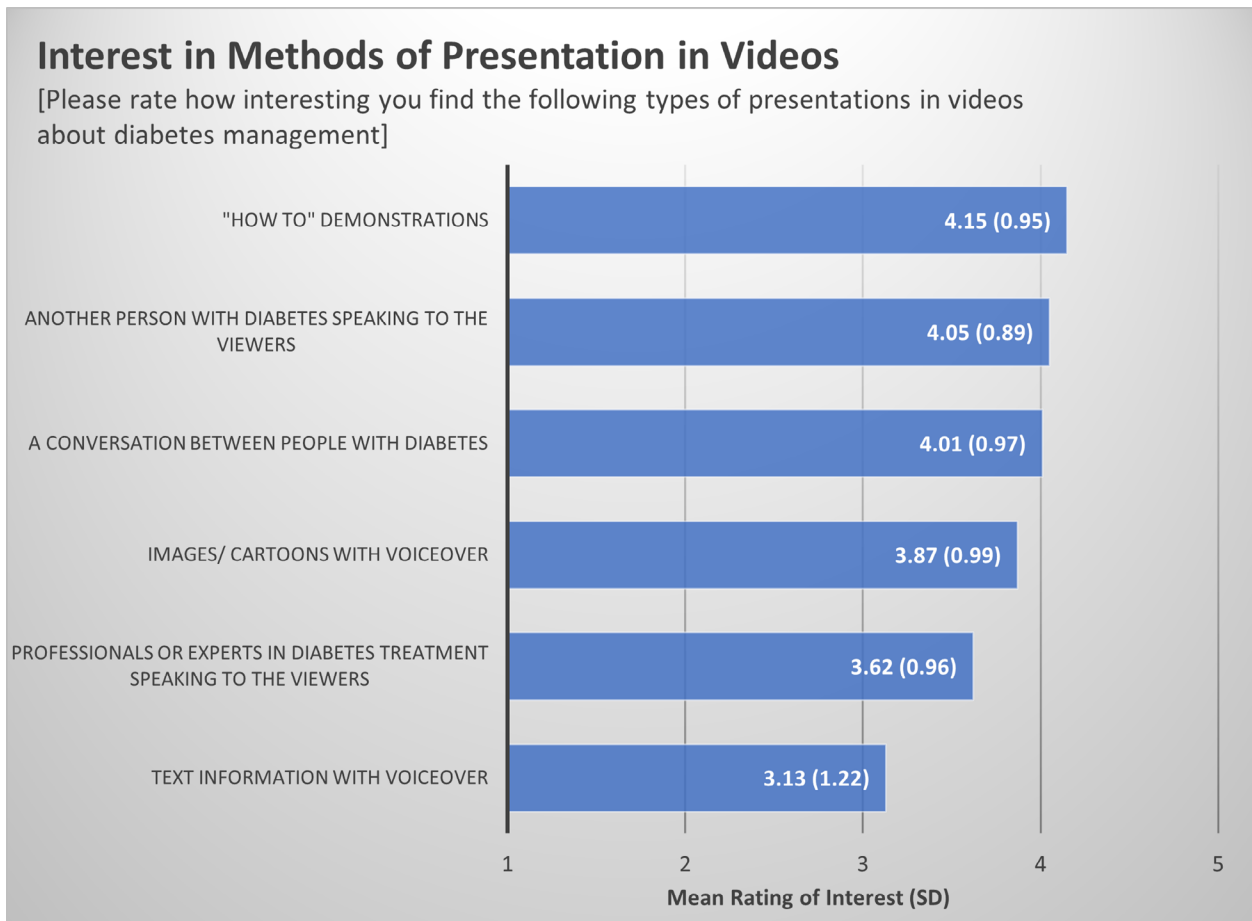
The results show that this population of young adults uses social media platforms, except for Facebook, more often than professional websites, though they rate professional websites the highest in terms of the credibility of information. Participants rated YouTube and Instagram the highest in terms of ease of finding relevant information.



Graph 2

The overall usefulness of online videos. We asked participants who had watched diabetes management videos to rate, in general, how useful they found the information they got from these videos. On a five-point scale (1=not all useful to 5=very useful), participants gave an average rating of 3.83 (SD= 0.86), indicating that they found the videos at least somewhat useful on average.

Methods of presentation. We asked participants to rate on a five-point scale (1=not at all interesting to 5=very interesting) their opinions about common methods of presentation in videos. The results, shown in Graph 3 below, demonstrate a preference for information delivered by peers that is somewhat dynamic, rather than a presentation by a professional or expert speaking directly to viewers or over text on the screen.



Graph 3

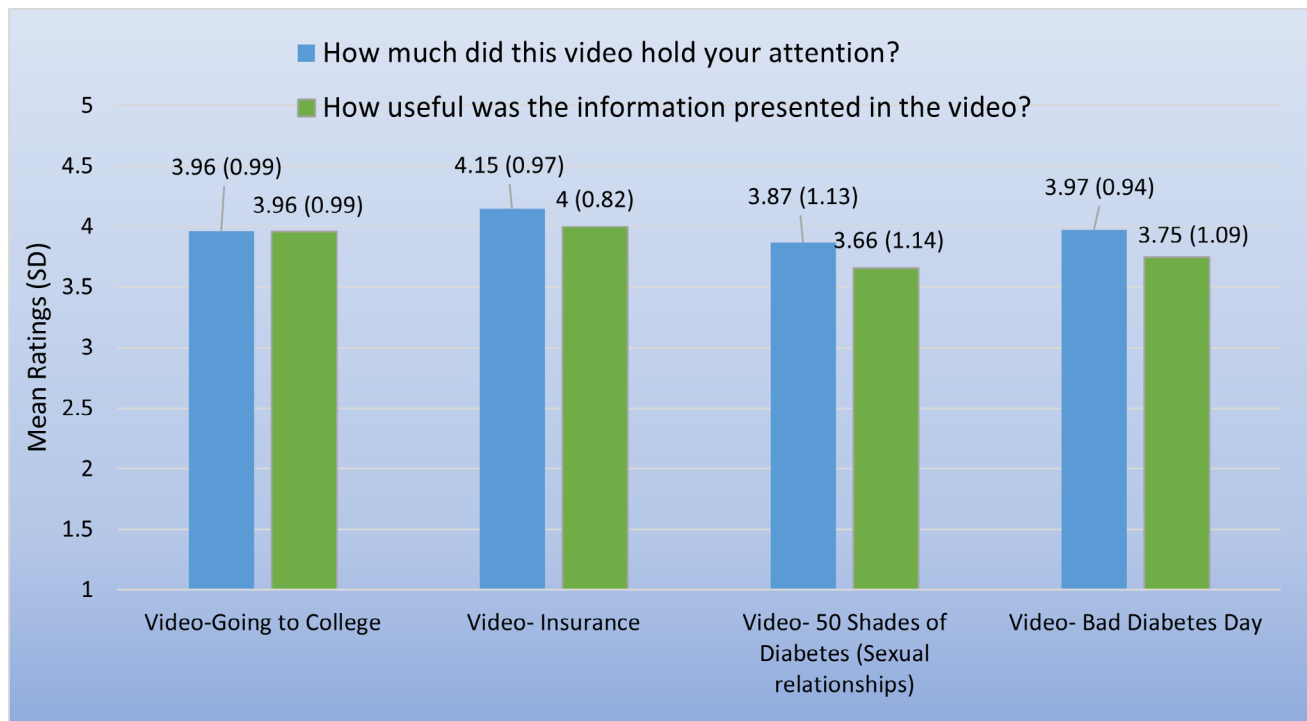
Feedback on sample videos. In the final section of the survey, we asked participants for their perspectives on four sample videos related to diabetes management to get a sense of the content and video characteristics that resonated with the participants. Each survey participant saw the same set of videos, but the order in which they were presented varied at random for each participant. The video topics were:

- Managing college life, a conversation among four young adults offering tips about managing diabetes when transitioning to college life, based on their experiences.
- Navigating health insurance, a mixture of clips from several young adults offering insights based on their experiences with insurance and information presented by a professional, interspersed with textual information.
- Managing sexual relationships, a parody of “50 Shades of Grey” called “50 Shades of Diabetes,” in which young adult actors offered tips on navigating diabetes management and sexual interactions, for example how to manage an insulin pump.

- Dealing with “bad days” of diabetes control, in which an individual living with diabetes described experiences with days when diabetes control does not go well and offered coping tips for such days.

Following each video, we asked participants questions about whether the video held their attention, the usefulness of the content, the length of the video, and the ease of understanding and credibility of the presenters, and solicited feedback on some of the unique features of each video.

The videos were approximately 4.5 to 7 minutes long. On average, participant ratings indicated that the videos were about the right length. The responses to each video showed that over 90 percent of the 115 participants who responded to this portion of the survey had viewed the entire video; 80 percent of the participants viewed all the videos fully. Graph 4 below shows ratings (on a five-point scale where five is the most positive rating) of the extent to which the videos held participants’ attention and how useful they found the information. Participants gave the highest ratings for usefulness to the video about navigating health insurance, followed by the video about managing college life.



Graph 4

Over 85 percent of the participants said they would recommend to a friend the videos about managing college life, navigating health insurance, and dealing with a “bad diabetes day.” In contrast, 61 percent said they would recommend the video about managing sexual relationships. Ratings of credibility of presenters and the ease of understanding them were also the lowest for the “50 Shades” video, at 3.71 (SD= 0.98) and 3.95 (SD= 0.98) on a five-point scale where five is the most positive rating. Notably, the presenters in this video had British accents. The average ratings of the other videos ranged from 4.28 (SD=0.81) to 4.5 (SD=0.63) for the credibility of the presenters and from 4.32 (SD=0.88) to 4.47 (SD=0.82) for ease of understanding the presenters.

Finally, responses to a set of open-ended questions about the videos allowed us to identify major themes in the respondents’ feedback, which informed the design of the focus groups in the next stage of our research. Participants indicated that, while the “50 Shades of Diabetes” video covered an important topic, the presentation style and music were “cringey” and uncomfortable. The responses also indicated a desire for more concrete information and links to resources.

The narrative responses to questions about the other videos were largely positive but included suggestions for improvement. The video about a “bad diabetes day” was seen largely as relatable but as too slow or boring. Two responses, however, expressed that individuals who are not as organized as the presenter or do not have well-controlled diabetes would not find it relatable. The responses also indicated a desire for more content addressing the mental health impacts of difficulties with diabetes control.

Participant comments indicated that the video about going to college was useful as an introductory video but that more detailed information, such as about college disability services, would improve its utility. Similarly, participants found the video about insurance useful and appreciated the opportunity to hear multiple perspectives, but would like to have seen links to more resources and more practical information such as how to talk to insurance companies. A common theme across comments on all the videos was a desire for more content reflecting the experiences of people of color.

Patient Focus Group

Following the completion of the patient survey, we conducted a virtual, ninety-minute focus group with individuals from the same 18-25-year-old patient population, to understand in more depth their use of videos related to diabetes management. We opened recruitment for the focus group to survey participants and to people who had not participated in the survey through an advertisement in the CDN newsletter.

Participants

Seven individuals participated in the focus group, six of whom had previously completed the survey and expressed interest in offering additional feedback. Six of the participants identified as female and one as male. The average age of the participants was 23 years (SD=1.91). All participants were individuals with Type 1 diabetes, and the average age at diagnosis was 10.86 years (SD=3.24). Six of the participants were White and one participant was biracial. Participants were all from the eastern part of the United States, two from the New England region, two from the middle Atlantic region, and three from the south Atlantic region. Four of the participants had a bachelor's degree, two had a graduate degree, and one had completed some college. Four of the participants were current students. Three of them were working full-time and four were working part-time.

Focus Group Questions

We asked questions to generate discussion on the following topics.

- **The content that participants seek out in videos about diabetes management:** questions about topics of interest, content that they find the video format useful for, examples of video content they have found particularly useful, and how they use content from different sources on the same topic.
- **Their experience of finding video content they desire:** questions about platforms they turn to for video content, whether that varies based on the type of content they seek, the ease of finding the information they want, and their perceptions of differences between platforms in terms of ease of use, credibility, and relevance of content.
- **Effective features in videos about diabetes management:** questions about the types of presenters, formats or presentation styles, the length of the videos, and other features that participants find effective and how that varies based on the type of content.

- **How they assess the credibility of what videos present:** we asked participants about the characteristics of videos that help them determine the trustworthiness and plausibility of a video.

Findings

Characteristics of Useful Content

All the participants in this focus group were individuals with Type 1 diabetes who were diagnosed on average around the age of 10 years. They informed us that, given the amount of time they have been living with diabetes, they seek less online content about basic diabetes management, such as generic information about diet and exercise, than they did when they were first diagnosed.

They described several categories of content they seek most often now. They seek videos about how to use diabetes management devices, either troubleshooting problems with their equipment or learning about new technology. Additionally, participants said they seek information about very specific topics related to diet and exercise, such as what foods to eat prior to a long-distance run, whether to use an insulin pump on the elliptical, and the varying impacts of different types of alcohol on blood sugar. They added that the sample videos in the survey had very basic information and they wished for more in-depth information on some of the topics. They wouldn't mind longer videos if they had more nuanced information.

Participants added that they especially look for “lived experience” of someone with diabetes in the information they seek or choose to view. They described vlogs (video blogs) as particularly useful in this regard. In the case of equipment, they added that the vlogs report both the good and bad experiences, instead of what they said could be ‘biased’ promotional materials from a company. One participant described the desire for learning about real-life experiences by saying, “I don't want to be sold information. I want, like, a real perspective about what it's actually like — a day in the life with someone wearing the technology that I'm considering.” Another participant provided a different example of how a vlog could be helpful. They described the need for information about traveling with diabetes and how a vlog that is experiential and describes things like the experience of going through TSA (security check) with an insulin pump would be more informative and interesting than written material. Another participant added that this format could be useful for students preparing to study abroad.

In addition to presenting the experiential aspect, participants described that videos were particularly useful for presenting complex information and for demonstrating techniques used by others in various aspects of diabetes management. They cited the video about health insurance that was included in the survey as an example of how the video format was useful for presenting that complex information in a digestible and interesting way, using a mix of personal stories and a simplified presentation of the content by a professional. They added that this example demonstrates the value of the video format for content that might be overwhelming because it allows for quickly going back to listen to specific portions later. Videos can also offer the comfort that comes from hearing others' experiences directly from them, which factual written materials cannot do.

One of the participants also described videos as a useful format for 'taboo' subjects, saying, "I also feel like more taboo subjects kind of lend themselves to videos over... written material, like specifically ...drinking and ... how to navigate romantic relationships with diabetes, I just feel like sometimes when you're handed ...papers about that, it just feels too clinical." Other participants agreed.

Experiences Finding Relevant Information

Participants shared that most often they do not actively seek out video content about diabetes management. Rather, apps such as TikTok automatically show them content and they choose whether to view the videos. As one of the participants said, "I don't really seek out that much video content. So, it's not a matter of how I go about seeking out but whether I choose to watch it when I happen to see it."

Participants described that video content they receive passively through various social media feeds about 'hacks' — tips or tricks in using diabetes-related equipment — or other life hacks related to diabetes are often useful.

Participants agreed that if a video shows up on their TikTok feed they are likely to watch it, but they are less likely to actively search for videos. In general, participants said that looking for video content is not their first step when looking for information. One participant described their process as doing a Google search and then, if the resulting articles and blog posts do not have the answers, they will look for videos. Participants described YouTube as the easiest to navigate when actively searching for videos, due to its 'searchability' and the option to scroll through multiple options by title. This contrasts with other sites they use to view videos, such as TikTok and Instagram, where they

explained they must watch the videos to know what they are about. Participants described using professional websites more (e.g., Beyond Type 1, CDN, Juvenile Diabetes Research Foundation [JDRF]) earlier in their diabetes journey than they do now.

In addition to not searching for video content as actively as they did when they were first diagnosed, participants noted that videos on very specific topics they now desire are not easy to find. One participant added that sometimes a space like Reddit, which has discussions on several sub-topics within diabetes, is more helpful to quickly search through instead of spending several minutes on a video, adding that even seven minutes seems too long sometimes. As a result, videos are not the option they immediately turn to when looking for information. Participants added that videos are good for wider topics and can provide useful information about topics they didn't know they had questions about.

Effective Characteristics

Participants described the following as the key characteristics of videos they find interesting and engaging.

- **Humor.** One of the participants said this about the importance of humor and others concurred. “I think for me, the main thing is just humor. I feel like the funnier the video is, the more likely I am to continue watching it.”
- **Variety.** Participants described several ways of adding variety to videos so that they are not monotonous or, as one participant said, “just not having people like spit words at you for like five straight minutes.” Ways to break the monotony that participants found effective were changing the angle of filming in a long demonstration and interspersing talk with text and music. Having multiple presenters in a video was not enough if the only variety it offered was moving from one presenter talking to another.
- **Length.** The length of the video was another important criterion. One participant described the reason, which resonated with others: “I feel like so much of my day is dedicated to diabetes just in general. Like you have to count carbs, you have to do your palm, you have to do your sensors. You know, there's just so many things that you have to do that when I seek out information, I don't want it to feel like oh my god, this is another chore ... So, I really look for content that is digestible. And that's what makes TikTok so powerful because the videos are really nice and quick and usually it's people who have diabetes. And it's very visual.”

- **The relatability of the presenter.** As noted previously, this group of participants especially preferred content presented by individuals with “lived experience.” Participants described wanting a professional perspective on topics such as insurance, then also looking for the perspective of a person with Type 1 on how they’ve dealt with insurance.

Among presenters with Type 1, it was important to the participants that the presenter also be someone of similar age who has dealt with diabetes for a similar amount of time. Further, what they looked for most from presenters with Type 1 was candor. So, participants preferred videos that were less scripted and did not aim to look perfect. One of the participants said, “the more real and vulnerable it is, the more I value it.” Another participant described a presenter with Type 1 who has multiple videos and how the videos not being very scripted make it seem like the presenter is inviting the viewer into her life and that it contributes to the presenter’s trustworthiness.

Assessing Credibility of Video Content

Participants described several ways in which they determine the accuracy and trustworthiness of the information they obtain via videos. First, if the video content is about others’ experiences, then they form their own opinion based on what they gather from different perspectives. However, if the content is related to something where factual accuracy is critical, they either check with their endocrinologist or do more research in cases where they come across contradictory information.

Overall, participants believed presenters who were themselves individuals with Type 1 diabetes were as credible as professionals, as they have been living with diabetes for a long time and “know what they are doing.” The perspective of individuals with lived experience was an important aspect of video content for these participants and they believed that they were experienced enough, themselves, to be able to discern the quality and credibility of video content. They described that features they pay attention to in determining the credibility of videos are the quality of the video, such as whether the text is grammatically correct. Participants described skepticism when a video has clickbait-like captions, for example making claims to cure diabetes, and how self-promotional content and advertising for products in videos diminish the credibility of the presenter. Additionally, participants also paid attention to the publication date of the content to assess how up-to-date and relevant the information is.

Participants predominantly focused on the features of videos rather than the platforms they were on to determine the credibility of the content. One participant differed slightly, adding that they believed videos on YouTube to be overall more credible than TikTok based on the amount of time spent on making them. The participant added, however, that both platforms have official channels for groups like CDN, which lends credibility, irrespective of the platform.

Clinician Focus Group

We conducted a virtual, sixty-minute focus group of clinicians who work with young adults with diabetes. The purpose was to understand clinicians' perspectives on their patients' use of diabetes management videos and to solicit their reactions to the findings from the patient survey and focus group. We recruited participants for the focus group through word-of-mouth among clinicians who work with young adults and were known to the project team.

Participants

Six professionals participated in the focus group: five endocrinologists and one diabetes educator. Three endocrinologists practice at a diabetes specialty center, and two endocrinologists and the diabetes educator practice at a large children's hospital. All the endocrinologists treat young adults. One endocrinologist conducts research on adolescents' and young adults' use of technology and social media to improve the management of their diabetes; another endocrinologist researches barriers to transition from pediatrics to adult care.

Focus Group Questions

We asked questions to generate discussion on the following topics:

- Reactions to patient feedback on video content and characteristics they value
- How they use videos in their work with young adults
- Their perspectives on balancing patient preferences in video content with the reliability of the information

Findings

The focus group participants were supportive of young adults using videos to inform themselves about diabetes management. They considered it positive that the young adults spend some of their spare time educating themselves about diabetes and

consider it a sign that the patients have “internalized” their diabetes in a way that not all of their patients have. Participants found that useful information can sometimes reach patients through this medium when a clinician is unable to get through. The participants agreed, however, that videos cannot replace a strong, trusting patient-physician relationship, to reinforce the relevant and appropriate information the videos convey, and to support patients in discerning what information is reliable and applicable to their circumstances. Several themes emerged from the focus group.

“Relatability” matters

Participants offered that the videos their patients responded to most are those that the patient considers “relatable.” Participants described that, based on feedback from patients, a relatable video is one that is clear, concise, and engaging, and is presented by peers. Their patients prefer information that comes from peers in similar circumstances to theirs and is not “cringey” or “corny.” They noted that content is important, but so is aesthetics.

Length of videos

Participants commented on their patients’ preferences for shorter videos. They said that attention spans are short, and platforms like TikTok and others have conditioned users to expect brief content and to lose interest after a few minutes. So, videos must be brief and immediately engage the viewer.

Patient platform preferences

Focus group participants reported that many of their young adult patients use TikTok as a source for videos. One participant explained that TikTok is a “passive” platform in that content appears in a person’s feed with no additional effort required: “TikTok is passive spoon feeding and just gives individuals content while they are scrolling, which they would be doing anyway.” This was contrasted with videos that a clinician might recommend on websites of organizations such as Beyond Type 1 or CDN. While the content of such videos can be useful, they require the user to go to the website and look up the video. The participants believed there is a better chance of a young adult patient viewing a video produced by an organization such as Beyond Type 1 by directing the patient to the organization’s TikTok.

Recommending videos

The focus group participants said they generally prefer not to recommend videos but may do so in limited circumstances, such as when a patient requests one. Participants understand that their recommendations must be “relatable,” as described above, if they are to be viewed. They recommend videos from device manufacturers that demonstrate how equipment is used. As telemedicine took on a more important role during the COVID-19 pandemic, one participant said she would direct patients to specific videos for educational purposes, in place of a live demonstration when they were changing something about the patient’s technology, for example.

One participant reported that when patients ask for recommendations, they are asking about online content generally, not videos specifically. The topics patients ask about, according to the focus group participants, include exercise, diet, and technology, such as the differences between pumps and CGMs. One participant noted that her newly diagnosed older adolescent and young adult patients are more likely to ask for recommendations for online content, which is an opportunity for the clinician to suggest websites such as Beyond Type 1 and CDN. The participants pointed out that there is very little content available online specifically for adolescents and young adults with Type 2 diabetes.

In general, participants said they are more reactive concerning their patients’ use of videos, rather than actively recommending videos to them. In that reactive capacity, they see their role as helping patients sort through the veracity and applicability of what they view. If a patient asks them about something the patient has seen in a video, the participants said they respond and try to educate them about what is reliable information and what should be viewed with skepticism. For example, one participant said she steers her patients to “.org” and “.gov” websites, and explains to patients that TikTok financially rewards influencers for the number of views they receive, not for the accuracy of the information they provide, and that they should be skeptical of these sources. As one participant put it, “I often will tell them, just think about it as you would in your normal life. If you have somebody that tells you something that seems too good to be true, or seems crazy, ... then maybe you want to question it.” Other participants described situations when patients asked about something they saw in a video and the clinician took the opportunity to educate the patient about the accuracy of the information and its relevance to their own situation.

Regarding private individuals who post videos, one participant said she would be reluctant to make a blanket recommendation of a particular account, because individuals often are inconsistent in their accuracy and because, even if accurate, a video may not be appropriate for a specific patient. “They’ll post things that are accurate, but are very damaging in terms of like what’s a good a1C and that means you’ve been working hard, and what does it mean? You know, people can have messaging that is scientifically or clinically accurate, but it’s psychologically damaging, and or judgmental.”

Further discussing the credibility and reliability of videos, the focus group participants were not familiar with the “From Health Sources” tag on YouTube search results. One participant was happy to know about it, but the group overall did not think it would greatly affect how they vet and recommend videos. One participant noted that a “health source” may not have much experience or relevant training. Another elaborated, saying she had seen inaccurate information posted online by doctors with the same credentials she has. And a third pointed out that “it might make sense for 99 percent of people, but maybe not for that one person that you’re seeing because each person has his own story and his own... diabetes.”

Relationships are critical

Online content is growing at a pace beyond the ability of a diabetes practitioner to keep up, participants said. They added that quality varies and what is useful often differs by individual patient circumstances. For these reasons, all focus group participants stressed the primacy of a strong patient-clinician relationship. Social media is ubiquitous and available around the clock, so physicians need to have the trust of their patients so that the patients feel comfortable asking questions about the information they have found online. A participant pointed out that patients are sometimes embarrassed to admit that the information they are asking about is from social media, but noted it is important that they ask. Even good information is not one-size-fits-all, and it is difficult for videos to customize advice. Everything is patient-dependent, a participant said, so it is important that patients feel safe bringing content to their clinicians to discuss.

Conclusions

The information collected in the survey and focus groups have certain limitations. The survey respondents were not randomly selected and the distribution of their characteristics are not necessarily representative of all young adults with diabetes. The survey results are therefore not generalizable to the population at large. All of the participants in the patient focus group had Type 1 diabetes, and all were from the eastern United States and had at least some college education. The participants in the clinician focus group all practice in academic medical centers. Further inquiry into the questions and perspectives reported here should seek a broader, more representative set of respondents to expand knowledge in this area.

With these caveats, this project shed some new light on how young adults with diabetes use information from the internet, particularly from online videos, to help them manage their illness. The patients and clinicians who participated in the survey and focus groups agree that videos can be a useful tool for young adults, many of whom use the internet routinely and are adept with the major social media platforms that supply video content. Videos with certain characteristics — brief, dynamic and humorous, presented by peers — are more likely to engage a young adult’s attention, and particular topics — demonstrations of technology, sensitive areas of personal behavior — lend themselves more to video presentation. Young adults are aware of the varying quality of videos and apply discriminating criteria to assess credibility. At the same time, clinicians want to be able to assist their patients in making the best use of videos, less by making specific recommendations than by helping patients curate the content they encounter and understand what information is relevant to their situations. Finding ways to encourage this dialogue may be helpful.

References

- Agarwal, S., Kanapka, L. G., Raymond, J. K., Walker, A., Gerard-Gonzalez, A., Kruger, D., Redondo, M. J., Rickels, M. R., Shah, V. N., Butler, A., Gonzalez, J., Verdejo, A. S., Gal, R. L., Willi, S., & Long, J. A. (2020). Racial-Ethnic Inequity in Young Adults With Type 1 Diabetes. *The Journal of Clinical Endocrinology & Metabolism*, 105(8), e2960–e2969. <https://doi.org/10.1210/clinem/dgaa236>
- Banbury, S., & McCloud, N. (2021). *An exploration of the experience of young people with type 1 diabetes as they transition into adulthood—DiabetesontheNet*. 11(01). <https://diabetesonthenet.com/diabetes-care-children-young-people/an-exploration-of-the-experience-of-young-people-with-type-1-diabetes-as-they-transition-into-adulthood/>
- Battineni, G., Baldoni, S., Chintalapudi, N., Sagaro, G. G., Pallotta, G., Nittari, G., & Amemta, F. (2020). Factors affecting the quality and reliability of online health information. *DIGITAL HEALTH*, 6, 2055207620948996. <https://doi.org/10.1177/2055207620948996>
- Butalia, S., Crawford, S., & Pacaud, D. (2019). 132—Health-Care Visits in Youth With Diabetes of Transitioning Age. *Canadian Journal of Diabetes*, 43(7, Supplement), S45. <https://doi.org/10.1016/j.jcjd.2019.07.141>
- Butler, A. M., Weller, B. E., Yi-Frazier, J. P., Fegan-Bohm, K., Anderson, B., Pihoker, C., & Hilliard, M. E. (2017). Diabetes-Specific and General Life Stress and Glycemic Outcomes in Emerging Adults With Type 1 Diabetes: Is Race/Ethnicity a Moderator? *Journal of Pediatric Psychology*, 42(9), 933–940. <https://doi.org/10.1093/jpepsy/jsx092>
- Fergie, G., Hilton, S., & Hunt, K. (2016). Young adults’ experiences of seeking online information about diabetes and mental health in the age of social media. *Health Expectations*, 19(6), 1324–1335. <https://doi.org/10.1111/hex.12430>
- Fernandez-Llatas, C., Traver, V., Borrás-Morell, J.-E., Martínez-Millana, A., & Karlsen, R. (2017). Are Health Videos from Hospitals, Health Organizations, and Active Users Available to Health Consumers? An Analysis of Diabetes Health Video Ranking in YouTube. *Computational and Mathematical Methods in Medicine*, 2017, 8194940. <https://doi.org/10.1155/2017/8194940>

Garvey, K. C., Markowitz, J. T., & Laffel, L. M. B. (2012). Transition to Adult Care for Youth with Type 1 Diabetes. *Current Diabetes Reports*, 12(5), 533–541. <https://doi.org/10.1007/s11892-012-0311-6>

Gaus, Q., Jolliff, A., & Moreno, M. A. (2021). A content analysis of YouTube depression personal account videos and their comments. *Computers in Human Behavior Reports*, 3, 100050. <https://doi.org/10.1016/j.chbr.2020.100050>

Kong, W., Song, S., Zhao, Y. C., Zhu, Q., & Sha, L. (2021). TikTok as a Health Information Source: Assessment of the Quality of Information in Diabetes-Related Videos. *Journal of Medical Internet Research*, 23(9), e30409. <https://doi.org/10.2196/30409>

Liu, X., Zhang, B., Susarlia, A., & Padman, R. (2020). Go to You Tube and Call Me in the Morning: Use of Social Media for Chronic Conditions. *MIS Quarterly*, 44(1), 257–283. <https://doi.org/10.25300/MISQ/2020/15107>

Madathil, K. C., Rivera-Rodriguez, A. J., Greenstein, J. S., & Gramopadhye, A. K. (2015). Healthcare information on YouTube: A systematic review. *Health Informatics Journal*, 21(3), 173–194. <https://doi.org/10.1177/1460458213512220>

Majumder, E., Cogen, F. R., & Monaghan, M. (2017). Self-Management Strategies in Emerging Adults With Type 1 Diabetes. *Journal of Pediatric Health Care*, 31(1), 29–36. <https://doi.org/10.1016/j.pedhc.2016.01.003>

Nip, A. S. Y., & Lodish, M. (2021). Trend of Diabetes-Related Hospital Admissions During the Transition Period From Adolescence to Adulthood in the State of California. *Diabetes Care*, 44(12), 2723–2728. <https://doi.org/10.2337/dc21-0555>

Paragas Jr., E. D., & Barcelo, T. I. (2019). Effects of message-framed informational videos on diabetes management knowledge and self-efficacy. *International Journal of Nursing Practice*, 25(4), e12737. <https://doi.org/10.1111/ijn.12737>

Peters, A., & Laffel, L. (2011). Diabetes Care for Emerging Adults: Recommendations for Transition From Pediatric to Adult Diabetes Care Systems. *Diabetes Care*, 34(11), 2477–2485. <https://doi.org/10.2337/dc11-1723>

Pyatak, E. A., Sequeira, P. A., Whittemore, R., Vigen, C. P., Peters, A. L., & Weigensberg, M. J. (2014). Challenges contributing to disrupted transition from pediatric to adult diabetes care in young adults with Type 1 diabetes. *Diabetic Medicine: A Journal of the British Diabetic Association*, 31(12), 1615–1624. <https://doi.org/10.1111/dme.12485>

Ramchandani, N., Way, N., Melkus, G. D., & Sullivan-Bolyai, S. (2019). Challenges to Diabetes Self-Management in Emerging Adults With Type 1 Diabetes. *The Diabetes Educator*, 45(5), 484–497. <https://doi.org/10.1177/0145721719861349>

Saylor, J., & Calamaro, C. (2016). Transitioning Young Adults With Type 1 Diabetes to Campus Life. *The Journal for Nurse Practitioners*, 12(1), 41–46. <https://doi.org/10.1016/j.nurpra.2015.09.010>

Thind, K., Wiedrick, J., Walker, S., & Hasan, R. (2022). Emergency Department Visits Increase in Transition-Age Patients Empaneled in a Primary Care Network at a Major Academic Medical Center. *Journal of Adolescent Health*, 70(1), 77–82. <https://doi.org/10.1016/j.jadohealth.2021.07.024>

Zhang, Y., Nitschke, M., Krackowizer, A., Dear, K., Pisaniello, D., Weinstein, P., Tucker, G., Shakib, S., & Bi, P. (2016). Risk factors of direct heat-related hospital admissions during the 2009 heatwave in Adelaide, Australia: A matched case-control study. *BMJ Open*, 6(6), e010666. <https://doi.org/10.1136/bmjopen-2015-010666>

