ABSTRACT

Objective: Young adults with type 1 diabetes face multiple challenges managing their disease and navigating the life transitions of emerging adulthood. This places them at increased risk for poor health and psychological outcomes. The purpose of the present formative evaluation study was to assess the impact of diabetes on their lives and identify salient messages for health promotion using an online photo-elicitation technique.

Research Design and Method: Thirty young adults participated by submitting photographs and written narratives describing how diabetes has impacted their lives.

Results: Diabetes negatively impacts young adults’ social connections, identity, and self-perceptions; yet, mechanisms for coping and personal growth were identified among participants.

Conclusions: Young adults with diabetes face significant challenges in coping with the disease; however, they are able to reframe their experience in positive ways using effective coping strategies, such as communicating with others who understand what life with diabetes is like and developing social connections.
INTRODUCTION

For young adults living with type 1 diabetes (T1D), life is wrought with daily challenges. Managing T1D involves a host of personal behaviors like daily insulin injections, blood glucose monitoring, and dietary and physical activity regulation [1]. The goal of self-management is to maintain normalized blood glucose levels and avoid complications. Advances in technology and treatment options have significantly improved the longevity and health outcomes for people with T1D, yet despite advances in treatment and technology, young adults with diabetes are at risk for serious health threats such as microvascular complications, anxiety, depression, and gaps in clinical care [2, 3]. The psychological impacts of diabetes resulting in depression, anxiety, and distress can negatively affect self-management and quality of life, especially for young people [4]. Balfe and colleagues found that young adults with type 1 diabetes experienced distress regarding their daily management needs, stigma, and worry about their future [5]. In a study by Palladino et al. [6], emerging adults with diabetes report lower level of life satisfaction and life purpose than peers living without type 1 diabetes. Management challenges are often complicated by developmental transitions of emerging adulthood such as attending college, obtaining employment, or living independently [7].

Given the additional strain diabetes can pose in the lives of young adults, understanding the factors that impact self-perception and coping are crucial for addressing and discussing their needs [8]. The goal of our study was to assess the intrinsic beliefs and experiences of young adults using their own voices. The use of photography and narrative allowed young adults’ voices to be communicated in an engaging and empowering way. This qualitative study was conducted as a component of a formative evaluation of the experiences and perceptions of young adults living with type 1 diabetes.

METHODS

This project follows the tradition of participatory visual methodologies in health and community research. In particular, it borrows aspects of photo-elicitation [9], a technique in which images are provided by the researcher, or created by participants, to guide and enhance the depth of interviews with individuals [10]. The images serve as a conduit for communicating tactic information that participants may take for granted in a traditional interview or focus group setting.

Image-based research methods have gained popularity in social science and health research because the use of images helps elicit and communicate personal and tactic perceptions [11, 12]. Photography-based techniques offer strengths for qualitative inquiry, and the use of images allows for an alternate means of reflective communication [13]. Participants take on an active role in research by determining what is photographed and hence guide the data collection [14-16]. Furthermore, the depth of response is enhanced because the reflection process begins with the action of taking the photograph and thinking through its composition and meaning, and then the explanation of the image becomes the key focus in analysis. The combination of the image and the context in which it was created reflects the individual’s environment and perceptions [17]. This technique provides a flexible format for a range of research designs, and it elicits information about cultural domains, physical artifacts, experiences, and environments. This methodology has also been effective in researching patient health experiences. Specifically, photos have been used as integral components in studies of the experiences of adolescents with established renal failure [18], women’s experiences of chemotherapy [19], and employees’ perceptions and barriers to healthier dietary and physical activity choices [20]. Furthermore, visual methods have been shown to be useful in developing health promotion messages to encourage physical activity with older Hispanic women [21]. The qualities of photo-elicitation make this a useful technique for exploring a chronic disease experience like diabetes that impacts all facets of one’s life.

In our study, photo-elicitation was used to assess how diabetes impacts young adults’ experiences and self-perception. This project was a component of a formative evaluation of the efficacy of the Students With Diabetes model. Students With Diabetes (SWD) is a national organization for young adults ages 18-30 living with diabetes. The goal of the organization is to promote healthier living with diabetes by providing social support and diabetes education. SWD facilitates the creation of local chapters, provides diabetes education programs and resources, and hosts conferences. These programs are offered in-person and virtually.

The SWD evaluation included a survey component and a qualitative component. In the larger evaluation study, a
sample of SWD members (n=76) completed a survey and HbA1c blood glucose measure while attending the 2013 SWD National Conference. The survey included quality of life measures and customized questions about participants’ experiences with the SWD program and its effects on their diabetes self-management and coping. The purpose of the evaluation was to assess the challenges young adults in this population face in managing diabetes, identify benefits of SWD participation, and identify ways to address young adults’ challenges through SWD program development. This photo-elicitation project was designed as a complementary project to the survey study to specifically inform program planning and the development of a national social marketing campaign among SWD members.

PARTICIPANTS

Participants were recruited for the study through the Students With Diabetes membership base. The eligibility criteria included having type 1 diabetes and being 18-30 years old. Thirty young adults participated. All but two participants were female. The mean age was 22.2 (range 18-30 years). The average years of disease duration was 10.5 years (range 6 months-21 years). The participants resided across the United States, and all participants had access to computers, digital cameras or smart phones, and internet connections.

Due to the geographic dispersal of SWD participants across the United States, the study was designed to be completed electronically through online recruitment, email communication, and a website for submissions. SWD members were targeted in recruitment efforts. Study flyers and advertisements were disseminated by email to the SWD membership database and posted on social media sites such as the SWD Facebook page and SWD Twitter page. Participants were given three months to respond to study advertisements. Willing participants self-selected and responded to study advertisements. Participants were provided with information on the study, along with instructions for creating and submitting both an image and a written narrative that responded to the research question. The study used an open-ended research prompt, “What does diabetes mean to you?” Additional cueing questions were provided to assist in writing the narratives. The additional questions were: “Who or what is in the photo?”, “What is happening in the photo?”, and “How does this photo capture what diabetes means to you?”

Through email, participants were given submission instructions and directed to a submission site where consent was obtained, image and written narrative submissions were uploaded, and a brief questionnaire was completed with basic demographic questions. Each participant used their own digital camera or smart phone to create either one photograph or a collage of photos constituting one master image, along with an accompanying narrative. If necessary, a camera would have been offered for use in this project; however, this was not necessary. Using their own camera was determined not to be a barrier to participation for this population. Further, we had concern that providing a film-based camera to participants might be considered out-of-date technology [22] and would have decreased participation.

Research procedures were approved by the University of South Florida Institutional Review Board. Informed consent was obtained from participants through an online form. Contact information was provided to participants so that questions about the consent process could be addressed by the researchers. To further address ethical considerations, participants were informed that their images may be used for publication purposes, and that submissions could be displayed at an exhibit during the 2013 SWD National Conference, which coincided with the end of the data collection phase. At the conference, thirteen participants provided permission for images and narratives to be displayed in the form of an art exhibit. Participants were also informed that including likenesses of themselves or other people in the photos was at their discretion, and that permission should be obtained before photographing other people. These steps were deemed important for protecting the privacy of the participants. Participants were offered a $20 e-gift card for participation.

ANALYSIS

Photos were analyzed for content, and narratives were thematically analyzed using Atlas.ti v.7 qualitative data analysis software (GmbH, Germany). A grounded theory approach was taken in that a priori codes were not established; rather, the codes inductively emerged from the data. The analysis began with multiple readings of the nar-
ratives and reviews of the photographs. Following the initial reading of the narratives, open codes were applied to text line by line [23]. Repeated readings resulted in the refinement of codes and the creation of groups of codes into themes. The same process was followed to categorize the content and composition of the photographs. The codes were reviewed by the second author, and the coding was refined until full inter-coder agreement was reached for all data [24].

RESULTS

The composition of the photos provided a look at the daily lives of the participants. The photographs were comprised of a variety of images and reflected the themes expounded upon in the narratives. The participant was included as a subject in 16 of the photo submissions, 7 submissions included peers, and 4 submissions included family members. Images of diabetes supplies and equipment were captured in 11 submissions. A total of 8 images were creatively constructed to portray an abstract concept or to be artistic. These images included carefully constructed scenes of diabetes supplies, or people positioned in formation for visual effect. In one photo provided by a 20 year-old female, a circle of clasped hands is captured in sepia tones symbolizing the strength gained from social connections (Figure 1). In another image, a blue bull’s eye target is shot with insulin syringes around the perimeter, indicating how challenging it is to reach the center goal of consistently maintaining in-range blood glucose measures (Figure 2). Another submission was a scene of a country road that symbolized the diabetes journey experienced by a 26 year-old female (Figure 3).

Diabetes supplies played a prominent place in many photographs. In one photograph, a 20 year-old woman arranged glucose meter test strips and insulin pump insertion sites in a heart shape at her feet while displaying her insulin pump (Figure 4). The remaining images were straightforward in their composition and typically included photos of family members or friends with smiling faces.

The desired outcome of the study was to gather a breadth of perspectives about diabetes. This was accomplished through an open-ended research question that resulted in four overarching themes. The themes described the challenges diabetes poses in lives, ways to cope with type 1 diabetes, how diabetes has affected identities and self-perception, and how diabetes encourages young adults with diabetes to give back.

CHALLENGES

Diabetes presents struggles that impact all aspects of daily life. The challenges presented in the submissions were
categorized as physical, emotional, and social. The physical pain and difficulty controlling diabetes was described repeatedly. In order to maintain diabetes control, participants explained they must engage in physical tasks such as checking blood glucose, monitoring diet, exercising, and administering insulin and other medications. These daily tasks can be burdensome and painful. Furthermore, the tasks of diabetes “don’t stop.” Diabetes self-care is unrelenting. One 19 year-old male participant likened the monotony of diabetes management to a football stadium in his photo and narrative. He explained, “The repetitive and parallel arrangement of seats and stairs reminds me of my daily routine. Although checking blood sugar, correcting insulin dosage and bolusing [with insulin] can become monotonous, their significance should not be undermined...every finger prick, injection, and [insulin pump] site change contributes to the overall goal of effective diabetes management.”

Furthermore, diabetes was often described as “uncontrollable.” The participants have diabetes tools and technology such as insulin, blood glucose meters, insulin pumps, and continuous glucose meters at their disposal, yet it is still challenging to maintain blood glucose values within a desired range. Despite the significance of the physical discomfort and pain of diabetes, the emotional pain of the disease was described as more onerous. The emotional challenges were described as more difficult to handle and mentioned more frequently across participants. Fear of complications from diabetes, feeling different from peers, and frustrations with management obstacles resulted in feelings of isolation, worry, and hopelessness. The emotional toll of diabetes was described as profound and something participants often cannot fully handle. This can leave young adults vulnerable to diabetes distress.

For some participants, the emotional toll became a personal trial. As a 21 year-old woman stated, “We bleed internally, silently, invisibly...No one sees our pain, nor our joy—which they likely would understand even less...Why must I bear all to see, just to prove that I struggle constantly?” Feeling isolated in their emotions is a common theme.

The narratives also indicated how diabetes can impact social relationships. Diabetes affects relationships with family, peers, and friends. An emotional toll is also carried by parents, as well as other family members and friends who worry about the health and well-being of the young adult with T1D. This was explained by a 29 year-old woman as, “It [Diabetes] involves everyone I love and everyone who cares about me.” Management of diabetes can be a source of conflict, especially with family members or significant others. Furthermore, they described experiencing rejection from peers due to their diabetes. This further led to feelings of isolation for several participants.

**COPING STRATEGIES**

Finding ways to cope with the demands of diabetes took on multiple forms. These coping strategies included sharing with others who have diabetes, deepening of spiritual faith, taking advantage of diabetes technology and tools, and maintaining a sense of humor about “uncontrollable” frustration in life with diabetes. These young adult participants recognized social connections as powerful coping mechanisms. Seeking out social support, and giving back to others helps them take personal responsibility for their lives and disease.

Several young adults in this study indicated that they use technology to cope. This was reflected in the narratives and in the content of the photographs. Items like insulin pumps are symbols of their experience worn on their bodies and often visible to
others. Family and friends provide instrumental assistance in diabetes care, and are therefore seen as coping tools. Spiritual faith was mentioned by several participants as a way of gaining personal strength. This notion was explained by a 19 year-old woman who attributes her faith to helping her handle her diabetes diagnosis a year ago. She stated that, “what gets me through every single day is the faith I have in God, knowing that His love for me is unconditional and that He has great plans for my life.” Finding strength through personal beliefs helped participants aspire to better management, and humor helps when things do not go well. Humor about diabetes allowed these young adults to cope with the negative emotions, and as one female participant wrote, “laugh through the tears.”

Finding other people who understand what life with diabetes is like was a fundamental coping mechanism for many participants in this study. As one young woman stated, “Diabetes is a very lonely disease, and although insulin is the best physical medicine, a community of friendship and understanding can have such a powerful impact and save lives as well.” The idea of connecting with others who can relate is reported as extremely powerful in combating the loneliness from feeling different due to diabetes. Connecting with the type 1 diabetes community allowed young adults in the study to feel normal and “more than the girl with the disease.” One 29 year-old female participant explained that, “Everything I do will always be different than what others do. Sure I can do the same things as others but whatever I do diabetes is always there, a part of the experience, a part of the equation.” Their experiences with the struggles of diabetes also lead many of them to want to give back to the diabetes community. Volunteering, advocating, and pursuing careers in diabetes-related fields are mechanisms to turn their struggles into positive action. A young woman who has had diabetes for seven years stated that diabetes “is a continuous race where the only winners are those that keep running, despite any obstacle put in their way. It is using your own discord to help someone else going through the same thing.” Giving back helped many young adults in this study feel their struggle is worthwhile, and several participants reported finding personal strength by witnessing the accomplishments of others who are like them.

**TRANSFORMATION**

A dominant theme among respondents concerned the transformative experience of diabetes, which often resulted in increased personal responsibility and renewed outlooks on life. Taking control of diabetes and their own lives was a salient theme among the sample. Many described the self-efficacy they gained by coming through past challenges and recognizing the positive effects of diabetes. As a 21 year-old young woman stated,

“I am grateful for my diabetes because….It motivates me to be healthy. It has taught me that balance of all things in life is crucial. It has made me organized. It has taught me to stand up for myself. It has taught me to believe in mind over matter. It has challenged me to break out of my comfort zone. It always keeps life interesting.”
Through these personal reflections, several participants acknowledged the negative effects of diabetes, but most highlighted the lessons gained from life with diabetes and how diabetes has uniquely shaped who they are. This acknowledgement of how diabetes has changed them was described by a 19 year-old woman as, “I’m not saying diabetes is a great gift. It sucks! But I know I wouldn’t be this successful in life without it. I’m able to value life and follow my dreams to its fullest. It has taught me independence, gratitude and most importantly adversity.”

**DISCUSSION**

Photo-elicitation was useful for identifying internalized coping strategies and understanding personal experiences. Through this approach we were able to identify key issues that affect young adults in this population, and determine next steps in the development of the SWD program. The open-ended approach was useful in capturing a variety of perspectives of how diabetes affects young adults. The photo-elicitation method allowed participants to control their self-representation and resulted in rich descriptions of personal life with diabetes. The challenges young adults face are significant. The emotional strain and distress described among this sample resonate with previous research identifying psychological issues among people with diabetes [4]. Diabetes distress was expressed by participants in descriptions of the pain, frustrations, and unrelenting nature of caring for diabetes. As previous studies have reported, young adults in the study struggle to cope with diabetes [8], yet participants identified tools that help them function and thrive. Coping strategies included using available diabetes technology and tools, using humor to diffuse stress, relying on spiritual faith, connecting with others and giving back. Sharing their experiences and seeing the accomplishments of other people with diabetes was uniquely gratifying for these young adults. This was a core theme throughout this study, and it demonstrates the benefits of peer mentoring and support highlighted in previous research on young adults with diabetes [25]. Social connections allow for these young adults living with a chronic condition to feel normal with others like themselves. Participants described how connecting with the diabetes community socially and giving back to others helps to alleviate the isolation they feel from being different than their peers. It also allowed for expressing gratitude and a means to reframe their personal struggles into a larger meaning. Reframing the negative aspects of diabetes into positive, self-affirming thoughts has been found to be a useful mechanism for coping, especially during the young adult transition period [26]. Through overcoming personal obstacles and illness, many of these young adults reported finding meaning and motivation to live healthier lives and help others live better as well. Future research could further explore the role of reframing chronic disease experiences for positive coping and personal growth [27].

Key themes from this assessment were used for program development including the need to address psychosocial issues in relationships, the need for up to date informa-

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**Figure 4**
tion on diabetes technology, and the importance of social support. This insight served as kindle for a social marketing campaign to engage young adults in the diabetes community by serving others and advocating for diabetes. One outcome is the #SWDServes campaign, which is a way for SWD members to share their diabetes community service endeavors through social media. It highlights the positive contributions young adults with diabetes are making in their communities by sharing stories of service. This campaign is supplemented by educational programs on advocacy and service projects such as a mentor pilot project that links young adults newly diagnosed with type 1 diabetes with volunteer peer mentors.

In this study, photo-elicitation methods were useful in the process of revealing the perceptions of this well-defined group. The potential weaknesses of the study are the small convenience sampling, which limits generalizability. The study is a component of a larger evaluation, and therefore, the present photo-elicitation method cannot be judged as a standalone method. However, the visual images proved to be a powerful form of self-expression for participants. The study also benefited from the reach and scope of recruiting made possible with internet-based interactions. Participants had time to consider and design their photo presentations and to compose their narratives of the photo. The creative staging of images and emotional depth of the narratives was made possible due to the extended time frame. The participants in this study were familiar with digital technologies and photography, and had access to a digital camera or cell phone to capture the pictures. This tech-savvy sample may be inherently different from the general population of young adults with diabetes. The participants’ willingness to share their images and stories may reflect other intrinsic differences as well. In this study, the inclusion of images and narratives provided for rich contextual details. The results provide insights into the kinds of messages and images that resonate with this young adult population, and allowed participants to construct their own self-representation and voice.

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REFERENCES


