

# The “Face” of Diabetes: Insight Into Youths’ Experiences as Expressed Through Drawing

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## Abstract

**Objective:** The purpose of this descriptive pilot study was to assess the ability of youth to create a meaningful drawing related to living with type 1 diabetes and explore the benefits of expressing emotion through drawing in future interventional work. **Methods:** Youth aged 4 to 19 years (N = 242) with type 1 diabetes attending routine follow-up appointments within a pediatric specialty clinic were asked to draw: “If diabetes had a face what would it look like?” **Results:** Drawings reflected many emotions and ranged from simple to complex in detail. Drawings reflected multiple experiences of living with diabetes including emotions, tools used for management, and effects of self-care. **Conclusions:** Youth were able to create drawings reflecting their experience of living with diabetes. Youth conveyed a variety of emotions, attitudes, and experiences in drawing the “face” of diabetes. Drawing during clinic visits provides opportunity to explore the unspoken experiences of living with a chronic health condition, which may not be obtained during routine clinical information gathering. Deeper understanding of patient’s lived experience may assist providers in therapeutic management.

## Keywords

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

## Introduction

Diabetes is the most common chronic condition in youth (1-3). Timely diabetes self-care is essential to maintain metabolic control and prevent complications. Poor metabolic control can impact physical health, mood, psychological functioning behavior, and ability to perform self-care tasks (4,5). To understand the daily experiences and stressors of youth living with diabetes and assess the need for clinical intervention, information beyond the routine clinical approach may be beneficial (5-8). Few interventions beyond cognitive-behavioral therapy have been used to improve quality of life or decrease stress for youth with diabetes. Drawing may provide an additional avenue for clinical intervention among youth with diabetes. The act of drawing improves stress management, thus impacting quality of life (9). Drawing also provides an opportunity for self-expression of emotions or issues that may not be verbalized (6). The act of drawing can be therapeutic even if the youth does not discuss the drawing (10).

Studies using art intervention in youth with type 1 diabetes mellitus (T1DM) are limited. Nuvoli et al (11) indicated youth with T1DM created drawings reflecting images of a “sick person” and were less apt to depict a stereotypical

smiling, happy image of a “healthy person.” More recently, art therapy was shown to improve metabolic control when used as a clinically integrated intervention (3,12). In addition, art has been used in diabetes camp to provide opportunity for youth to decipher the emotional aspects of diabetes in a safe, secure environment (2).

Malchiodi (13) used a phenomenological approach to understanding youth drawings, which emphasize openness to meaning, context, and way of viewing. Drawing “in-the-moment” experiences has been used effectively for reflection of thoughts and emotions (14,15). Faces are consistently noted for the highest expression of emotion in both photographs and drawings (15). Providing an opportunity for youth with type 1 diabetes to reflect on their experiences by drawing the “face of diabetes” allows expression of

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feelings. The purpose of this descriptive study was to gain greater understanding of the diabetes experience from youth's perspective. The goal was to observe whether youth living with T1DM were able to make a meaningful drawing and/or express feelings and emotions.

## Methods

This descriptive pilot study was performed in the diabetes clinic at a Midwestern pediatric specialty clinic affiliated with a tertiary care children's hospital. The clinic patient population was primarily Caucasian, middle socioeconomic status. Drawings were collected during routine diabetes follow-up clinic visits with a single nurse practitioner during the fall of 2014. A minimal risk protocol was submitted to the institutional review board of the hospital. The protocol was determined to be exempt from full review.

## Sample

A convenience sample of patients with a known diagnosis of T1DM between the ages of 4 and 19 attending routine follow-up outpatient diabetes clinic appointments were utilized for this study. Stratification by gender and age, as described by Chase and Maahs (16) reflecting developmental expectations for diabetes self-management, was used to select the following groups: 4-7, 8-11, 12-15, and 16-19 years. Age ranges matched expected developmental tasks and levels of autonomy with diabetes self-care. The wide age range was purposeful for this study, as it was unknown whether age would affect the ability to create a meaningful drawing.

## Inclusions and Exclusions

Youth, currently on insulin therapy with an established diagnosis of T1DM of at least 1 year duration, who verbally assented to drawing in clinic were included in the study. Youth who refused to draw ( $n = 2$ ), or those with physical or developmental disabilities affecting their ability to draw ( $n = 4$ ), were excluded from the study.

## Procedure

Upon entering the exam room, the nurse practitioner asked youth if they would like to draw a picture. Youth who assented were asked: "If diabetes had a face, what would it look like?" Participants were given a clipboard with standard white paper and a cup containing a random variety of crayons. While clinical information was collected, participants completed their drawings. Participants sat on the exam table, separate from parents and provider while drawing to minimize prompting or coaching. Drawings were collected by the practitioner upon completion. If unsolicited comments were offered by youth, these were noted on the drawing. Gender and age were written on the drawing by the practitioner upon completion. Drawings were kept separate from the medical record. Original drawings were stored in a binder in a locked file drawer in

**Table 1.** The Face of Diabetes: Youth Age and Gender Stratification.

| Age   | Total, N = 242 | Female, n = 128<br>(53%) | Male, n = 114<br>(47%) |
|-------|----------------|--------------------------|------------------------|
| 4-7   | 28             | 17                       | 11                     |
| 8-11  | 76             | 45                       | 31                     |
| 12-15 | 114            | 55                       | 59                     |
| 16-19 | 24             | 11                       | 13                     |

the provider office. Deidentified, numbered drawings were scanned into the secure, password-protected healthcare system data drive for analysis by the research team.

## Data Analysis

Drawings were collected from August through December 2014 and grouped according to the selected age brackets. Each drawing was reviewed individually and then collectively by the 3 members of the research team. Drawings were reviewed for the "first impression" of the message conveyed. Next, using the assigned number, evaluation for degree of complexity (minimized, simple, standard for age, complex), percentage of page used (some, all, and most), position on the page, eye placement (up, down, conjugate, disconjugate), expression (smile, neutral, frown, and sad), human likeness, auxiliary content, symbols, and use of color was recorded on the art analysis page for coding purposes (10,12,17-19). Researchers also noted details such as other body parts, word use, diabetes tools, and likeness to the devil or other nonhuman features. Collective analysis included discussion of the individual drawings and researcher evaluation to confirm internal reliability in the analysis. Upon completion of the individual and collective analysis, findings were tabulated by gender and age.

## Results

A total of 242 drawings divided by age and gender were evaluated (see Table 1). Most drawings ranged from simple to average in level of complexity. Each age-group contained a myriad of expressions with older participants including additional expressive features. Females had more detailed drawings, more varied expressions as well as other features (such as hearts, flowers, and earrings) included in their drawings. While not all drawings included eyebrows, for those that did eye and mouth features were consistent (ie, smile with arched eyebrows, neutral mouths with neutral brows, downturned or sad mouth with furrowed brows). A few drawings had different shaped pupils in each eye (ie, one had a normal pupil, the other with the shape of a cat eye). Some drawings depicted a disconjugate gaze. Some drawings depicted teeth that were jagged, jack-o-lantern-type patterns, or full mouth. Some of the mouths were open widely, with a few including a small to exaggerated tongue and/or uvula. Tears were noted in drawings in each age-group. While all age-groups depicted images of nonhuman form, this was noted most in the 12- to 15-year-olds.

Diabetes tools and use of words were also more prevalent in this age-group. A few drawings in each age-group were completed in a single color.

Younger school-age youth depicted mostly smiles, though some drawings had a large, open mouth (distinguished by a straight upper border, with a lower border curving upward in an exaggerated “U” shape). Additional findings were exaggerated ears, nonhuman forms, and tears. There was minimal use of words or diabetes tools. Older school-age youth commonly depicted a large open mouth followed by a sad/frown. Neutral types of expression were noted. A new expression of a small, open, rounded mouth was depicted by females. The degree of complexity was mostly simple for males, whereas females were divided between simple and complex drawings. Females used a higher percentage of the page. Eye placement was primarily centered, though some had iris/pupil placement to the right and/or eyes looking up. Tears were also noted from one or both eyes; some tears streamed down the face. Other notable features were bloodshot eyes or disproportionately large ears. Use of the nonhuman form increased among males. Depiction of low blood glucose was most common in this age-group. Word use related to low blood glucose included “ahh and help,” “confused,” and “I feel dizzy.” Additional words expressed included “mad, red-angry, scared, it hurts”; “diabetes has an effect on everyone, even people you don’t think about”; “mad and confused.” One all ink drawing depicted an oval mouth with many sharp teeth, 10 eyes above the mouth, each with a round pupil, and below the mouth a beard, with 11 small circle faces, all with sad mouths and dots for eyes. This drawing was described as “kids stuck; these are all kids trapped with diabetes.” A split face drawing incorporating mixed emotions depicted an image with one half smiling, the other half distressed appearing with a thought bubble stating “so confused.” Several of the split face drawings had the words “normal me/me with diabetes.”

Younger adolescent drawings depicted more facial expressions, with the large open mouth most frequent, followed by the horizontal dash, smile, sad/frown. A new expression included a squiggly line was depicted only by females. Drawing complexity was increased; however, many simplistic images were also noted. One exaggerated drawing used the entire page depicting a large devil-like creature with exaggerated facial features. The eyes were round, black circles with red pupils and included a serpentine tail extending outward from the right eye area across the front of the body wrapped over the left shoulder. The drawing used multiple colors with shading throughout, black flames along the bottom of the page, and included spikes along the back of the creature. One male divided the page into 4 quadrants, depicting high, low, frustrated, and angry including words “heart beats fast,” “tired,” and “clammy” with drops coming off the head in 1 quadrant. Diabetes tools, horns, tears, nonhuman form, and use of words persisted.

Older adolescent drawings were simpler and less complex. Drawings depicted large open mouth and smiles,

followed by sad/frown, line, slant line, squiggly mouth. In females, a new “grim” expression was noted (a zigzag-type mouth with furrowed brows). Eye placement was mostly centered. One teen created a simple drawing with a face and body holding a large bundle with a note, “Diabetes is like an unwanted pet, as long as you take care of it, nothing bad happens.” An image of a person occupying most of the page beneath several dark clouds with lightning bolts on the sides of the cloud had written: “I’m going to control your life . . . muhahaha.” A sport-themed drawing depicted a player sitting on the sideline of the football field with the word “benched” in a thought bubble and a text bubble above a figure labeled “athletic trainer” asking, “What is your blood sugar?” One drawing had a full page depicting a stop sign while another had the words “YME”? A tied game of tic-tac-toe with the words, “no one wins” was also observed. Several drawings by older youth portrayed their experiences with high or low blood sugar: A female drawing reflected a high blood sugar displayed on a meter with the words, “What is it this time?” while another referenced being “benched” in sports due to blood sugar readings.

Diabetes tools were noted most often in the 8 to 11 and 12- to 15-year-olds, primarily by females. Diabetes tools included syringes, pumps, meters, with few including more than 1 tool. Other drawings included vials, blood drops, medical alert symbol, and lancet devices. Some tools were included as accessories, whereas others were incorporated into body features (ie, a smile that was 1/2 syringe, a syringe imbedded in the skin or sticking out of the arms, meters for eyes, and a medic alert for the nose or the whole face). One drawing with an insulin pump included a downturned mouth and tears, whereas others depicted smiles. Syringes were noted to be drawn disproportionately larger than traditional insulin syringes. Pumps were drawn similar to scale.

Limited use of color (ie, 1 or 2 colors) was noted in all age-groups, higher in males than in females. One simplistic drawing depicted a blank page (left white), whereas another colored the whole page black. Red was used most often as an accent color in drawings to depict blood, bloodshot lines to the eyes, devil images, and flames. Other use of red was in lips, heart shapes, clothing, stop sign, or words (ie, “Y Me,” “Angry”). A variety of examples of these drawings are included (see Figure 1).

## Discussion

To our knowledge, this is the first study that uses drawing in routine follow-up visits for youth with T1DM. The variety of drawings demonstrated creativity, thoughtfulness, and displayed a wide range of emotions about diabetes. Participants were able to communicate a variety of experiences through drawing and self-expression, which provided opportunity for insight into the unspoken. At first glance, drawings with disconjugate gaze, exaggerated features, asymmetrical drawings, or overtly negative images caused researchers to pause before continuing with the analysis (see Figure 1). The pause was



**Figure 1.** Youth drawings: the “face” of diabetes.

unintentional but allowed researchers time to understand the drawing. Noy and Noy-Sharav (20) noted when viewing art, the area of the brain involved with the emotional response is activated. This is described as aesthetic chills (21).

The request to draw the “face” of diabetes may appear straightforward, however, the final product revealed deeper introspection and reflection. The struggle for balance was evident as even simplistic drawings portrayed a wide variety of emotion and experiences. Younger participants commonly had less symmetry and displayed less variety of emotion, which is developmentally anticipated (6). Younger participants had more smiles, middle-aged youth added words, while older youth added artistic depth. As the youth matured, the complexity of expressions may reflect ability to display inner emotions through drawing (15). Unlike previous findings (17,22), drawings were not always consistent with developmental age as some older participants drawings were simplistic. This may have been the result of limited engagement, reflection of emotional attitude, or personal concerns regarding drawing with crayons as an activity for younger children (15,17).

Drawing ability did not interfere with expression of feelings, as both positive and negative expressions of emotion were depicted in each age-group and gender. Some youth expressed guilt, anger, judgment, or resentment in their drawings and included written messages to describe their experience. The experiences are reflective of findings from other authors regarding feelings of being judged based on blood sugar numbers or A1C results (5). However, our

findings differ from Parkins (23) who found that females depicted emotions of happiness, sadness, and fear in their art, whereas males were more characteristically angry.

Some drawings were perceived by researchers as being darker and more reflective of negative emotion as depicted through the use of tears, often giving the impression of helplessness or frustration. Given the demands of diabetes self-care, expressions of sadness were an anticipated finding (5). It is unclear what the open mouth in drawings was intended to convey. Was it yelling? A silent scream? A cry for help? A contradiction in terms of depicting a happy face with inner turmoil? Skybo et al (17) also noted that as children grow, they associate various sensations, perceptions, and emotions with their bodies.

Several drawings by older youth portrayed their distressful, emotional experiences with hypoglycemia ranging from confusion, sadness, frustration, and helplessness. Split faces reflecting opposing emotions (happy vs sad, uplifted vs downturned, real me vs me with diabetes) were similar to findings from Pera et al (8) who noted use of symbolic imagery; diabetes was personified as an inseparable friend or devil that held them prisoner.

A variety of tools (both overt and discreet) were depicted in drawings. Syringes, often disproportionately large, were noted in both human and nonhuman drawings. The most unique use of a syringe was as a component of the mouth depicting half of a smile. Consistency between presence of tools and facial expressions was not observed. The incorporation of diabetes “tools” within the facial features may be indicative of how intrusive or burdensome these items are in participant’s lives. Pera et al (8) also noted diabetes tools in their drawings (ie, oversized needles, blood glucose meters); however, tools were not incorporated into facial features.

Images of the devil as the face of diabetes are reflective of literature on magical thinking, which is a normal developmental phase and may be expressed in the form of ghosts or demons (17). The devil’s head or monster-like figures can indicate poor self-esteem or reflect something that “behaves” like a devil (24). Although we did not interview youth regarding their drawings, the depiction of monster-like images in the face of diabetes is consistent with findings from Forsner et al (24) who studied fear among hospitalized youth ages 7 to 11 years. Youth reported medical care as “being threatened by a monster” reflecting themes such as awareness of danger, being treated unfairly, feeling overpowered, or wishing for rescue (24).

The findings of our study are limited in terms of generalizability due to a primarily Caucasian sample with a single practitioner. Other limitations include use of drawing without discussion. Involvement of an art therapist may provide opportunity for therapeutic discussion and interpretation of drawings from the youth perspective. Practitioners may consider the value of using drawing in a clinic setting to gain additional insight into their patients’ experiences of living with diabetes. Discussion of drawings with youth is recommended to enhance understanding and potential for supportive care. Future work will explore the applicability and

benefits of using drawing as an intervention in coping, stress management, and self-expression in diabetes care.

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### Authors' Note

All authors have approved the manuscript and this submission. All authors were employed, worked in the project, and participated in this manuscript.

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