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# Power and Ethics in Photovoice Research: Exploring the Implications of Human Subjects' Protections on Self-Determination and the Belmont Principles

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## Abstract

### Background:

Photovoice is community-based participatory research method in which community members partner to take photos and provide narrative to inspire social or political change, and to raise critical consciousness. Of particular value is the potential for this method to bring voice to a population that is systematically silenced from public advocacy efforts due to fear of legal or social repercussions. The photos and narrative products become the 'voice' and offer a vehicle for safe participation in the advocacy process. However, the risks of using identifiable photography may negate the benefits of having photos speak for participants, prompting researcher or review board decisions to use only anonymous photography. Little is known about how these decisions might affect participant power and self-determination in the research process, and perceptions of partnership in this collaborative method.

### Methods:

N=25 people who inject drugs (PWID) were recruited to be part of a Photovoice project addressing the pervasive stigma they face in Chicago communities. Participants partnered to provide anonymous photos and narrative to prompt critical consciousness about stigma and the need for social and political change. The sample was also engaged in a qualitative, phenomenological study to examine how Human Subjects protections in this study affected perceptions of autonomy, competence, and relatedness throughout the research process. The purposeful sample was reflective of the local PWID community demographics and met published estimations required to reach saturation in phenomenological data. Participants were engaged in semi-structured interviews that were audiotaped, transcribed verbatim by a professional transcription service, verified by the research team, and assigned as documents in software designed to aid analysis of qualitative data. Weiss' issue focused analysis guided the team, with index codes to start the coding process, and coded by two members of the research team. Interrater reliability was assessed using Cohen's Kappa and evaluated using benchmarks established by Landis & Koch. Member checking of emerging themes occurred with the use of a Community Advisory Board of local PWIDs, convened for this study.

### Results:

Thematic analysis examined conceptualizations of partnership, power, safety, voice, and capacity to fulfill research expectations were further distilled through a Self-Determination Theory Lens. The Theory stipulates that autonomy (defined here as choice of photos and active participation), competence (capacity to answer questions within the safety constraints),

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and relatedness (to the research team) foster voluntariness, motivation to participate, and participant voice, leading to a strong partnership and full engagement in the process. Findings reveal the tense and delicate balance between protecting human subjects while creating a research partnership that fosters self-determination. While most PWID understood, and even appreciated, safety concerns, many reported less autonomy and competence, and a select few refused to participate within those constraints. While most did participate, the photo taking process was affected, resulting in less organic (but more creative) efforts to express the experience of stigma through photography in this study. These findings suggest that human subjects' protections may interfere with self-determination among research participants.

**Discussion:**

Researchers who engage stigmatized communities in Photovoice efforts should understand the potential of human subjects' protections to provide safety from harm while also affecting autonomy and competence. This presents an interesting dilemma for the researcher, who must consider the Belmont principles of respect for persons and beneficence as they weigh options to either maintain protection and diminish voice, or advocate for less protection to maximize participant voice. Such a decision is complicated by common perceptions of stigmatized communities as inherently vulnerable and compromised in their ability to make decisions to protect themselves. It is also complicated by researcher concerns about the use of photographs in a digital age, where Photovoice products may be diverted by others and used for reasons not covered by informed consent processes. Ethical and practical implications for photo-based research projects moving forward will be discussed.

**Keywords:** Photovoice, Ethics, Power, Research, Self, Determination