

Chapter 9

Ethical Considerations with the Photovoice Research Method: A Narrative Reflection



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Abstract This paper explores ethical considerations and challenges of using the community-based participatory research method of photovoice with marginalized populations. Experiences with conducting photovoice in an urban setting in the Midwestern United States with women refugees from the Democratic Republic of Congo (DRC) are described along with reflection on ethical aspects of that experience. Two key related ethical considerations emerge: the roles that empathy, cultural competence, and cultural humility play in working with communities and the tension in research between benefits perceived by individual research participants and greater public health benefits for the groups they represent.

Keywords Photovoice · Refugees · Women · Democratic Republic of Congo · Ethical tension · Culture · Research

Public Health Ethics Issue

This paper explores ethical considerations and challenges of using the photovoice method to conduct community-based participatory research (CBPR) with marginalized populations. More specifically, I will recount my experiences in conducting photovoice in an urban setting in the Midwestern United States with women refugees from the Democratic Republic of Congo (DRC) and reflect on ethical aspects of that experience. My reflection takes as its point of departure, Principle 4 of the *Ethical Principles of the Practice of Public Health* (Public Health Leadership Society 2002, 4): “Public health should advocate and work for the empowerment of disenfranchised community members, aiming to ensure that the basic resources and

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conditions necessary for health are accessible to all.” But as my story unfolds, two related ethical considerations emerge: the roles that empathy, cultural competence, and cultural humility play in working with communities and the tension in research between benefits perceived by individual research participants and greater public health benefits for the groups they represent.

Background Information

CBPR has evolved over the past three decades with diverse roots across multiple disciplines such as social work, education, and international development. Over the past 20 years, it has emerged as a common approach to research within public health (Minkler and Wallerstein 1999). Key principles of CBPR include facilitation of collaborative partnerships throughout the research process, promotion of co-learning with participants, and empowerment of participants to redress social inequalities (Israel et al. 1998, 178–80). It may particularly appeal to public health professionals and researchers specializing in the social, cultural, and behavioral aspects of health promotion and education and has more recently been described as an opportunity for “giving underserved communities a genuine voice in research” (Wallerstein and Duran 2008, S40). CBPR offers public health researchers concerned with holistic approaches an option to interrogate the multiple social, political, economic, and cultural roots of public health problems.

One specific CBPR method is photovoice. Photovoice owes its creation to global public health researchers doing international development work with women in rural China. They adapted it to better understand economic and social determinants of reproductive health issues (Wang and Burris 1994, 1997; Wang 1999). Simply put, photovoice is, “a process by which people can identify, represent, and enhance their community through a specific photographic technique” (Wang and Burris 1997, 369). When following the original approach of Wang and Burris, three overarching goals characterize photovoice: (1) enable people to record and reflect their community’s strengths and concerns; (2) promote critical dialogue through discussion of photos; and (3) reach policymakers (Wang and Burris 1997, 370). However, as Catalani and Minkler (2010, 447) demonstrate, public health researchers who use photovoice display a wide range of adherence to those goals.

Photovoice researchers have used the method with diverse populations internationally and across disciplines for over 20 years (Breny and Lombardi 2017; Castleden et al. 2008; Keller et al. 2008; Livingood et al. 2017; Mamary et al. 2007; McMorrow and Smith 2016; McMorrow and Saksena 2017; Saksena and McMorrow 2020; Strack et al. 2004; Wang and Burris 1997; Wang et al. 1996). Researchers often employ the photovoice method with marginalized populations to amplify voices of the group and gather often-ignored perspectives. Photovoice researchers usually hold a series of meetings with a participant group to introduce them to the process. The group learns what photovoice is, how to use a camera, the plan and timelines for taking photos, and the ethical and safety considerations for taking

photos of people in their communities. Health topics and specific goals of Photovoice projects often vary widely between groups. Researchers offer broad guidelines to participants about what to photograph based on the research questions, with careful attention to avoiding social desirability bias and encouraging both positive and negative depictions of their community. After taking their photos, participants reconvene in a modified focus group to discuss their photos. The researcher guides participants in how to choose which photos they wish to share, discuss them with the group, identify common feelings and experiences related to the content of the photos, and have further discussions that build on discussion of the photos. To accompany the photos, all discussions are recorded and transcribed. The ideal outcome is for the photos and accompanying stories to reach key decision makers and policy influencers either through a public exhibition or advocacy. Examples include participants attending a local school board meeting to discuss their photos, an exhibit at a public library with a reception inviting community leaders, or direct meetings with state or federal representatives where researchers and/or participants share the photos and stories. Figure 9.1 below shows a photo and story from a woman who came to the United States as a refugee after fleeing the ongoing wars in the Democratic Republic of Congo (DRC), (McMorrow and Saksena 2017, 8). In this project, researchers asked participants to photograph things that made them feel happy, sad, or surprised about their new life in the United States.



Fig. 9.1 Photovoice example that illustrates a participant’s daily experience of health (McMorrow and Saksena 2017, 8). *Participant photo story*: “This is sad because they find they have cockroaches and other insects in my house so I have to do all this laundry and pack all of the like that so they can...spray the medication. That picture is of packing. It reminds me of war in Africa where you have to pack and keep running, keep on the run”

Sometimes participants may photograph a blank wall or a mundane set of stairs. However, the impact of photovoice ultimately depends neither on the actual photograph nor on photography skills. It depends instead on the string of stories in conjunction with the photos, which produces compelling qualitative data with the potential to inform public health practice and policy. Just as important, participation in a photovoice project often empowers participants by facilitating their acquiring the knowledge, attitudes, and skills needed to improve their health and their lives.

Approach to the Narrative

The following narrative takes as its point of departure the photovoice project that produced Fig. 9.1. The story centers around the perspectives of Harriet, a research team member whose cultural and ethnic background mirrors that of the research participants, and of Julie, one of the research team leads. Though fictional, the characters represent composites based on the author's actual experience in conducting photovoice research. The moral lesson of the story illustrates an ethical tension that may result from the use of photovoice. On the one hand, by empowering disenfranchised community members, photovoice can in the long run enhance their access to basic resources and conditions necessary for health. On the other hand, in the short term, photovoice and other participatory research methods may reveal immediate needs of individual participants that cannot be met during the course of a photovoice project. Nested within the story are enduring questions about ethical relationships with communities and the clash between service delivery and empowerment activism that can occur in public health research and practice. These are critical to reflect upon because ethical, intentional partnerships with communities are a mainstay of public health practice.

Narrative

Harriet

Here it was 2019 and Harriet was struggling yet again over whether to become a member of the photovoice research team to help follow-up on the study she had worked on back in 2016. The researchers needed her help in recruiting participants and serving as an interpreter. She was the ideal person, because the research would focus on women and she felt connected to in her local community, refugees with families who had fled the Democratic Republic of Congo (DRC). Harriet shared a strong affinity with the study participants as she too, had fled her home in Rwanda. Though her circumstances were different from the participants in that she had not

undergone the official UNHCR¹ process as a refugee, she empathized strongly with these women. This was because she had also experienced the trauma of conflict and horrific violence in her home country as well as many of the challenges of integrating and adjusting to life in the United States that the participants now faced.

In any case, the upside of working on the photovoice project again was that she needed the money and the work would thankfully only be temporary. Also, she would get a chance to re-connect with the study participants since part of her job would be to recruit the same women she had recruited to participate in the 2016 photovoice study. On the downside, she had uncomfortable memories about the challenges of working on the study back then. Harriet had continually struggled to see how sitting and talking about photos actually helped the women. After all, being a local health navigator for the refugee resettlement agency had opened her eyes to the range of ongoing adverse mental and physical health conditions the women suffered. Those were on top of the daunting social and economic barriers facing them in adjusting to life and surviving in the United States. The last time around, during the 2016 project, she had felt overwhelmed and caught in the middle. She had to answer to both the refugee resettlement agency and the researchers, and her work for the research study was on top of her normal job duties. It had certainly become more trouble than it was worth. With the new follow-up study, they would hire her as an independent contractor and pay her directly as a “research assistant.” She would work on multiple parts of the project such as helping find a community meeting space, recruitment, and interpreting.

Would the project create false hopes for the women that the researchers were going to do something direct and specific to help them? It was already clear in 2016 that the women needed a variety of support services, so would the project do more to provide those services this time? Harriet had doubts but decided to move forward despite her reservations. Julie and Ren, the project researchers, were both women who appeared well intentioned and had some understanding of the women’s cultural background. Julie who was leading the research, at least had lived in East Africa for 3 years, with some travel to the DRC, and knew more about where the women were coming from than the average American. Ren, like Harriet, also immigrated to the United States from a developing country. She could sympathize more with some of the cross-cultural barriers Harriet faced when trying to recruit and guide participation of the women in the study. However, Harriet also thought they lacked full understanding of some of the social and economic hardships faced by the participants as they were both college professors and researchers working in high status jobs with reliable incomes. That gap in status left Harriet with a solid dose of skepticism about whether the researchers truly grasped the gravity of some of the challenges the women faced. That skepticism only added to her nagging doubts about how the photovoice project could help the participants improve their health and access to healthcare.

¹United Nations High Commissioner for Refugees.

In her day job as health navigator, Harriet was a service provider, giving refugee women concrete, practical information that helped them learn the ropes in their new country. Photovoice struck her as more roundabout. Both researchers had conducted training with Harriet, detailing the steps of photovoice, highlighting the focus on empowerment of participants as opposed to service delivery, and coaching her on how being the interpreter for a research study differed from her work with the women in her health navigator role. The researchers also started out the photovoice group meetings with the participants by explaining that the immediate project goal was to gather information directly from the women, encouraging them to share about their experiences as refugees. Later, the researchers would eventually use this information to advocate for change. However, as much as Harriet tried to translate this message clearly into Kinyarwanda and Kiswahili, the languages the study participants spoke, she still could sense the women expected the researchers to do something beyond ask questions and listen to their stories. Every now and then, the women would ask Harriet a question in their preferred language that she would not translate to the researchers lest they become offended or frustrated. For example, sometimes the women wondered if the researchers were available to help transport them to doctor appointments. After all, the women were communicating this need through their photos and discussions (see Fig. 9.2), so it made sense that the next step would be for the researchers to help them with these needs.

Fig. 9.2 Photovoice example illustrating transportation barriers (Saksena and McMorro 2020, 11). *Participant photo story*: “I took a picture of this place because it is the bus stop where we stop and just leave around that bus stop early. You go take a bus for two hours and you have a car back home. It is a pain. It is a sad picture”



Even when participants were not directly asking for help, Harriet found herself looking to the researchers to see what actions they would take after participants had shared grave concerns and experiences about their health. For example, during the initial 2016 study, they learned that one of the participants, Eliza, suffered from type 1 diabetes and had trouble paying for her medication. When Eliza participated in the 2019 study, she again offered photos and narrative stories detailing financial barriers she still faced that caused her to skip taking medication, ending up hospitalized, and as she acknowledged, fearing she might die. Harriet felt a mixture of sadness and frustration that Eliza was still facing these barriers to accessing her life-saving medication. Eliza's desperate lack of access to the resources she needed to stay healthy was the most important, immediate issue at hand. What was needed was urgent action to get her the ongoing, sustainable access to healthcare services of medication and care to manage her Type 1 diabetes. How could the researchers be so concerned about Eliza's story and seemingly care so little about helping her now?

Harriet looked to the researchers to respond when Eliza shared that she sometimes missed her medication. They appeared to be listening and sympathetic, but instead of offering her advice or consolation, they proceeded to other questions for the group to discuss. The researchers even asked a question to the group about their collective ideas and suggestions for how Eliza might handle this problem of not having access to her medication. Harriet found it ridiculous that the researchers would ask the participants how to solve Eliza's problem because it seemed clear that these women were in need and unable to solve their own problems. They needed help from her and from the researchers. At that point, Harriet deviated from her role as an interpreter for the research study to talk with Eliza in Kinyarwanda. Harriet offered advice from her other role as a health navigator to let Eliza know that the medication should be covered by Eliza's insurance. Harriet clarified that it must be an issue that Eliza was facing in terms of the complexities of using the version of Medicaid in their state and assured Eliza that after the photovoice meeting was over, she would assist her with the paperwork and other case management support needed to help her navigate the challenges.

Julie

By spring of 2019, Julie had been conducting photovoice as a community-based participatory researcher in public health for 7 years. Before that, she had worked as a public health educator in community settings for 20 years. She embraced the nuanced and messy process inherent to CBPR methods and particularly, to photovoice. Still, lingering ethical questions related to this work dogged her. She often thought about her commitment to empower disenfranchised community members and wondered if she were doing enough.

At first glance, Julie's public health career seemed to follow a crooked path. Viewed as a whole, however, pivotal experiences had guided her path to CBPR, a

road less taken in public health research. Twenty years earlier, she had taken her first public health job for Planned Parenthood, delivering sex education in California's Bay Area. Despite having attended a racially, ethnically, and socioeconomically diverse public school in the Midwest, she came off to coast dwellers as a naively underexposed Midwesterner. Her sex education delivery combined wholesome enthusiasm with an utter lack of cultural humility (Tervalon and Murray-Garcia 1998). The latter went unnoticed by her equally culturally tone-deaf supervisor, but not by colleagues and community members in whom it provoked resistance and resentment. Convinced of her good intentions of empowering the disenfranchised, she failed to fathom why her educational sessions provoked such negative reactions.

Answers began to emerge during her time with Planned Parenthood once she embarked on a Master of Public Health in Community Health Education. That course of study commenced a journey of lifelong learning that deepened her cultural competence and cultural humility. Her initial fumbling and bumbling through "on the job training" in cultural competence did, however, have an upside. The practical experience generated a deep-rooted discomfort with the way public health practitioners and researchers unwittingly plied their interventions and hypotheses. Due to their lack of cultural humility and competence, they often did more harm than good in their endeavors to empower the disenfranchised.

That lingering discomfort eventually guided Julie to zero in on photovoice as a means to both work *for* and *with* disenfranchised community members. The participatory nature of photovoice and most CBPR research in public health offered some decision making and control of the research process to participants including choices related to where to share the data. One of the core underpinnings of photovoice was empowerment and consciousness raising with the goal of sustainable change for participants (Wang and Burris 1994, 1997). However, there was also the inherent power imbalance that occurs with all research that gave Julie and the research team the opportunity and responsibility to identify how and where to use the data for advocacy. That partly explained why she felt it important that Harriet had agreed to be their Research Assistant and Interpreter. Harriet already had photovoice experience and could follow up with the Congolese refugee women who had participated in their 2016 study. Julie, who had visited the DRC several times during a three-year stint in public health in Uganda, was familiar with the study population. However, her outsider familiarity paled in comparison to Harriet's insider perspective and the ethnic and linguistic background she shared with the women in the study. Even better, Harriet's professional experience as a health navigator working for the local resettlement agency added cultural depth and insight to the bare data and its analysis. During the 2016 study, participants had demonstrably trusted Harriet; the hope going forward was that this trust would help with the 2019 recruitment and implementation. That hope was not misplaced; she managed to recruit many of the early participants into the 2019 study.

Returning participants shared their experiences of what had happened to them over the 3 years since they had last interacted with the researchers. Julie listened to these experiences with a mixture of responses. Sorting out her professional response from her emotional response was always challenging. Hearing the women tell their

stories often made her feel helpless or like she should be doing something more beyond “just research” for the participants. Though the photovoice research method had participant empowerment as a core tenet, clear and pressing service delivery needs were evident during photovoice implementation. Eliza’s distressing story, recounted during a data collection session, offered a case in point. With Harriet serving as interpreter, Eliza shared her ongoing struggle to access medications for her type 1 diabetes. Missing several doses of medication shortly after being resettled in the United States had led to her hospitalization and a flirtation with death. The story clearly unsettled Julie and Ren, who become more discomfited when Harriet, pausing from interpreting, expectantly turned to them. What decisive response would the researchers have to Eliza’s story?

Julie had listened to Eliza’s story intently, but the group sat in awkward silence when Harriet stopped interpreting. She could tell that Harriet expected her to offer advice about Eliza’s case. Instead, adhering to the methods of qualitative data collection, Julie posed further probing questions based on what Eliza had shared. All these questions nudged the group to consider ways to collectively address Eliza’s predicament. For Julie, CBPR’s overarching purpose and the project’s whole point was to empower the participants, helping them find ways to solve their problems. Moreover, harnessing, capturing, and scientifically sharing the breadth and depth of these women’s experiences had a larger, public health aim. It could ultimately impact all of the refugee women’s access to health care and their health, thereby reducing the group’s health disparities. Gathering the participants’ stories and experiences formed a crucial piece of a puzzle they could widely share and use to advocate for resources that could improve the lives of Congolese refugee women in the United States and potentially, other refugee groups. The reason that it was so crucial, from Julie’s perspective, was that first-hand stories were an important complement to the quantitative evidence that public health tended to prioritize. In the case of photovoice, both stories and photos taken by the participants added depth and a more holistic picture of how to build what would ideally guide public health practice for this population.

Despite this being the “right” way to conduct research, both then and later, it troubled Julie not to focus on Eliza’s grave challenges and try to “fix” them. Harriet’s initial reaction and subsequent actions only amplified Julie’s unease. Harriet had first shot an alarming glance at the researchers, then took matters into her own hands. She ceased interpreting for the researchers and switched to Kinyarwanda for a few moments to discuss the issue with Eliza. Harriet had prioritized the immediate end of ensuring that Eliza had the resources necessary for her to stay healthy. By contrast, Julie was attempting to discover whether the photovoice method could be an effective means for ultimately empowering women. Once again, Julie would find herself struggling with how to square what her heart and what her head were telling her.

Questions for Discussion

1. How do the differing perspectives of Harriet and Julie illustrate the potential for conflict in approaches to addressing ethical obligations (in this case the obligation to empower disenfranchised community members and ensure access to basic resources and conditions necessary for health)?
2. What was the role of money and economic need in Harriet and Julie's narratives? How might that apply when working with other "disenfranchised" community members as a public health practitioner or researcher?
3. What are potential implications and consequences when a public health practitioner or researcher endeavors altruistically to adhere to Principle 4 by "advocating and working for the empowerment of disenfranchised community members ..." without a baseline of cultural humility and training specific to working with and for such "communities"?
4. Why might some public health professionals argue that training in cultural humility and competency is an ethical obligation for the public health profession? What are some approaches for acquiring these skills? Should training on these topics be required?
5. What does it mean for public health to work *with* disenfranchised communities as opposed to *for* disenfranchised communities?
6. Do public health practitioners and researchers have an ethical obligation to include team members as staff that are "insiders" of the community like Harriet? Why or why not?
7. Do public health researchers have ethical obligations beyond the requirements of an Institutional Review Board to ensure populations comprehend the nature of scientific research aiming for long term change such as photovoice? How would they actualize this?

References

- Breny, Jean M., and Deidre C. Lombardi. 2017. 'I Don't Want That Guy Walking in the Feminine Product Aisle': A Photovoice Exploration of College Men's Perceptions of Safer Sex. *Global Health Promotion* 26 (4): 1757–1759.
- Catalani, Caricia, and Meredith Minkler. 2010. Photovoice: A Review of the Literature in Health and Public Health. *Health Education & Behavior* 37 (3): 424–451. <https://doi.org/10.1177/1090198109342084>.
- Castleden, Heather, Theresa Garvin, and Huu-ay-aht First Nation. 2008. Modifying Photovoice for Community-Based Participatory Indigenous Research. *Social Science & Medicine* 66 (6): 1393–1405. <https://doi.org/10.1016/j.socscimed.2007.11.030>.
- Israel, Barbara A., Amy J. Schulz, Edith A. Parker, and Adam B. Becker. 1998. Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health. *Annual Review of Public Health* 19: 173–202.
- Keller, Colleen, Julie Fleury, Adriana Perez, Barbara Ainsworth, and Linda Vaughan. (2008). Using Visual Methods to Uncover Context. *Qualitative Health Research* 18 (3): 428–436. <https://doi.org/10.1177/1049732307313615>.

- Livingood, William C., David Montcalvo, Jay M. Bernhardt, Kelli T. Wells, Todd Harris, Kadra Kee, Johnathan Hayes, Donald George, and Lynn D. Woodhouse. 2017. Engaging Adolescents Through Participatory and Qualitative Research Methods to Develop a Digital Communication Intervention to Reduce Adolescent Obesity. *Health Education & Behavior* 44 (4): 570–580. <https://doi.org/10.1177/1090198116677216>.
- Mamary, Edward, Jacqueline Mccright, and Kevin Roe. 2007. Our Lives: An Examination of Sexual Health Issues Using Photovoice by Non-gay Identified African American Men Who Have Sex with Men. *Culture, Health & Sexuality* 9 (4): 359–370. <https://doi.org/10.1080/13691050601035415>.
- Minkler, Meredith, and Nina Wallerstein. 1999. Improving Health Through Community Organization and Community Building: A Health Education Perspective. In *Community Organizing & Community Building for Health*, ed. Meredith Minkler, 30–53. New Brunswick: Rutgers University Press.
- McMorrow, Shannon, and Shannon Smith. 2016. Photovoice as a Participatory Assessment Approach for Examining Disparities in Obesity for African American Teen Girls. *The International Journal of Health, Wellness and Society* 6 (3): 77–85.
- McMorrow, Shannon, and Jyotika Saksena. 2017. Voices and Views of Congolese Refugee Women: A Qualitative Exploration to Inform Health Promotion and Reduce Inequities. *Health Education & Behavior* 44 (5): 769–780. <https://doi.org/10.1177/1090198117726572>.
- Public Health Leadership Society. 2002. *Principles of the Ethical Practice of Public Health*. https://www.apha.org/-/media/files/pdf/membergroups/ethics/ethics_brochure.ashx.
- Saksena, Jyotika, and Shannon McMorrow. 2020. Through Their Eyes: A Photovoice and Interview Exploration of Integration Experiences of Congolese Refugee Women in Indianapolis. *Journal of International Migration and Integration* 21: 529–549. <https://doi.org/10.1007/s12134-019-00672-1>.
- Strack, Robert W., Cathleen Magill, and Kara McDonagh. 2004. Engaging Youth Through Photovoice. *Health Promotion Practice* 5 (1): 49–58. <https://doi.org/10.1199/1524839903258015>.
- Tervalon, Melanie, and Jann Murray-Garcia. 1998. Cultural Humility Versus Cultural Competence: A Critical Distinction in Defining Physician Training Outcomes in Multicultural Education. *Journal of Health Care for the Poor and Underserved* 9 (2): 117–125. <https://doi.org/10.1353/hpu.2010.0233>.
- Wallerstein, Nina, and Bonnie Duran. 2008. The Theoretical, Historical, and Practice Roots of CBPR. In *Community-Based Participatory Research for Health*, ed. Meredith Minkler and Nina Wallerstein, 25–46. San Francisco: Jossey-Bass.
- Wang, Caroline C. 1999. Photovoice: A Participatory Action Research Strategy Applied to Women’s Health. *Journal of Woman’s Health* 8 (2): 185–392. <https://doi.org/10.1089/jwh.1999.8.185>.
- Wang, Caroline C., and Mary Ann Burris. 1994. Empowerment Through Photo Novella: Portraits of Participation. *Health Education Quarterly* 21 (2): 171–186.
- . 1997. Photovoice: Concept, Methodology, and Use for Participatory Needs Assessment. *Health Education & Behavior* 24 (3): 369–387.
- Wang, Caroline C., Mary Ann Burris, and Xiang Yue Ping. 1996. Chinese Village Women as Visual Anthropologists: A Participatory Approach to Reaching Policymakers. *Social Science & Medicine* 42 (10): 1391–1400.

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