

Using Photography as a Data Elicitation Technique with African American Mothers Living with HIV

Background

- ❖ The strength and vulnerability of **African American mothers living with HIV** functions at a complex intersection of gender-, race-, and class-inequality, HIV-related stigma, and motherhood.
- ❖ Multidimensional and transdisciplinary approaches such as photo elicitation can help illuminate **social determinants of health** in this vulnerable population.¹
- ❖ **Photo elicitation** = inserting photography into a research interview; gives participants the opportunity to create and reflect on visual images; emphasis is on the authority of the participant rather than the researcher.²
- ❖ **Why photography?**¹⁻²
 - Evokes different information than words
 - Generates and facilitates discussion
 - Fosters collaboration and participant empowerment
- ❖ Images created and disseminated using photography are central to the power and effectiveness of this methodology, but they can generate **methodological issues** and **ethical challenges** when working with vulnerable populations.³

Purpose of Pilot Study

To explore the methodological issues and ethical challenges of using photography as a data elicitation technique with a highly stigmatized social group of women

Methods

Eligibility & Recruitment

- ❖ Women who are: age 18 or older; self-report HIV infection; self-designate race as Black/African-American; are able to communicate in English; have one or more dependent child(ren) aged 0-18 years residing in the home; and live below the federally designated poverty line
- ❖ Letter of invitation describing this study mailed to potentially eligible women (n=30) who had participated in a previous study of women living with HIV.
- ❖ Telephone contact number included in invitation letter for women interested in participating
- ❖ Screened for eligibility by telephone
- ❖ 6 responded; 1 dropped out prior to enrollment; 5 participants enrolled (**n=5**)

Procedures

- ❖ Qualitative data collection methods of in-depth interviewing and photo elicitation
- ❖ **Time point 1:**
 - Began informed consent process (included guidelines for what may and may not be photographed)
 - Conducted rapport-building, in-depth interview about motherhood and HIV
 - Explained **goal** of photo elicitation method ("taking pictures") for this study:

To capture images representing the social and economic experiences in the participant's daily life which act as strengths or vulnerabilities (concerns) in maintaining her health or ability to care for her HIV

Methods

- ❖ **Time point 1 (cont'd):**
 - Brainstormed potential photographs
 - Provided camera (single-use disposable film camera, 27 exposures) with a self-addressed stamped envelope for return
 - Demonstrated camera use
 - Explained procedure for returning camera by mail
 - Reiterated **ethical issues** that were agreed to in the informed consent:

You may take pictures of yourself or your children, but we ask that you only take pictures of the children if they agree to be photographed.
Please **do not** take a picture of anyone other than yourself or your children. Any pictures developed containing images of persons other than yourself or your children will be shredded according to the study protocol.

- ❖ **Time point 2:**
 - Reviewed all photographs with participant; participant confirmed identity of any persons who were photographed
 - Conducted interview regarding content of each photograph using a modified **SHOWed** Framework¹
- ❖ Digital records of interviews were transcribed verbatim, proofed for accuracy, and kept electronically on secure server at Duke University School of Nursing
- ❖ Qualitative content analysis used to conduct preliminary analysis of text and associated photographs

What do you **See** here?
What is really **Happening** here?
How does this relate to **yOur** health?
Is it a concern or strength for you? **Why?**
What can be **Done** about it?

Results

Sample Description

Characteristic	Mean	Range
Age at time of enrollment	44.4	39 to 57
Number of years living with HIV	16.4	5 to 23
Number of dependent children living in home	1.4	1 to 2
Total yearly income	\$13,552	\$0 to \$24,000
Years of education	13	11 to 16

- ❖ Participants captured visual representations of the social complexities of their lives and in conjunction with verbal explanations offered detailed descriptions of the impact of those complexities on health at both the individual and community level. Example photograph and text representing participant **vulnerability**:



It's the steps...going outward and that means that I'm going to have to go out into the world It's always a concern ... crossing paths with people that have some negative things to say or whisper or may know me or you know, for whatever reason.

Results

Example photograph and text representing participant **strength**:

That's my van. My van is a strength for me. A lot of people not fortunate to ... come and go as they please. And for me, it helps me with my doctors appointments that's a positive, because I know to be on time. Because I know if you don't be on time, they'll cancel certain things.



- ❖ **Confidentiality issues** specific to mothers, children, and people in their support network created ethical challenges in using photography as a data elicitation technique
 - Only 2 out of 5 participants were willing to have the photos of themselves or their children used in presentations or publications; may reflect the mothers' concerns about disclosure of HIV status and associated stigma
 - 3 out of 5 participants took photographs of identifiable persons other than themselves or their children; these photos were shredded per the study protocol.

Conclusions

- ❖ Participants can express sociological ideas such as social determinants of health through photography, and their images evoke different and more robust information than the interview questions alone.²
- ❖ Photography is an effective method for describing social determinants of health, but requires keen attention to ethical concerns.
- ❖ Piloting photo elicitation research protocols is recommended in order to anticipate and address ethical challenges specific to the population of interest.
- ❖ Based on the findings of this pilot study, the research protocol and informed consent process for the first author's dissertation study were changed such that participants are asked not to take pictures of any identifiable people. Instead, participants are being encouraged to photograph objects (ex. wedding ring, child's toy, etc.) that represent support people or children and the roles they play in the participants' health outcomes.

References

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3. Teti M, Murray C, Johnson L, Binson D. Photovoice as a community-based participatory research method among women living with HIV/AIDS: ethical opportunities and challenges. *J Empir Res Hum Res Ethics*. 2012; 7(4): 34-43.

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