Understanding Perceptions of New-Onset Type 1 Diabetes Education in a Pediatric Tertiary Care Center

A Thesis Submitted to the
Yale University School of Medicine
in Partial Fulfillment of the Requirements
for the Degree of Doctor of Medicine

by

Gabriel Betancur Vélez, Class of 2023
UNDERSTANDING PERCEPTIONS OF NEW-ONSET TYPE 1 DIABETES EDUCATION IN A PEDIATRIC TERTIARY CARE CENTER

Gabriel Betancur Vélez and Jennifer L. Sherr. Section of Endocrinology, Department of Pediatrics, Yale University, School of Medicine, New Haven, CT.

**Background:** Youth newly diagnosed with type 1 diabetes (T1D), and their families, require intensive education on the management of this chronic condition during this overwhelming period. Traditionally, our center conducts training in person during a hospital admission.

**Methods:** We studied family perceptions of our current patient education methods in an effort to elucidate strategies to augment education in the post-pandemic environment, where provider time in the room and visitation rules may limit face-to-face encounters.

**Results:** 25 families completed the survey (distributed to 156 in total, with approximately 21% response rate). The mean age at diagnosis was 9.52 ± 4.29 years old with diabetes duration ranging from 8-57 weeks. Most (n=21) have been followed out to 12 months post-diagnosis with 62% using insulin pumps and 100% using sensors at the 1-year mark. Almost all participants reported being satisfied with new-onset education.

**Conclusions:** Current strategies utilized to educate families of youth newly diagnosed with T1D are well received by primary caregivers. Yet, issues with understanding how to manage sick days, how to train secondary caregivers, and how to easily share educational content with others remain. To address these issues video content, that can augment training, has been created and we continue to explore the utility of this strategy.
I want to express my sincerest thank you to every person who has supported us with this project. I want to note special appreciation to all the members of the Yale Children’s Diabetes Group for welcoming me and having great enthusiasm for this endeavor as well as the team at the Yale School of Medicine Office of Communications for all their guidance, time, and effort in helping us achieve our goals.

Thank you as well to all my teachers who have helped me during my time in medical school and have had an impact on my career. Most notably, I would like to acknowledge Dr. Jennifer Sherr, my personal and academic role model. I am most grateful for our relationship and thank you for your invaluable mentorship, unwavering support, and sincere investment in my education and well-being since I first moved to the United States. You are my inspiration to become a pediatric endocrinologist and pursue a career as a clinician-scientist.

Lastly, I want to express my infinite gratitude and appreciation for my parents, Pedro and Catalina, my sister Catalina, and my partner Valentina for supporting me in every step along the way not only with this project but with everything in life. I am the most fortunate to have your love and support.
Table of Contents

INTRODUCTION ............................................................................................................. 1

STATEMENT OF PURPOSE ........................................................................................... 8

METHODS ..................................................................................................................... 9

Student Contributions ................................................................................................. 9

Ethics Statement .......................................................................................................... 9

Laboratory Animals ..................................................................................................... 10

Methods Description .................................................................................................. 10

  Study Design .............................................................................................................. 10
  Creation of Video Content ......................................................................................... 11
  Web Addresses and QR Codes for Video Access ...................................................... 13
  Survey Development & Distribution ......................................................................... 15
  Participant Population ............................................................................................... 17
  Inclusion & Exclusion Criteria .................................................................................... 17
  Potential Risks for Participants ................................................................................... 17

Statistical Methods ...................................................................................................... 18

RESULTS ....................................................................................................................... 19

Participant Characteristics ......................................................................................... 19

Survey Results ............................................................................................................ 21

Video Utilization ........................................................................................................ 27

DISCUSSION ............................................................................................................... 30

Analysis of Survey Responses ..................................................................................... 30

Future Directions ........................................................................................................ 34

CHALLENGES & LIMITATIONS ................................................................................... 36

CONCLUSION .............................................................................................................. 38

DISSEMINATION .......................................................................................................... 38

REFERENCES .............................................................................................................. 39

APPENDIX ................................................................................................................... 42

  Appendix A: Consent Form Distributed for Survey Participation ......................... 42
  Appendix B: New-onset Education Survey ................................................................. 44
  Appendix C: Poster presentation at the 2021 American Diabetes Association 81st Scientific Sessions .... 47
INTRODUCTION

Type 1 diabetes (T1D) is a complex autoimmune condition that occurs when the immune system destroys the insulin-producing pancreatic beta cells. While previously thought of as a singular disease, it is now clear there are three distinct stages of disease onset. Disease progression has not been fully elucidated, but it is known that the destruction of pancreatic beta cells and the eventual presentation of hyperglycemia comes about after months or years of preclinical disease activity. Individuals at increased risk of developing T1D can be identified by serological evidence of an autoimmune pathologic process and by genetic markers prior to requiring insulin therapy, which is known as stage 3 type 1 diabetes. The FDA recently approved the first drug that has been shown to delay the progression of T1D in those with stage 2 disease in November 2022. In follow-up from the initial study published in 2021, Teplizumab led to a median time to disease diagnosis of 5 years vs. 2 years for the placebo group, and half the treated group vs. 22% of placebo group remained disease-free. While this therapy has vastly altered the landscape of diabetes treatment, regulatory approval is limited to those with stage 2 disease, and clinic implementation of this therapy is in its nascent phase.

Progression to stage 3 diabetes is associated with insulin deprivation due to beta cell destruction and hyperglycemia ensues. If untreated, this can lead to death. Currently, it is estimated that there are approximately 1 million to 1.2 million individuals currently living with T1D in the United States. The mainstay of treatment in clinical T1D is exogenous insulin therapy. The importance of insulin therapy was evidenced by data from the Diabetes Control and Complications Trial (DCCT). In that study, attaining targeted
glycemic control was demonstrated to reduce long-term micro- and macrovascular complications.\textsuperscript{8,9} This cohort has continued to be followed for decades as part of the Epidemiology of Diabetes Interventions and Complications (EDIC), showing that the early beneficial effect of intensive diabetes management continues to persist in a phenomenon termed metabolic memory. This highlights the need to strive for glycemia targets in all who are diagnosed with the condition.\textsuperscript{10}

At diagnosis, insulin therapy is initiated and individuals, or in the case of children and their families, are taught how to self-administer insulin using syringes or insulin pens. Subsequently, people with T1D can be transitioned to more advanced technology, such as insulin pumps and continuous glucose monitors, to manage their diabetes. Nowadays, there are several different types of insulin pump systems available, each with different, individual characteristics and advantages.\textsuperscript{11} Further there has been rapid development of technologies that integrate sensor glucose levels to inform insulin delivery based on algorithms, known as automated insulin delivery systems.\textsuperscript{12} The benefits of diabetes technologies have been widely demonstrated and due to this a number of academic societies advocate for the use of diabetes technologies, including the American Diabetes Association (ADA), the American Association of Clinical Endocrinology (AACE), and the International Society of Pediatric Diabetes (ISPAD).\textsuperscript{13,14} Each of these organizations highlights that the choice needs to be individualized and based on each person’s specific needs, preferences, and skill level.\textsuperscript{15}
The diagnosis of T1D is often a very traumatic event for the people who are diagnosed, as well as their families. It can be a time full of uncertainty and distress. For many families, it is not uncommon to go through the stages of grief. As they grapple with accepting the “new normal”, they are faced with an overwhelming amount of information being presented including the importance of monitoring glucose levels and steps for administering insulin subcutaneously, while reframing their approach to nutrition and learning that exercise is now a double-edged sword. All aspects of everyday life, such as amount of sleep and stress levels, can have a significant effect on blood sugar, and it is especially challenging for families and caregivers of youth diagnosed with T1D to learn to adapt to life with this chronic condition. Youth with diabetes and their families must carry the heavy burden of maintaining glucose levels in a tight range while realizing that prolonged deviations can lead to potentially severe consequences.

Each year, around 125 youth are diagnosed with T1D and referred to Yale New Haven Children’s Hospital for care. As this is a complex, chronic disease, education on the management of this multi-faceted condition is a cornerstone of care. Currently, education is primarily provided through face-to-face interactions with members of our team, particularly our inpatient diabetes nurse practitioner, our pediatric endocrinology fellows, and our attending physicians. The floor staff, including the nursing, social work, and nutrition teams also play a vital role in rounding out the foundations of diabetes care. To standardize our education, a new-onset booklet, developed and refined by the Yale diabetes team, has been in use for over 10 years. The content of this booklet has been continuously updated over time to reflect changes in practice.
Delivery of this essential information is classically conducted when youth are admitted for a 2 to 3-day hospitalization at the time of diagnosis. Families are sometimes faced with the challenge that only one parent is able to remain with their child. Subsequently, that individual is tasked with training other caregivers, including parents, stepparents, grandparents, babysitters, daycare/school staff, and even coaches. Additionally, since the onset of the COVID-19 pandemic, we have been faced with an unprecedented need to transition some of the education, whenever possible, to outpatient care delivery. This has been facilitated by our inpatient nurse practitioner meeting with families at an outpatient clinic location to review content over a 2 to 3-hour period.

Although there are certain topics that are considered essential to review, there is currently no standard curriculum across hospitals and clinics for new-onset T1D education. There have been several different strategies described in the literature in attempts to optimize the educational process for both pediatric and adult individuals with T1D. One group has had success using formal vignettes and a human patient simulator with a mannequin. This method included a series of three sessions (at the time of diagnosis, four weeks postdiagnosis, and twelve weeks postdiagnosis) where nurse certified diabetes educators met with families and reviewed pertinent topics such as hypoglycemia, hyperglycemia, and pattern management through the discussion of relevant situational vignettes and with the use of child-size robots to mimic specific scenarios. In addition to resulting in improved clinical outcomes, this strategy was enthusiastically supported by both participants as well as those administering the education, the certified diabetes
educators, who continued to use the vignettes and simulator long after the study had ended.\textsuperscript{17,18}

Another strategy that has been described is the delivery of educational content in a group setting.\textsuperscript{19} In this approach, two-hour sessions were held every two weeks for the duration of twelve months.\textsuperscript{19} At the beginning of every session, there was dedicated review time for discussing the application of material covered during the previous meetings. The novelty of this approach is that sessions took place in groups; each group consisted of a physician leader (either an endocrinologist or an internist with experience in diabetes management), a diabetes educator, and six to eight individuals with diabetes. Of note, the educator was also a person living with T1D. At the end of the program, Hemoglobin A1C (HbA1c) levels, a 3-month measure of glycemia, as well as the incidence of hypoglycemic episodes significantly decreased.\textsuperscript{19} Daily glucose fluctuations were also significantly reduced. This shows the potential benefit of a group-based educational approach.

Another engaging method, which is particularly appealing to children and adolescents, is a game-based intervention.\textsuperscript{20} Creative game strategies have ranged from web-enabled game software and tablet and robot pairings to the development of hardware that can be plugged into a Nintendo DS Lite\textsuperscript{TM} and provide blood glucose readings.\textsuperscript{21,22} In other studies, interactive games have been used to help with practical, everyday aspects of T1D management such as insulin administration, obtaining blood sugar measurements, and carbohydrate counting.\textsuperscript{23,24} Depending on the setting and the particular interests of the individual, different types of games could be adapted for both new-onset training and
subsequent reinforcement of educational topics. As a whole, the gaming approach has proved advantageous in improving knowledge, behavior, and engagement with T1D care. Thus, there is strong potential for the development of game-based interventions, particularly for youth with diabetes.20

The use of internet-based content delivery has also been increasingly explored, especially since the onset of the COVID-19 pandemic. eLearning is a growing area in T1D care, offering a flexible and low-cost intervention aiming to increase reach through improved accessibility.25 Massive open online courses (MOOCs) are an example of eLearning where a cohort simultaneously progresses through structured educational material. Recent studies have shown that MOOCs could be an effective way to improve the digital health literacy of people with diabetes and empower them to optimize their self-management, with participants reporting these types of programs to be beneficial, easy to use, and motivating.25,26 Through discussion boards and livestreams, MOOCs can provide a social space moderated by healthcare professionals for learners to ask questions, share experiences and benefit from peer support. Additionally, interspersed quizzes can facilitate self-assessment of the incremental knowledge gained.25

Telehealth has also grown exponentially as a method of diabetes care delivery over the past several years.27 Telehealth can be used as a way to provide both new-onset education as well as ongoing care in months and years postdiagnosis. There is even a case study describing the successful use of a telehealth platform for providing education for a child with new-onset T1D and concomitant COVID-19 while in the inpatient setting.28
The adaptability of telehealth to fit well in many types of clinical scenarios is a great strength of this method. Given the benefits of telehealth and the expectation that this tool is here to stay for the future, at least in a hybrid version of health care delivery, it is worthwhile to consider how best to optimize this method and other online and asynchronous teaching strategies for implementation in both long-term diabetes care as well as new-onset education.\textsuperscript{27,29}

Recognizing the opportunity to rapidly alter methods for care delivery for youth with new-onset diabetes, consideration was given to strategies that could be implemented. Given the need to not increase disparities in access to such education based on literacy or primary language spoken, the decision was made to seek to create video content based on the pre-existing template for diabetes education, the “What to Know When you are Newly Diagnosed” booklet developed here at Yale.
STATEMENT OF PURPOSE

We hypothesize that the use of videos to supplement face-to-face education will improve the educational experience for children with diabetes, their immediate families, and even extended caregivers like babysitters, school staff, and coaches. To assess this, we conducted surveys of those who received new-onset education using traditional methods to understand their experience. Additionally, surveys of those families who were exposed to our new video content were conducted to see how the videos altered the educational experience.

Specific Aims

1) To create instructional videos based on our standardized new-onset education booklet that will be used to supplement education for newly diagnosed individuals with T1D. These videos are easily accessible on our website; therefore, families will be able to view for reinforcement of topics and share them with extended caregivers.

2) To translate the new-onset education booklet into Spanish to increase access to educational materials. Additionally, video content will be created in Spanish with the aim of improving the educational experience for our Spanish-speaking population.

3) To assess the impact of our videos on the management of newly diagnosed individuals using surveys sent out to two cohorts: those diagnosed prior to the creation of the videos (traditionally trained) and those who received new-onset education with the supplemental videos.
METHODS

Student Contributions

With the supervision and guidance of Dr. Jennifer Sherr (PI), the student, Gabriel Betancur Vélez, contributed in all steps of the research process and in the preparation of this thesis. Specific steps of the research process included the coordination of the creation of our videos, the preparation of materials for Institutional Review Board approval of this project, the translation of all new-onset educational materials to Spanish, the development and distribution of our survey, the analysis of our survey response data, the chart review for survey participants, and scientific write-up of this project. Distribution of the data was led by Gabriel Betancur Vélez at both local and international meetings. Other contributors to this project include Michelle Brei, APRN, DNP, Kate Weyman, APRN, FNP-C, CDCES, Kerry Stephenson, APRN, Lori Carria, MS, and Michelle VanName, MD. Each of these team members helped with IRB approval, circulation of video content, survey distribution, and project troubleshooting. All members of the Yale Children’s Diabetes Program assisted by presenting in the videos. Dr. Jennifer Sherr supervised the entirety of the study, and critically reviewed both this thesis and prior presentations of this work.

Ethics Statement

This project was carried out under the highest standard of ethical conduct. All components of this work were conducted keeping the best of intentions in mind for participants and involvement in this study posed a minimal risk for youth with T1D and their families. It is our hope that lessons and conclusions from this project may lead to improvements in care delivery and outcomes for people with diabetes around the world.
Human Subjects Research

This study was approved by the Yale University Institutional Review Board on August 30, 2020, under the IRB Protocol ID #2000028793. The IRB found this study to meet the requirements of 45 CFR § 46.404 in that it presents no more than minimal risk to the minor subjects. Permission of one parent or guardian was deemed sufficient to carry out the study and assent from minor subjects was considered not necessary. Survey data obtained from participants was collected following all HIPAA protocols using the online Qualtrics XM® Survey Tool. All information on individual participants was stored electronically following HIPAA protocols through Microsoft Teams® and was secured at all times during this study.

Laboratory Animals

Since no laboratory animals were used in this study, there was no requirement to obtain approval from the Institutional Animal Care and Use Committee.

Methods Description

Study Design

In recognizing the need to reinvigorate our pediatric new-onset education at Yale, different strategies were considered. We decided to approach the restructuring of our educational curriculum in two ways. Firstly, we determined that it could be advantageous to have various members of our clinic create video clips to describe the chapters contained within our new-onset booklet. Secondly, we recognized the importance of having all
educational materials be translated into Spanish, in addition to filming videos in Spanish. Given the growing population of Spanish-speaking individuals in New Haven and the United States, as a whole, it would be a disservice to our community if we did not make sincere efforts to provide this essential content in languages other than English. Indeed, we have previously demonstrated the importance of speaking the same language in a qualitative study of Hispanic Youth cared for at Yale Pediatric Diabetes. Recognizing the importance of language in relation to medical care and its critical role in provider-patient communication, we deemed it vital to create standardized education for both our English and Spanish-speaking populations, with the hopes of expanding to other languages in the future.

Creation of Video Content

The educational videos were created with the intention that they could be implemented in a variety of settings. For new-onset education, even if youth and their families are seen face to face, they can review the video content for reinforcement of topics. Additionally, these videos can be used during routine care. Data from the U.S.-based Type 1 Diabetes Exchange Registry highlights that most youth with T1D fail to meet prescribed glycemic targets. This is despite significant advances in technology used for the management of T1D. With improved accuracy and increased access to continuous glucose monitoring, the key now is to teach youth and their families how to translate sensor glucose data to changes in insulin doses and behaviors to achieve glycemic targets. Therefore, methods to help reinforce concepts reviewed during routine care and implement asynchronous learning, such as through video content, hold the promise to improve care
for all youth with T1D. This instruction may better permit individuals with T1D to leverage the technology prescribed to attain treatment success.

We based the topics of each video on individual chapters from the new-onset booklet that was already in place at our institution. We benefitted from the enthusiastic participation of all members of the Yale Children’s Diabetes Group, including physicians, nurse practitioners, physician assistants, social workers, dietitians, and clinical fellows, in presenting the educational content. Our intention in including the entire group was also to allow families to see their providers being featured in the videos and feel more connected to the materials. We determined that for audience engagement, it was best to have a mix of direct speech, figures, tables, and on-screen text distributed throughout each video. For the filming, editing, and publishing of the videos, we relied on the expertise of the team at the Yale School of Medicine Office of Communications. The filming of speakers was all completed virtually using the Zoom® video calling platform in an effort to minimize the spread of infection at the height of the COVID-19 pandemic. In total, thirty video clips were created and uploaded, fifteen in each English and Spanish. The topics of all videos in both languages and their length are outlined in Table A and Table B. The average length for the English videos is 5 minutes and 6 seconds, while the average length for the Spanish videos is 6 minutes and 13 seconds.
Web Addresses and QR Codes for Video Access

- English: https://medicine.yale.edu/pediatrics/endocrinology/cdp/videos/

![QR Code for English Site]

- Spanish: https://medicine.yale.edu/pediatrics/endocrinology/cdp/videos/espanol/

![QR Code for Spanish Site]
### Table A. English Video content.

<table>
<thead>
<tr>
<th>Video Title</th>
<th>Length</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome to The Yale Diabetes Program</td>
<td>4:36</td>
</tr>
<tr>
<td>The Ins &amp; Outs of Giving Insulin</td>
<td>12:41</td>
</tr>
<tr>
<td>What Is Diabetes?</td>
<td>4:54</td>
</tr>
<tr>
<td>Testing Your Blood Sugar</td>
<td>4:16</td>
</tr>
<tr>
<td>Hemoglobin A1c &amp; Time in Range</td>
<td>4:58</td>
</tr>
<tr>
<td>Low BG &amp; Treatment</td>
<td>2:05</td>
</tr>
<tr>
<td>Exercise &amp; Diabetes</td>
<td>3:37</td>
</tr>
<tr>
<td>High BG &amp; Ketones</td>
<td>5:15</td>
</tr>
<tr>
<td>What Can I Eat Now?</td>
<td>6:56</td>
</tr>
<tr>
<td>Sick Day Management</td>
<td>4:38</td>
</tr>
<tr>
<td>Diabetes &amp; School</td>
<td>7:49</td>
</tr>
<tr>
<td>Mental Health &amp; Diabetes</td>
<td>2:18</td>
</tr>
<tr>
<td>Tidepool &amp; Uploading Diabetes Data</td>
<td>5:53</td>
</tr>
<tr>
<td>Leaving the Hospital &amp; Coming to Clinic</td>
<td>2:31</td>
</tr>
<tr>
<td>Insulin Carb Ratios &amp; Correction Factors</td>
<td>4:08</td>
</tr>
</tbody>
</table>

### Table B. Spanish Video Content.

<table>
<thead>
<tr>
<th>Video Title</th>
<th>Length</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bienvenidos</td>
<td>3:50</td>
</tr>
<tr>
<td>Detalles para la Administración de la Insulina</td>
<td>12:33</td>
</tr>
<tr>
<td>¿Que es la Diabetes?</td>
<td>5:10</td>
</tr>
<tr>
<td>¿Como Evaluar el Azúcar en la Sangre?</td>
<td>5:31</td>
</tr>
<tr>
<td>Hemoglobina Glucosilada (HbA1c) y Tiempo En Rango</td>
<td>4:10</td>
</tr>
<tr>
<td>Niveles Bajos de Azúcar en la Sangre</td>
<td>8:03</td>
</tr>
<tr>
<td>Niveles Altos de Azúcar en la Sangre</td>
<td>7:59</td>
</tr>
<tr>
<td>El Ejercicio y la Diabetes</td>
<td>5:09</td>
</tr>
<tr>
<td>¿Que Como Ahora?</td>
<td>6:17</td>
</tr>
<tr>
<td>Manejo de un &quot;Dia de Enfermedad&quot;</td>
<td>9:36</td>
</tr>
<tr>
<td>La Diabetes y la Escuela</td>
<td>5:36</td>
</tr>
<tr>
<td>La Salud Mental y la Diabetes</td>
<td>3:31</td>
</tr>
<tr>
<td>Tidepool y Datos de Diabetes</td>
<td>6:53</td>
</tr>
<tr>
<td>Salida del Hospital y Visitas a la Clinica</td>
<td>4:13</td>
</tr>
<tr>
<td>Proporciones de Carbohidratos y Factores de Corrección</td>
<td>4:54</td>
</tr>
</tbody>
</table>
Our initial hope with the advent of video content was that we would be opening an opportunity to alter practice moving forward. Indeed, there are clinical visits that indicate to a provider that families need a refresher on a certain topic. Now, the appropriate video can be recommended. Furthermore, for youth diagnosed in childhood, the video content allows for review of evolving topics as they become more mature and independent. In many situations, having relied on their families for care, adolescents and young adults who are less aware of sick day management can access this content at their convenience and ensure a safe transition of care. The penetrance of technology as a means to deliver instructional content additionally helps this asynchronous delivery of educational materials extend further and even get to harder-to-reach audiences.

*Survey Development & Distribution*

To understand the perceptions of traditional educational methods and to assess the impact of our videos on individuals newly diagnosed with T1D and their families, we created an online survey using the Qualtrics XM® Survey Tool. The survey was designed to ask about the experiences of caregivers relating to managing diabetes at home after their child was first diagnosed. It was carefully structured to take approximately five to ten minutes to complete, and participants could choose to complete the survey with any device that has internet connection, including a computer, a tablet, or a smartphone.

The survey is made up of four main sections. The first section uses a 5-point Likert scale to inquire about educational experience, asking families to only reflect upon their initial education at the time of diagnosis and to not include any additional learning done
through follow-up in clinic. The second portion also uses a 5-point Likert scale to ask about the participant’s perception of the accessibility of the educational content. The third section is made up of two true/false questions and four multiple-choice questions designed to measure knowledge of general diabetes topics, which are all covered in both the new-onset booklet and the videos. The last section is composed of open-ended questions created to allow participants to express themselves freely and provide more feedback regarding their new-onset educational experience. Complete copies of both the consent form and the survey that were distributed can be found in the Appendix.

Along with the survey responses, other relevant data was also gathered from each participant’s electronic medical record. These included age at diagnosis, duration of new-onset admission, as well as metrics collected both at diagnosis and follow-up including hemoglobin A1c levels, time-in-target range (70-180 mg/dL) from continuous glucose monitoring (CGM) (if available), mode of insulin delivery, and the number of parent or school nurse calls between clinic visits.

The survey has been distributed for the most part using individualized links sent out via email through the Qualtrics XM® platform. To a smaller degree, some survey links have been shared at outpatient clinic visits and through the use of QR codes.
Participant Population

Children and adolescents under 18 years of age who were recently diagnosed with T1D and treated at the Yale Children's Diabetes Program and their primary caregiver were enrolled in this study.

Inclusion & Exclusion Criteria

Inclusion criteria for the study are as follows:

- T1D diagnosed within the past year
- Child with diabetes must be under the age of 18
- Diagnosed at Yale New Haven Children's Hospital and first received education about diabetes management from the Yale Children's Diabetes Program
- Able to give consent

Exclusion criteria for the study are as follows:

- Participant is unable to read, write, and speak English

Invitation to participate in the study was offered to those whose medical records indicated they met eligibility criteria.

Potential Risks for Participants

Although this study posed a minimal risk for participants and their families, two reasonably foreseeable risks were identified. First, as is the case for any study, there was a risk of loss of confidentiality. Second, the study questionnaire carries the risk that
participants may experience some distress when discussing factors important to diabetes, diabetes management, and psychosocial stressors. Specific steps were taken to minimize these risks, including following all HIPAA privacy regulations for maintaining protected health information safe, keeping participant names and study records completely confidential, and ensuring that study staff and social work is available to support families as needed in case of any distress brought on by study participation.

**Statistical Methods**

All data were processed and analyzed using GraphPad Prism 7 (GraphPad Software, Inc.). No outliers were identified and only data from completed surveys were included in the analysis. Continuous data are presented as mean ± standard deviation. For all normally distributed parameters, unpaired t-tests were used to compare the two conditions with α set at 0.05, and two-tailed. Non-normally distributed data were assessed using the Wilcoxon Rank Sum Test.

Of note, due to having recorded only two survey responses from families trained with video content at the time of this write-up and the inability to draw any meaningful conclusions with such minimal data, no data from these responses are included in this analysis.
RESULTS

Participant Characteristics

To date, 156 distinct survey links have been distributed. We have received 32 total responses (response rate of approximately 21%), of which 5 are incomplete surveys and 27 have been completed. Of the complete responses, 25 participants experienced new-onset education in the traditional method (no videos) and 2 received training with the videos.

For the 25 participants who received traditional education (no videos) and completed the survey in its entirety, the mean age at diagnosis was 9.52 ± 4.29 years old with diabetes duration ranging from 8-57 weeks. Most (84%) have been followed out to 12 months post-diagnosis. HbA1c values decreased significantly by 3 months post-diagnosis, as expected, while time-in-range values remained constant throughout the first-year post-diagnosis (Figure 1). The mean duration of new-onset admission was 40.2 ± 13.59 hours, and there was no significant difference between participants admitted prior to the COVID-19 pandemic and those admitted afterward. By 9 months post-diagnosis, more than half of the participants (56.5%) were on pump therapy. Remarkably, by 3 months post-diagnosis, 84% of participants were on a glucose sensor, and by 9 months, 100% of participants were using a sensor. The number of contacts between visits (both phone and MyChart interactions) also decreased significantly within the first 6 months post-diagnosis.
Figure 1 (A-G). Characteristics of the 25 participants who received traditional education (no videos) and completed the survey in its entirety.
Survey Results

The survey results for the first section of our questionnaire regarding educational experience at the time of diagnosis are summarized in Table C. Based on these responses, youth with diabetes and their families seem to be comfortable and satisfied with our traditional new-onset educational methods. Primary caregivers received the necessary education, but education for secondary caregivers such as school personnel, babysitters, and coaches seems to be lacking. Sick day management is another topic that had mixed responses across the scale. Respondents felt that they could review topics as needed. Specific areas that participants feel adequately trained on include identifying and managing low and high blood sugars, administering insulin, checking blood glucose, and explaining to others what diabetes is and how to manage it. These topics form the minimal education deemed necessary to ensure safe discharge home.

Table C. Distribution of survey responses regarding educational experience at the time of diagnosis, n=25 participants.

<table>
<thead>
<tr>
<th>Survey Question Topic</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree or Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfort with education method used</td>
<td>40%</td>
<td>52%</td>
<td>4%</td>
<td>4%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>All the primary caregivers received education</td>
<td>48%</td>
<td>44%</td>
<td>4%</td>
<td>0%</td>
<td>0%</td>
<td>4%</td>
</tr>
<tr>
<td>School personnel, babysitters, coaches, etc. had pertinent education</td>
<td>20%</td>
<td>20%</td>
<td>20%</td>
<td>20%</td>
<td>0%</td>
<td>20%</td>
</tr>
<tr>
<td>Question</td>
<td>44%</td>
<td>36%</td>
<td>4%</td>
<td>16%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>Could review topics repeatedly to feel adequately prepared with the content</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The education took too long</td>
<td>0%</td>
<td>8%</td>
<td>8%</td>
<td>56%</td>
<td>28%</td>
<td>0%</td>
</tr>
<tr>
<td>Too much emphasis on all topics instead of focusing on items pertinent to our family</td>
<td>0%</td>
<td>12%</td>
<td>16%</td>
<td>56%</td>
<td>16%</td>
<td>0%</td>
</tr>
<tr>
<td>Knows how to identify a low blood sugar</td>
<td>60%</td>
<td>36%</td>
<td>4%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Knows how to treat a low blood sugar</td>
<td>60%</td>
<td>36%</td>
<td>0%</td>
<td>0%</td>
<td>4%</td>
<td>0%</td>
</tr>
<tr>
<td>Knows how to identify a high blood sugar</td>
<td>56%</td>
<td>40%</td>
<td>0%</td>
<td>4%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Knows how to manage a high blood sugar</td>
<td>56%</td>
<td>36%</td>
<td>0%</td>
<td>4%</td>
<td>4%</td>
<td>0%</td>
</tr>
<tr>
<td>Is unsure how to manage diabetes during a sick day</td>
<td>4%</td>
<td>16%</td>
<td>16%</td>
<td>40%</td>
<td>24%</td>
<td>0%</td>
</tr>
<tr>
<td>Can easily explain to others what diabetes is</td>
<td>44%</td>
<td>48%</td>
<td>8%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Can easily explain to others how to manage diabetes</td>
<td>36%</td>
<td>44%</td>
<td>12%</td>
<td>8%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Had difficulty understanding how to check blood glucose</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>48%</td>
<td>52%</td>
<td>0%</td>
</tr>
<tr>
<td>Feels able to administer insulin</td>
<td>64%</td>
<td>36%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Overall satisfied with new-onset education</td>
<td>56%</td>
<td>32%</td>
<td>12%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>
The figure below (Figure 2) highlights responses to several of the survey questions from above.

**Figure 2 (A-E).** Responses to select questions regarding educational experience at the time of diagnosis, n=25 participants.
"I had the opportunity to review topics repeatedly to feel adequately prepared with the content"

"I can easily explain to others how to manage diabetes"

"I am unsure of how I would manage my child’s diabetes if they had a sick day"
Next, Table D presents the responses for the second portion of our survey concerning the participants’ perceptions of the accessibility of educational content. Based on these answers, the vast majority of participants felt as if the educational content was organized, clear, easy to understand, and easy to access. Most also felt that the topics discussed are relevant, and 92% of respondents would recommend the Yale educational content to a friend with T1D. On the other hand, there was a greater diversity of responses when asked about the difficulty of sharing the educational content with other people. Figure 3 highlights several of these survey responses.

**Table D.** Distribution of survey responses regarding participants’ perceptions on the accessibility of the educational content, n=25 participants.

<table>
<thead>
<tr>
<th>Survey Question Topic</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree or Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational content was organized and clear</td>
<td>40%</td>
<td>56%</td>
<td>4%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Educational content was easy to understand</td>
<td>36%</td>
<td>64%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Educational content was easy to access</td>
<td>32%</td>
<td>48%</td>
<td>4%</td>
<td>8%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>The education received was difficult to share with others</td>
<td>4%</td>
<td>16%</td>
<td>16%</td>
<td>48%</td>
<td>16%</td>
<td>0%</td>
</tr>
<tr>
<td>The topics discussed are relevant</td>
<td>44%</td>
<td>48%</td>
<td>4%</td>
<td>4%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Would recommend the Yale educational content to a friend with T1D</td>
<td>64%</td>
<td>28%</td>
<td>4%</td>
<td>4%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>If education in Spanish, felt as if the language used in the educational content was properly translated</td>
<td>4%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>96%</td>
</tr>
</tbody>
</table>

**Figure 3 (A-C).** Responses to select questions regarding participants’ perceptions of the accessibility of the educational content, n=25 participants.
Video Utilization

About two years after the creation and upload of all thirty videos, we obtained data related to the number of views and the average watch time for each video. These data are presented in Table E. Overall, there are low view counts for our videos. Although the English videos have more views on average, the view count for most videos is under 10. The video on *Insulin Carb Ratios & Correction Factors* stands out as an outlier with the highest view count (64) and the highest average percentage watched (over 64%). This
video specifically has been widely used by on-call providers to guide youth with diabetes and their families when they have called asking for assistance, especially during insulin pump failures and the need to revert to injection therapy, which can help explain its popularity.

**Table E.** Number of views, average watch time, and average percent viewed for all 30 videos approximately 2 years after being uploaded. English videos are listed first and Spanish videos are subsequently presented.

<table>
<thead>
<tr>
<th>Video Title</th>
<th>Views</th>
<th>Average Watch Time</th>
<th>Average % Viewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome to The Yale Diabetes Program</td>
<td>20</td>
<td>1:14</td>
<td>27.17</td>
</tr>
<tr>
<td>The Ins &amp; Outs of Giving Insulin</td>
<td>11</td>
<td>2:15</td>
<td>17.72</td>
</tr>
<tr>
<td>What Is Diabetes?</td>
<td>8</td>
<td>1:04</td>
<td>21.94</td>
</tr>
<tr>
<td>Testing Your Blood Sugar</td>
<td>10</td>
<td>2:14</td>
<td>52.18</td>
</tr>
<tr>
<td>Hemoglobin A1c &amp; Time in Range</td>
<td>6</td>
<td>0:14</td>
<td>4.88</td>
</tr>
<tr>
<td>Low BG &amp; Treatment</td>
<td>7</td>
<td>0:52</td>
<td>41.97</td>
</tr>
<tr>
<td>Exercise &amp; Diabetes</td>
<td>2</td>
<td>0:24</td>
<td>11.3</td>
</tr>
<tr>
<td>High BG &amp; Ketones</td>
<td>1</td>
<td>0:45</td>
<td>14.55</td>
</tr>
<tr>
<td>What Can I Eat Now?</td>
<td>8</td>
<td>1:09</td>
<td>16.56</td>
</tr>
<tr>
<td>Sick Day Management</td>
<td>4</td>
<td>1:21</td>
<td>29.1</td>
</tr>
<tr>
<td>Diabetes &amp; School</td>
<td>2</td>
<td>0:21</td>
<td>4.63</td>
</tr>
<tr>
<td>Mental Health &amp; Diabetes</td>
<td>2</td>
<td>0:30</td>
<td>22.1</td>
</tr>
<tr>
<td>Tidepool &amp; Uploading Diabetes Data</td>
<td>13</td>
<td>1:25</td>
<td>24.16</td>
</tr>
<tr>
<td>Leaving the Hospital &amp; Coming to Clinic</td>
<td>2</td>
<td>0:05</td>
<td>3.59</td>
</tr>
<tr>
<td>Topic</td>
<td>Duration</td>
<td>Score</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------</td>
<td>----------</td>
<td>-------</td>
<td></td>
</tr>
<tr>
<td>Bienvenidos</td>
<td>0:32</td>
<td>13.86</td>
<td></td>
</tr>
<tr>
<td>¿Que es la Diabetes?</td>
<td>1:34</td>
<td>30.43</td>
<td></td>
</tr>
<tr>
<td>Detalles para la Administración de la Insulina</td>
<td>0:05</td>
<td>0.7</td>
<td></td>
</tr>
<tr>
<td>¿Como Evaluar el Azúcar en le Sangre?</td>
<td>0:13</td>
<td>4.01</td>
<td></td>
</tr>
<tr>
<td>Hemoglobina Glucosilada (HbA1c) y Tiempo En Rango</td>
<td>0:03</td>
<td>1.54</td>
<td></td>
</tr>
<tr>
<td>Niveles Bajos de Azúcar en la Sangre</td>
<td>0:51</td>
<td>10.63</td>
<td></td>
</tr>
<tr>
<td>Niveles Altos de Azúcar en la Sangre</td>
<td>1:43</td>
<td>21.55</td>
<td></td>
</tr>
<tr>
<td>El Ejercicio y la Diabetes</td>
<td>0:00</td>
<td>0.00</td>
<td></td>
</tr>
<tr>
<td>¿Que Como Ahora?</td>
<td>0:00</td>
<td>0.26</td>
<td></td>
</tr>
<tr>
<td>Manejo de un &quot;Dia de Enfermedad&quot;</td>
<td>0:00</td>
<td>0.12</td>
<td></td>
</tr>
<tr>
<td>La Diabetes y la Escuela</td>
<td>0:14</td>
<td>4.36</td>
<td></td>
</tr>
<tr>
<td>La Salud Mental y la Diabetes</td>
<td>0:00</td>
<td>0.28</td>
<td></td>
</tr>
<tr>
<td>Tidepool y Datos de Diabetes</td>
<td>0:01</td>
<td>0.38</td>
<td></td>
</tr>
<tr>
<td>Salida del Hospital y Visitas a la Clinica</td>
<td>0:00</td>
<td>0.34</td>
<td></td>
</tr>
<tr>
<td>Proporciones de Carbohidratos y Factores de Corrección</td>
<td>0:02</td>
<td>0.94</td>
<td></td>
</tr>
</tbody>
</table>
DISCUSSION

Analysis of Survey Responses

Our survey responses provide insight into how caregivers of youth newly diagnosed with T1D perceive the education they received. Prior to this project, while much work had gone into the creation of the New-onset Booklet, no systematic assessment of this content had been conducted. It was therefore beneficial to note that for the overall educational experience, respondents indicated that they are comfortable and satisfied with our traditional educational methods. They also feel well-trained in important, specific diabetes management topics such as checking blood glucose, administering insulin, and identifying and managing low and high blood sugars. Therefore, the foundational skills that are identified to permit safe discharge home are being adequately covered. Yet, there are two key areas of interest that stand out due to participants having mixed perceptions on the effectiveness of training: education for secondary caregivers and management of diabetes during a sick day. These topics are of utmost importance because children oftentimes spend at least a third of the day with secondary caregivers like school staff, coaches, and babysitters. These individuals must be well-versed in at least basic diabetes management topics to help the person with diabetes thrive. Additionally, sick days are particularly dangerous situations where people with diabetes are especially vulnerable to fluctuations in glucose that can have severe consequences. Therefore, these two areas appear to benefit from alternative educational methodologies. Further, one could posit that sick day management may only become crucial when a family is faced with their first sick day experience, and not during the new-onset period. Therefore, methods to allow for asynchronous access to this content may be of great benefit.
In terms of participants’ perceptions of the accessibility of the educational content, the majority of respondents indicate that the educational content was organized, clear, easy to understand, and easy to access. Notably, 92% of respondents indicate that they would recommend the Yale educational content to a friend with T1D, again reinforcing the notion that participants feel well-served with the new-onset education they received. Although participants feel that they could easily access the education, there was a less favorable response when asked about the ability to share the educational content with other people.

Video content, or any other type of asynchronous education, could serve as a valuable tool for not only helping families review challenging topics like sick day management whenever needed, but the flexibility of these methods also allows for easy sharing of materials with secondary caregivers and other individuals interested in learning. Unfortunately, our video usage has been lower than anticipated. Two possible contributors to this finding are the long duration of several of the videos and too much on-screen text instead of more engaging animations or content. In efforts to increase video use, we have increased awareness of the existence of this content and we have created the QR codes included above. Initially, stickers were printed and attached to the new-onset booklets to ensure families were aware of this content. More recently, with re-printing of the books, we have been able to directly include the QR codes in the books. While the stickers were beneficial, distribution of the codes required someone to manually place one on a book, something that was inconsistent in a busy clinical service with no singular point person who would oversee this. Additionally, we have informed the inpatient teams of the video
content. This allows them to also highlight the utility of the video content when they interact with families following their diagnosis. Finally, work has been done to highlight the video content during routine clinical follow-up, including having the QR codes on after-visit summaries which are printed after each outpatient clinical encounter. It is possible these methods will permit greater penetrance of the video content in the education of those with diabetes.

It is also critical to note that while the video content was created following the onset of the COVID-19 pandemic, our hospital quickly realized the importance of admitting youth with new-onset T1D, and thus priority was given to permit these admissions to continue. It has been rare that there has been a need to convert to outpatient education, which only re-surfaced for a brief period in the late fall/early winter of 2022 with the “tripledemic” leading to high inpatient censuses. Thus, the utility of the video content may have been offset by the inpatient education that was resumed. Understandably, families are comforted by the personalized attention of the inpatient staff who review in an individualized manner new-onset education using the new-onset booklet as a template for their discussions.

While currently there are low view counts, it is important to recognize that the video content development is not a failure. Instead, methods to improve the content can be explored including conducting stakeholder engagement sessions to understand how our content is viewed and what could be improved. In particular, discussions have been held regarding whether shortening the video clips or using more engaging screen content may
be of benefit. Yet, we have learned that only by assessing the needs of the end user can we ensure content created is what they desire. Additionally, while our target population has been youth newly diagnosed with T1D and their families it is important to note that we have informally received extremely positive feedback about the video content from attendings, pediatric residents, and other providers at Yale, who all feel the content has helped them, and this has encouraged them to share these resources with those they treat. Video content can serve as a powerful tool for improving patient education in T1D and we must work to optimize its use and fulfill its potential.

With any studies focused on the collection of survey data, survey completion is often quite low. Indeed, many report that of all surveys distributed one can expect a return rate of roughly 30-40%. Understandably, as families grapple with a new-onset T1D diagnosis and the stressors of pandemic, and now, post-pandemic life, it is not surprising that our survey completion rates were low. Additionally, given the limitations of time and our desire to focus on the largest population possible, we did not conduct surveys in Spanish. Finally, as the surveys were self-administered, those with low literacy would have been unable to complete the surveys. It is important to note that these are two of the populations targeted due to concerns about inequity of care delivery with our current education methods. To further understand experiences, having staff speak with families and verbally conduct surveys during follow-up visits, in either English or Spanish, would likely increase our response rate. Yet, the lack of funds to cover this staffing need has limited this option.
With the relatively low video view counts that were reported when the data was requested from the Yale School of Medicine Office of Communications in June of 2022, we implemented the strategies to increase video content distribution. It is our hope that with increased video use and as we continue to gather more survey responses, we will be able to reach meaningful conclusions about the use of video content in new-onset education.

**Future Directions**

As noted above, to further refine the video content created, stakeholder engagement studies could be undertaken to help get feedback on the current videos and how they can be altered. Our study also did not focus on the collection of data from the more peripheral individuals who may benefit from the video content. One potential area of interest may be to inform the Association of School Nurses of Connecticut about the content and then distribute surveys to this group. Additional video topics could be added to specifically spend more time on how to monitor sensor glucose data in the school setting or to discuss automated insulin delivery, a technology that is becoming more pervasive in clinical care.

Additionally, the integration of video content to supplement small group discussions regarding diabetes care could be of benefit. Use of the video content could be assigned and followed by peer interactions leveraging Zoom or other HIPAA secure platforms with an informed provider and potentially a young adult with T1D to serve as discussion leaders. Exploration of the combination of simulation, online discussion boards, or game-based interventions with asynchronous video content would also be warranted.
With new virtual reality platforms, video content could be used followed by peer-based gatherings using this technology. Finally, the creation and distribution of video-based education to benefit individuals with other chronic medical conditions and their families could be explored.

Another area of potential exploration is the idea of providers “prescribing” the viewing of particular video clips in specific situations. As we have seen with our on-call providers guiding families toward the video on Insulin Carb Ratios & Correction Factors when insulin pumps break, we expect that specific instruction from a medical provider to watch a given topic may increase video use. Indeed, for youth who present with diabetic ketoacidosis (DKA), efforts have now been focused on highlighting the availability of the videos on Sick Day Management, which may help them recall what steps to take, when to reach out to our team, and could potentially prevent future DKA admissions.

Lastly, these videos can be expanded to allow for a formal online education series for patients transitioning from pediatric to adult care. As this is the time when youth are noted to have the largest deviation from targeted glycemic control, re-engagement and re-education are critical. By not only relying on written materials but instead leveraging video content and the ability to access information asynchronously, the transition of care may be greatly improved and help our most vulnerable patients, adolescents and young adults, achieve more targeted glycemia.
CHALLENGES & LIMITATIONS

Although this project has important strengths, such as the short length of our survey and the ability to complete it using any internet-capable device, the data is currently limited by our minimal survey responses from those who received training with video content. Another limitation is the timing of families taking the survey in relation to their child’s diagnosis. If they took the survey weeks or months after diagnosis, there could be recall bias that influences their perspective as they have already had multiple clinic visits, where this content would have been continually reviewed. Further, as surveys are only completed by those who engage, we may not be capturing a generalizable sample of our clinic. Oftentimes, those who are the most satisfied and those who are least satisfied may be willing to participate. Thus, completion of surveys facilitated by engagement with a staff member by all in clinic at their follow-up appointment around 2 weeks after diagnosis may provide a more representative understanding of our education methods.

We have also experienced several important challenges throughout the duration of this project. The idea of video content first came to mind at the height of the first wave of the COVID-19 pandemic in the Spring of 2020. Due to completing the videos in the Fall of 2020, it is possible that we may have missed the critical window of opportunity for integration of this strategy into our new-onset education since by the time all videos were uploaded, many of the clinic visits and hospital inpatient teams were back to functioning in-person instead of virtually.
Lastly, the COVID-19 pandemic also had a significant impact on the type of project I would pursue for completion of the MD Thesis. We had originally planned to develop and implement an online insulin dose adjustment calculator that would be used between face-to-face visits. Unfortunately, with our inability to see youth with T1D in person early in the pandemic, that project was no longer feasible and subsequently, the idea for this current study was developed. What this has taught me is how to be flexible and I have been fortunate to have opportunities that otherwise would not have been possible: 1- being the primary person to draft and obtain regulatory approval for a research project, 2- to integrate my desire to ensure equitable health care access with the creation of the new-onset booklet in Spanish and the Spanish video content, and 3- how to facilitate and conduct project management for a large team as we filmed the video content. Each of these will serve me well in future research endeavors.
CONCLUSION

Current strategies utilized to educate families of youth newly diagnosed with T1D are well received by primary caregivers. Yet, issues with understanding how to manage sick days, how to train secondary caregivers, and how to easily share educational content with others remain. To address these issues video content, that can augment training, has been created and we continue to explore the utility of this strategy.

DISSEMINATION

Earlier versions of this project have been presented at both local and international meetings: One poster presentation at the 2021 American Diabetes Association 81st Scientific Sessions (found in the Appendix), a second poster presentation at the 2021 Yale School of Medicine Student Research Day, and one oral presentation at the 9th Annual Yale Pediatric Research Forum (2021).

Additionally, it is our hope that our video content continues to gain traction and that we can keep sharing these resources with other hospitals, clinics, and providers to help improve new-onset T1D education around the United States and the rest of the world.
REFERENCES

APPENDIX

Appendix A: Consent Form Distributed for Survey Participation

Dear X,

Hello from the Yale Children's Diabetes Program!

Dr. Jennifer Sherr is conducting a research study: Understanding the Effect of Instructional Videos on Type 1 Diabetes Management in Newly Diagnosed Patients - HIC 2000028793. Our goal is to learn more about your experience relating to managing diabetes at home after your child was first diagnosed and to hear about your interactions with our educational materials and resources. We ask that the primary caregivers of the person with diabetes are the ones who answer the questions in this survey. Along with your responses, we will also gather other data from your child's electronic health record for approximately one year after their diagnosis date, which may include:

- Information about your child including age, gender, ethnicity and zip code
- Measures of his/her diabetes management (like hemoglobin A1c levels and/or time-in-ranges, which can be calculated from blood glucose meters or sensor wear)
- The number of urgent phone calls from caregivers or school nurses
- Rates of severe hypoglycemia (low where someone needs assistance, passes out or has seizure like activity)
- Rates of diabetic ketoacidosis
- How your child’s insulin is delivered (pump or injections)
- How your child measures his/her sugar levels (sensor or fingersticks)

We are asking you to complete a survey. The survey will take approximately 5-10 minutes to complete. All of your responses will be confidential and will not impact the care you receive. Only the researchers involved in this study and those responsible for research oversight will have access to the information you provide. Your responses will be numbered and the code linking your number with your name will be stored in a separate locked file cabinet. The information you provide will be destroyed when the study is complete.

You can choose whether you would like to participate; it is optional and will not impact the individual care you receive in our clinic.

You may not benefit directly from answering these questions but the information you and others provide through this survey will be combined to improve our educational resources for newly diagnosed patients.

You may experience distress over the nature of the questions. You don’t have to answer any questions you don’t want to. If you need assistance with diabetes management or
have other questions for our team, answering this survey will not alert us to that. If you need assistance, please contact our team at (203) 785-5831.

If you would like to talk with someone other than the researchers to discuss problems or concerns, to discuss situations in the event that a member of the research team is not available, or to discuss your rights as a research participant, you may contact the Yale University Human Subjects Committee, 203-785-4688, human.subjects@yale.edu. Additional information is available at https://your.yale.edu/research-support/human-research/research-participants/rights-research-participant

If you agree, you may open the survey in your web browser by clicking the link below:

X

If the link above does not work, try copying the link below into your web browser:

X

This link is unique to you and should not be forwarded to others.

Thank you!
Appendix B: New-onset Education Survey

Was the setting of your initial diabetes education in-patient or outpatient?
- Inpatient (we stayed overnight upstairs in the hospital, i.e. not in the emergency department)
- Outpatient (we came to the clinic for education, did not stay overnight at the hospital)

Scale of 1-5: 1= Strongly Agree; 2=Agree; 3=Neutral; 4=Disagree; 5=Strongly Disagree, N/A=Not Applicable

Educational Experience at the time of diagnosis
Please only reflect upon your initial education at the time of diagnosis and do not include any additional learning done through follow up in clinic.

- I was comfortable with the method used to educate our family about diabetes.
- All the primary caregivers (all those living in the home) who needed to learn about this new diagnosis were able to get educated on pertinent topics.
- Additional caregivers (school personnel, babysitters/nanny, coaches) who needed to learn about this new diagnosis were able to get educated on pertinent topics.
- I had the opportunity to review topics repeatedly to feel adequately prepared with the content.
- The education took too long.
- There was too much emphasis on all the topics instead of a focused approach to items most important to our family.
- I know how to identify a low blood sugar.
- I know how to treat a low blood sugar.
- I know how to identify a high blood sugar.
- I know how to manage a high blood sugar.
- I am unsure of how I would manage my child’s diabetes if they had a sick day.
- I can easily explain to others what diabetes is.
- I can easily explain to others how to manage diabetes.
- It was difficult to understand how to check the blood glucose.
- I feel able to administer insulin to my child.
- I am overall satisfied with the new-onset education I received

Accessibility (Content and Style)

- The educational content presented by the diabetes team was organized and presented in a clear manner.
- The educational content presented by the diabetes team was easy to understand.
- It was easy to access educational diabetes content.
- It is difficult to share the education received with other people.
- I believe the topics discussed in the new-onset education are relevant.
- I would recommend the Yale educational content to a friend with T1D.
• If you received education in Spanish:
  o I feel as if the language used in the educational content was properly translated

**Knowledge-based questions (Effectiveness)**
*Multiple choice, please select the best answer for each question*

• True or False: Insulin is mainly produced by the kidneys  
  o True  
  o False
• True or False: Vomiting is considered a diabetes emergency  
  o True  
  o False
• How many grams of carbohydrates are recommended to treat a mild (non-severe) low blood sugar?  
  o 2-5 grams  
  o 10-15 grams  
  o 30-35 grams  
  o 35-40 grams
• When should you consider checking for ketones?  
  o Every time you exercise  
  o When you have 2 blood sugar levels in a row (at least 2 hours apart) that are less than 70 mg/dL  
  o Every day in the morning  
  o When you have 2 blood sugar levels in a row (at least 2 hours apart) that are greater than 300 mg/dL
• What is the duration of action of rapid-acting insulin?  
  o \( \frac{1}{2} \)-1 hour  
  o 3-4 hours  
  o 14-24 hours  
  o 48-72 hours
• The information in the nutrition facts label is based on:  
  o One Serving  
  o The entire package  
  o Two servings  
  o The amount consumed by an average person

**Miscellaneous**

• How did you receive education when your child was diagnosed with diabetes?  
  o Printed materials  
  o In person training  
  o Videos  
  o Other (please specify):  
• What topic did you feel was most important for you? OPEN COMMENT
• Are there any topics you feel like we did not cover that you wish we had included? OPEN COMMENT

• Have you used any outside resources (website, books, etc.) to learn more about diabetes?
  • No
  • Yes (please tell us which resource):

• What feedback do you have about your educational experience? OPEN COMMENT
Appendix C: Poster presentation at the 2021 American Diabetes Association 81st Scientific Sessions

BACKGROUND
• The diagnosis of Type 1 Diabetes (T1D) is often traumatic for persons with diabetes and their families.
• New-onset education at our center is traditionally in-person during a 2-3 day hospital admission with use of a set curriculum in a booklet specifically designed to date with key concepts.
• As families grapple with accepting the “new normal” they are faced with an overwhelming amount of information being presented including the importance of monitoring glucose levels, administering insulin subcutaneously, while refining their approach to nutrition and exercise.
• Teaching is done at the bedside only to those present at time of admission. Thus, clinicians identified challenges including the need for:
   - Ensuring all caregivers can access content.
   - Availability of content for later review.

AIMS
• To analyze family perceptions of our current education methods and elucidate strategies to augment education.
• The pandemic has made the need for new strategies to facilitate education even more pressing.

METHODS
• Persons with type 1 diabetes 18 years old and younger and diagnosed between August 2019 and November 2020 were recruited.
• A 25-question online survey was sent to 93 families from the Yale Children’s Diabetes Program.
• To date, we have a 24% response rate.
• The survey is composed of both knowledge-based and experience-based questions.
• We gathered subjective data through patient input, and objective data, including hemoglobin A1c levels, time-in-range and sensor usage data from CGM (if available), number of parent or school nurse calls, rates of severe hypoglycemia and DKA, patient demographic data and insulin delivery modality.
• A 5-point Likert scale was used to assess attitudes towards education.

Table 1. Participant demographic information.

<table>
<thead>
<tr>
<th>Baseline Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at diagnosis (&lt;18)</td>
<td>66.2</td>
</tr>
<tr>
<td>Duration of diabetes</td>
<td>6.0</td>
</tr>
<tr>
<td>% with severe acute events</td>
<td>30</td>
</tr>
<tr>
<td>% with diabetes education at home</td>
<td>70</td>
</tr>
</tbody>
</table>

*Based on asking “strongly agree” or “agree” with statement that they are overall satisfied with education

Of the 77 participants followed for 6 months:
- 35% reported using pumps
- 94% using sensors

CONCLUSIONS
• While limited to those who took the time to respond, our survey indicates overall satisfaction with traditional education.
• Yet, certain areas would appear to benefit from newer methodologies:
   - Access of content to secondary caregivers
   - Alderhage education
   - Personalized content

VIDEO CONTENT
• Videos serve as a novel education method
• Keep it short. We created 5-minute videos on each topic from the new onset booklet.
• The content is not limited to only persons followed by Yale or Yale affiliates.
• Benefits to video content include:
   - Families can review the videos any time, even months after initial diagnosis.
   - Access of content to secondary caregivers, whereas the new onset booklet has the risk of being misplaced or lost.
   - Videos are easy to share with secondary caregivers (coaches, babysitters, etc.)
• The content is available in both English and Spanish.

NEXT STEPS
• T1D education has been restructured with the creation of video content:
  - New short families continue to receive a new onset education that focuses on online mental health and hospital admission.
  - Diagnosed persons with diabetes are informed of online content at follow-up visits.
• To determine the impact of new educational strategies, surveys are being sent to those diagnosed after the release of video content.

Presented at the American Diabetes Association’s Annual Scientific Sessions (2021). Contact gabriel.betancur1@yale.edu

47