

# Using Photography as a Method to Explore Adolescent Challenges and Resilience in Type 1 Diabetes

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## ABSTRACT

Patient-centered approaches to disease management are consistently recognized as valuable tools for improving health outcomes, yet studies are rarely designed to elicit adolescent perspectives. This study sought to better understand the perspectives of youths with type 1 diabetes according to key demographic variables. We conducted an exploratory study through which 40 youths were provided with disposable cameras and prompted to take five photographs each that captured what diabetes meant to them and to provide narratives to accompany their photo choices. Demographic variables examined included sex, age, disease duration, socioeconomic status (SES), race, and glycemic control (A1C). Content analysis was used for photos and open-ended responses to assign photo index scores, which were then analyzed by demographic variables using Mann-Whitney *U* tests for statistical significance. Analysis of photos/narratives ( $n = 202$ ) revealed five main types of representations depicted by at least 50% of the young people. “Challenge” photos included diabetes supplies as tethering, food as a source of frustration, and the body as a territory for disease encroachment. “Resilience” photos included coping mechanisms and symbols of resistance. Overall, these representations were consistent across demographic categories with two exceptions. Males took more food depictions than females ( $P < 0.005$ ) and had fewer coping depictions ( $P < 0.05$ ). Youths from more affluent households were more likely to take photos of resistance ( $P < 0.05$ ). The use of photo index scores expands previous studies using photography by comparing demographic variation within a sample. Our findings provide insight into coping strategies and indicate that SES may provide an advantage for affluent youths in meeting diabetes-specific challenges.

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Some of the most recognized research efforts in type 1 diabetes today rely on large national and multinational studies aimed at better understanding epidemiological factors in disease prevalence or at addressing health complications associated with glycemic control (1–5). Data from these studies are garnered through the use of survey instruments with closed-ended questions most often directed at adult populations with type 1 diabetes or at parents of youths living with type 1 diabetes.

This research is understandably paramount for ensuring health and vitality and uncovering possible triggers for disease onset, but its focus rarely leaves room for the inclusion of basic perspectives about living with diabetes from youths themselves. Additionally, although racial and socioeconomic status (SES) disparities have been documented consistently in glycemic control and related disease complications (2,3,6–10), little is known about differences in experi-

ences with diabetes that may inform health outcomes for youths.

There is growing recognition of the value of incorporating pediatric perspectives into strategies for disease management and development of patient-centered models of health care delivery (11–13). The incorporation of such perspectives must begin with a consideration of the methodologies used to gain insight into patients' experiences, especially when it comes to capturing the "voice" of pediatric populations. The limitations of using traditional survey research formats with youths have been noted (14–17). These critiques posit that common tactics in survey research, such as Likert scale measures (strongly agree to strongly disagree question series), lengthy surveys, and the use of jargon, are inappropriate for youths given their levels of overall cognitive maturation (14–17). Rather, scholars of research methodologies advocate the use of less traditional methods that allow youths to answer questions in more open-ended and age-appropriate ways, such as drawing, journaling, storytelling, and using photography as well as "photo-voice" (16,18–21), a method whereby participants in research studies are encouraged to frame their own lived experience through photography (18–21). These techniques involve activities more familiar to youths and also allow them room to insert their own creativity into expression.

This study used data from surveys of 40 youths living with type 1 diabetes in an effort to better understand the ways in which they define and experience diabetes in everyday life. Participating young people provided their wisdom through five pictures they took with disposable cameras of what diabetes means to them, accompanied by narrative explanations of their photo choices. In addition to bolstering existing approaches to type 1 diabetes through the inclusion of pediatric perspectives, we also sought to pay particular attention to the ways in which social demographic

variables such as sex and SES may inform such definitions and experiences. Drawing on the rich and established history of photovoice, we expanded the commonplace use of photography as a methodological tool by assigning "photo index scores" to specific types of representations and quantifying images according to demographic variables. A systematic content analysis of these photos and narrative explanations not only showed the ways in which youths framed diabetes in terms of its challenges, but also revealed strategies young people engage in to minimize such difficulties.

### Methods

Recruitment took place at a pediatric endocrine clinic and related camps housed within a large university research institution during the summers of 2011 and 2012. The research was conducted in accordance with the institutional review board at the university where recruitment occurred and included Health Insurance Portability and Accountability Act waivers for determining eligibility from patient rosters and informed consent/assent with full disclosure of study parameters for parents/guardians and participating youths. Selection criteria for participation included having a diagnosis of type 1 diabetes, being between the ages of 12 and 19 years, and having had a diagnosis for at least 2 years (to ensure completion of the honeymoon stage of disease onset). Demographic measures included sex, age, disease duration, race/ethnicity, parental education, total household income (using Gilbert's typology of U.S. economic stratification), and glycemic control (captured through A1C test results) (22).

Participation required completion of a parent/guardian survey and a separate survey for youths. Both surveys were designed to help researchers better understand social experiences of living with diabetes and overall perceptions about diabe-

tes from the caregivers' and youths' perspectives. Here, we focus specifically on the youth's surveys, which involved taking five pictures with a provided disposable camera of "what diabetes means to you" and explaining in narrative form what each photo represented to them about diabetes. Having the youths take five photos allowed for a range of representations without requiring too much time or effort. Directions for the photography part of the project were provided verbally in person when youths enrolled in the study and were also included in writing in the survey materials.

Instructions were as follows: "You know better than anyone what it is like to live with diabetes, and your involvement in this study will allow us to better understand your experiences. With the disposable camera you have been provided, take five pictures that show what diabetes means to you. As you take each picture, keep the following idea in mind: To me, diabetes is \_\_\_\_\_. Imagine explaining what it means to live with diabetes to someone who has no idea what that may be like. For each picture you take, make sure to complete the table on the next page to help explain your choices."

All materials, including the parent survey, youth survey, and disposable cameras were sent home with participating families to allow them the time needed to complete the project and to ensure that youths could have access to their lives outside of the clinic when taking photos. A postage-paid envelope was also provided for families to return materials, and we developed the film so that there was no economic expense incurred by families. Also, once survey materials were returned, youths participating in the project received a \$30 money order in appreciation for their time. We used disposable cameras to ensure that all youths had access to the technology needed to complete the project. Allowing participating families to leave the

clinic with the survey materials was necessary given what we were asking the youths to do, but this approach created the expected problem of actually getting completed materials back. To avoid attrition, youths were sent reminder postcards after 2 weeks, given reminder phone calls after 1 month, and, if materials had not been returned after 2 months, families were sent a new set of survey materials (including another camera and postage-paid envelope).

### Data Analysis

Multiple analysis techniques were used to examine the data. First, a basic content analysis of photos was conducted to determine the most common themes of photographic representations. This involved quantifying the total number of pictures taken and systematizing those images into major categories of representation based on narrative explanations provided for the photos, using a technique of constant comparison associated with Grounded Theory (23,24). Photos were examined by lead contributing authors on a regular basis through this process, and two research assistants were used to ensure intercoder reliability (established at >95%) (25,26).

In an effort to examine possible variations within photo representations according to demographic variables, youths were assigned photo index scores, numeric indications of how many photos they took of a particular representation. For example, a youth who took two pictures out of her five of diabetes supplies would be assigned a diabetes supplies index score of 2. Photo index scores were analyzed by demographic variables with IBM SPSS Statistics version 20 (IBM Corporation, Armonk, N.Y.) through the use of Mann-Whitney *U* tests of statistical significance for nonparametric measures. Photo index scores were treated as discrete variables (possible values of 0–5) and dichotomous variable rankings were created to see if mean scores were sig-

nificantly different among the groups. Dichotomous groups were as follows: sex (male or female), age (12–15 or 16–19 years), disease duration ( $\leq 6$  or  $> 6$  years), SES by income ( $\leq \$40,000$  or  $> \$40,000$ , as this divided our sample evenly between income thresholds), SES by parental education (Associate in Arts [AA]/Skilled Trade diploma or lower or baccalaureate degree or higher), race (white or nonwhite), and glycemic control ( $< 8.0\%$  or  $\geq 8.0\%$ ).

### Results

Characteristics of our population are presented in Table 1. Just less than 90 youths were enrolled in this project, and 40 completed packets were returned. The demographics of the 40 participating youths in the sample mirrored those of the total enrolled sample, as well as larger etiological trends in type 1 diabetes. Participants had a mean age of 15 years, and there were equal sex ratios, a range of SES levels, and an overrepresentation of whites. A content analysis of photos and narratives ( $n = 202$  photos; some participants turned in fewer or more photos than the five requested) revealed five main types of representation categorized broadly under themes of “Challenge” and “Resilience.” Challenge photos included diabetes supplies as tethering (30% of photos), food as a source of frustration (28%), and the body as a territory for disease encroachment (10%). Resilience photos included coping mechanisms (18%) and symbols of resistance (12%). Overall, these representations were consistent across demographic categories, with two exceptions. Mann-Whitney *U* tests revealed that males tended to take more challenge photos of food ( $P < 0.005$ ) and fewer resilience photos of coping mechanisms ( $P < 0.05$ ). Also, youths from more affluent households took more pictures of certain types of coping mechanisms and were more likely to depict resistance photos ( $P < 0.05$ ).

### Challenge Themes

The most common pictures youths took to capture what diabetes means to them were of diabetes supplies: 88% took at least one photo of the supplies associated with diabetes, and these pictures constituted 30% of the overall photos taken (60 photos). Supplies pictures included photos of needles/syringes, meters, pumps, insulin, ketone strips, test kits, and other materials specific to managing diabetes. There were no discernable patterns in who was most likely to take supplies photos according to demographic variables examined. Overall, narrative explanations about the supplies photos overwhelmingly centered on themes of challenge related to diabetes given the necessity of supplies for survival and the amount of space they occupy in daily living. Ninety percent of the supplies narratives focused on their unavoidable presence in daily living, as well as the annoyance of this constancy:

*“MANY drawers in my house are designated to diabetes supplies.” White female, age 19, describing a photo of a drawer full of supplies*

*“Diabetes means the burden of supplies.” White male, age 17, describing a photo of miscellaneous supplies*

*“I have to have everything in one place, near me constantly.” Hispanic male, age 16, describing a photo of a test kit*

*“I have to do my part to get a good report just like [school] homework but this is all the time.” Black female, age 16, describing a photo of diabetes supplies and a workbook*

*“Because this is my life now. Needles and medicine, needles and medicine.” White male, age 18, describing a photo of miscellaneous diabetes supplies*

**TABLE 1. Sample Characteristics (n = 40 Participants) and Mann-Whitney U Tests for Photo Index Scores\* (n = 202 Photos)**

	Challenge Photos			Resilience Photos	
	Supplies Index Score	Food Index Score	Body Index Score	Coping Index Score	Resistance Score
Sex					
Male (n = 20)	1.3 ± 0.48	2.2 ± 1.30	1.2 ± 0.57	1.2 ± 0.97	1.8 ± 0.84
Female (n = 20)	1.3 ± 0.58	1.0 ± 0.50	1.0 ± 0.21	1.9 ± 0.62	1.9 ± 0.88
		(P < 0.005)		(P < 0.05)	
Age					
Older (≥16 years) (n = 21)	1.1 ± 0.36	1.8 ± 1.40	1.4 ± 0.51	1.8 ± 0.83	2.0 ± 0.94
Younger (≤15 years) (n = 19)	1.4 ± 0.61	1.5 ± 1.10	1.4 ± 0.42	1.6 ± 0.76	1.7 ± 0.71
A1C					
Optimal (<8%) (n = 17)	1.3 ± 0.49	1.5 ± 0.55	1.1 ± 0.53	1.9 ± 1.1	1.7 ± 0.87
Not optimal (≥8%) (n = 23)	1.3 ± 0.56	1.5 ± 0.63	2.0 ± 0.14	1.5 ± 0.52	2.0 ± 0.86
Income					
<\$40,000 (n = 13)	1.2 ± 0.58	1.3 ± 0.42	1.1 ± 0.38	1.8 ± 0.71	1.6 ± 0.58
≥\$40,000 (n = 26)	1.3 ± 0.47	1.4 ± 0.13	1.3 ± 0.17	1.3 ± 0.53	2.1 ± 0.78
(\$40,000–80,000 [n = 14]; >\$80,000 [n = 12])					(P < 0.05)
Missing data (n = 1)					
Parental education					
High school diploma or lower (n = 15)	1.3 ± 0.59	1.6 ± 0.77	1.7 ± 0.32	1.7 ± 0.72	1.6 ± 0.82
AA degree or higher (n = 25)	1.3 ± 0.49	1.9 ± 0.72	1.2 ± 0.65	1.6 ± 1.00	2.1 ± 0.87
					(P < 0.05)
Disease duration					
>6 years (n = 21)	1.2 ± 0.41	1.6 ± 1.1	1.0 ± .72	1.6 ± .67	2.0 ± 1.00
≤6 years (n = 19)	1.4 ± 0.65	1.7 ± 1.2	1.2 ± .44	1.8 ± 1.03	1.7 ± .90
Race/ethnicity**					
Black (n = 3)					
Hispanic (n = 3)					
White (n = 33)					
Arabic/Hispanic (n = 1)					

\*Photo index scores are presented in terms of the mean number of photos taken for each demographic variable's categorical grouping.

\*\*Photo index scores are not presented for the race/ethnicity category because of a lack of diversity in our sample.

The second most common category of challenge pictures were of food: 68% of the youths took at least one photo of food, and these represented 28% of the total photos (57 photos). Males in particular were more likely to take food photos than their females counterparts when looking at photo index scores ( $P < 0.005$  for Mann-Whitney  $U$  tests). These photos framed food as

a source of frustration, with 86% of the narratives describing foods that were perceived as off-limits, work-inducing, and cumbersome. Youths took pictures of candy, cookies, breads, cake, and ice cream, accompanied by bold statements such as “Diabetes SUCKS” (14-year-old white male) or “This is what I hate about diabetes” (15-year-old white female). Similar to the photos of dia-

betes supplies, youths also denoted the constancy of food mindfulness as a challenge and highlighted the work it takes to manage food intake. Examples of narratives that framed food in the categories of off-limits and work-inducing are as follows:

*“The enemy of diabetes.”  
Hispanic male, age 17, describing a photo of a bag of sugar*

*“Many small sacrifices.” White female, age 17, describing a photo of a Diet Coke*

*“Diabetes means accuracy in counting carbs.” White male, age 17, describing a photo of a cereal bowl on a scale*

*“Diabetes is all about counting carbs. You have to know how many carbs are in what food you’re eating to keep your blood sugar at your goal number. It makes life easier if only a little amount of carbs is consumed.” White female, age 14, describing a photo of a nutrition label*

*“Low BG!!! It’s such a pain to eat when you aren’t hungry.” White female, age 15, describing a photo of a can of frosting*

The third and final category of challenge photos were in body images of bruises, calluses, or pricked fingertips and were taken to show the physical pain and bodily “evidence” of diabetes. Half of the youths (50%) took at least one body photo to show what diabetes means to them, representing 10% of the overall photos (20 photos). These images typically showed the aftermath of testing blood glucose or insulin injections, with close-ups of various body parts. All of the narratives that accompanied these photos were themed as “challenge” because in all, the youths described the images in terms of pain or burden (actual or symbolic):

*“Diabetes hurts.” White male, age 13, describing a picture of his fingertips*

*“This is a scar. Diabetes is about learning to get used to what hurts.” White female, age 16, describing a photo of her thigh*

*“I always have to keep up with my feet so I don’t get ulcers.”*

*Black male, age 17, describing a photo of his feet*

*“Diabetes means bruises from pump sites.” White male, age 17, describing a photo of his leg*

*“Constant reminder of my pain.” White female, age 17, describing a photo of blood on her fingertip*

### Resilience Themes

In contrast to challenge photos, resilience photos and narratives were provided to demonstrate the ways in which youths overcome the hardships associated with diabetes and to capture the message that they will not be defined by diabetes. The first category of resilience photos were of coping mechanisms: 53% of the youths took at least one photo of a coping behavior or activity, and these photos represented 18% of the overall photos (36 photos). The broad categories of coping mechanisms represented in this project were (in order of frequency) leisure activities (e.g., journaling, reading the Bible, writing poetry), person/pet support systems (fellowship with friends, family, and pets, with photos of pets outnumbering photos of people 3 to 1), and extracurricular activities (e.g., participation in sports teams, band, or theatre performance groups). Overall, coping pictures were more likely to be taken by females ( $P < 0.05$  for Mann-Whitney  $U$  tests). Also, the nine photos provided of extracurricular activities as a coping mechanism were all taken by youths with household incomes  $> \$80,000$ . Youth coping can be discerned in the following:

*“First-degree black belt in Tae Kwan Do. An important part of my life. Exercise helps me.” White female, age 14, describing a photo of Tae Kwan Do belts*

*“I took a picture of my dog just to show that animals will*

*always be there when you need them.” White female, age 14, describing a photo of her dog*

*“My babies are the two animals that I know will always love me unconditionally for who I am.” White female, age 18, describing a photo of her two cats*

*“Friends mean the world to me and we are quite the unique crew. I would never ask for another set of friends. TLC from friends/fam[ily] really helps.” White male, age 16, describing a group photo with his friends*

*“Music is my escape from diabetes. It makes me feel normal.” White female, age 17, describing a photo of a violin*

The second type of resilience representations can be categorized as “resistance” photos: 53% of the youths took at least one photo illustrating that they will not be defined by diabetes; these constituted 12% of the overall photos (24 photos). Resistance photos included representing something that defied negative or false associations of diabetes as a disease or a symbol that demonstrated their resolve to live without limits (Figure 1). Affluent youths were the most likely to take resistance photos, whether in examining income ( $P < 0.05$  for Mann-Whitney  $U$  tests with total household income  $\geq \$40,000$  as the cusp) or parental education ( $P < 0.05$  for Mann-Whitney  $U$  tests with an AA degree or higher as the cusp). Examples of resistance photos and narratives from the youths include:

*“The hope for tomorrow. Diabetes is not a curse; it’s an opportunity to show everyone that this disease does not have to hold you down.” White female, age*



■ **FIGURE 1.** Photo of resilience. “Diabetes is like a ‘speed bump.’ It slows you down for an instance but doesn’t stop you from reaching your final destination.” White male, age 19.

*19, describing a photo of blue flowers*

*“This shows that diabetes does not limit what you can do in your life.” White male, age 12, describing a photo of a map with red dots on places he had traveled during the summer months*

*“They are the biggest trees in my yard, but the wind has the capability to knock them down, but still they choose to grow. Diabetes is like the wind, but I choose to stand firm.” White female, age 16, describing a photo of trees*

*“My bedroom proves that non-diabetics are not the only ones that decorate their rooms to their liking. Diabetics also decorate their rooms to their likes as well.” White female, age 14, describing a photo of her bedroom decorated with a Star Wars theme*

*“Be strong and make the best of it :)” White female, age 12, describing a photo of herself smiling*

## Discussion

When prompted to take five photos of what diabetes means to them, youths in this study clearly showed that diabetes means facing challenges

such as constant mindfulness about supplies and food and also that their bodies are the site at which diabetes trespasses in unwanted ways. Equally so, the youths also showed purposeful and creative strategies they engage in to minimize the hardships of their disease and even to overtly reject larger negative cultural associations that accompany their diagnosis. Thus, in representing what diabetes means to them, the youths frequently elected to depict strategies and messages of what it will not mean to them.

The tendency for males to depict more challenge photos of food and fewer photos of coping mechanisms can perhaps be explained through larger cultural expectations that accompany sex roles in adolescence within American culture. For example, research demonstrates that limiting caloric intake or a general concern over nutrition is seen as “feminized” behavior (27,28). For males in the crux of adolescent development to engage in food mindfulness in the presence of others may create socially awkward situations (29). Similarly, certain coping behaviors such as journaling or artistic expression may not have been captured as readily in photos by males given norms surrounding the expression of emotions (30–32).

The findings from this project with regards to SES are particularly important given well-noted disparities in type 1 diabetes health outcomes (2,3,6–10). That youths from the most affluent households were more likely to take pictures of resistance may indicate that, even in childhood, there are psychosocial differences in how diabetes is perceived and experienced according to SES. As with our findings regarding the sex of participants, there is need for more research into how depictions associated with SES may be connected to opportunities for behaviors that foster resilience (33).

Some limitations in our sample are noteworthy. First, we did not have enough racial or ethnic diversity to adequately examine these import-

ant demographic variables. Second, attrition was significant; less than half of the families enrolled in the study returned completed materials. We attribute the high attrition rate to the tremendous demands on the lives of youths and families in our sample or simply just a loss of interest in participating in the project after enrollment. It is important to note, however, that the sample we were able to obtain mirrored the total enrolled sample (equal sex ratios, an overrepresentation of whites, and a range of household SES) and was in keeping with larger etiological trends in type 1 diabetes. In all, more research is needed with larger samples that can capture more racial/ethnic diversity in varying locations to foster the reliability and generalizability of our findings.

Notwithstanding these limitations, this research has important implications. By allowing youths to identify their own perspectives on what diabetes is in an open-ended way, we can better understand how to direct future research efforts and possible interventions. Also, their perspectives can be better understood not only by health care providers, but also by parents and family simply by sharing photos and narratives. Several parents wrote to us on their own about how much they learned by looking at and reading their youths’ photos and narratives. Photo representations could better train health care providers and caregivers about the ways in which diabetes is experienced by young people. And finally, by systematizing the photo categories by demographic variable, we were able to examine how experiences of type 1 diabetes may vary within a given population—a method that, to our knowledge, has not been used in existing research with photography and photovoice. We posit that the use of nontraditional methodologies such as photography with pediatric populations will allow for improved advocacy, refinement of care delivery,

and identification of focus areas for future research in type 1 diabetes.

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## Duality of Interest

No potential conflicts of interest relevant to this article were reported.

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