Talking with Pictures: Envisioning Community Integration of Older Adults with Acquired Brain Injury

Breakout Session

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Outline Today

• My Story in Pictures
• Foundations of Photovoice
• Photovoice Process
• Community Integration – why care?
• Hands-on with Photos and Captions
• Discussion, Q&A, Conclusion
My Story in Pictures
My Story in Pictures
Photojournalist in Africa and India
Photovoice with Girls, Inc. in Lowell, MA
Photovoice with the Youth Academy in Mdantsane, South Africa
Photovoice with the ‘Amazing’ Brain Injury Support Group, Framingham, MA
Including the Perspectives of People Whose Voices Are Often Ignored:

Is a social justice issue
We learn new things:

When we focus our attention on them
Methods that “Talk with Pictures” are Participatory

Participants—individually or in teams—create:

Art
Videos
Photographs
Maps

Today we will focus on a project using photography....
Photovoice projects have had diverse participants...

- Illiterate women in rural China
- Youth—in US and overseas
- Teen mothers
- Homeless
- Medical students and their patients
- **People living with chronic conditions and disabilities**: mental illness, HIV/AIDS, asthma, brain injury, spinal cord injury, tuberculosis, substance use disorders, and disabilities
...& Purposes

• Understand lived experience with health and illness
• Learn/document perspectives of “underserved” groups
• Raise awareness—among community members, policymakers, patients, etc.
• Inform or initiate action – individual or group
• Promote healing—of individuals & communities
• Identify POSITIVES as well as NEGATIVES in communities and lives

With Photovoice participants can “see” talents, strengths, problems, and feel energized, empowered, heard

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From a “Talking with Pictures” participant...

• Video clip of a “Talking with Pictures” participant
What is photovoice?

➢ A group process of community and personal reflection using photographs and captions

➢ Consciousness-raising education

➢ Dialogue with policymakers, peers, clinicians, and self (reflection)

➢ Representing experience and producing knowledge through images and text

Looking at a situation through the camera can prompt new thinking and understanding
A Photovoice Path

1. Learn about Photovoice
2. Take photographs
3. Discuss photographs & reflect on experience
4. Write or dictate narratives
5. Option to choose photos for sharing
6. Option to invite people to share in discussion
7. Option to present & exhibit
8. Reflect & move forward

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Setting the Stage: Photovoice as...

- Participatory Action Research
- Person-Centered Care/Person-Centered Research & Narrative Medicine
- Education, Identity Development, Empowerment—for prevention and healing
What is PAR?

• Social investigation of problems
• Participation of “subjects” as researchers
• Educational process for ALL participants—clinicians, patients, researchers, communities
• Collective action toward social change

Photovoice can be a type of PAR – especially when participants help determine the research question and focus
Freire: Critical consciousness

“The fact exists; but both the fact and what may result from it may be prejudicial to the person. Thus, it becomes necessary, not precisely to deny the fact, but to ‘see it differently.’” (Freire, 2000)

With the photo:
- We “see” our situation differently
- We can discuss experiences more easily with others
Health Care: Person-Centered Care Needs

Person-Centered Research

• An individual’s experience of illness and health care is a determinant of quality (IOM, 2001)
  ✓ What outcomes do people care about?
  ✓ How do people live with chronic conditions in their daily physical, psychological, and social environments? (Rich et al, 2000)

• The health-care system needs new conceptual approaches (NIH, 1998)

• Clinicians (and others!) need to elicit and listen to stories (Charon, 2006)
What People Think and Feel Matters

• Research to understand individuals’ perspectives may:
  
a) “maximize relevance and impact of the research to their real-life situations” (Bruyere, 1993)
  
b) result in “medical care that is more responsive, sensitive, and effective” (Rich & Patashnick, 2002)
  
c) allow people with disabilities to be “competent participants” in research (Booth, 2003)
“The disorder that I’m living with right now”

“Truth” versus “Narrative truth”
Community integration—why care?

- In 2014, the Centers for Medicare and Medicaid Services (CMS) issued ruling to enhance quality care for people with disabilities through a greater focus on participation in community life.
  - This ruling followed the stage set by ADA in 1999 and ICF in 2002.
  - Community integration/participation of people with disabilities is now a universal norm.
What is community integration?

An ongoing process of adaptation throughout life that ebbs and flows (Reistetter et al, 2005)

Having something to do, somewhere to live, and someone to love (Jacobs, 1993)

Access to opportunities to obtain residence, maintain a social support network, and engage in productive activity in the least restrictive environment possible (Dijkers, 1998)
“Talking with Pictures” in Lexington, MA

Project purpose:

“Let’s break down our barriers and silos and create a community where all members enjoy freedom and choice, human interaction, and meaningful things to do.”

The Photovoice Group
“Talking with Pictures” in Lexington, MA

Participants
- 5 Lexington residents aged 53-69
- 3 Student interns
- 1 Facilitator

Stakeholders
- Cary Memorial Library
- Lexington Senior Services
- Council on Aging
- Church of Our Redeemer
- Minuteman Senior Services
- Commission on Disability
  • And YOU!

Sponsors
- Supportive Living, Inc.
- SLI Brain Injury Wellness Center
- Dana Home Foundation
- Brandeis University (IRB, Intern)
- Boston University (Interna)
| **Got acquainted** | Discussed community integration  
| **Learned about research ethics** |  
| **Learned how to use the camera** | Took photographs – sometimes with assistance  
| **Shared photos and experiences** | Heard the emotion of exclusion and inclusion  
| **Invited small group to view our work** |  
| **Wrote or dictated captions** | Chose some photos for exhibit  
| **Exhibited at local library, local community center, and a state-wide policy forum** |  

**Impact:** Walkway entrance to City Hall rebuilt (twice!) to be more accessible  

**Ongoing:** Bring concerns and rights of people who have disabilities to the attention of the community

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Interactive Exercise with Study Photos

Purpose: To gain hands-on experience with

- Reading photos
- Considering photos and text
- Reflecting on relevance (if any) to your life, community, or work
Exercise Guidelines

On your own, with a partner, or in a small group:

• Review photo and discuss/reflect
• Uncover caption and discuss/reflect
• Reflect on the meaning (if any) of the photo from your perspective
• “Write” a new caption – that is relevant to your experience with community integration
• Share in plenary (optional)
Interactive Exercise with Study Photos

• What was your experience with this exercise?
• Did anything surprise you?
Discussion, Conclusion, Q&A
Participants’ data in a CI framework

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How do the data expand our understanding?

CI concepts overlap

Independence needs relationships

Meaning varies

Meaningful Things to Do

Independence

Relationships

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What if anything is Photovoice useful for?

(from the literature)

• **Activism/action**—plant a seed
• **Identity**—understand self
• **Learn by doing**—deeper learning (skill building)
• **Empowerment**—work in a group, connect
• See diverse members of society as **resources**; and provide an opportunity to have a **voice**
• **Visual literacy**—learn to read images (a life skill)
[After 4 years of rehabilitation] I was like a bird hatching and ready to leave the nest to try a new beginning. Did I have the courage to fly on my own? I sure was scared. Now I know I can soar, yes I “can”. --Individual with TBI, Northern Virginia
Co-participants can be transformed by Photovoice; co-participants include all of us...
Photojournalism raises issues from “outsider’s” perspective
With photovoice, “insider” perspective takes precedence

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With photovoice, we can recognize challenges and strengths.

We can bridge our differences and work together toward common goals.
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