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Evaluating the Role of Community Advisory Boards: with Persons Who Inject Drugs in Photovoice Research

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Evaluating the Role of Community Advisory Boards: with Persons Who Inject Drugs in Photovoice Research

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BACKGROUND

The use of community advisory boards (CABs) is a source of leadership in the partnerships of community-based participatory research (CBPR) and provides structure to guide the partnership's activities; however, not all researchers have incorporated CABs, and others have restricted CAB involvement for feasibility purposes. Although there is literature about utilizing CABs globally, less is known about the challenges and successes of working with CABs in photovoice methodology as well as CAB members' perceptions throughout the process. This project worked with participants from the Chicago Recovery Alliance (CRA) to:

- (1) Investigate CAB member experiences in a photovoice study
- (2) Ensure community has voice in data interpretation & dissemination
- (3) Explore persons who inject drugs' (PWIDs) perceptions of partnership

PURPOSE

The purpose of this study was to investigate the role CABs play in qualitative photovoice research while determining PWIDs' capacity to fulfill this role while identifying their feelings about being given a voice in the research partnership.

METHODS

A semi-structured interview guide was developed in collaboration with key informants and pilot tested with the community. Participants were recruited, consented, enrolled, and trained. Interviews were held in private mobile spaces, audio recorded, and transcribed. Raw data was coded individually by two researchers utilizing an open coding system. Another round of coding was conducted by independent researchers to mitigate any potential research bias.

Description of sample:

N = 6 PWID recruited from mobile van in 3 Chicago neighborhoods

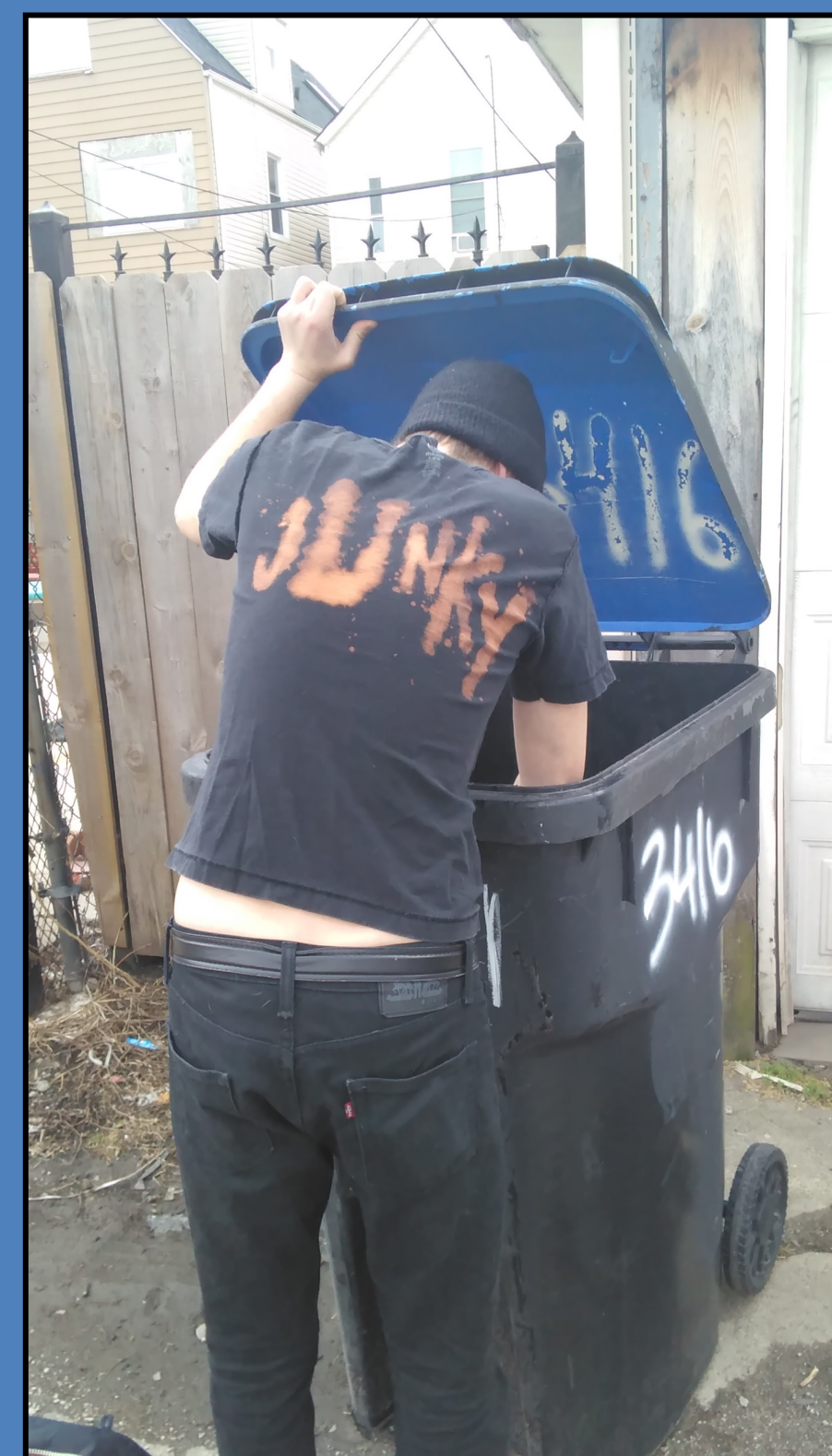
Gender: 50% female, 50% male
Race: 67% Caucasian, 33% Hispanic
Age: Mean = 34, Range: 30-39

Interviews (N=6) lasted 60 – 120 minutes and 132 photos were analyzed. Analysis yielded the following themes, ideas for dissemination, and perceptions of involvement:

RESULTS

What themes do you see?

Humans as waste: *"I saw a lot of rejected items, like garbage. The toilets: human waste. I just see a lot of waste, trash ... people seem to feel useless and not actually a part of the community at all."*



Need for education and public awareness: *"This problem isn't going away, and that there are a lot of people affected by it ... communities need to work together to create a plan for how to educate and protect the people in their community without judging and isolating the people who are affected."*

Judging a book by its cover: *"There is a huge gap between community and addicts. There is a huge gap and people need to close that. You ain't gonna help somebody by ignoring them or tough love, it does not work."*



How would you use the photos to create positive change?

"Put them up in public places, in the public eye, like churches, licensing bureaus, transit stops. People need to read them and understand every one of them [photos] is saying the same thing pretty much ... Saying that they want help, that tough love is not the answer. They want help, but they need somebody to extend that arm, extend that hand."

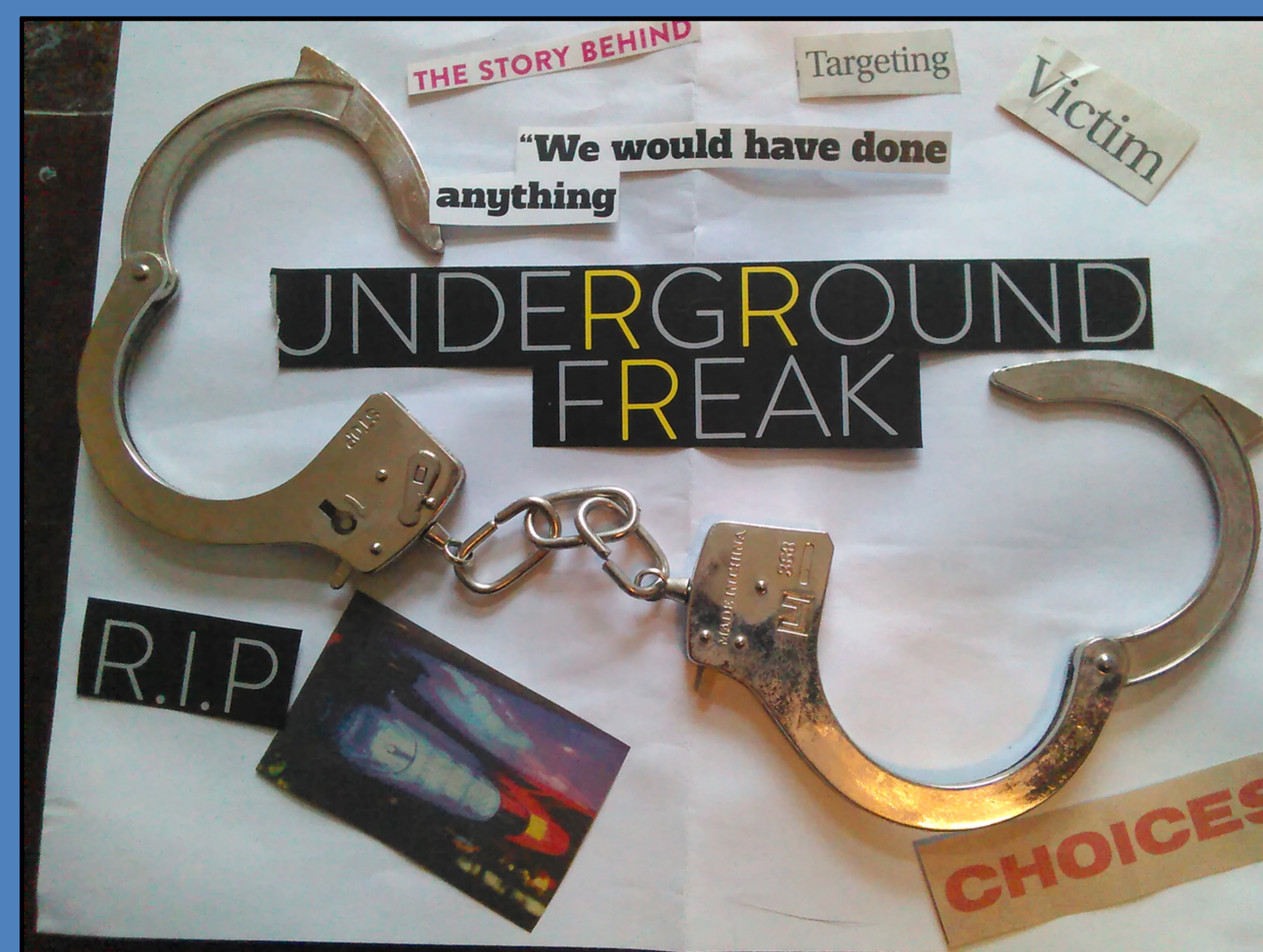
"There's a big barrier between me, as an addict, and even with you, as a regular, normal person doing the right thing, to even get ahold and get these people's attention. The only way I'm going to get their attention if I go on some killing spree or do something crazy that's going to get me on the news. Seriously, I can't walk up and, 'We should sit down and talk about what's going on.' They're going to look at me like I'm crazy."



"Maybe put them on an L or on a bus or something. Maybe you have a picture like, 'I want help, but I'm afraid to get it, because everyone thinks I'm a monster.'"

What do you think is the most critical message?

"The harshness of the stigma is the most important message ... It's just all about public awareness and understanding because things like treatment programs and outreach programs, those don't come until after the understanding is reached."

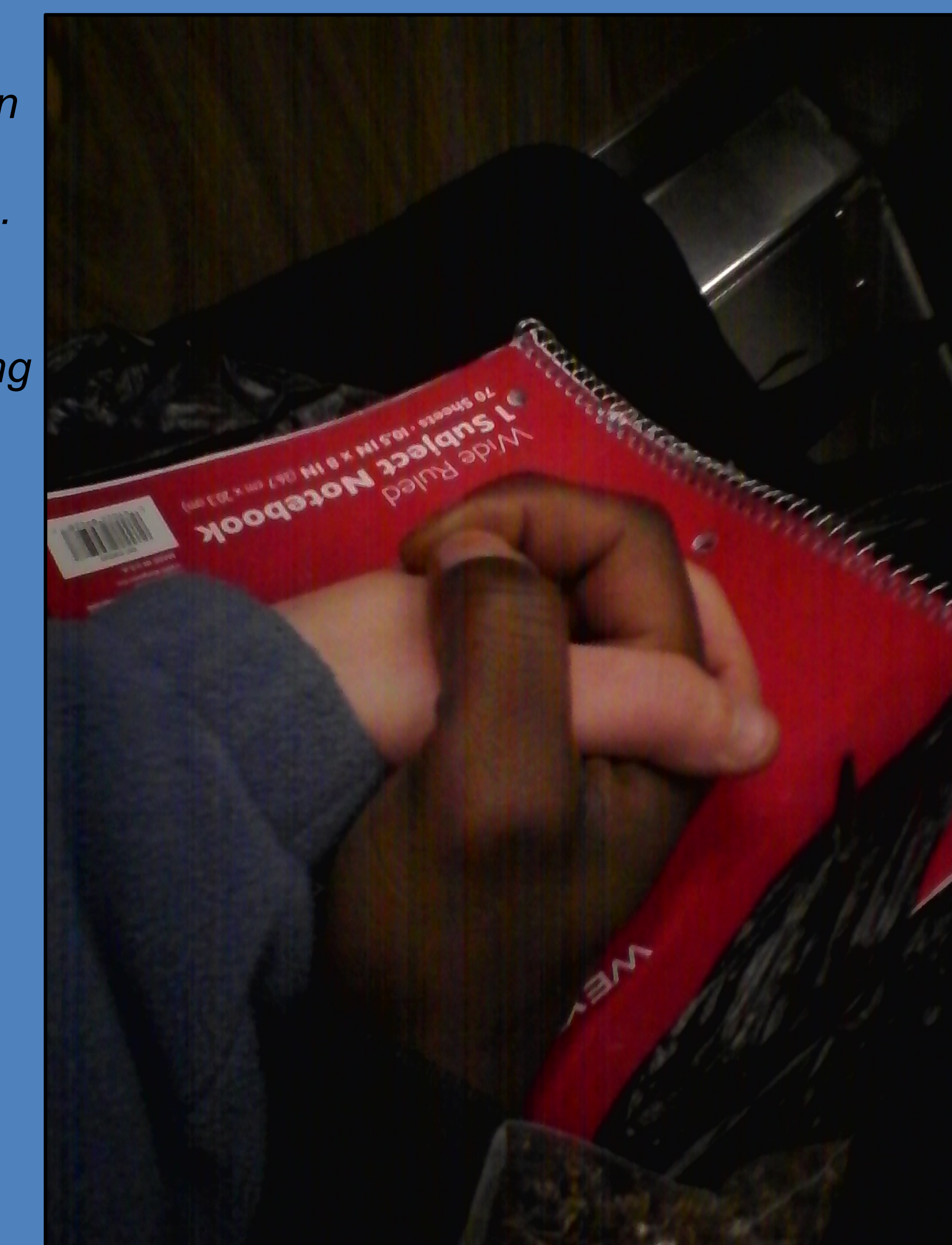


How did it feel to participate as a CAB member?

"Overall, I don't have much to look forward to, but looking forward to being able to sit down with you and go over all the photos is very positive for me ... maybe I'm contributing something that could do something really good in the long run or maybe the short term."

"Just the fact that you have people like us participating. It makes all of it seem like you really are after something legitimate, and you're trying to get to those places honestly."

"Then this part [CAB], this is good that you've got us doing this part ... unless you've been there or are there, it's literally impossible to understand it completely, without question. I don't care how smart you are, how many books you've read."



DISCUSSION

1. PWIDs **should be engaged** in all aspects of the research process
2. Participants:
 - Brought meaningfulness to the researcher partnership
 - Filled important gaps in the photovoice process
3. Alignment with harm reduction + ongoing community involvement facilitates trust + motivation of PWIDs to play a role in positive change

IMPLICATIONS FOR PRACTICE

1. Nurses have the opportunity to play a vital role in the role in reducing community-level stigma towards PWIDs
2. PWIDs have the **basic human right** to be treated with dignity, respect, and the same quality of care as other patients
3. Nurses and other allied health providers are in a unique position to help break the pattern of stigma that has a negative impact on the care of PWIDs
4. Nurse's role in reducing and eliminating stigma:
 - Advocate for patients' needs
 - create a nonjudgmental environment
 - develop a rapport with the patient and family
 - patient education
 - incorporate harm reduction philosophies

CONCLUSIONS

It is evident through this study that PWIDs are not only fully capable of data analysis and generating ideas for dissemination of findings, but also empowered enough by CAB roles to desire ongoing involvement. Study findings reveal critical implications for inclusion of PWIDs in the research partnership because of the meaningfulness they bring and gaps they fill. Themes also highlight that researcher alignment with harm reduction and ongoing community involvement facilitates trust and motivation of PWID to play a vital role in advocating for positive change.

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