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Using Photovoice to Explore the Unique Life Perspectives of Youth With Sickle Cell Disease: A Pilot Study

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Abstract

Objectives: Sickle cell disease (SCD) has been associated with multiple physical and psychosocial challenges but less is known about the experience of living with the disease, particularly from the perspective of children/adolescents. Photovoice uses photography to access the experiences of individuals living with a disease and provides them with a voice for expression. It provides a unique approach to exploring the perspective of children/adolescents with SCD. This pilot study examines the perspective of children/adolescents with SCD using photovoice, both to gain understanding of the perspective of these patients and the utility of the research method with this population. **Method:** Twelve participants with SCD between the ages of 6 and 14 years participated in this study. Participants took photographs during camp and completed qualitative interviews afterward to explore their perspective on life with SCD and experience with the photovoice method. **Results:** Main themes derived from content analysis of the qualitative interviews included the following: (*a*) importance of friends, (*b*) controlling symptoms, and (*c*) importance of camp. **Conclusion:** This study demonstrated that (*a*) a camp can provide a beneficial social outlet with peers with SCD, (*b*) children/adolescents with SCD are able to manage their complex symptoms at a young age, and (*c*) photovoice is a useful methodology for children/adolescents with SCD and potentially other chronic illnesses.

Keywords

sickle cell disease, photovoice, qualitative research

Introduction

Research indicates 133 million Americans (Wu & Green, 2000), including approximately 44% of children/adolescents (van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007), are currently living with at least 1 chronic health condition. Among these pediatric chronic health conditions, one of the most complex is sickle cell disease (SCD). SCD is a genetic disorder most common in persons of African or Mediterranean descent (Platt et al., 1994). The disease has an autosomal recessive inheritance pattern. Within the United States, approximately 1 in 12 African Americans are carriers of the sickle cell gene, and 1 in 600 African Americans have SCD (Steinburg & Embury, 1994). Complications from SCD occur due to a percentage of normal hemoglobin A being replaced by hemoglobin S, a form of hemoglobin that is highly sensitive to environmental stressors, both within the body and in the surrounding environment. In the presence of stress, hemoglobin S changes to a rigid shape, which blocks blood flow (Ashley-Koch, Yang, & Olney, 2000). Physical manifestations include pain, the most common symptom, and also chronic anemia and increased risk for infection. This disease and its complications have negative effects on the affected children/adolescents' overall well-being and health-related quality of life (Brandow, Brousseau, Pajewski, & Panepinto, 2010). For example, these complex disease complications can lead to frequent hospitalization, absenteeism from school, and other activities (Gustafson, Bonner, Hardy, & Thompson, 2006). Research has demonstrated that children/adolescents with SCD are at risk for poor social functioning and peer relationships. Additionally, children and adolescents with SCD often experience inadequate social competence, which can lead to psychological and academic problems that carry negative implications into adulthood (Barakat, Lash, Lutz, & Nicolaou, 2006). Children/adolescents with SCD can experience social and externalizing difficulties, have

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reported spending less time with peers and often are less accepted in peer groups compared with healthy individuals their age (Barakat et al., 2006; Rodrigue, Streisand, Banko, Kedar, & Pitel, 1996). Furthermore, a large body of literature has found psychological symptoms such as anxiety and depression to be prevalent among children and adolescents with SCD (Barbarin, Whitten, & Bonds, 1994; Belgrave & Molock, 1991; Benton, Ifeagwu, & Smith-Whitley, 2007; Yang, Cepeda, Price, Shah, & Mankad, 1994).

Given these complex negative outcomes, further understanding of perspectives and experiences among children/adolescents with SCD would be a beneficial contribution to patients and families with SCD, the health care system, and guidance for future research with this population. However, limited research to date has used qualitative design to give voice to the perspectives and experiences of young people with SCD.

Photovoice is a form of participatory action research, particularly valued in health care research, that gives voice to personal and community strengths and concerns through images (Wang, Kun Yi, Wen Tao, & Corovano, 1998). This approach is grounded in feminist inquiry giving the participant control to express their everyday reality (Wang et al., 1998). By using individually selected visual images and accompanying dialogue, participants act as recorders of their reality in a particular situation or condition. Both the strengths and problems of these situations/conditions are documented, which promotes dialogue about the condition (Wang & Burris, 1994). The method seeks to improve the life and health of the target population through the expression and analysis of personal experiences (Wang, 1999). Three main goals are included in photovoice: (*a*) to enable individuals to record and reflect their community's strengths and concerns, (*b*) to promote critical dialogue and knowledge about important community issues through discussion of photographs, and (*c*) to reach policy makers (Wang & Burris, 1997). This methodology has been useful in various populations, including students from rural high schools (Davison, Ghali, & Hawe, 2011), children in physical activity programs (Fitzgerald, Bunde-Birouste, & Webster, 2009), recently immigrated Latino/Latina adolescents (Streng et al., 2004), older adults with chronic pain (Baker & Wang, 2006), and adolescent mothers (Stevens, 2006). These studies have demonstrated photovoice to be a useful tool to examine psychosocial aspects of life that surveys may not be able to capture. By allowing the participant to express their perspective through a tool they are able to control, researchers can gain more specific information tailored to the individual without the limitations of structured psychometric measures. Furthermore, no research to date has used the photovoice method within the pediatric SCD population. Given the complex physical complications and psychosocial difficulties associated in children/adolescents with SCD, an exploratory examination is warranted.

This pilot study examines the perspective of children/adolescents with SCD using photovoice, both to gain understanding of their perspective and the utility of the research method with this population of children/adolescents. Given the previous success using photovoice among other adolescent populations, the lack of research from the perspective of SCD-affected children/adolescents, and the accessibility of the method, the research team felt that photovoice would provide a unique and beneficial approach to qualitatively explore important themes that arise when the photovoice method is used.

Objective

Photovoice was used to better understand the lives of children/adolescents with SCD from their own perspective. This approach allowed researchers to gain insight into the world of children/adolescents with SCD, as well as the usefulness of photovoice as a method to give this group a voice. Minimal research has used photovoice with a population this young. Therefore, testing its usefulness in this population was an appropriate first step. This pilot study provides information that can be used to develop future studies using this method, in this population and age group.

Methods

Design

This exploratory, descriptive study used photovoice to qualitatively identify themes related to living with SCD. Photovoice allowed participants to visually express issues that they identified as related to life with SCD. For the purposes of this current study, photovoice was modified from prior studies in 2 ways: (*a*) there was no plan to meet with policy makers as a part of this pilot work and (*b*) participants completed a qualitative interview rather than keeping a journal about their photographs. With regard to the first modification, since this study was a pilot study, it would have been premature to involve policy makers. The second modification was a direct response to the age and data collection environment for the study. Typically, photovoice methodology includes the use of journals to capture the thoughts and meanings ascribed to the photographs taken. In our sample, participants were children/adolescents at camp using disposable cameras. Journaling at the moment that a photograph was taken was impractical in this setting. In an effort to ensure that important data were not lost, the study team conducted qualitative interviews after camp. These audio-taped interviews were conducted

by a single study team member in a quiet, private room in the clinic. The study team member conducting the interviews (KS) is a pediatric hematology/oncology nurse with almost 20 years of experience working with children and adolescents and a researcher with almost 10 years of experience conducting qualitative interviews with children and adolescents. In addition, the photos themselves acted as both a rapport builder, since they represented a memory of camp, and the reason for the interview. During the interview, the participants and interviewer discussed each photograph individually to allow participants to consider what they wanted to convey with each photograph and to decrease the likelihood of missing data. The interviewer would simply ask the participant to "tell me about this picture" with probes to follow such as "tell me how this picture relates to your life with sickle cell disease" or "tell me more about that" until the participant indicated that there was no further information to share.

Sampling/Recruitment

Institutional review board approval was obtained for this study prior to commencement of any study activities. Participants (N = 12; female = 42%; 83% Hgb SS disease, 17% Hgb $S\beta^0$ Thal) ranging from 6 to 14 years old (mean = 9.6 years) were recruited from a sickle cell clinic in a large Midwestern hospital prior to attending a summer camp for children/adolescents with SCD and their siblings. Parent permission and child assent was obtained from all participants prior to study commencement. Potential participants were approached at the time of sign in at the camp drop-off site. No participants or parents who were approached declined study participation or withdrew after consenting; however, due to the number of campers checking in, some being dropped off by someone other than a parent or with a parent who did not stay to hear about the study, not all children/adolescents who came to camp were able to receive information about study participation.

Inclusion criteria included any camp participant aged 6 to 14 years diagnosed with SCD. Exclusion criteria included only the inability to speak English, as the instructions and qualitative interviews were conducted in English.

Screening was done prior to the date of the camp start by the sickle cell data coordinator since the sickle cell team was aware that the drop-off point would be very busy. All sickle cell team members who were checking camp participants in sent eligible participants to the research team to receive information about the study if they had a parent or guardian with them.

The camp environment offered a unique opportunity for this population to explore the use of cameras in a controlled setting where researchers were present if help was needed. The setting also allowed study team members to observe participants using their cameras, which provided further insight into challenges and opportunities related to the method for this population.

Data Collection

All participants were given a 27-photograph disposable camera labeled with their name, in order to return if lost, and instruction on how to use the camera. Given the outdoor elements of the camp environment, the age of the participants, and the preliminary nature of the study, the decision was made to use disposable cameras as opposed to digital cameras. The study aims and conditions of privacy were explained in age-appropriate terms to participants. Areas that were off-limits (showers, changing areas, etc) were explicitly defined. Finally, participants were encouraged to think about what types of photographs would best help others understand their perspective of living with SCD. Since the method was new to this population, every attempt was made to avoid putting additional constraint on self-expression.

All participants returned their cameras and photographs were developed. Participants received copies of their photographs to take home as well, if they desired; all participants chose to retain copies of their photographs. Film development yielded between 10 and 27 useable pictures per camera. Although all cameras were equipped with flash capabilities and participants received instruction on camera use, including when to use the flash, the predominant problem with unusable pictures was flash error.

Following camp, researchers scheduled qualitative interviews with participants to share their photographs and explain the message each conveyed about their life with SCD. Interviews were subsequently content analyzed and coded for salient themes related to the experience of children/adolescents with SCD. At the end of the qualitative interview, therapeutic benefit was examined through open-ended questions assessing for positive and negative aspects of the methodology. Interviews lasted from 15 to 40 minutes and included a trained researcher and the participant in a quiet, private room in the hematology/oncology clinic.

Data Analyses

All audio-taped interviews were transcribed verbatim by a professional transcription service then checked for accuracy by a study team member (KS). Then both authors used qualitative content analysis to analyze these data. The process consisted of each transcript being read from beginning to end, as one would read a novel. Then, each transcript was read again carefully, and key words

Figure 1. Picture of water bottles and buddy doll taken by a participant.

Figure 2. Picture of campers playing basketball taken by a participant.

were highlighted that appeared to describe an important aspect of that participant's experience with SCD. Keywords were written in the margins, and after the first 4 interviews had been open coded, preliminary codes were developed. These codes were used for subsequent transcripts and the first 4 transcripts were recoded using these identified codes. New codes were added when data were encountered that did not fit into an existing code. The codes were then placed into categories as appropriate to qualitative content analysis (Elo & Kyngas, 2008).

Results

Three categories emerged from data analysis: importance of friends, controlling symptoms, and importance of camp. The main category that emerged from participants' responses was the importance of friends. One participant shared, "That's a picture about us being friends and when we first met and stuff." Another participant shared that she took a photograph because "we're all sitting down, talking and having fun." For these participants, having friends was more than a social experience. These were peers who could also understand what it was like to have SCD "because they feel what it's like, they feel what I feel." However, when asked, participants stated that they did not spend time talking about SCD with their peers at camp. They shared that they chose to talk about "other stuff."

A second category that emerged from these data was controlling symptoms. Participants chose to take pictures that depicted the need to control symptoms, in order to avoid problems associated with their SCD. One participant took a photograph of his water bottle (Figure 1). When asked about that photograph, he replied, "That is what keeps me from getting dehydrated." Another participant also took a photograph of a drinking glass and reported, "You're supposed to drink healthy stuff . . . because you don't want to get sick . . . your leg's going to hurt, you're probably going to fall out." Yet another participant took a photograph of the swimming pool, which might seem positive, but when asked, he explained that because of his SCD there were complications to consider. He stated, "Swimming is fun. But sometimes when I get out of the water my stomach hurts and I have to go back to the cabin." Participants acknowledged that having SCD requires them to consider the implications of things that other kids take for granted (eg, swimming can trigger painful episodes if the water or ambient temperatures are too cold).

Participants also shared photographs about the importance of camp. This category was multifaceted and included participants discussing ways to reconnect each year with friends ("that one's been my best friend since the day we started coming"), a place to get away and not think about SCD, and a place where they could have fun while having people nearby who could help them if SCD-related problems developed. As such, another aspect that emerged was the importance of health care providers and counselors whose presence at camp allowed these children/adolescents to participate in a camp experience. Participants stated that their counselors were fun and took good care of them and that their doctors and nurses at camp helped them stay well and took care of them when they experienced problems. They made comments such as, "He [doctor] gives me medicine. He helps me get better."

Participants also shared photographs of activities at camp that they looked forward to from year to year. For example, one participant said, "I took this one because I like basketball and I look forward to playing it." He also wished he could take a picture of everyone at camp because he wanted to make a memory of camp as a positive part of his life with SCD (Figure 2).

Discussion

Although this was an exploratory study, it provided several implications for practice. Given that children/

adolescents with SCD often experience social difficulties related to their disease (Barakat et al., 2006; Rodrigue et al., 1996), opportunities to build friendships are highly important. Therefore, a camp setting can provide a useful outlet for social interaction with peers, especially peers with similar disease experience. Camp provided a meaningful outlet for information sharing and socialization with peers that does not exist for many children/adolescents with SCD in their everyday lives. It also provides a beginning awareness for nurses providing care to these patients about the importance of social interactions.

Controlling symptoms is an integral component of living with SCD, and it emerged as an important category within this study. Environmental stressors, both within the body and in the surrounding environment, can cause hemoglobin S to change to a rigid shape blocking blood flow (Ashley-Koch et al., 2000). Because children/adolescents with SCD are particularly sensitive to environmental influences, their disease requires management of complex responsibilities to avoid complications (ie, hydration, appropriate temperature regulation, etc). This study demonstrated that children as young as 6 years old are able to understand and execute these basic responsibilities (eg, photographs of water bottles and expression of its importance). The results of the study demonstrated that medical educational efforts were successful in communicating preventative techniques to these children/adolescents and they were able to communicate the ways that they sought to prevent complications of SCD in their everyday lives through the photovoice methodology. Further research is certainly warranted exploring the likely developmental nuances of this aspect of disease management, but this study raises the awareness that children as young as 6 years old are aware of ways to avoid complications of their disease and can "show" others what they do to avoid these complications visually.

Overall, the photovoice methodology was useful for children/adolescents with SCD. All participants in this study reported finding photovoice enjoyable and accessible. However, further research is needed with this population. We also recommend that this future research be modified in 3 areas: technology, flexibility, and location. In their interviews participants shared how much they enjoyed having a camera. Some expressed a desire to take photographs that capture camp memories and, as such, felt constrained by study instructions. Other participants simply chose to take some of their pictures to suit themselves and therefore had fewer photographs with which to share information about their life with SCD. Adding digital technology to the next study would address both the first and second concerns above. Using digital cameras in the next study would decrease the number of photographs developed that had flash error (and were therefore of no value to participant or researcher), build in the freedom to take photographs for self-expression and memory making, as well as address the research questions outlined in the study. Although the cost differential of digital technology needs to be considered in future research, digital technology continues to become more affordable; this allows the technology to be more accessible even for studies with smaller research budgets.

The third modification would be to implement data collection in a more natural setting. The venue and timeframe within which the study was conducted may have contributed to biases within the results. Conducting a study like this at camp had inherent risks and opportunities. The research team had an opportunity to watch the participants use their cameras, but they were also using them in a social environment, thus potentially increasing the bias toward photographs of a social nature. The next step is to explore how findings might differ in a less social environment, for example, a larger study with participants in their regular home environments, so that they can capture the strengths and challenges of everyday life with SCD. Photovoice could certainly be extended to additional family members as well, given that chronic illness in one member affects whole families.

Future research conducted within the home environment, exploring issues related to SCD in daily life, would both allow a larger picture of the impact of SCD on the individual and family as well as allow participants the opportunity to engage with policy makers. Although the participatory action aspect of photovoice was not explored from that standpoint in this pilot study, future research including children/adolescents with SCD and the impact of the disease on their lives through photographs has the potential to have a powerful impact on policy makers on the community, local, and state levels.

Limitations

The sample size was small but appropriate for a pilot study of this method. It limits generalizability of results but yields some key strategies for future research. In addition, as previously identified, data collection during camp may not have allowed all important themes to emerge. However, the study demonstrated that photovoice is an appropriate, accessible, and enjoyable research method for this population. All 3 of these are key to future success in giving voice to the needs of this population.

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