

USING PHOTOVOICE AND PHOTO- ELICITATION METHODS IN VA RESEARCH: ADDRESSING QUESTIONS AROUND ETHICS, PRACTICE, AND MEASUREMENT

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What is your main interest in learning about Photovoice (PV) or photo-elicitation (PEI) methods?

1. I've heard of PV/PEI and wanted to learn more.
2. I'm thinking about using PV/PEI in an upcoming project.
3. I will be using PV/PEI on an upcoming project.
4. I have used PV/PEI, but still want to learn more.

Photo by Drew B., Staff Sergeant, Army, OIF



- ❖ **Why use visual-narrative methods in health services research?**
- ❖ **What are some of the practical and ethical considerations for using PV/PEI methods in participatory research?**
- ❖ **How can we document and measure impact of a Photovoice collaboration?**

Visual data in health research

- Incorporating photographs, maps, illustrations into data collection process and/or interview can:
 - Stimulate new thoughts, memories, awareness
 - Allow for verbalization and/or exploration of sensitive or difficult to articulate topics
 - Build rapport and common understanding between interviewer and respondent
- Yield novel and rich insights rooted in real-world conditions and experiences
- Enhance dissemination of findings, ability to “tell a story”

Photo elicitation interviewing (PEI)

- Originated from Anthropology (Mead and Bateson 1942; Freire 1970)
- Visual data used during interview as mutual focus for interviewer and respondent
- Images may be produced by respondent, or introduced by researcher
- Who controls images and interpretation of images varies— researcher, respondent, both
- Not necessarily embedded in action/advocacy or participatory research agenda

Photovoice (Wang and Burris 1997)

- Community Based Participatory Research
- Use of camera allows participants to record, discuss, and communicate their realities
- Participants as collaborators
 - shared authority and ownership of findings
 - Empowerment, advocacy
 - Dialogic process between researchers, participant-collaborators, and audience
- Dissemination beyond traditional academic products

**PV is an approach
with CBPR
principles
underpinning**

**PEI is a method
that may be used
as part of a PV
collaboration**

**Both require
attention to
special practical
and ethical
considerations
related to visual
data (see Padgett
2013)**



Photo by Chantelle B., Corporal, Marine Corps, OIF

Rationale & Specific Aims for PV/PEI

- Explore lived experiences
 - Elicit rich description of 'hidden' phenomena, sensitive topics
 - Generate person- and community-oriented understanding of gaps in systems of care
 - Develop and evaluate strategies to ameliorate those gaps
- Empower participant-collaborators to articulate needs, challenges, solutions
 - and advocate for change (PV)
- Align goals, strategies, and resources of different stakeholders to improve systems of care
- Dialogic process involving an audience (PV)

Specific aims for study using PEI

Specific Aim 1: Understand and describe experiences and perspectives of transgendered youth related to health, self care, and encounters with health care providers and organizations

Specific Aim 2: Explore relationship between measures of mental and sexual health of transgendered youth and themes represented in photo-narratives

Specific Aim 3: Develop conceptual model to guide implementation of patient-centered care practices for transgendered youth, informed by photo-narratives

Photovoice as an Educational Intervention to Improve Care of OEF/OIF Veterans*

- 40 Veterans ≥ 1 deployment in support of OEF/OIF
- Given cameras, asked to tell their stories with focus on 4 questions:
 - **How does a deployment impact your physical, mental, and emotional health?**
 - **What challenges do you face in making the transition home?**
 - **What are the barriers and facilitators to getting the care you need?**
 - **Where do you find strength and support?**

Photovoice pilot aims

- **Primary Aim:** Establish feasibility of Photovoice as an educational intervention through enrollment of **40 OEF/OIF Veterans** and creation and dissemination of photo-narratives to VA leadership, clinicians, and staff at a VA Medical Center.
- **Secondary Aim:** Explore preliminary effectiveness of Photovoice participation as an intervention to improve post-deployment health outcomes and engagement in health care for OEF/OIF Veterans. Specific outcome variables for this aim include increased health communication self-efficacy and perceived health competency and decreased social anxiety and barriers to care.
- **Secondary Aim:** Explore potential impact of attending a Photovoice exhibit/presentation on employees of a VA Medical Center. Specific outcome variables include number of Photovoice events held, number and type of VA employees attending each event, qualitative comments from VA employees collected through post-event discussion and written remarks.

Participant-collaborators: who and how many?

Will you be building upon prior relationships with community organization(s) or existing group(s)?

- How much is known already?
 - What are goals/scope of project?
 - How much variation in experiences & perspectives is expected?
 - Is it important to ensure representation of diverse experiences & perspectives?
 - What are the constraints of timeline & budget?
- Studies using PV/PEI have been funded and published ranging from N-of-1 (Lorenz 2010) to N=29 (True 2015)

Challenges to defining community & identifying participant-collaborators



Photo by Christopher W. Specialist, Army, OEF

Definition of “community”

Group of people with diverse characteristics, linked by social ties, share common perspectives, & engage in joint action in geographical locations or settings

(MacQueen 2001)

Recruitment and engagement

- Identifying partners & building collaborations/relationship
- Determining roles and responsibilities
- Engaging partners (at different levels of intensity) over time
- Time commitment (of researchers and partners)
- Funding, resources and resource sharing

Photovoice study procedures modified from Wang and Burris model

- **1st visit: one-on-one**
 - Consent, baseline quant data collection, purpose of PV, orientation to project
- **2nd visit: one-on-one**
 - Photo review, recorded interview, consent for use of photos
- **3rd visit: small groups**
 - Review of initial themes, identification of additional themes, select photos, discuss what comes next (exhibit, interview requests)
- **Contact prior to exhibit**
 - Ongoing exhibit planning, review of selected photos/text, preferences for credits, what to expect at exhibit opening
- **Follow-up quant data collection via mail, ongoing contact post-exhibit (>3 years)**

Human subjects' protections

- Confidentiality guided by self-determination, project goals
- Co-ownership of data may raise concerns for IRB/PO/ISO
- Compensation may include camera, photos or SD card, photobook
- Tips:
 - Pay careful attention to default wording of templated documents
 - Be prepared to educate members of IRB, PO/ISO
 - Think of consent as ongoing process

Additional ethical considerations

- Protecting against different types of harm
 - Could photo-text cause harm to individual veteran?
 - Veterans as a community?
 - Audience?
 - Research team?
 - Institution, others (in photos)
- Safeguards and processes for dealing with potentially upsetting or sensitive disclosures
- Acknowledging that power differentials between research partners persist, changing role of different partners
- Accounting for the shifts that come with different venues, new platforms for dissemination

Multiple consent forms and processes for checking in

- Written informed consent
- Consent to be included in photo
- VA consent for use of picture and voice (global release)
- Consent for use of photos in research and dissemination (individual preferences for use of name or pseudonym, withdrawal or use of pseudonym for specific images)
- Willingness to participate in press interviews, dissemination activities
- Ability to withdraw specific images, retain control over inclusion

Interview questions guided by goals

- Wang and Burris: SHOWeD
 - What do you see here?
 - What is really happening here?
 - How does this relate to our lives?
 - Why does this situation exist?
 - What can we do about it?
- Photovoice pilot:
 - Can you tell me the story of this photo?
 - How does this relate to your life today?
 - How does this relate to the lives of people around you?
 - Why do you want to share this photo? What do you want others to learn?
 - What else do you want others to know that is not represented in one of your photos?

Visual-narrative data analysis

- Acknowledge that coding of visual data, photos differ from text
- Incorporate methods and processes for member checking
- Engagement of participant-collaborators essential, but may vary based on goals, scope of project, individual preferences, institutional or IRB constraints
- Different stages of analysis may be guided by short- and longer-term goals, products
- Requires special attention to expectations of different stakeholders, censoring of themes or images, bias towards striking stories or storytellers

Example: Process for Photovoice pilot*

- All photos and transcripts coded using Atlas.ti qualitative data analysis software
- Two-phase, collaborative coding process
 - Phase 1: linking relevant quotations to photos, creating individual photo-narratives, checking accuracy with individual veterans
 - Phase 2: identification of themes and exemplar photo-quote pairs, member checking through group meetings
- Develop innovative dissemination products through consultation and collaboration with different groups

* True et al 2014



Photo by Toby B., Specialist, Army, OIF&OEF

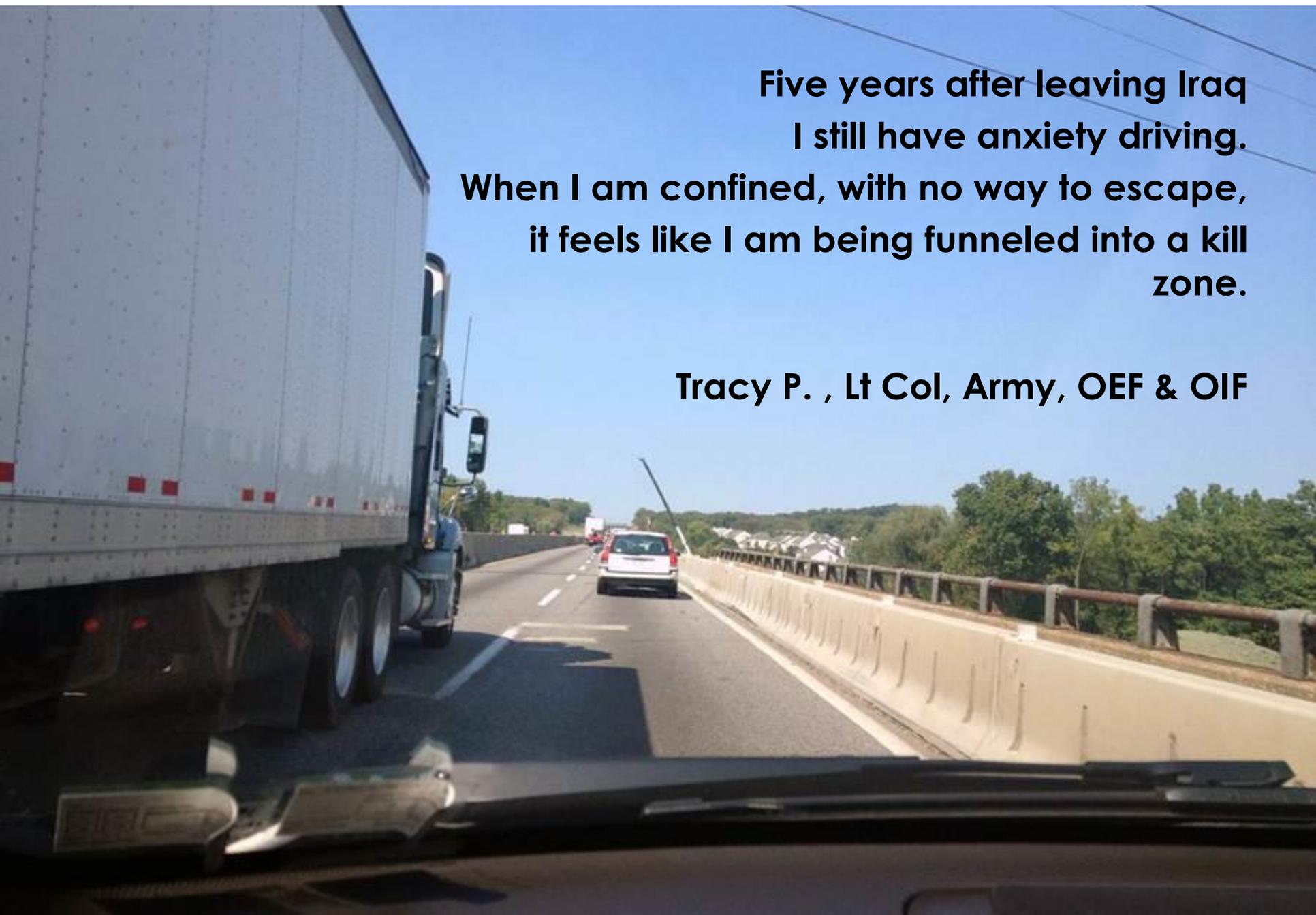


**I have a lot of issues with the things
I should be judged for;
things I did when I was in Iraq.
It's heavy for me,
trying to balance out that bad karma,
or whatever it is that I built over there.**

**The stereotype of a stoic soldier who
is proud and strong and doesn't have
nightmares;
it's wrongly imposed on me.**

**When I think about my time there,
I don't have a welling of pride.
Overall, it was a damning experience.**

Toby B.



**Five years after leaving Iraq
I still have anxiety driving.
When I am confined, with no way to escape,
it feels like I am being funneled into a kill
zone.**

Tracy P. , Lt Col, Army, OEF & OIF

We had a lot of females that got raped. We had males that got raped.

You're in that situation where people don't want to see, don't want to hear, don't want to speak. It's like a triple effect. So, it's not reported.



And when the soldiers come back, they're living with that. A lot of them could lose their job. Seeking help could be a flag in your record. So you have a lot of people who don't want to say.

Raquel R., Staff Sergeant, Army, OIF

Image ethics

- Context in which images are consumed
- Limited control over interpretation
- Photos are static, but people and events are not
- Negotiations over messaging with hosts, press, home institution



Photo by T.C., Sergeant,
Marine Corps, OIF



That was a bad day. There were U.S. Forces staying in a building, and a car bomb detonated out front. We were sent to dig through the mud to recover body parts to send home. I've got a lot of bad dreams from that day. LRD,, Sergeant, Army, OEF

Issues of 'fit' between CBPR, traditional research protocol, and the IRB (see Sieber and Tolich 2013)

Action Research

- Communitarian ethics, critical consciousness
- Responsive to conditions in the field & community needs
- Reflexivity/Relationships
- Collaborators/partners
- Sharing of data and dissemination
- Sustained engagement, varies by individual participant

Clinical Research

- Principle-based ethics
- Timetables based on institutional calendar
- Objectivity/distance
- Subjects
- Protecting PHI, data security
- Controlled dose/intervention, standardization, formal schedules for data collection

Challenges and quandaries beyond the protocol: Lessons from Fieldwork (Wolcott 2004)

Reciprocity

Boundaries

Ambivalence

Professional ethics, personal ethics

Measures to explore potential benefits of photovoice participation

Veteran participants (baseline , 3 & 9 months):

- Perceived Stigma and Barriers to Care
 - 11-item scale developed to assess barriers to care in Veteran populations
- Health Communication Self-Efficacy Scale
 - 6-item scale to assess confidence in ability to communicate health needs and concerns to family, friends and health care providers

Healthcare providers & trainees (post-exhibit/panel discussion)

- Evaluation of impact on knowledge, perceptions, practice
 - 5 sentence-stem completion, 8 Likert-type
- Formative evaluation of spread and sustainability of exhibit travel

Expanding platforms for dissemination & measuring impact

- Exhibits, website, photobook
 - Build on and expand exhibit
 - Joint exhibits and events with community partners
- Audience and community engagement through events, social media
- Empowerment and advocacy
 - For participant-collaborators
 - Impact on policies and processes
- Communication and understanding between dyads
- Art therapy intervention to increase empathy or reduce stigma (Betts and Potash 2015; Potash 2013)

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The views expressed in this presentation do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States government.

Questions?

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www.va.gov/FromWarToHome



Photo by Micky D., Specialist, Army, OIF

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