Using Fair Process to Cross the Quality and Health Care Chasm:

Eliciting the Perspective of Brain Injury Survivors

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Abstract

Traumatic brain injury (TBI) is a serious public health problem in the U.S., with 1.4 million new injuries diagnosed each year, and 80,000 to 90,000 new long-term disabilities. The Institute of Medicine’s Quality Chasm report calls for providing patient-centered care that reflects patients’ values, preferences, and expressed needs. Yet brain injury can affect many aspects of a survivor’s life, from cognitive functioning, to emotional, psychosocial, and physical well-being, ability to work and participate in the community, socio-economic status, and perception of self. These consequences pose challenges to including the brain injury patient’s perspective in treatment decision-making processes and quality improvement efforts. This study used the participatory research method photovoice with eight adult brain injury survivors between the ages of 40 and 60 who represented their lives, point of view, and experience using self-generated photographs. They discussed their photos together in a group, wrote personal narratives for selected images, and grouped their photos and narratives into nine categories: The Journey, Lost Dreams, Chaos, Challenges, Strategies, My Advocacy Story, Comfort and Support, Acceptance, and Hope for the Future. Taking photographs engaged survivors in reflecting on their situations and encouraged dialogue. Talking about photographs prompted deep discussions of emotional issues and fostered a sense of shared learning. The project opened opportunities to understand and incorporate brain injury survivors’ perspectives on quality of care into rehabilitation approaches. This presentation will use participant photographs and narratives to explore lived experience with brain injury.

Key words: fair process, organizational behavior, brain injury, patient-centeredness, qualitative research, participatory action research, photography, visual methods, photovoice
Background

An acquired brain injury (ABI) is any brain injury received after birth and includes injuries from brain tumors, strokes, and TBI, which is an injury to the brain caused by a force or shock to the head. Traumatic brain injury (TBI) is a serious public health problem in the U.S., with 1.4 million new TBIs diagnosed each year. The major causes of TBI in the U.S. are car accidents, falls, and violence. An estimated 5.3 million Americans are living with disabilities resulting from TBI, and 80,000-90,000 people join their numbers each year (Langlois et al, 2005; Langlois et al, 2004).

Brain injury frequently affects many aspects of a survivor’s life, from cognitive functioning, to emotional, psychosocial, and physical well-being, self-esteem, ability to work and participate in the community, socio-economic status, and perception of self (Chamberlain, 2006; NIH, 1998). Even a brain injury diagnosed as “mild,” indicating that any loss of consciousness was brief, may have serious, long-term consequences. For example, ABI survivors may have trouble focusing or concentrating, have short-term memory problems, and get easily frustrated by these challenges. They may tire easily, impinging on their ability to work. Yet brain injury may not be apparent either visually or clinically. Often, survivors look the same as ever—it is on the inside that they are different, and their injury is invisible.

In Crossing the Quality Chasm, the 2001 Institute of Medicine (IOM) report on quality and health care, one of six areas that the authors target for improvement is patient-centeredness: “the patient’s experience of illness and health care and the systems that work or fail to work to meet individual patients’ needs” (p. 48). As the IOM report notes, an important dimension of patient-centered care is respect for patient’s values, preferences, and expressed needs.

One aspect of person-centered care is the outcomes that an individual may hope or aim
for. “Personal outcomes are the expectations that people with disabilities have for their lives, including what they expect from the services and supports they receive” (National Center on Outcomes Research, 1999). Yet providers may focus on the empirical knowledge that they bring to the clinical encounter and find it challenging to comprehend the “social and symbolic environment” that inevitably influences the patient’s “intersubjective knowledge” and health decision making (Rich, Lamola, Gordon, & Chalfen, 2002). Physicians may “lack the capacities to recognize the plights of their patients, to extend empathy toward those who suffer” (Charon, 2001, p. 1897). However, person-centered care can lead to better outcomes. Expressions of empathy for the patient and his or her illness experience can have a positive impact on health through the “social engagement of emotions” by the patient and a reduction of stress hormones (Adler, 2002, p. 883).

Providing person-centered care may be a particularly urgent issue for persons with ABI, for whom each brain injury and each path for healing is different. Traditional models of rehabilitation “are underpinned by medical principals of cure” (Burton, 2000, p. 301). However, the social dimensions of brain injury recovery and rehabilitation are gaining increasing attention (Burton, 2000), and it is the social dimensions of brain injury that may be most important to the survivor, especially after the acute rehabilitation phase.

The Quality Chasm report does not specify how providers and organizations can take steps to understand patient values, preferences, and expressed needs. Nor does this important report provide guidance on how to translate future understanding about the patient’s perspective to quality improvement efforts. For the patient, quality is experienced at the micro-level of the organization, in the patient-provider interaction. It is at this micro level that we must consider justice in health care and conceptualize and apply learning about the patients’ perspectives to
cross the quality and health care chasm. One way to improve patient-centeredness is to consider justice in the patient-provider interaction, which illuminates the importance of the patient-provider relationship and leads us to reconceptualize both outcomes and processes of care.

A Patient-Centered View of Quality: Satisfaction, Relationships, and Outcomes

From a patient perspective, quality is not a simple concept but is best understood in terms of five dimensions: *technical outcomes* in terms of quality of life; *decision-making efficiency* in terms of efficient routes to health; *amenities and convenience*; *information and emotional support* (relationships); and *overall patient satisfaction* (Chilingerian 2004). This five-pronged concept of quality from the patient’s perspective is illustrated in Figure 3: Star quality, a patient-centered view. The quality dimension of relationships may be improved through empathetic listening and considering the ABI survivor’s life-context. Other dimensions, such as amenities and convenience, are organizational and systemic issues with which clinicians as well as patients may struggle. For example, visit limits of 15 minutes have been described by physician Gretchen Berland as examples of “our dysfunctional health care system” (Berland, 2007).

Failure to include these five aspects of quality from the patient’s perspective can be considered a justice issue (van den Bos et al, 1998).

Figure 3: Star quality: A patient-centered view
Failure to consider quality from the patient’s perspective is also an organizational issue. Kim and Mauborgne (1997), in their seminal study of fair process in corporations, noted that people care about outcomes, but “they also care about the processes that produce those outcomes. They want to know that they had their say—that their point of view was considered...” (p 65). Kim and Mauborgne’s research with 19 companies found a direct link between organizational processes, attitudes, behavior, and performance. As shown in Figure 4: Two complementary paths to performance, Kim and Mauborgne argue that procedural justice in the form of fair process leads to trust and commitment, voluntary cooperation, and exceeded expectations. Applied to health care for chronic conditions, such as traumatic brain injury, examples of exceeded expectations might be increased functionality, greater community integration, or continued progress in healing over time.
Fair Process and the Patient-Provider Interaction

In health care organizations, fair process occurs at the patient-provider interaction. Fair process at this level is interactional, informational, and procedural justice. Conceptually, fair
process opens the door to bringing the patient’s expertise into the work of developing health care goals and strategies.

Chilingerian (2006) and van der Hayden (2004) describe some key elements of fair process. Fair process engages patients in the care process to help analyze the patient’s situation resulting in a framing of the problems, explores and narrows the list of diagnostic issues, treatments, and therapies, explains the rationale for decisions, sets expectations about patient-provider roles and responsibilities, and implements a care plan with an eye toward prognostic evaluation and mutual learning.

In the patient-provider interaction, fair process builds relationships and trust. Fair process is circular rather than linear, as engagement, exploration, and explanation may occur simultaneously and in any order as patients and providers work together to explore challenges and find solutions. Each interaction becomes a new opportunity for mutual learning and engagement.

The fair process model focuses on relationships in health care. With this model, the “normal” quality improvement solutions—more time with patients, or marginal changes in incentives for example—are not necessarily helpful. Rather, improving the provider-patient relationship and bringing a different expertise into the interaction are what may make the difference.
In order to be holistic, the concept of healing from brain injury needs to include the survivor’s perspective (Chamberlain, 2006). Yet the cognitive challenges related to brain injury may impinge on survivors’ abilities to reflect on their situation, develop their ideas, and communicate with providers and policy makers. These challenges require a creative approach to eliciting the brain injury survivor’s perspective on their experience of illness, healing, and health care. One solution is to put cameras in the hands of brain injury survivors and provide an opportunity for survivors to reflect on their lives, take photographs of their situations, and use their photographs to communicate their challenges and strengths to professionals and peers.

*Visual methods in research.* In a seminal 1957 study, the visual anthropologist John Collier compared the quality of data gathered by interviewing alone and by interviewing using photographs as prompts. Collier states that the interviewees provided more concrete information
with the photographic prompts. The pictures helped respondents to stay on track, relieved the strain of being questioned, sharpened memory, and reduced misunderstanding. Salient to brain injury survivors, Collier suggests that photographs may help to “trigger responses that may lie submerged in verbal interviews,” “overcome the fatigue and repetition encountered in verbal interviews,” and “function as a language bridge with informants who lack fluency” (Collier, 1957, p. 854, 857, and 858 respectively).

In the past ten years, studies carried out through Children’s Hospital Boston with adolescents with chronic conditions have found that asking patients to create visual illness narratives using video “reveals hitherto inaccessible information about the life contexts in which patients try to manage their chronic conditions” and provides increased opportunities for clinicians to incorporate patient knowledge and experience into “management plans that are sensitive and responsive to patients’ everyday lives” (Chalfen & Rich, 2004, p. 25).

These types of visual methods work with groups as well as in one-to-one interactions. Since 1991, participatory action projects around the world have used the methodology photovoice, a type of action research that involves asking participants to represent their lives, point of view, and experience using photographs and narratives (Wang et al., 1996). Action research in the tradition of Kurt Lewin involves scholar-practitioners integrating science and practice in a dynamic group and organizational setting (Adelman, 1993). Action research is a systematic investigation carried out in collaboration with people who are affected by a particular issue, in this instance, living with brain injury.

Action Research Using Photovoice with Brain Injury Survivors

In 2006, I carried out a 10-week photovoice project with eight members of the ‘Mild’
Brain Injury Survivor Support Group in Framingham, MA, one of a dozen brain injury survivor support groups throughout the state that receive funding and other support from the Statewide Health Injury Program (SHIP) of the Massachusetts Rehabilitation Commission (MRC) and the Brain Injury Association of Massachusetts (BIA-MA). Two brain injury survivors co-facilitated this project with me: Barbara Webster, the support group co-founder and facilitator, and Laura Foley, who participated in a small photovoice pilot study with me.

During the spring and summer of 2006, Barbara, Laura F. and I planned the project. We developed a session outline and budget, and decided how best to adapt photovoice to brain injury survivors. We each took on vital roles: Barbara as a grounded, discerning facilitator who knew what would work and what wouldn’t with survivors, Laura F. as a survivor who had hands-on experience with photovoice, and me, Laura L., as a visual researcher, an adult educator and instructional designer, and a photovoice facilitator since 2001. Together we determined the study purposes, to 1) provide an opportunity for participants to a) reflect on living with brain injury and their progress in dealing with this major life change, b) use their brains in new ways, and c) employ a variety of cognitive skills, 2) raise awareness about brain injury and 3) help professionals and policymakers understand ways to support healing from brain injury.

Eight members support group members volunteered to participate in the photovoice project, an optional support group activity. They are all in the 40s and 50s, have a recognized disability from brain injury, and are actively seeing social and practical support in a group setting. All were injured between three and 31 years ago and are high functioning: At the time of the project, more than half were working part time or volunteering in their communities. They travel to group meetings from a wide range of communities: Boston, Framingham, Hudson, Natick, Newton, Medfield, and Wayland. Most drive their own cars; some use the personalized
public transportation program called “The Ride.”

The study followed the photovoice methodology as modeled by Wang et al (1996) in a seminal photovoice study with rural women in China. After discussing the ethical issues related to being visual researchers of their own lives, in their homes and communities, participants learned how to operate the disposable cameras provided by the study. They took photographs of living with brain injury from their perspective and selected some for discussion with the group. They wrote narratives for their selected images and created an exhibit of 50 self-generated photographs and written narratives grouped into nine categories, from The Journey, to Chaos, Strategies, Acceptance, and Hope for the Future. They tested out their exhibit in November 2006 for the wider support group and invited guests, and reflected on their experience with this project. They initiated an outreach phase in January 2007, and a key activity was to present their finalized exhibit of 50 photographs and written narratives at the BIA-MA Annual Conference in March 2007. Another has been to participate in a training workshop for facilitators of other brain injury survivor support groups throughout Massachusetts. They have presented their exhibit at two public libraries in Massachusetts and have several future exhibits planned, including one with at the Statehouse in March 2009.

The following section, “Brain Injury X-Posed: The Survivor’s View,” provides an example of one photograph and narrative from each of the nine exhibit categories. These examples include at least one photo from each of the eight participating survivors.
Category: The Journey

Maybe there will be a good view

It’s a muddy, rutty, hands-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 and will not end. There is no final healed bone or mended tear of the skin to get over. 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 this journey that I hadn’t expected........

Category: Lost Dreams

A light at the end of the tunnel?

... 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…
I feel chaos. I leave the dishes to be done later. I procrastinate... I make no time for completing my tasks.... I watch cable television or daydream 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.

Category: Challenges

Trying to run on ice

...imagine yourself trying to run on ice.... The faster you run, the more you get nowhere. 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.
**Category: Strategies**

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.

**Category: My Advocacy Story**

They helped me

These are my counselors at Metro West Independent Living Center. They helped me to focus by bringing me to the statehouse to talk to my Senator and Representative.
Category: Comfort and Support
They make my heart sing

With TBI certain parts of my life have added much comfort and support. God has blessed me with Teddy (part Corgi) and Betty Marie (full bred, Jane Russell Terrier).

They welcome me home with hugs and slurps, we eat together, they sleep beside me and muzzle their noses 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.

Category: Acceptance
I need to accept this death of my “old self”

Whose grave is this? Surely it’s not mine. This is not my fate, it is? I need to make the best of this situation, but how? ...This was not my doing, nor my choice! I’m trying to be gracious. I need to accept this death of my “old self”.
Category: Hope for the Future

New identity

New Identity. New passion of gardening. First baby step was planting in containers so as to not fall into dirt because of imbalance. 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.

Discussion

The participating survivors played a participant-expert role in this research into lived experience with brain injury (Booth & Booth, 2003; Bruyere, 1993; Balcazar et al, 1998). The outreach phase is providing new opportunities to use prior experience with communication, layout, and group dynamic skills in a supportive environment. Many participants shared their binders of photographs and narratives with providers, family, and friends and found them useful for showing others what is happening “inside my head.”

They state that their rehabilitation goal is healing, not recovery. They see healing as cognitive, physical, emotional, and even spiritual. For them, recovery implies a narrower definition, limited to physical and cognitive aspects, and implies a desire to return to a pre-injury
status. These survivors have accepted that they will not recover the same level of physical and
cognitive function they had before being injured. What matters to these survivors now is to have
meaningful relationships and activities—“work” in a broader sense of contributing to others.

These survivors feel that their healing has progressed over time, and has not been limited
to the narrow rehabilitation services window of six months, for those who receive rehabilitation
services at all. These survivors perceive that are continuing to heal even years after their injury.
Their perception coincides with current neuroscience research on the plasticity of the human
brain, even for adults. Their data resist the current medical model and insurance parameters for
brain injury services, based on the view that improvement in brain function is impossible beyond
six months post-injury.

This study is an example of fair process in action. With photovoice, survivors have time
to reflect on both the positive and the negative in their lives and can lead the line of inquiry and
discussion if they wish. The picture becomes an opportunity, a “record” if you will, to remember
what they wanted to say, and the support group setting provides both time and space for
participants to share their thinking and feelings with others. The photograph becomes the focus
of the interaction and engages both professionals and peers in exploring experience and building
relationships. For this study, the camera becomes an instrument of justice.

Policy Implications

Rehabilitation professionals have long advocated for gaining an insider or patient
perspective on living with disability, including brain injury (Prigatano, 2000). This study is one
example of possible methodologies or approaches that can be used to gain this insider or patient
perspective. Collaborative visual research, of which this study is an example, may be particularly
appropriate for use by brain injury survivors, given the cognitive and communication challenges that can arise in living with this injury, and the social isolation that can result.

The concept of fair process helps us bring the environment into the therapy mix for rehabilitation from brain injury. When providers apply fair process in the patient-provider interaction and in group therapy settings, perhaps patient and provider expectations and goals may be better aligned. Will this improve outcomes, as predicted by the Kim and Mauborgne model? This may be a useful topic for future research.

With fair process, power in the patient-provider interaction, the brain injury research process, and even in brain injury survivor interactions with family and peers, may become more balanced. With fair process, brain injury survivors may feel that they are being heard. This could allow health care organizations, providers, and family members to see brain injury survivors as part of the solution, not just the problem.

Using cameras is not the only way to achieve fair process, and it is not an approach for everyone. It is a good example, however, of a way to engage professionals and patients, improve communication under difficult circumstances, and work toward procedural, informational, and interactional justice. Finally, implementing fair process in rehabilitation organizations, patient-provider interactions, and support groups may activate brain injury survivor motivation to take action to progress in their healing.

In conclusion, using the lens of fair process helps to illuminate gaps in our knowledge and new avenues of research. Rich et al (2000) have noted that involving people with a disability in research about their lived experience may increase the relevancy of research to real-life situations. One of the challenges to recovering from brain injury is that are no cookie cutter solutions for rehabilitation. Each patient’s injury and healing are different, and quality means
tailoring rehabilitation plans to the individual. Potentially the lens of fair process will help us to identify ways to translate the visual, narrative, and other qualitative data and findings from this and other participatory action research studies with brain injury survivors to quality improvement interventions to encourage “patient-centeredness” in future. The medical model that has guided our health care policies to date has led the health care system and its providers to treat diseases. A model of health care founded on justice may help us to treat patients.

References


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