Published in final edited form as:

Fam Community Health. 2013 ; 36(2): 97–108. doi:10.1097/FCH.0b013e318282b2f2.

Understanding the Experiences of Youth Living with Sickle Cell Disease: A Photovoice Pilot

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Abstract

A Photovoice pilot was conducted with a sample of youth living with sickle cell disease (SCD), in order to further understand their lived experience and examine the acceptability, feasibility, and utility of this method for use in this population. SCD is an inherited genetic condition whose primary symptom is severe pain. Youth were able to reflect on their experiences with SCD using Photovoice and the adapted SHOWeD method. Parents and youth found Photovoice to be valuable for children and adolescents with SCD. Emerging themes included the impact of SCD, coping with the disease, and the importance of family and support.

Keywords

Photovoice; pediatrics; qualitative research; participatory; chronic disease

Sickle Cell Disease (SCD) is one of the most prevalent genetic disorders in the United States with estimates of approximately 100,000 US residents affected by the disease.¹ It occurs in

about 1 in 500 African-American births in the United States (NHLBI, 1996). SCD is a multi-systemic disease that can cause pulmonary and renal complications, stroke, delayed puberty, bone and joint damage, anemia and unpredictable pain.² The pain can be recurrent, chronic or sporadic³ and typically increases in intensity and frequency in adolescence and adulthood.⁴ Youth with SCD often miss days of school/work due to pain episodes resulting in underachievement.⁵ Youth may also miss school due to treatments for SCD (e.g., monthly transfusions), routine screenings (e.g., hearing, vision, dental), and medical procedures (e.g., TCD, MRI). In addition, SCD requires daily disease management activities including taking medications, drinking fluids, avoiding extreme changes in temperature, eating a well-balanced diet, and behaviors that help prevent infections (e.g., hand washing, avoiding children who are sick). As a result, youth with SCD have been reported to experience lower health related quality of life (HRQOL).^{6,7}

The past two decades have resulted in an increase in research studies examining the impact of SCD on youth. However, the majority of these studies have utilized cross-sectional and longitudinal designs together with quantitative measures.^{2,5} Some studies have utilized qualitative research methods to explore these issues^{8–10} but few studies have used participatory methods to better understand the impact of SCD on youth. In addition to managing a chronic illness, youth with SCD are most often from racial/ethnic minority backgrounds. For these youth, feelings of limited power may be common given their status in society, their experiences with a chronic illness, and the many medical interventions and powerful adults important in helping care for their illness (e.g., providers, parents). Therefore, participatory methods may be particularly beneficial for this population, because these methods allow youth to be “experts” about their own experience.

Photovoice is a participatory method that comes out of community-based participatory research (CBPR) and participatory action research (PAR) approaches in which a collaborative partnership is formed between researchers and particular communities. These research approaches are increasingly being utilized in the health care arena especially in areas of health disparity and health outcomes perhaps because of the complexity of such issues and the need to integrate many different factors within particular communities.¹⁷ In these types of research approaches, the community or group is actively engaged with researchers in a partnership in order to advance personal and community change.¹⁸ Photovoice is a method whereby people are given cameras to document their lives. Participants then share and engage in a critical dialogue about the photos in order to capture information about personal and community/group issues. Using photos in this manner can provide a vehicle for the presentation of participants’ lived experiences as self-defined and can be used to foster community growth and change by reaching local institutions and policymakers. Such an approach allows for participants’ voices to truly be heard and for a deeper understanding of how people make meaning in their lives rather than imposing a research objective upon a community often with predetermined assumptions and outcomes. The photos provide a creative and effective way to discuss often difficult and deeply felt issues and mobilize a group to affect change.

Studies suggest that children who participate in Photovoice are engaged, more educated about community health needs and assets, and empowered to act in ways that promote

health.^{14,15} In addition, Photovoice with children has the potential to engage children with other youth in a way that builds capacity for community, and has the potential to benefit youth in terms of critical thinking and leadership skills. Because youth are asked to reflect on their own work without the requirement of a high level of literacy, even younger children can benefit. Finally, a recent study which specifically examined Photovoice as a participatory method in youth with a chronic disease (i.e., asthma, diabetes or cystic fibrosis) found that it promoted reflection and communication about disease management.¹² Hence, Photovoice may be a well-suited and innovative strategy for understanding the impact of a chronic illness on youth from the patient perspective, and engaging youth in reflection about their disease in a meaningful way.

This pilot study aimed to understand how children and adolescents with SCD perceive their lives and disease using Photovoice. This study is significant because it is the first of its kind engaging youth with Sickle Cell Disease in a participatory method to better understand their disease within a community of their peers. In addition to providing information regarding the experience of SCD as self-defined by youth, the pilot will examine the feasibility, acceptability and utility of using Photovoice to promote self-expression, social engagement and empowered activity in a pediatric SCD population.

Methods

Procedure

Participant Recruitment—Children and adolescents with SCD were recruited as part of an annual Sickle Cell Research and Education Day. This community event is held each year and engages a large and representative sample from a Comprehensive Sickle Cell Center (CSCC) in the Midwest to attend, drawing as many as 70 families and patients diverse in age (ages 6–17).¹⁶ Youth who met criteria for study inclusion (sickle cell disease diagnosis, age range within 8–17 years) were identified at the event. The proposed Photovoice study activities were verbally explained to parents and they were given a consent form which outlined the study and the risks and benefits of participating. The parents were asked to sign a consent form giving permission for their child(ren) to participate in the study. Likewise, the project was explained to the children and they were given an assent form which explained the study and were asked to give written assent to participate. As recommended by Strack and colleagues¹⁵ enrolled participants were then grouped by age (one group for children 8–12 years old and another for adolescents between 13–16).

Photographs and Discussion Group—In the present study, all youth received inexpensive digital cameras and training about the research method in an information session. Then, youth determined their first photographic assignment related to SCD and spent a week photographing their lives according to the assignment. They did this for a total of three weekly assignments. Youth were given notebooks where they could take field notes about their photographs, such as why they took them and what they wanted to share with the group about their photo. The notebook included a small reference with questions developed to help youth be thoughtful about taking meaningful pictures. It reminded youth to think about (1) why they took the picture, (2) what others might see in the photo, (3) how they

were feeling when they took the photo, and (4) next steps including what they hope will happen or what might happen next.

At the end of each week's assignment, the youth brought their cameras to the next meeting and were given time to review their photographs in their cameras, choose 1–3 photos, and upload their selected photographs to a computer to share with the group. Each group session included a review of the previous week's themes and then selected photographs from the current week were projected onto a large screen for participants to share and discuss. Children and teens both used an adapted version of the SHOWeD questioning technique^{19,20} to discuss their selected photos, but they were also allowed to deviate from these questions if they could not relate a photo to the question easily or had additional comments that they felt were salient about the photo. The adapted SHOWeD questions included: 1) *What do you SEE in this photograph?*; 2) *What is really HAPPENING in this photograph?*; 3) *How does this relate to OUR lives?*; 4) *WHY does this issue exist?*; 5) *How can we become EMPOWERED by this, and what can we DO about it?*; and 6) *What does this say about your sickle cell disease?* Following each participant's description of their photo, others in their group commented on and discussed the photo. Generally, group discussion centered on what others saw in the photo, what the meaning of the photo was to them, and whether or not they had captured similar images or had similar or different experiences. A member of the research team facilitated group discussions. Finally, youth were asked to spend the last part of each group discussing the theme for the next week's photos and planning for presenting their photos in a final exhibit.

In addition to the three discussion groups, youth met for one additional session. In this session both parents and youth completed satisfaction surveys to measure the acceptability of this method. They also responded to brief open-ended questions about their experiences in the group (e.g., What was the hardest part of this project?; What did you enjoy the most?; How could you use this experience to make a difference?; etc.).

Youth were given a small item at each of the four sessions after the initial meeting on Research and Education Day (e.g., a photo frame, digital photo keychain, and a small movie gift card). Parents were given a \$10 gift card at each of the four meetings, as well as any help needed with transportation (e.g., taxi voucher to the group meeting site) and/or child care (provided on site). Approval was received from the Institutional Review Board before any study procedures were initiated.

Community Exhibition—Following the photo group sessions, participants planned an exhibition to display and describe their photographs to family members, community leaders and health care providers across the community. At each weekly Photovoice session, youth contributed ideas about how they would like to exhibit their photos, who they would like to invite to an exhibit, and what other elements should be part of the event. With the assistance of the research team, participants chose to prepare several mediums for presenting their work including a presentation which included their own voices playing in sync with select photo images, “photo-boards” that they created and stood next to in order to answer questions during the exhibit, and streaming slideshows on laptops that allowed them to include many more of their photographs for community members to view. In addition, a few

youth volunteered to briefly describe the Photovoice sessions and their experience, and all youth participated in a Question and Answer panel where they answered questions that guests asked about the project and about their experience with SCD. Youth participants and attendees completed a brief program evaluation survey at the event. Participant surveys measured to what extent they felt involved in planning the event, how well the event represented their experiences, and how satisfied they were with the event. Attendee surveys measured what attendees learned about and found most valuable about the event, as well as how much they enjoyed it.

Data Analysis

After each photo discussion session, the transcripts, facilitator notes, and corresponding photographs were reviewed by research team members. According to standard qualitative research procedure, all the data were organized into broad conceptual categories and verified among participants for clarification, consensus and validation (Glaser & Strauss, 1967). Descriptive statistics were used to summarize attendance, as well as feasibility and acceptability data from youth, parents, and exhibit guests. Qualitative data from parent, youth, and exhibit guest surveys are summarized. All evaluation data was entered into IBM SPSS Statistics 19 (SPSS: An IBM Company) and analyzed descriptively.

Results

Youth Participants

A total of 16 youth participated as photographers; the younger group (ages 8–12; $M = 11.2$, $SD = 1.25$) was composed of eleven youth and the older teen group (ages 13–17; $M = 15.2$, $SD = 1.08$) consisted of five youth who participated in all of the sessions. All youth participating in the study were African-American, which is typical of patients seen at the CSCC (SCD patient population is 96.6% African-American). Almost half of the participants were male ($N = 7$, 43.8%), and over half (56.3%) reported an annual household income of \$30,000 or less. Half of the youth in the sample were diagnosed with SS disease ($N = 8$, 50.0%), and over 30% were diagnosed with SC disease ($N = 6$, 37.5%). These two disease genotypes represent the most common genotypes in the United States as well as the CSCC. Parent-report indicated diversity in the impact of SCD on the child's daily functioning, reporting 0 to 60 days absent from school due to pain episodes ($M = 13.4$ days, $SD = 17.0$).

Photographs and Discussion Group

Youth Themes—The following themes emerged from the photographs, group discussions, facilitator field notes, and participant freewrites: 1) the impact of SCD and its management, 2) coping with SCD, 3) family relationships and support, and 4) friends and peer relationships.

Theme 1: The Impact of SCD and Its Management: While a small minority of the selected photos discussed by youth in group were visibly related to SCD (0% of photos in the child group; 24% in adolescent group), group discussion using the SHOWeD technique often resulted in reflection on how SCD impacted youth and a jumping off point for other youth to discuss their experiences and feelings about the disease (Figure 1).

Participants in the adolescent group were more likely to take photos that related very directly to their disease and its management. They were also more likely to be able to describe their disease care in nuanced terms, such as the costs and benefits of blood transfusion (Figure 2).

In addition to medical procedures such as transfusion, adolescents discussed the benefits and challenges of taking medication at home (including Hydroxyurea and pain medications) and their experiences staying at the hospital due to pain crises (Figure 3).

Of note, adolescents also described widely variable feelings about their care providers, particularly school nurses, ranging from “my school nurse is like my best friend (16-year-old girl)” to “my school nurse is mean and I try not to go there (14-year-old boy).”

Theme 2: Coping with SCD: Overall, both child and adolescent group themes included the importance of “normal” everyday activities and interests. Both groups were likely to take pictures of things they liked to do (e.g., go to hair salon, visit an amusement park, etc.). Boys in both age groups took a number of photos of cars. One youth took a picture of his neighborhood library. He felt that it was an important picture to him now because he likes to read, but it would also be an important part of getting an education in the future. He was also able to tie the photograph into his illness, indicating that reading was something he liked to do when he was in the hospital in order to pass the time. During the photo discussions, several children and adolescents indicated that doing things they liked made them feel more “normal” and helped them take their mind off of the illness. For example, one photographer shared a photo of a rollercoaster and commented that “when you are on a rollercoaster you don’t really think about your SCD, just the ride (12-year-old boy).”

Theme 3: Family Relationships and Support: Both children and adolescents emphasized the importance of support from family, as well as friends and pets, in their photos. In fact, photos of “supportive others” comprised 18 out of 80 total photographs. One youth said, “I took this picture of my mom ‘cause she helps me with my sickle cell. When I have pain, she takes me to the doctor and she gets my medicine (11-year-old girl).” Another mentioned the importance of her grandparents understanding the disease (10-year-old girl):

My grandparents help me out a lot. They also know what I go through when I have a sickle cell crisis because my dad has it too and that is their son.

Pets were identified as both a source of support and something for the youth to care for. Youth mentioned that knowing their pet was waiting for them when they got home from the hospital made them happy. When sharing a photo of her dog, one adolescent girl (16 years old) said, “...dogs know when there is something wrong with you and stay beside you. When I’m sick, everywhere I go (my dog) goes with me.” Another youth said, “Just because I have sickle cell doesn’t mean I can’t help others (16-year-old girl).” Because they have to depend on others so much, some youth felt that it was important that their relationships be reciprocal.

Theme 4: Friends and Peer Relationships: Participating youth identified the importance of friends who provided support for their SCD. While most youth in the child group focused

on how doing things with friends makes them feel better, many more of the teens described both the ups and downs of peer relationships. For example, a few teens described being teased because of their disease (e.g., “they sometimes call me yellow eyes,” “they think I am weak and they are bigger or badder than me because I have sickle cell,” etc.) or having difficulty disclosing their diagnosis to peers. One adolescent girl (16 years old) said the following about a photo she shared in group:

(These are) my two best friends, the ones that I told about my sickle cell. The one on my right [in the photo] has been my friend for 9 years. The one on my left has been my friend for 5 and they are not like any other friends. Other friends- if I tell them I have sickle cell, they stop being my friends. These friends have been there since day one, since I told them. They come visit me in the hospital and they spend the night with me.

Evaluation of Photovoice Process—Youth attended on average 4.6 (SD=.89) of 5 Photovoice sessions, with all but one participant completing all five Photovoice sessions. Fourteen (87.5%) youth completed the brief Photovoice evaluation survey and all youth participated in the final session discussion about their experience with Photovoice. When asked about multiple aspects of Photovoice, youth most frequently gave the highest possible satisfaction rating for receiving photo supplies (76.9% of youth gave highest rating), taking pictures (69.2%), and talking with youth in the photo discussion group (53.8%). All youth (100%) reported that other children and teens with SCD “should get the opportunity to participate in Photovoice.” The most often provided reasons for including other youth in activities like these were to spend time with other youths with SCD, to learn about their disease, and to discuss their experiences/feelings about their disease.

Parent-report on a brief Photovoice evaluation survey indicated that most caregivers found the Saturday discussion group meetings “convenient” (71.4%) or “neutral” (21.4%), and that all caregivers found it valuable for their child(ren). Parents indicated that compared to other studies and programs they had been involved in within the CSCC, this program was more “fun,” “exciting,” and “hands on.” They felt that Photovoice kept their children engaged and “got them to think.” When caregivers were asked what they felt was the most beneficial aspect of the program, the most common responses were that they valued their child’s interaction with peers who had SCD and their ability to learn from one another and express themselves.

Of note, the field notes that the group facilitators kept indicated that youth at first had difficulty selecting photography themes of relevance and sufficiently specific to help guide their photo activity throughout the week. However, by the end of the groups all youth reported that they understood what it meant to take photos as of ideas as part of the process. Another early problem with photo taking that was reported in facilitator field notes was that two adolescent group members complained of parents who were trying to direct their photo activity during the week between group sessions (e.g., parents suggesting photos to them or telling them that they did not feel they were doing the photo assignments correctly). Facilitators spoke to parents early on to help them understand the photo activity and the importance of youth choice in selecting photos.

Community Exhibit

Eleven (62.5%) of the youth were able to participate in a community exhibit of their photos (due to medical concerns and another SCD event at the time of the exhibit, some youth were unable to attend). Those participating completed a brief survey about their experience with the exhibit. Overall, youth felt “some” (54.5%) or “a lot” (45.5%) of the important things discussed in group were represented in the exhibit, and that the exhibit represented their life “very well” (72.7%) or “somewhat” (27.3%). Youth indicated the following as the most valuable aspects of planning for the community exhibit: showing their pictures to others (81.8% gave the highest possible satisfaction rating), preparing the photos for the exhibit (e.g., creating photoboards, slideshows, etc.; 72.7%), inviting people to come to the event (63.6%), and helping other people learn about SCD (63.6%; Figure 4).

Approximately fifty-eight people attended the exhibit; forty-eight of these (83.0%) completed a brief survey. Based on the survey, most of those in attendance were related in some way to one of the youths exhibiting their work (83.3%); this includes parents (25.0%), grandparents (16.7%), aunts/uncles (20.8%), and brothers/sisters (8.3%). In addition, 14.6% of attendees identified themselves as friends of the youth exhibitors, and another 14.3% had diverse relationships with the participant and were part of the larger community (e.g., case worker, teacher, etc.).

Ninety-one percent of attendees reported that they enjoyed the exhibit “a lot.” Most felt that that the exhibit was valuable (97.9%). When asked about the most beneficial aspects of the exhibit, attendees indicated that a variety of aspects of the exhibit were valuable including viewing youths’ photos, getting to know children with SCD, learning about SCD and about youths’ experiences, and the program providing youth with an opportunity to express themselves (e.g., the photos, the youth Q&A panel).

Discussion

The present study is the first to pilot Photovoice methodology with children and adolescents diagnosed with SCD. Study results indicate that a Photovoice program is feasible with high acceptability among youth and caregivers. Through photos, youth were able to represent important aspects of their lives, including the impact of SCD, coping strategies and family and social support. The majority of the photos that youth took were not about SCD, but rather about their everyday lives, highlighting the importance of normal activities such as going to school, being with friends, and the importance of staying “healthy” or being a “normal kid.” These findings remind us of the importance of ensuring a developmental framework in chronic illness management.

While the photos themselves revealed common themes (e.g., the importance of family and peer support, important aspects of SCD care, etc.), the process (even more than the photos themselves) seemed to be highly valued among youth and caregivers. The opportunity and ability to work together with peers, both in weekly photo discussion groups and in developing a community exhibit, were major strengths of the program. Because children with SCD often miss a lot of school⁵, participating in social interaction elsewhere is important. The fact that these groups were comprised of youth with SCD is highly unique

and allows for a shared understanding. Being able to meet and share experiences is part of the positive impact of social capital.^{21,22} For example, others have noted that youth involved in Photovoice programs often take many pictures of their friends and family, sometimes more so than photos of “community assets and deficits”¹⁵. In the present study, a progression in youths’ ability to focus on disease-related assets and deficits (e.g., how SCD affects their lives and what they could do to improve their situation) happened over time, and may be due in part to building rapport and a sense of community with their peers in the Photovoice discussion groups. Limited research exists and further research is needed in order to examine the process of “creating community and social capital” through Photovoice in children.

Parents’ feedback about the program indicated that it was very different from other research or programs available to their youth, because it emphasized connecting their child to other children with SCD and because their child was engaged and active throughout the process. Youth highlighted the importance of peers in the Photovoice discussion groups, as well as the potential for youth with SCD to learn something about themselves and SCD in the process. They enjoyed being active in taking pictures and sharing them with their peers and their community. As opposed to other qualitative methodologies that include photo elicitation where the point is to use photos to learn something “about” the participants²³, Photovoice has the goal of helping participants learn something “about themselves” and share it with others. Additional research should examine the role of Photovoice groups in building a sense of “self-efficacy” and “self-awareness” in racial/ethnic minority youth with a chronic condition, like those in this study.

Some youth in the present study, especially in the younger group, had difficulty using the SHOWeD technique. They had particular difficulty thinking about how issues could be different or what could be done to change a situation. For example, one youth described relative to her photo, “(transfusion) takes all day. I have to get one every three weeks otherwise my sickle cell acts up and I get sick/have crisis. A crisis is when you have pain... I don’t know what I could do to make the situation any better.” Future programs should consider a model like that used by Wilson and colleagues (2007), whereby Photovoice is used in order to evaluate what social action issues to tackle. This model could be particularly helpful to SCD youth because it would provide them with a space to work together with other kids who have SCD (social support), but it would also give them the chance to improve critical thinking and leadership skills. In addition, the mentorship and leadership of older youth in a Photovoice program may be beneficial and allow for peer modeling and identification. The teen group in the present study expressed an interest in becoming involved as mentors in a future Photovoice project, where they could help younger youth with SCD take photos and discuss their lived experience with the illness.

Overall, Photovoice holds promise as an innovative and effective way for youth to express their feelings about SCD, share their work, and develop a sense of accomplishment and community. In addition, it seems that it could be adapted to provide opportunities for youth to develop important leadership and critical thinking skills. Youth and their families were very engaged in this project with nearly all youth completing every session and attending the community photo exhibit. Through Photovoice, participants in this project offer valuable

insights on their life as a youth living with sickle cell disease, and invaluable perspectives on how they balance managing their disease with “just being a normal kid.”

Acknowledgments

The authors would like to acknowledge Alexandra Bruck, Demaree Bruck, and Venita Robinson for their assistance with data collection and data entry.

The present study was funded by Grant#: U54HL070871, Comprehensive Sickle Cell Center, Project 3: Improving Hydroxyurea Therapy in Sickle Cell Disease (PI: Mitchell), funded by the National Institutes of Health (NIH), National Heart, Lung, and Blood Institute (NHLBI)

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Figure 1.

I took this picture because the clouds look like they are about to form a tornado and I hate tornados and it looks like it's gloomy outside... (Facilitator asks "What does this say about your SCD?") Well, my life is kind of gloomy sometimes. It is kind of gloomy like when I go to the hospital and get shots and stuff. (10-year-old girl)

Figure 2.

I don't know the name of this machine. It is both a positive and a negative. The positive is that it keeps you well, but the negative is that you get too much iron... it is mostly a good thing. (16-year-old girl)

Figure 3.

This is my Hydroxyurea. I take it every day of my life. I need to take it to stay healthy (14-year-old boy).

Figure 4. Adolescent group participant at the Photovoice community exhibit displaying her photoboard and a slideshow of her work.