

## PSO 17

### Using Photovoice with the Bleeding Disorder Population: A Pilot Project

Littner, Lisa; Schulte, Christine; Lamping, Helen; Raterman, Lisa

#### Submission Group

Peer Support/Outreach/Integration Models

#### Abstract

**Introduction:** Photovoice is a qualitative research method that has been used for communities to share pictures as a tool for discussion that is often used at a grassroots advocacy level. Photovoice can show both strengths about a topic or concerns. Photovoice can create empowerment by sharing perspectives and can also create a foundation to advocate for awareness and change. **Long-term Goal:** To create more awareness surrounding bleeding disorders during the month of March, which is bleeding disorders awareness month. **Objectives:** To apply Photovoice methodology to the use of social media among the hemophilia population in the Cincinnati, Ohio geographical area. To engage people with hemophilia and their families in sharing their stories related to their bleeding disorder by sharing photographic images on social media during bleeding disorders awareness month. **Methods:** People that follow the Tri-State Bleeding Disorder Foundation on social media as well as members of a closed social media group that consist of parents of children who are patients at Cincinnati Children's Hospital were asked to participate in the pilot Photovoice project. Participants were asked to share pictures on their own social media pages and to use hashtags to link the photos to the Tri-State Bleeding Disorder Foundation's page. The project was promoted by sharing an infographic that explained Photovoice and the details of the project. Several community stakeholders were identified as people active on social media and they were personally asked to participate so that examples of the project could be shared with others. There were weekly themes and a weekly contest for pictures that best exemplified that week's theme with the winners winning a small gift card. **Summary:** This innovative pilot project applied the methodology of Photovoice to social media to generate awareness and advocacy during bleeding disorders awareness month. The theme of this Photovoice project was "Living with Hemophilia". Weekly themes consisted of: living with a new diagnosis, living with treatment, living and learning about a bleeding disorder, and living with health and being physically active. **Conclusion:** Utilizing Photovoice and applying this methodology to social media as a pilot project with the bleeding disorder population is an innovative idea. This grass roots level movement is a modern way for people to share their story of living with a bleeding disorder. To date, the use of this methodology with the bleeding disorder population has not been documented in the literature. Participants in this project reported satisfaction with being a part of the project. The project's authors reported that it was a positive and creative way to create more awareness on a personal level about bleeding disorders and they plan to repeat the project in the future.