

Growing Up with Type 1 Diabetes: A Photo Elicitation of Memory

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Abstract

The aim of this study was to learn from the lived experiences of children who were diagnosed with type 1 diabetes using photo elicitation. Five participants were chosen from the endocrinology clinic at Holston Medical Group in Kingsport, Tennessee. The participants were asked to take photographs that illustrated aspects of their experiences growing up with type 1 diabetes. The number of photographs taken was at the discretion of each individual participant. Interviews with each participant were conducted utilizing prepared open-ended questions. All participants completed the project. Some common themes that emerged are: the perception of a life changing experience; lack of understanding from school staff and coaches; feeling different from friends; embarrassment; no plan or structure during the transition period; belief that diabetes education focused more on the negatives; and thoughts that diabetes education tells you what to do, but not how to do it. The information obtained from this study supports the need for education for all individuals who are involved in the life of a child with type 1 diabetes. It also supports the notion that education for children with type 1 diabetes and their parents should be on-going instead of a one-time event. This study is limited due to the small amount of participants, and further research is needed to help providers give quality patient centered care to this population.

Keywords: Adolescence; Type 1 diabetes; Diabetes management

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“You have diabetes.” A devastating diagnosis at any age but especially to a child. It is overwhelming for the child and the parents. Children diagnosed with type 1 diabetes enter a new reality. Their days revolve around blood sugar monitoring, dietary modifications, and insulin injections. It is not an easy path to follow.

Approximately 176500 children in the United States have type 1 diabetes [1]. Over the last 20 years there has been on average a 2.8% yearly increase in the incidence of type 1 diabetes in children and teenagers throughout the world [1]. It is clearly on the rise. Education is key to reducing associated complications.

Adolescence is difficult. Diabetes care shifts from the parents to the child. Adolescents are not as compliant with treatment recommendations as are younger children [2]. Treatment obstacles identified include changing behaviors, new family roles, and peer pressure, all of which are compounded by increased insulin requirements during adolescence [2]. Adolescents report feeling “burdened” by their responsibility, yet they view freedom as a positive component in the transition of care [3]. It is difficult to find balance between freedom and responsibility, which is important for glycemic control. Hyperglycemia can cause complications such as diabetic ketoacidosis, cardiovascular disease and nephropathy [4]. The Diabetes Control and Complications Trial revealed that tight glycemic control could reduce 27-76% of complications in individuals over the age of 13 [1].

The aim of this study is to learn from the lived experience of growing up with type 1 diabetes and discover innovative ways to

provide education and support to type 1 diabetic children and their families. This researcher strives to tell the stories of 5 individuals and their journey from diagnosis through the teen years, utilizing photo elicitation.

Photo elicitation is a research technique that utilizes photographs in research interviews [5]. John Collier first used photo elicitation, in 1957, while interviewing families to determine how they adapted to living among ethnically different people. Collier found that photographs “prod latent memory, to stimulate and release emotional statements about the informant’s life” [5]. One study found that photo elicitation allows the participants to examine and release their feelings; this in itself may have therapeutic benefits [6].

This study utilized a convenience sample of adult type 1 patients at the Holston Medical Group Endocrinology Clinic. Approval for the study was obtained from the Institutional Review Board at Union University, as well as Dr. Robert Lee, Medical Director of Holston Medical Group. Eligible participants had to have been diagnosed with type 1 diabetes before age 13, be between the ages of 18 and 30 years, be able to speak English and have a cell phone with photographic capabilities. They could be of any race, gender, socioeconomic status or health status.

Seventeen patients met criteria for the study. Ten signed consent and agreed to participate. Of these ten, four females and one male emailed pictures and returned for an interview. The participants were informed of their role and were given 2-4 weeks to take photographs of anything that reminded them of growing up with type 1 diabetes. One on one interviews were conducted after submission of the photographs. The interviews were audio recorded and notes were taken by Jamie Givens, NP, a provider in the Holston Medical Group Endocrinology Clinic.

After the interview process was completed, the recorded interviews, written notes and photographs were reviewed. Information from the interviews, along with some of the photographs was used to compile five brief accounts of how growing up with type 1 diabetes impacted each of these individuals. For privacy purposes the names have been changed and no personal identifiers are represented in the photos included. Participants provided signed consent to allow utilization of the photos.

Some common themes found in these five stories are: life changing experience, lack of understanding from school staff and coaches, feeling different from friends, embarrassment, no plan or structure during the transition period, and inadequate diabetes education. Following are the participants' stories, as described through interviews and photographs. Each story has an identified theme.

Hope's Story Themes: Life Changing Experience, Lack of Understanding from School Staff and Coaches, No Plan during Transition and Diabetes Education Tells You What to Do but Not How to Do It (Inadequate Diabetes Education)

Hope was diagnosed with type 1 diabetes at age 9. Upon diagnosis, she was admitted to the hospital. She remembers her mother crying all night the first night. Her family was taught how to check her blood sugar and how to give insulin injections. Dietary instructions were to watch sugar content.

Hope tried to learn about the disease by ordering an education kit called "How to Juggle Diabetes." It taught her how to juggle literally, while it taught her how to juggle food, insulin and exercise. In her 5th grade journal she wrote about having diabetes. Photo 1 shows this excerpt from her journal.

After diagnosis, she rarely got to stay over at her friends' homes, instead they stayed with her. She remembers having hyperglycemia while at a friend's. She knew if her blood sugar did not improve she would have to go home and she knew exercise would help. She jumped on the "baby trampoline" in an effort to be allowed to remain at her friend's house. However, despite her effort to lower her blood sugar, her parents came to pick her up early and take her home. Photo 2 is a bracelet she made with a friend. It signifies the last time she stayed with this friend before her diagnosis.

She was home schooled during middle school, because of diabetes. Her mother was able to control her food intake, ensure exercise and help her control her blood sugar. After each meal they took a walk. Photo 3 is a road that reminds her of those walks.

She resumed public school in 9th grade. The high school years were "rough." Previously diabetes was the focus of her day. Someone was always with her; now she felt alone. She felt "zoned out" in class daily after lunch. She needed to check her blood sugar, but her teacher was "strict." It was unacceptable to get into your backpack during class. This made her nervous; she did not want to disrupt class. If it had been a onetime occurrence it would not have been a problem, but it was "constant." Her teacher knew she had diabetes, but she did not want to use this as a "scapegoat." Daily she silently endured this nervousness in class.

Sometimes Hope felt diabetes was used as an "excuse" against her. Softball was one example. When she started softball, she was allowed to play, but a new coach was afraid to "put her in" because of her diabetes.

These are Hope's words: "She didn't understand and she didn't try to understand. It was frustrating to have that used against me." Hope recalls being "let go" from a job. She believes this was directly related to her diabetes. Later she learned the manager would not have hired her had he known she had diabetes.

Hope embraced type 1 diabetes initially, but things changed in adolescence. She admits she did not take care of herself. Her blood sugar was out of control. She remembers feeling "mad and bitter." She felt restricted. Her parents required her to stay within a 2 h drive from home.

She gradually took over her diabetes management, though her mother questioned her often about her blood sugar. This transition of care "just naturally happened," Hope recalls.

Hope believes one of the negatives of type 1 diabetes is that you become more dependent on others, which is scary. It concerns her that she may be out alone and "faint" and no one will know what to do. A positive Hope says is that diabetes has made her who she is today. She realizes people do not understand what she goes through. Therefore, she is more understanding of what others go through.

Hope believes instructions on coping and transitioning through life should be included when educating newly diagnosed type 1 diabetics. She feels there is a "disconnect" between the education provided and the reality of living life with type 1 diabetes. Hope shares some words of encouragement. "It is definitely not the end, definitely not the worse, there is worse, it is livable, if you control it you do better, and if you don't, it controls you. You can do it".

Kathy's Story- Themes: Lack of Understanding from School Staff and Coaches, Life Changing Experience and No Plan during Transition

Kathy was diagnosed at age 6, just before Halloween. She was admitted to the hospital where she and her parents were taught how to check her blood sugar, give insulin injections and read food labels.

At school, Kathy had her own box of "sugar-free" ice cream in the freezer so she was not different from the other children. At school parties there was always an un-iced cupcake for Kathy, or sometimes there was fruit pizza. Kathy remembers being disappointed one year when her teacher did not give her a Valentine card because it included a lollipop.

The teenage years were "a little rough, but not terrible." She says "you had to trust your friends" and feel confident they would know what to do if something happened. Her friends and potential boyfriends knew she had type 1 diabetes. She says it "scared off a boyfriend or two." She learned carbohydrate counting and started wearing an insulin pump just before her 16th birthday. Shortly after that she had an episode of "being done with diabetes." She quit wearing the pump, but after about a week of daily injections, she resumed the pump.

Kathy recalls at least two, diabetes related, major disappointments during high school. After signing up for a school trip to New York City, she was informed she could not go. She was told the trip would involve lots of walking. They did not want to spend a day in the hospital if something happened. Kathy's parents filed a complaint. The school was found to be noncompliant in the management of diabetic students. The Board of Education ruled all staff had to be trained in diabetes

management. Kathy was then told she could go on the trip, but opted not to go.

Kathy was admitted to ICU with diabetic ketoacidosis on the day of her senior prom. The high school was located beside the hospital. Kathy's physician allowed her to go to the prom for two hours. She had elbow length gloves that covered the intravenous needles in her arms. Her date picked her up at the hospital. Her parents waited just outside the school. She was advised not to eat anything while there. From the prom she went straight back to the hospital. Photo 4 is a picture of Kathy's gloves covering the IV tubing.

Kathy attended a support group regularly and met with a dietician yearly for many years. Transition to self-management was slow. She did not completely manage her diabetes on her own until she got married.

Growing up with type 1 diabetes made playing sports difficult. She worried about her blood sugar. Her dad would not allow her to roller skate. He "sheltered" her. Kathy's mom chaperoned every elementary school fieldtrip. She considers these some of the negatives of growing up with type 1 diabetes.

Kathy was the first of three grandchildren to be diagnosed with type 1 diabetes, and she readily offered encouragement and support to her two cousins upon their diagnoses. Part of the reason she agreed to participate in this study is due to her desire to help others.

Anthony's Story- Themes: Feeling Different from Friends, Embarrassment, Lack of Understanding from School Staff and Diabetes Education Focuses on the Negatives (Inadequate Diabetes Education)

Anthony was diagnosed at age 9 on Thanksgiving weekend. He spent three days in the hospital. He learned how to check his blood sugar, give insulin injections, check his urine for ketones, dietary basics, and proper management of hypo- and hyper-glycemia.

Anthony remembers being told, "You have this disease that you can't get rid of," and being "given a list of things you can't do," such as: "you can't eat this, you can't drink that, you can't join the military, you can't drive an 18 wheeler, you can't be in charge of heavy equipment, and you can't fly a plane." He felt the education focused upon the negatives. Photo 5 is of a plane. Being told he could not fly a plane left a lasting impression.

Anthony was ashamed and did not want others to know he had diabetes, which made managing highs and lows at school difficult and embarrassing for him. When Anthony was in elementary school, if his blood sugar went too high during the school day, he was sent to the gym to walk. This made him uncomfortable, as it brought attention to him. Photo 6 is a gymnasium. Once, his hypoglycemic behavior was misinterpreted as disrespect. His mother was a teacher at the school and intervened on his behalf. Otherwise he would have gotten detention. Anthony carried this burden as he moved on to college. He recalls having a hypoglycemic episode prior to an anatomy exam. He was given the option to take it later, but he did not want special treatment so he took it as scheduled.

Like Kathy, Anthony agreed to participate in this study because he saw it as an opportunity to help others. Anthony believes diabetic education should come down to the child's level. He says if a child does not know his/her body has a pancreas then how is he/she supposed to know what a pancreas is supposed to do. He suggests that educators

stress the seriousness of this disease, while explaining why they are asking a child to check his blood sugar and take insulin injections.

Sandy's Story- Themes: Embarrassment, Life Changing Experience, No Plan during Transition. Feeling Different from Friends and Diabetes Education Focuses on the Negatives (Inadequate Diabetes Education)

Sandy was 7 when she was diagnosed. She learned to check her blood sugar and give insulin injections during her hospital stay. Sandy was told to eat "sugar free stuff" and does not recall carbohydrate instructions.

After her diagnosis, some children were not allowed to play with her anymore. In middle school she did not make the cheerleading squad; she believes this was because she had diabetes. She tried out for volleyball, but developed hyperglycemia and had to leave try-outs. These are a few examples of what Sandy views as the negatives of diabetes.

Three years after diagnosis, Sandy started wearing an insulin pump. She did not tell others she had diabetes, but usually they would ask when they saw her pump. She says once someone pointed at her pump and said "you're a weird diabetic."

When she got her driver's license, she was not allowed to drive if her blood sugar was above 250. Between the ages of 14-15, she became more independent of her blood sugar control, but did not always make the best choices. Photo 7 is the Emergency Room at a local hospital, where she was admitted with diabetic ketoacidosis about every 4 months for a period of time, because she did not control her blood sugar. She recalls taking off her pump when going out with friends because she did not want anyone to ask about it.

Photo 8 is a clock that represents following a schedule and eating at scheduled times. Sandy believes the potential for hypoglycemia at uncertain times, maintaining a strict schedule, and frequent blood sugar checks are also negatives of type 1 diabetes. Photo 9 is that of her glucometer. Despite the negatives she believes managing her blood sugar made her more responsible, and she views this as a positive.

Sandy felt teaching focused more upon what she could not do or could not eat. She feels teaching newly diagnosed type 1 children should focus more on the positives. Sandy's advice to those who are growing up with type 1 diabetes is to "try not to focus on what you can't do and can't eat, focus on the positives."

Karen's Story- Theme: Life Changing Experience, Lack of Understanding from School Staff, Embarrassment and No Plan during Transition

Karen was diagnosed at age 7. Her blood sugar was 700 at the time, and she was referred immediately to the hospital. Photo 10 is a stairway that reminds Karen of her mother carrying her up the steps into the hospital. In the hospital she learned how to give herself insulin injections by practicing on oranges. Dietary education focused on sugar and carbohydrate exchanges instead of carbohydrate counting.

Karen knew "she wasn't the same" but her parents tried to help her live a "normal" life. She knew it was something she would have forever, but she did not understand it. Karen remembers she would "fight" against getting an insulin injection. After Karen's mother told her she did not have a choice, she had to take the injections or she would die,

she realized she would have to do this. While attending a camp for children with diabetes, she gave herself her first insulin injection.

Teachers and staff, at her school, had to learn about management of type 1 diabetes. Karen's mom came to school to help with her finger sticks, insulin injections and snacks. Karen remembers a "closet" at school where snacks were kept for her and at certain times she would check her blood sugar and go to the "closet" to get a snack. Once she had to eat an apple in class, because she had hypoglycemia. This made her feel embarrassed.

At school parties, her mom made sure she had appropriate food. She attended birthday parties at her friends' homes but was not allowed to sleep over because her friends' parents felt uncomfortable not knowing how to care for her. Her mother chaperoned school trips to assist Karen with her diabetes.

During her sophomore year of high school, Karen started wearing her first pump. She says this pump was noticeable and one teacher "grabbed it" thinking she had her cell phone in class. Karen wears her pump underneath her clothing now, choosing to "hide" her pump due to the experiences she had in high school.

When Karen started wearing her first pump, she gained responsibility for her blood sugar, but did not always make good choices. About her teen years Karen says "I was more worried about what I was doing than taking care of myself." Yet she says diabetes was always in the back of her mind. "It's a constant every day thing, you never get a break from it. She says even now she gets "down and out" about it and "kind of slips off the wagon a little bit." Diabetes led her down the career path she is currently following. She says, "It has definitely shaped me a lot."

Here we have five individuals with five different experiences in regards to growing up with type 1 diabetes, yet similarities exist to their stories. Upon diagnosis their lives changed; they were no longer carefree children. Growing up became a little more challenging and as children and adolescents they have dealt with a disease that most people know little about and understand even less.

Based upon these identified themes, this researcher concludes that education surrounding type 1 diabetes education needs to be extended beyond the children and their families. Teachers need to be aware of the symptoms of hypoglycemia, so they do not suspect disobedience or deliberate inattention. Coaches need to understand that children with type 1 diabetes can participate in sports, except they may have to check their blood sugar during practice or during the game, and they should always have a treatment for hypoglycemia available.

As the participants in this study reveal, many children with type 1 diabetes feel embarrassed or ashamed and different from their friends.

Their friends may say hurtful things or avoid them, because they do not understand type 1 diabetes. It seems reasonable that education about type 1 diabetes should be extended to children who do not have the disease, possibly through an educational program at school.

Four of the participants in this study reported a difficult time during the teenage years, therefore specific education and support should be available to the children and their parents during this time. Most of the participants, reported that transition, of blood sugar management from their parents to themselves, occurred gradually with no specific structure or guidance, which suggests a need for development of structured guidelines.

The diagnosis of type 1 diabetes is overwhelming. It is impossible to provide the appropriate education in the hospital or with one or two outpatient follow-ups. A structured educational support group would bring children and parents together with those facing similar situations. Support would provide opportunity to focus on the positives while providing continued guidance in living with this disease. Continued education and support should be from diagnosis forward. It may be appropriate to have an adolescent support group and a separate support group for parents.

This study strengthens support for creating innovative approaches to diabetes education that provides support to both children and parents from diagnosis throughout the teenage years. It supports diabetes education should be extended to all individuals involved in the child's life. This study is limited in that it includes 5 participants within a small area. Further studies are needed to further explore the themes identified in this study.

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