



Generating Patient Accounts of Quality Using Photography & Voice: Considering Methods



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Goal Today

Show some benefits and challenges of using participatory visual research methods to:

- **Generate patient visual illness accounts of their health and healthcare experience**
- **Uncover hidden information about quality**
- **Inspire mutual learning among researchers, providers, and patients**
- **Challenge our assumptions**



Glossary

Acquired Brain Injury (ABI): An injury to the brain that occurs after birth and results in deterioration of brain function

Traumatic Brain Injury (TBI): Harm or damage to the brain caused by a sudden jolt, blow or penetrating head trauma that disrupts brain function

Lived experience: An understanding of the nature or meaning of our everyday experiences

Participatory visual methods: Research in which participants produce visuals related to their experiences and lives

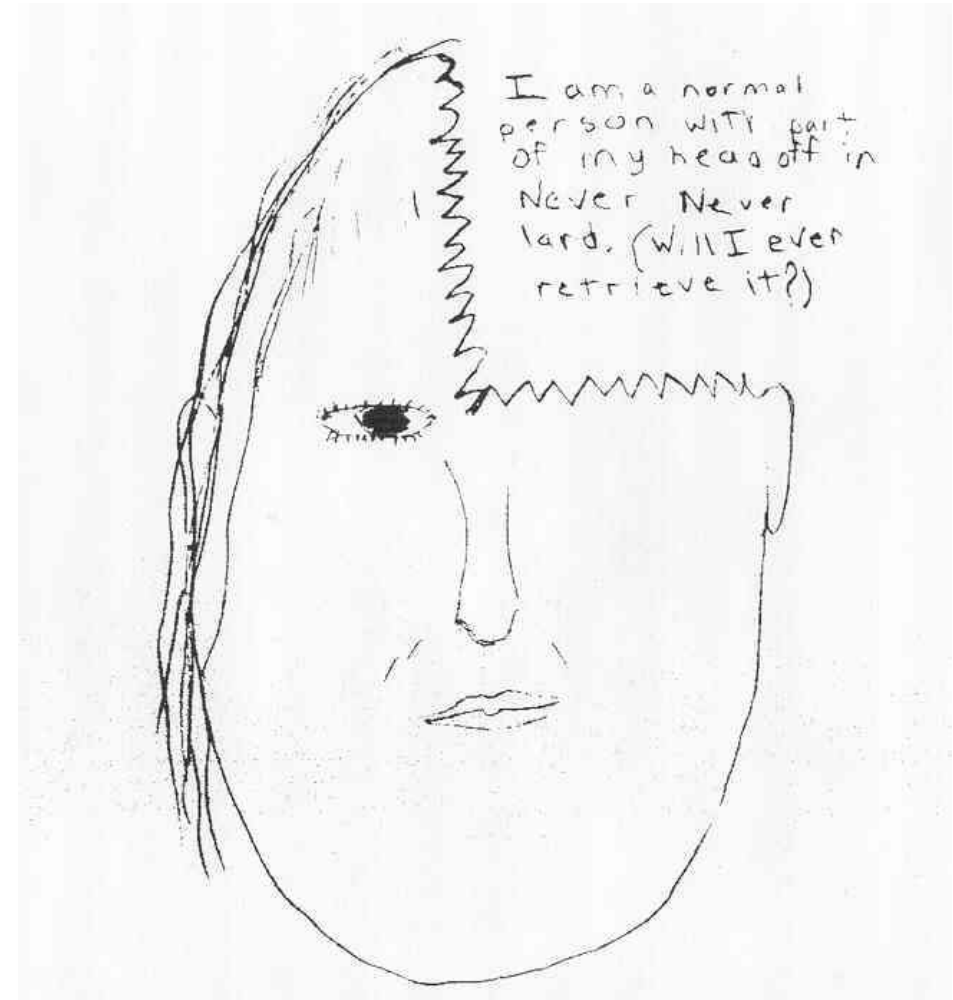


My Background





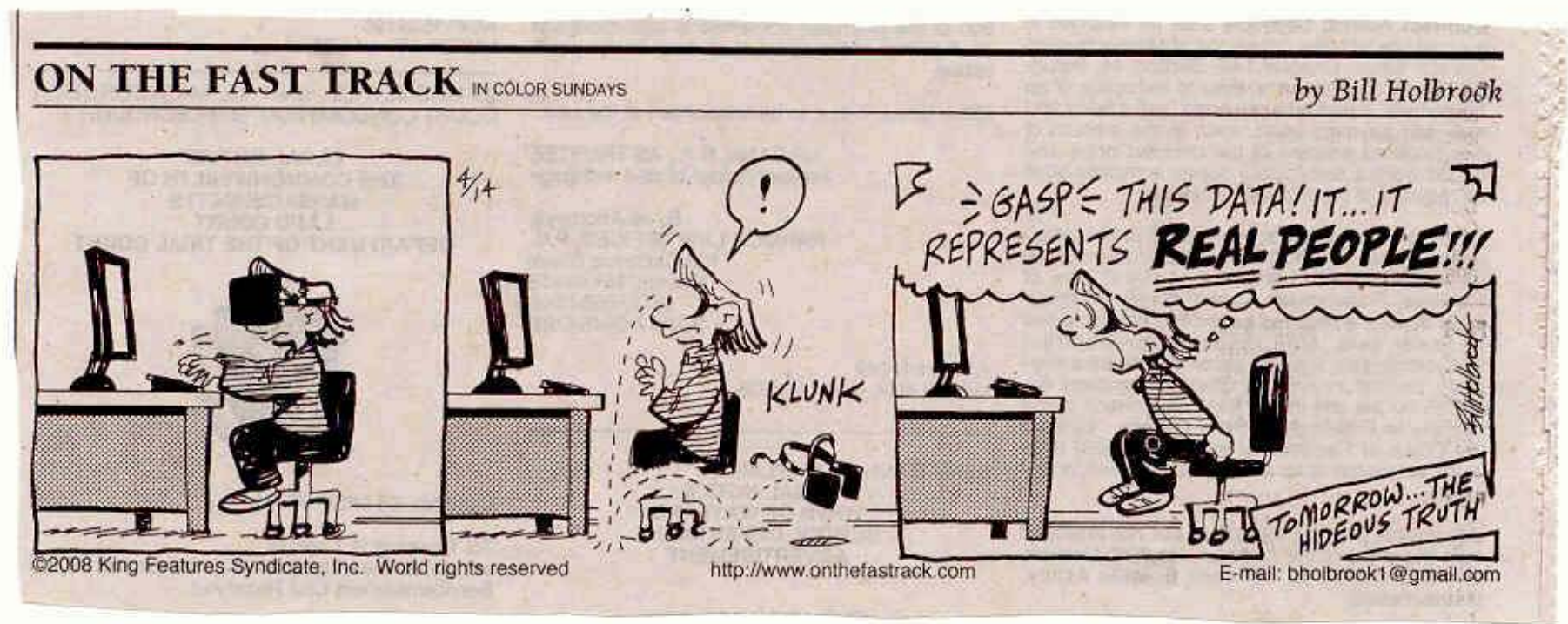
Inspirations



Prigatano, 1989



Including Survivors' Perspectives:



A Social Justice Issue

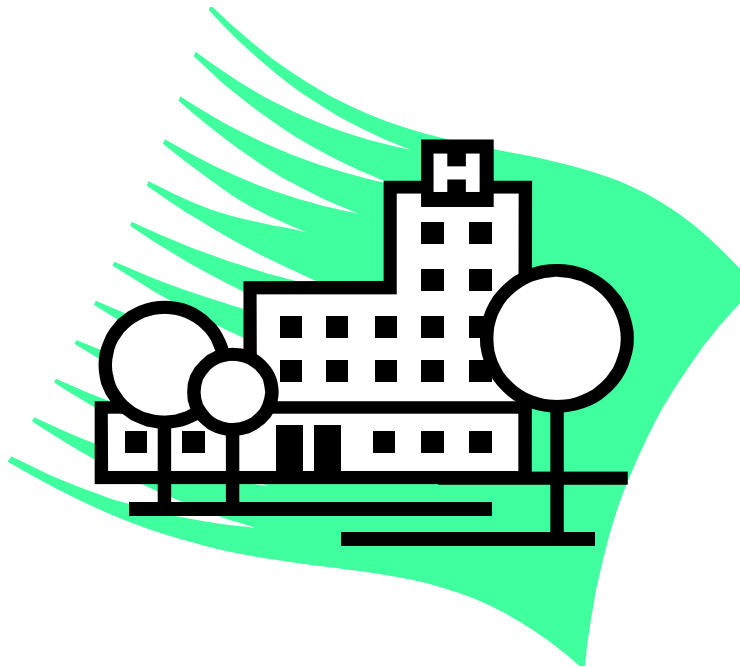


Study Purposes

- 1)** Elicit and understand quality of care from the perspective of brain injury survivors
- 2)** Promote researcher-participant dialogue about living with brain injury
- 3)** Uncover new knowledge about personal, practice, and policy issues related to brain injury
- 4)** Provide an opportunity for participants to reflect on their situation and use their brains



Sample: 14 ABI Survivors



**6 TBI survivors
accessing outpatient
services at a
rehabilitation hospital**

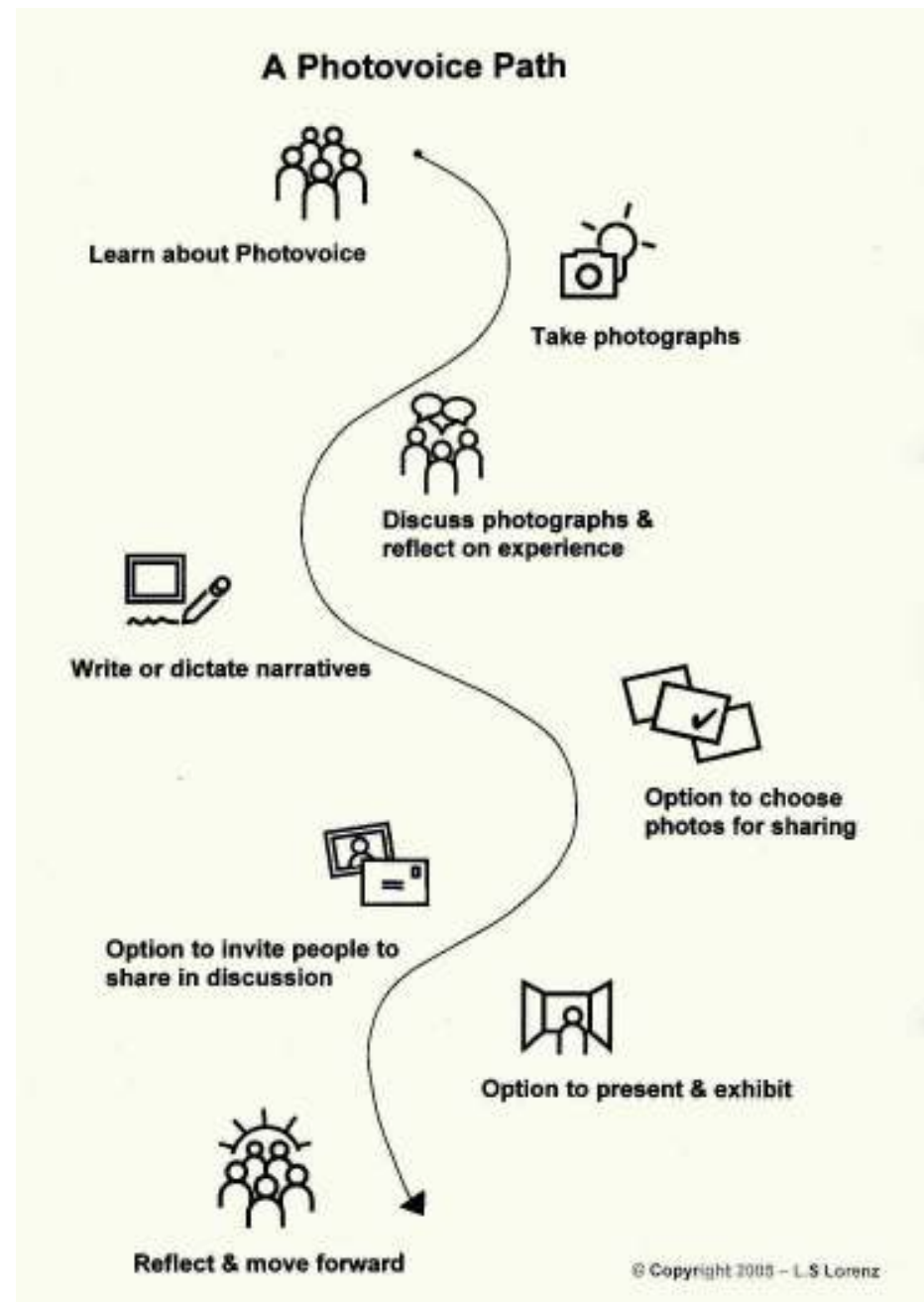


**8 members of a brain injury
survivor support group
supported by BIA-MA**



Photovoice (& Photo- elicitation)

ask people to
represent their lives,
point of view and
experience using
photographs and
narratives (Wang &
Burris, 1997)





Participant Photo-taking Practices

- Study used disposable cameras with 27 exposures each
- Each participant used 1 to 3 cameras and took between 15 and 50 photos
- Photo content was emphasized over artistic quality
- Some participants contributed family snaps
- Some gave the camera to others

Making Visible the Invisible: Using Photovoice to Understand Living with Brain Injury

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Abstract. Rehabilitation professionals have advocated for gaining an insider or patient perspective on living with disability, including brain injury, and facilitators and barriers to rehabilitation (Pigatano, 2000). Involving people with a disability in research about their lived experience may increase the relevancy of research to real-life situations (Roh et al., 2000) and provide an opportunity for those with a chronic condition to play a participant-expert role in the research process (Booth & Booth, 2003; Bruyere, 1993; Bolcazar et al., 1998). Action research in the tradition of Kurt Lewin involves integrating science and social practice (Adelman, 1993). For this study, carried out from September-November 2006, members of the 'Amazing' Brain Injury Survivor Support Group in Framingham, MA participated in a 10-week photovoice project (Wang, 1996), supported by BIA-MA and SHP. The participating survivors took photographs of living with their brain injury, discussed them in a group, wrote narratives to accompany selected images, and prepared an exhibit to inform and educate policymakers, providers, and peers. Grouped under nine categories, including Chaos, Strategies, and Hope for the Future, the images and narratives convey these survivors' challenges and sense of mutual support as they work to accept their different abilities and move on with their lives.

Research Objective. To gain an understanding of lived experience with brain injury and the issues, concerns, and strengths of brain injury survivors living in the community, while providing an opportunity for survivors to reflect on their lives, use their brains, and employ a variety of cognitive skills.

Sample. The participants are members of the 'Amazing' Brain Injury Survivor Support Group, which meets twice a month at the MetroWest Wellness Center in Framingham, MA. Eight members volunteered to participate in the study. All are long-term survivors, having received their injuries between three and 31 years prior to the start of the project. Six are traumatic brain injury survivors, one had a malignant brain tumor, and another had a non-malignant brain tumor with co-occurring stroke.

Study Design. This was a participatory action research study using photovoice, a type of action research in which people represent their lives, points of view, and experience using photographs and narratives (Wang et al., 1995). Action research in the tradition of Kurt Lewin involves integrating science and social practice in a dynamic group setting (Adelman, 1993). The first author, a doctoral student with extensive photovoice experience, co-facilitated this project with her two co-authors: the support group founder and a group member with photovoice experience.

The photography and discussion phase lasted 10 weeks, from September to November 2006. Using disposable cameras with 27 exposures, the participants took photographs of living with brain injury from their perspective and discussed them together as a group. They wrote narratives for images that they selected for exhibit, and grouped their photographs and narratives into nine categories. They held a final exhibit and reflected on their experience with this project. The group initiated an outreach phase in January 2007, and their efforts are ongoing.

Principle Findings. Taking photographs triggered participant reflection on their situation and what they wanted to convey to others about living with brain injury. Talking about their photographs with the group prompted deep discussions of emotional (and other) issues that had not surfaced during regular support group meetings. The participants' images and narratives convey their challenges and sense of mutual support as they work to accept their different abilities and move on with their lives. Study data indicate that from the perspective of these survivors, healing from brain injury is a gradual process that continues for years.

Conclusions. This research project provided the participating brain injury survivors an opportunity to play a participant-expert role in the research process (Bolcazar et al., 1998; Bruyere, 1993). The outreach phase is providing new opportunities to use prior experience with communication, layout, and group dynamic skills in a supportive environment. Participating in this study became a meaningful experience for participants and facilitators alike.

Implications for Policy and Practice. Rehabilitation professionals have long advocated for gaining an insider or patient perspective on living with disability, including brain injury (Pigatano, 2000). Involving people with a disability in research about their lived experience may increase the relevancy of research to real-life situations (Roh et al., 2000).

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The Journey

It's a muddy, rutty, hand-and-knees crawl up to the first rung of the ladder that begins to make some semblance of sense—and then you get to begin to really struggle. The climb does not end and will not end... Sometimes weekly, and sometimes daily there is a new step to attempt to get to your "new self". You can't even ever hope to get back to your "old self". Oh well! Maybe there will be a good view on the journey that I hadn't expected.....



Lost Dreams

...this picture symbolizes what living with brain injury can be like... On an overcast day... I gazed up at the sky and took this picture through a tube... In the minds of many of us there are thoughts that we will never achieve some of the dreams we once held so dear...



Chaos

I feel chaos. I know the desire to be more able. I procrastinate...I make no time for completing my tasks...I watch cable television or displace so I don't have to deal with what I should be doing. This is the piano that I should and would love to learn how to play, I must practice.



Challenges

...Imagine you will trying to run an errand... The longer you wait, the more you get members. These images parallel how each and every day of my life begins since I suffered my brain injury. I seem to spend a whole lot of time getting nothing accomplished.



Strategies

To compensate for my poor memory and organizational skills, I tend to put labels on everything in my house. Where are my books? Which of these is my schedule book? On which shelf did I put my Bible? These labels are necessary 3 years after my accident and probably for many years to come. It is painful to remind myself about all of the brain power which I lost at the time of my car accident.



My Advocacy Story

These are my contacts at Made My Independent Living Center. They helped me to focus by bringing me to the statehouse to talk to my Senator and Representatives.



Comfort and Support

With TB certain parts of my life have added much comfort and support. God has blessed me with Teddy and Betty Marie. They welcome me home with hugs and shares, we sit together, they sleep beside me and make their noise into my neck and face to gently wake me in the morning. They delight me with their personalities and antics. They warm my heart and comfort me. They make me smile and laugh. God has blessed me with a little glimpse of heaven.



Acceptance

Where's grass is dirt? Surely it's not mine this is not my lot, is it? I need to make the best of this situation, but how? It's all suddenly complex now. This was not my doing, but my choice? I'm trying to be genuine. I need to accept this death of my "old self".



Hope for the Future

New identity. New passion of gardening. First baby step was planting in containers so as to not fall over and dislocate or fracture. My garden has progressed as my new life has. Now I not only can plant in the ground, I dig up grass and now have three perennial gardens.

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Photovoice as research

See their photovoice exhibit on www.brainline.org



**Photo-elicitation
Case Study:
“Judy”**

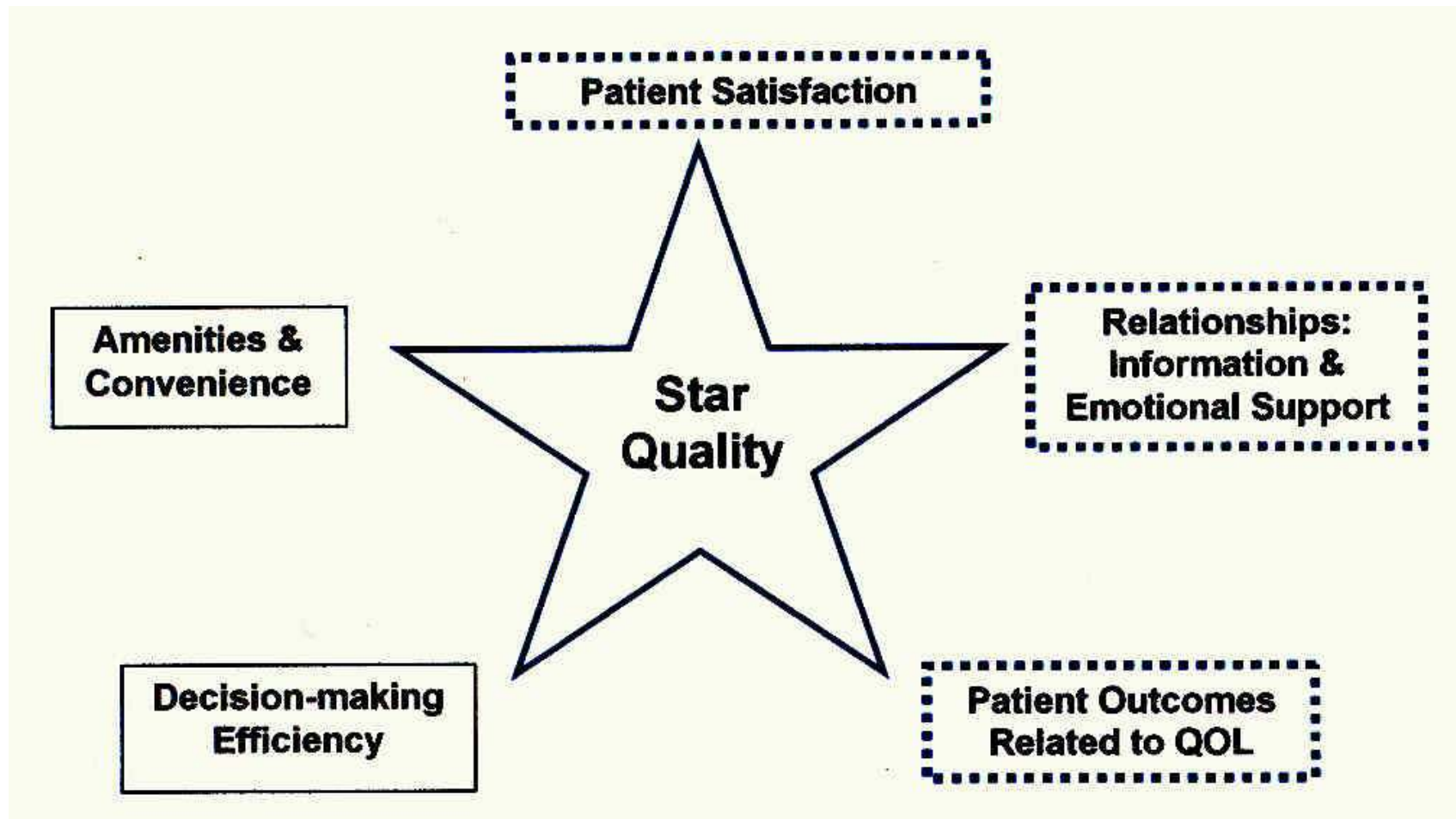
**“These are all my
brain injuries”**

**The photo and
what she said
about it illuminate
a problem AND a
resource**





A Patient's View of Quality





Connecting Patient Accounts to Quality

Photography makes a patient account vibrant while surfacing hidden information about vulnerabilities, experience with poor coordination, and effectiveness of post-acute care.

Amenities & Convenience

Patient Satisfaction



Relationships: Information & Emotional Support

Decision-making Efficiency

Patient Outcomes Related to QOL

Judy's pill box describes a confusing health care system, with silos of care, conflicting instructions, and poor coordination. The image reveals the importance of coordination, and "smarter" pill dispensers designed to alert patients to variances and monitor patient adherence.





Connecting Patient Accounts to Quality



Judy's account reveals that confusion about her pill regime was resolved in collaboration and coordination with her PCP—an example of a good patient-provider relationship

Judy has faced brain injury and poor quality of care and found new meaning and purpose in life

Taking photos allowed Judy to communicate her experience and her road to healing



Challenge: Off-topic Photos



O'Hare Airport in Chicago – People in their own worlds waiting for their planes. We are all waiting for a better flight and good times.



Challenge: Appealing to “Non-readers”

Lost Dreams



...this picture symbolizes what living with brain injury can be like....On an overcast day...I gazed up at the sky and took this picture through a tube. ...In the minds of many of us there are thoughts that we will never achieve some of the dreams we once held so dear...



Challenge: Permission

To compensate for my poor memory and organizational skills, I need to put labels on everything in my home. Where are my socks? Which of these is my schedule book? On which shelf did I put my Bible? These labels are necessary 3 years after my accident and probably for many years to come. It is painful to remind myself about all of the brain power which I lost at the time of my car accident.





Questions for the Future

- Can patient visual illness accounts test the premises of care being delivered?
- Are clinical assumptions consistent with patient visual accounts and clinical evidence?
- Where should visual accounts be stored, and what should be done with unused photos?
- Can visual tools become part of clinician training to realize the value of the patient's perspective?
- Is it ethical to separate photos and text?



So What?

- Photovoice results in shared experiences: An “interpretive account” of living with brain injury
- Patients use visual accounts to make sense of their experience—and to teach us
- Visual methods can help us to see patients’ lives in a different way—sympathetic and respectful
- Perhaps visual accounts can unite patients and providers in a more collaborative effort to achieve rehabilitation goals



Thank you!

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