

# Drawing and Dialogue: Youth's Experiences With the "Face" of Diabetes

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## Abstract

**Objective:** The purpose of this qualitative pilot study was to evaluate drawing, narration, color use, and meaning through discussion to increase insight surrounding youth's lived experience with type 1 diabetes. **Methods:** This qualitative study reflects a convenience sample of 20 (female = 12, male = 8) youth aged 8 to 15 years with an established diagnosis of type 1 diabetes. During a nonclinic session, 3 drawings—self-portrait, face of diabetes, and future self-portrait—were created. Interviews were completed with an art therapist or clinic nurse practitioner using a standardized script. **Results:** All "face" of diabetes drawings depicted images separate from self. The most frequent color noted was gray, due to pencil use. No significant difference in disclosures or dialogue were observed between interviews conducted by the art therapist or nurse practitioner. Emerging themes noted: diabetes is unpredictable and stigmatizing, causes fears, and impacts daily life, yet discussions evidenced overall coping and resilience. **Conclusions:** Drawing during clinic visits enhances communication and understanding of youth's lived experience. Findings offer clinical benefit when managing care and support for chronic health conditions.

## Keywords

youth, type 1 diabetes, picture drawing, emotions, dialogue

## Introduction

Type 1 diabetes mellitus (T1DM) is a chronic health condition, where insulin by self-injection is needed throughout the day. The "tasks" of diabetes self-care are done in a timely manner to prevent extreme blood sugar variations that impact mood, behavior, and ability to perform self-care tasks (1). The work to maintain diabetes control and prevent complications is challenging and never ending (1, 2). For health-care clinicians to fully comprehend the impact of lived experiences among youth with diabetes, information gathered beyond the routine clinic approach is beneficial (1, 3, 4).

Drawing, recognized as one of the most important ways youth express themselves, is a method of tapping into the inner world, reflecting feelings and relating information on function (5). Engaging in drawing "in the moment" experiences has been used effectively to encourage reflection and expression of thoughts and emotions (5, 6). Embedded meanings are manifested in drawing symbols and images that may then be explored (7, 8). By supporting youth in creation of drawings that reflect lived experiences with diabetes, clinicians obtain valuable insight into acceptance, barriers, and psychosocial effects (1, 2).

Drawing can be used spontaneously and at virtually any skill or linguistic level. It is participant centered and meaningful to the individual (4). Drawing facilitates the process of sorting through feelings and experiences expressing what might otherwise be suppressed (9–11). Detail and expression within facial drawings develop in tandem with maturation (7). According to Foley and Mullis (11), the act of drawing can be therapeutic even if results are not discussed.

Few studies use drawing in conjunction with routine diabetes-based clinic visits (10, 12, 13), but it has been used therapeutically with hospitalized children (9, 14). This study builds upon previous findings, wherein youth with T1DM drew their impression of the "face" of diabetes but were not

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interviewed. Drawings in that study demonstrated creativity, thoughtfulness, and displayed a wide range of unspoken emotions (3). The purpose of the current study is to determine the effectiveness of drawing including dialogue as an intervention to explore meaning, color use, and youth's lived experience with T1DM.

## Method

This qualitative study evaluated drawings and transcribed interviews with 20 youth to explore color use, meaning, and living with T1DM. The study occurred in a certified pediatric diabetes center in the upper Midwest region of the United States. A minimal risk protocol was approved by the hospital's institutional review board (IRB). Youth were recruited through the hospital web site, clinic postings, and mailings. The clinic population was primarily Caucasian, middle socioeconomic status. Recruitment, drawings, and interview sessions with the clinic nurse practitioner or registered art therapist were completed from July 2016 through April 2017. A convenience sample of 20 patients ( $n = 12$  female and  $n = 8$  male) with an established diagnosis of T1DM, aged 8-15 years ( $n = 14$  preadolescents,  $n = 6$  adolescents) were utilized for this study based on previous findings of developmental maturity and detailed drawings (3, 14). Youth with T1DM receiving insulin therapy were invited to participate. Youth with physical or developmental disabilities affecting ability to draw or participate in an interview were excluded.

## Procedure

Youth were scheduled for a 60- to 90-minute timeslot on a nonclinic day. Parental consent and participant assent were obtained. Following scripted instructions by the interviewer, youth were seated at a table and briefed that 3 separate drawings would be completed. After verbalization of readiness, a hand mirror, 8.5 × 11.5-inch white card stock paper, an 8-count packet of markers, a 24-count packet of crayons, one black ink pen, and a Number 2 pencil were provided.

For drawing number 1, youth were asked to draw a self-portrait. For drawing number 2, the Face of Diabetes, youth were asked to draw: "If diabetes had a face, what would it look like?" For drawing number 3, youth were asked to complete a self-portrait of how they might look in 3 years. The 3-year age advancement was purposeful, reflecting likely advancement to the next academic level, representing developmental maturation (15). Youth were observed without comment and then interviewed using a predetermined script in a structured format (16). The structured format was selected for consistency in the interview process to improve interrater reliability (17). Additional questions were asked to facilitate comparison and explore observations (see Table 1). Drawings were collected, placed in a numbered folder, and scanned electronically. Interviews were transcribed and stored on a secure,

**Table 1.** Drawing Interview Questions.

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Upon completion of each drawing, the following questions were asked:

1. Please tell me about your drawing.
2. Tell me about the colors you used for your drawing.
3. What was the reason for choosing that color?
4. If there are items on the drawing which the participant did not mention, the interviewer will specifically ask: please tell me about . . .
5. How did you feel while making the drawing?

Upon completion of all 3 drawings, the following questions were asked:

1. Please tell me about the things that are the same in the 3 drawings
2. Tell me about the things that are different in the 3 drawings
3. How did you feel about drawing your self-portrait and the drawing of yourself in 3 years?
4. Is there anything else about your drawings that you would like to talk about?

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password-protected network. Demographic data including gender, age, length of time with T1DM, age at time of diagnosis, type of insulin therapy, and most recent A1C were extrapolated from chart review. Youth received \$25.00 compensation and their art supplies.

## Data Analysis

Deidentified demographic data were compiled. Drawings and transcribed interviews were stratified into developmental groups of preadolescents (aged 8-12 years) and adolescents (aged 13-15 years). A total of 64 drawings and 20 interviews were analyzed for this study. Drawings were reviewed for first impression, expressions, color use, inclusion of diabetes tools, words, and nonhuman features. Color analysis utilized standard and customized Python script and graphics libraries, then grouped, and entered into Excel data summaries. Transcripts were reviewed for meaning of color choice, words, and narrated meaning. Content analysis and open coding were utilized to identify themes and patterns (18). Due to the small sample size, manual coding for themes was completed. Data saturation was determined by the repetition of responses without new theme identification. Common themes related to diabetes included understanding individual experience, expressed emotions, diabetes stigma, and reflections on the act of drawing.

## Results

Youth had a median age of 11 (interquartile range 3.5, range 8-15 years) with an average of 4.5 years since diagnosis (standard deviation [SD] 2.89, range 1-13.5 years). The average age for onset of T1DM was 6.5 years (SD 3.06, range 1-11 years). Five youth were on multiple daily insulin injections, and 15 received pump infusion. The average A1C at last clinic visit was 8.0% (SD 0.93, range 7.3-10.6).



**Figure 1.** Face of diabetes drawings.

### Color Use and Meaning

Some adolescents preferred to complete all drawings using a Number 2 pencil (gray) for erasability. Black was utilized in self and future drawings depicting hair, razor stubble, intentional shadowing, outlines, and future events such as cap and gown. Preadolescents reported black in the Face of Diabetes to represent lip color that was “not normal for real people” and roadblocks signifying limitations. Adolescents reported black represented “mood swings from sugar changes,” “unexpected outcomes you can’t see coming,” and “mystery, as in why me.”

Red was utilized by preadolescents to reflect “blood sucking,” blood on a glucose strip or dripping from a syringe. Red hair on the Face of Diabetes was reported “kind of rare, like diabetes is.” One 11-year-old drew a single red tulip in a field of yellow flowers representing how one “feels alone and different having diabetes” (see Figure 1). Red was utilized by adolescents on self and future drawings to depict rosy cheeks, light blush on future self, and for lips “that are always dry and chapped.” Adolescents stated red is for “angry, mad, and sad.”

Preadolescents used blue for rain on the Face of Diabetes for hair color, nonhuman face, and calluses on fingers from

blood glucose testing. Adolescents reported blue eyes symbolized blindness caused by diabetes, sweating from low blood glucose, and tears (see Figure 1). One adolescent's Face of Diabetes included multiple colors reporting diabetes is "different" every day (see Figure 1).

### Tools

Diabetes tools such as pumps, lancing devices, meters, and test strips were limited to preadolescent drawings. Several Face of Diabetes drawings depicted oversized syringes, while some had tools incorporated into the face (see Figure 1). No syringes were noted in self or future drawings; however, insulin pumps were included ( $n = 3$ ).

### Word Use

Word use inclusion and thought bubbles were limited to preadolescent drawings. One drawing included multiple words: "low, lazy, tired, shaky, dizzy, or sick" with narrative reporting, "When I am sick, I think about high numbers, but sometimes I am low. Dizzy can be high or low. If I am tired, I think, am I high or low? I get pale when I am low and feel weak." The word "Diabetes," or "D" or "T1D" were noted in several drawings. One drawing had "ME!" on a split face: the left side included "I am low, sweaty, and shaky"; the right side had "yum" with an enlarged cheek filled with foods used to treat "lows" (see Figure 1).

### Living With Diabetes

Several youth indicated positive aspects of living with diabetes such as healthy eating, attention to activity, attending diabetes camp, and participating in diabetes fund-raising walks. Both age groups stated the Face of Diabetes was separate from self, not real, and had its own identity. Preadolescents reported having diabetes made them "different, not like others who are diabetes-free." Fear of the unknown related to blood sugar was commonly noted. Youth felt "unsure without testing many times each day" and "pokes hurt." School and learning disruption were reported in both age groups due to the need to test blood sugars or treat hypoglycemia, while peers were able to "just carry on." Youth reported difficulty in discerning the difference between hypoglycemia and test anxiety during school exams and felt hindered by the need to leave class to check blood sugar levels. One youth drew the Face of Diabetes as a flattened ball intentionally "not round and bouncy" to represent the changing feelings related to managing blood glucose levels (see Figure 1). Mood swings, feelings of being different, and struggle for control of one's life were often reported, "Unexpected blood glucose numbers coming out of nowhere, like roadblocks are unpredictable." Diabetes was reported as "mysterious, sneaky, and evil; even glad to take over everyone's life."

### Expressed Emotions

Current and future self-drawings reflected either happy or neutral expressions. Both age groups reported a smile meant current and future happiness or reflected family love and support. While many self and future drawings had smiles, the Face of Diabetes smiles were consistently described as "evil". Preadolescents drew mouths that were sad, slanted, or squiggly reporting anger or feeling nervous and sad about dealing with diabetes. Many youth described mixed emotions about having diabetes "feeling ok, but angry at it too." One preadolescent female stated, "If diabetes had a face, I would punch it." She expressed gratitude seeing what the Face of Diabetes looked like, "Since it was just a blob of paper, I could rip him up." One adolescent reported a red, angry-appearing face and stern brow signified frustration with diabetes.

All Face of Diabetes drawings were depicted as different than the self-images. Two females depicted their Face of Diabetes as male. Preadolescents reflected nonhuman characteristics. One preadolescent drew a red blood cell, with decaying teeth, holding a syringe and vial of insulin narrated with a menacing-sounding inflection, "I'm going to give you a low blood sugar today" (see Figure 1). Some Face of Diabetes were intentionally drawn askew, while others purposefully added traits such as larger, uneven, or off-centered eyes. One male Face of Diabetes had a Holmes detective cap to reflect "getting diabetes is a mystery." Both age groups gave the Face of Diabetes power, a personality, including human characteristics. One adolescent drew an older, bearded male expressing him as "angry, authoritarian, and unyielding." "How diabetes likes to be. It runs your life, if you let it" (see Figure 1).

Youth collectively reported diabetes caused worry. Diabetes distress in preadolescents included having to miss school for diabetes clinic visits and blood sugar management. Youth reported even when knowing a recent meal and insulin were not yet absorbed, making a "low" unlikely, worry still interfered with play, and increased fear. Nighttime lows affected sleep resulting in feeling tired or waking "crabby." Some youth reported sadness or guilt related to receiving help with nighttime hypoglycemia that affected parental sleep. One youth reported nightly worry of going to sleep and not waking up due to an undetected low. Diabetes distress was also reflected in "constantly" counting carbohydrates, injecting insulin, and the threat of lows, "you do your best and it still sneaks up on you." Adolescents felt getting older and interacting with more people would increase their feelings of security, self-confidence, and coping.

### Diabetes Stigma

Stigma related to diabetes was reflected in both age groups. "It's hard to constantly tell people about it and why I can't do something or eat something." Frustration was expressed concerning other people "not knowing about diabetes, not understanding; or just pretending to understand." Preadolescents

reported future anxiety with managing diabetes in high school due to the increased activities and academic demands. Like the split face created on paper (see Figure 1), youth commented on having split feelings related to managing diabetes: “happy on the outside but frustrated on the inside.” One reported wanting “to hide the diabetes behind a mask or use a mask to hide from diabetes itself” (see Figure 1). Adolescents commented on feeling judged when people, specifically providers, “think they understand, but they don’t”; “in diabetes, doctors say they know . . . but have no clue what diabetes really is” referencing both impact on daily life and experiences related to trying to achieve glycemic control.

### *Drawing Experience*

Some preadolescents expressed feeling nervous about drawing, concerned about results. Some adolescents reported drawing was “not really my thing.” One adolescent reported that due to the difficulty in drawing “happy, sad, and nervous all at once; a neutral look seemed appropriate.” Many used the self-drawing and “age advanced” it for the future. Future drawings reflected growth through height, body size, defined features, and hair style. When all 3 drawings were compared, 1 preadolescent commented how the Face of Diabetes seemed to be looking at the future self. After consideration, he reported the Face of Diabetes may be thinking, “I hope they don’t develop a vaccine for me” and thought the future self might say back “We’ll see.” Some adolescent’s drawing techniques while creating the Face of Diabetes included harder, more defined strokes. Adolescents also ascribed power to diabetes, “roadblocks that stop me in my tracks,” “treat the low and I may let you pass,” and “it’s always like taking the hard way.” “There is not really a good side, diabetes changed everything.”

Although some youth expressed being nervous in their ability to draw, all participants reported satisfaction and were able to explain their drawings. No differences were noted in quality or length of discussion between youth interviewed by the nurse practitioner compared to those completed with the art therapist.

### **Discussion**

Communication is enhanced through drawing and dialogue. Carter and Ford (10) noted when researchers utilized a youth-centered, participatory approach, data elicited generally reflected youth’s perspective. Woolford et al (18) indicated use of draw and talk techniques increased disclosure of information by youth over 2 times compared to talking alone. These findings are consistent with the current study that facilitated expression and personal reflection about living with T1DM during interviews about the drawings.

Resiliency, through acknowledgment of difficulties in managing diabetes coupled with plans for future success, was observed in discussion about drawings, especially when comparing present to future portraits. Turmoil in managing blood glucose, feeling different, or frustrated yet envisioning a

future with increased support and personal competence are consistent with resilience among youth (19). Youth noted that although diabetes was separate from self, it was something that constantly impacted many areas of life. Stigma associated with living with T1DM related to the tools, the need for frequent testing, and carrying supplies were consistent frustrations. This is similar to Lambert and Keogh’s (19) observations regarding everyday life restrictions and adjustments and Babler and Strickland (20) on integrating diabetes into the outside world as part of the youth’s journey to acceptance.

Challenges were reported along with stories of overcoming obstacles and applying positive lessons learned along the way. Emotions expressed in the future self: happy, hopeful, growth and goal focused, handling adversity, and finding increased support indicate advancing autonomy (21). Drawing the Face of Diabetes supported exploration of feelings related to diabetes, and the self and future drawings afforded greater understanding regarding the influence of diabetes on everyday life.

### *Implications for Holistic Practice*

The research process revealed opportunities to reframe approaches to care, encouraging expression and discussion. Drawing and telling gives participants time to self-reflect and express, a subjective understanding of one’s own reality (8). The struggle for balance and adaptation is evident in youth drawings, as even simplistic drawings portray a wide variety of emotion and experiences (3). Lowes et al (21) noted youth did not see clinic as a source of emotional support as they felt clinicians could not understand what it is like to have T1DM. The current study revealed emotions such as anger, frustration, and sadness living with T1DM; however, youth reported increased engagement in the clinic experience with the draw and talk approach. Holistic practice recognizes the importance of self-efficacy and value of ongoing support (7). Practitioners can use drawing as a method to gather relevant and meaningful information from youth’s perspective to enhance communication and awareness. Utilizing drawing in clinical settings is inexpensive and beneficial for gathering information from youth who may lack the ability or desire to verbalize their feelings or concerns regarding a life event or an illness.

Study limitations include the structure of an extended timeframe during a nonclinic visit that may hinder replication. Compared to the first study, the separate drawing event in a classroom-like setting facilitated focus but was time-consuming. The current study required participants to attend an additional appointment which may have influenced recruitment. The opportunity to discuss drawings provided opportunity for enhanced dialogue and targeted support. However, in both studies, participants were able to create meaningful, detailed drawings reflecting personal experience of living with T1DM.

Understanding the lived experiences and exploration through drawing and dialogue need not be limited to diabetes clinic. Drawing has been successfully utilized in health-care

settings (13, 18, 19). Drawing and dialogue in those settings also increased understanding and provider insight on youth's challenges related to daily management of a chronic health condition (10, 13, 19). Future study using "in the moment" drawing and dialogue completed during clinic visits for chronic health conditions is recommended. Evaluating quality of life, condition control, and management in tandem with drawing and dialogue is beneficial in fostering communication and creating an enhanced clinical picture.

### Authors' Note

IRB approval for this study was received from Children's Hospital of Wisconsin. IRB study title: The Face of Diabetes-Art PILOT Study 2016. IRB number 822320-2. IRB approval: 45 CFR 46.404 Research not involving greater than minimal risk to the children.

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**Kathleen M Elertson**, DNP, APNP, CPNP-BC, FNP-BC, RN, received her DNP, MS, and Post Masters PNP from the University of Wisconsin-Madison in 2012, 2007, and 2008 respectively. Her BSN was obtained at Concordia University Wisconsin. Kathleen has worked in pediatrics in acute and community care settings with a focus on children with special healthcare needs for over 25 years. She is currently an associate professor at the University of Wisconsin Oshkosh College of Nursing and continues clinical work as an advanced practice nurse in a community outpatient setting.