

Video Article

Using Visual and Narrative Methods to Achieve Fair Process in Clinical Care

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Abstract

The Institute of Medicine has targeted patient-centeredness as an important area of quality improvement. A major dimension of patient-centeredness is respect for patient's values, preferences, and expressed needs. Yet specific approaches to gaining this understanding and translating it to quality care in the clinical setting are lacking. From a patient perspective quality is not a simple concept but is best understood in terms of five dimensions: technical outcomes; decision-making efficiency; amenities and convenience; information and emotional support; and overall patient satisfaction. Failure to consider quality from this five-pronged perspective results in a focus on medical outcomes, without considering the processes central to quality from the patient's perspective and vital to achieving good outcomes. In this paper, we argue for applying the concept of fair process in clinical settings. Fair process involves using a collaborative approach to exploring diagnostic issues and treatments with patients, explaining the rationale for decisions, setting expectations about roles and responsibilities, and implementing a core plan and ongoing evaluation. Fair process opens the door to bringing patient expertise into the clinical setting and the work of developing health care goals and strategies. This paper provides a step by step illustration of an innovative visual approach, called photovoice or photo-elicitation, to achieve fair process in clinical work with acquired brain injury survivors and others living with chronic health conditions. Applying this visual tool and methodology in the clinical setting will enhance patient-provider communication; engage patients as partners in identifying challenges, strengths, goals, and strategies; and support evaluation of progress over time. Asking patients to bring visuals of their lives into the clinical interaction can help to illuminate gaps in clinical knowledge, forge better therapeutic relationships with patients living with chronic conditions such as brain injury, and identify patient-centered goals and possibilities for healing. The process illustrated here can be used by clinicians, (primary care physicians, rehabilitation therapists, neurologists, neuropsychologists, psychologists, and others) working with people living with chronic conditions such as acquired brain injury, mental illness, physical disabilities, HIV/AIDS, substance abuse, or post-traumatic stress, and by leaders of support groups for the types of patients described above and their family members or caregivers.

Video Link

The video component of this article can be found at <http://www.jove.com/video/2342/>

Protocol

1. Introduction:

In *Crossing the Quality Chasm*, the 2001 Institute of Medicine (IOM) report on quality and health care, an area targeted for improvement is patient-centeredness, or the patient's experience of illness and health care. An important dimension of patient-centeredness is respect for patient's values, preferences, and expressed needs. Yet the IOM report did not specify how providers could take steps to understand their patients' values, preferences, and expressed needs. Nor did it provide guidance on how to translate future understanding about the patient's perspective to improving the quality of clinical care. It is in the clinical encounter that we must conceptualize and apply learning about patients' values, preferences, and expressed needs to crossing the quality and health care chasm. The medical model that has guided our health care practices to date has led providers to treat diseases. A model of health care founded on fair process may help us to treat patients.

To achieve person-centered care, clinicians need to understand patients' lives and their work adhering to treatment recommendations at home and in their communities. The medical model of care does not include the environment, where patients must take action to heal. It does not include the patient's perspective on quality of care and their healing process. The usual medical model is a challenge to patient-centered care.

From a patient perspective, quality is not a simple concept but 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 (Chilingirian 2004). This five-pronged concept of quality from the patient's perspective is illustrated in Figure 1: Star quality, a patient-centered view.

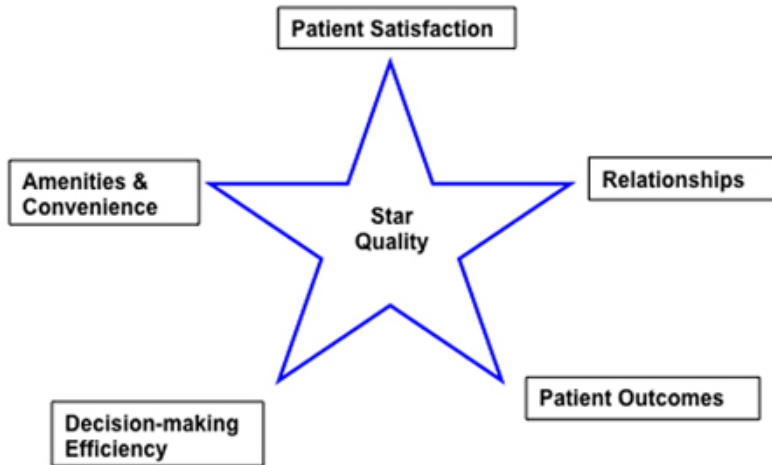


Figure 1. Star quality, a patient-centered view. (Chilingerian 2004)

Failure to consider quality from the patient's perspective results in a focus on medical outcomes, without considering the processes that are vital to achieving those outcomes. Kim and Mauborgne (1997), in their seminal study of fair process in corporations, noted that people care about outcomes but they may place even more importance on the processes used to produce those outcomes and they want to feel that their perspective is heard. Kim and Mauborgne's research with 19 companies found a direct link between organizational processes, attitudes, behavior, and performance. As shown in, Kim and Mauborgne argue that procedural justice in the form of fair process leads to trust and commitment, voluntary cooperation, and exceeded expectations.

Two Complementary Paths to Performance

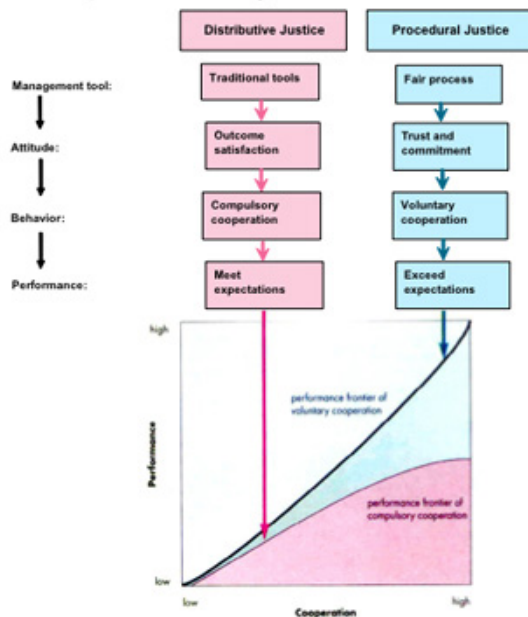


Figure 2. Two complementary paths to performance (Kim & Mauborgne, 1997; Used with permission of Harvard Business School Publishing).

Fair Process and Clinical Care

In clinical care, fair process occurs in the patient-provider interaction. Conceptually, fair process opens the door to bringing the patient's expertise into the work of developing health care goals and strategies. Van der Heyden *et al.* (2005) 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, as the clinician and patient work to explore and narrow the list of diagnostic issues, treatments, and therapies, explain the rationale for decisions, set expectations about patient-provider roles and responsibilities, and implement 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 deep 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 performance 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. Figure 3 the five elements of fair process in the patient-provider interaction, provides a model of fair process in clinical care.

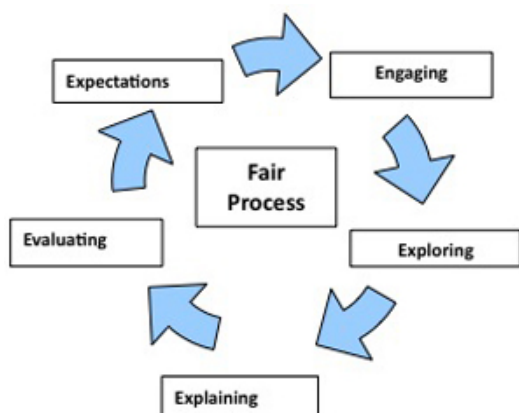
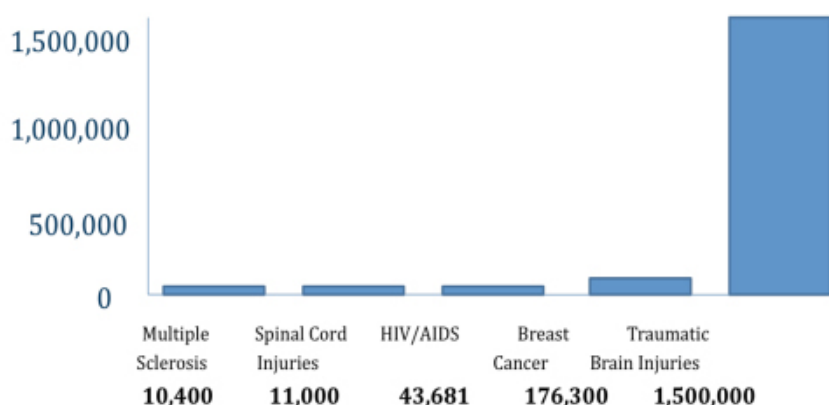


Figure 3. The five elements of fair process in the patient-provider interaction (Van der Heyden, Blondel, & Carlock, 2005; Chilingirian 2006; Lorenz, 2007).

Applying Fair Process to Care for Brain Injury Patients: Encouraging Dialogue and Engagement

There are a total of 650 brain-related disorders; together they affect 50 million Americans per year and account for more long-term health costs and hospitalizations than almost all other diseases combined (Boyle 2001). Acquired brain injury is any injury to the brain which results in deterioration in cognitive, physical, emotional, or independent functioning (Sherry 2006). Traumatic brain injury (TBI) is an injury caused by a blunt force, trauma, or shock to the head. In the U.S. each year, 1.4 million new TBIs are diagnosed in emergency settings and incur an annual cost of \$48 to \$56 billion (Langlois *et al.*, 2004). An estimated 5.3 million Americans are living with disabilities resulting from TBI (about 2 percent of the population), and 80,000 to 90,000 people join their numbers each year (Langlois *et al.*, 2005; Langlois *et al.*, 2004). Another 5 million Americans are living with brain injury due to stroke (ACBIS book). As seen in Figure 4 Annual incidence rate (TBI), TBI affects more Americans every year than multiple sclerosis, spinal cord injuries, HIV/AIDS, and breast cancer combined.



- 50,000 will die annually as a result of TBI
- 80,000 annually experience the onset of long-term disabilities following TBI
- 5,300,000 Americans currently live with a disability as a result of a TBI

* Centers for Disease Control. "Traumatic Brain Injury in the United States: A Report to Congress." www: Centers for Disease Control, (January 16, 2001)

Figure 4. Annual incidence (TBI)

Brain injury can affect 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). Any brain injury, even when diagnosed as "mild," indicating that any loss of consciousness was brief, may have serious, long-term consequences. For example, brain injury survivors may have slowed processing speed in their brains, trouble focusing or concentrating, and short-term memory problems, and become easily frustrated by these challenges. They may fatigue easily, impinging on their ability to work. Communication issues, including aphasia may be a problem (Levin *et al.* 2007). Often, patients look the same as ever it is on the inside that they are different, and their injury is invisible. Figure 5 Running on ice provides an example of what it is like to live with a brain injury from a participant's perspective follows:



Figure 5. Like trying to run on ice

From a clinical perspective, brain injury can be confusing. There are no cookie cutter solutions, and each patient's injury and healing are different. Quality means tailoring treatment plans to the individual. Yet brain injury's cognitive challenges may affect patients' abilities to reflect on their situations, remember important information, and communicate in the clinical setting. These challenges require a creative approach to understanding brain injury patients' perspectives on their experiences of illness and health care. Asking brain injury patients to reflect on their lives, take photographs of their situations, and use their photographs to communicate their challenges and strengths is an example of fair process in action.

Using Visual Methods to Understand Lived Experience

Visual methods are being used and accepted more and more widely in public health contexts (Lorenz and Kolb 2009; Wang and Burris 1997). Visual methods are often used in case study research (Yin 2003), and the investigation of illness experience (Lorenz 2010b; Berland 2007; Radley and Taylor 2003; Rich, Gordon, and Chalfen 2000). Visual imagery accepted as data in the social sciences include drawings, photographs, video, charts, and maps (Guillemin 2004; Oakley *et al.* 1995). Visual methods support communication in patients with slowed cognitive processing speed and aphasia (Levin *et al.* 2007). They can encourage patients to explore and evoke emotions, thus complementing clinical methods that measure their problems using statistical data and encouraging greater patient engagement in their health and health care (Entwistle, Tritter, and Calnan 2002). Participatory visual methods such as photo-elicitation and photovoice allow patients to bring their expertise into the clinical setting and teach clinicians (Lorenz 2010a; Chalfen and Rich 2004).

Some argue that the experiential knowledge of patients is inevitably limited and should not be put on a par with medical knowledge (Prior 2003). However, professional understandings of illness and disease are also limited and need to be considered alongside patients' understandings of their health and health care. Using participatory visual methods is one way to generate understanding of the wider context in which clinical care is nested, and develop a shared body of knowledge that integrates the expertise of both physicians and patients (Lorenz and Kolb 2009).

For example, the neuropsychologist George Prigatano (1989) has long called for clinicians to understand what their patients are experiencing and has argued that developing treatment plans in isolation from patients' real lives may diminish relevancy of the plan. In working with a brain-injured patient who was angry and upset at being asked to have herself video-taped performing a rehabilitation task, Prigatano asked her to draw a picture of how she felt about herself and her injury. Creating this drawing, presented in Figure 4, allowed the patient to discuss her fears and forge a positive therapeutic relationship with Dr. Prigatano, and in part inspired the study and procedure described in this video journal paper.

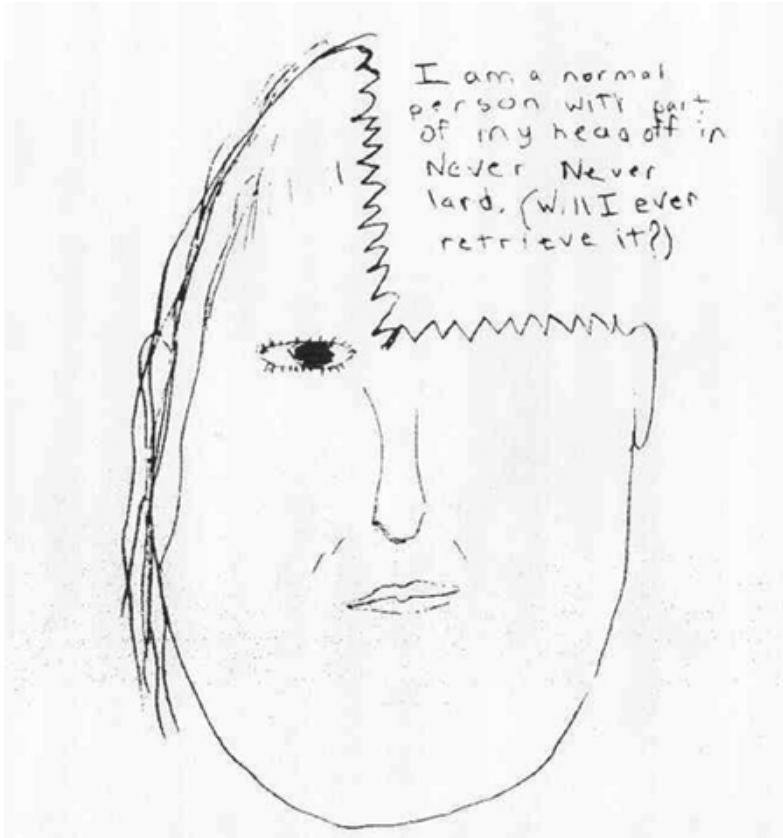


Figure 6. Drawing by a brain injury survivor. Used by permission of Oxford University Press, Inc. Page.112, Figure 7-1 from "Awareness of deficit after brain injury: Clinical and theoretical issues" edited by George P. Prigatano and Daniel L. Schacter (1991). www.oup.com.

2. Case Presentation:

The procedure illustrated in this paper was used between 2006 and 2007 with 14 adult brain injury survivors between the ages of 20 and 60 years: with six traumatic brain injury patients accessing outpatient services through Spaulding Rehabilitation Hospital and with eight members of a brain injury survivor support group.

Of the Spaulding Rehabilitation Hospital participants: all six have traumatic brain injuries and were injured approximately one year before working with Dr. Lorenz. Three are male, and three are female. One male and two females were aged 20 to 26 years, one male and one female were aged 40 to 50 years, and one male was aged 58 years. Several were hopeful about recovering prior abilities at the time of the study; two have returned to their previous education or work if in different capacities.

The study's clinical collaborator, a senior speech pathologist at Spaulding Rehabilitation Hospital, suggested using participant scores on the Rancho Los Amigos Revised Cognitive Levels of Functioning Scale (Revised) as our inclusion/exclusion criteria (Hagen, 1997). The scale defines ten levels of cognitive functioning from "no response" (Level I) to "purposeful and appropriate" (Level X). Clinicians often use a diagnosis of Level VII as a cut-off for participation when independent carryover is expected. In brief, persons at a cognitive Level VII:

- a. remain oriented to the person they are speaking to and the place they are in;
- b. attend to tasks for at least 30 minutes with minimal assistance;
- c. require minimal supervision for new learning;
- d. demonstrate carryover of new learning;
- e. initiate and carry out steps to complete familiar personal and household routine but may have shallow recall of what they have been doing; and require minimal supervision for safety in routine home and community activities.

Figure 7 shows the 10 Rancho Los Amigos Revised Cognitive Levels of Functioning Scale (Revised) and describes them.

Figure 1
Rancho Los Amigos Cognitive Scale

Level I-No Response: Total Assistance	No response to pain, touch, sound or sight.
Level II-Generalized Response: Total Assistance	Generalized reflex response to pain.
Level III-Localized Response: Total Assistance	Demonstrates withdrawal or vocalization to painful stimuli. Responds inconsistently to commands.
Level IV-Confused/Agitated: Maximal Assistance	Agitated. Alert, very active, aggressive or bizarre behaviors, performs motor activities but behavior is non-purposeful, extremely short attention span.
Level V-Confused Inappropriate Non-agitated: Maximal Assistance	Gross attention to environment, highly distractible, requires continual redirection, difficulty learning new tasks, agitated by too much stimulation. May engage in social conversation but with inappropriate verbalization.
Level VI-Confused Appropriate: Moderate Assistance	Inconsistent orientation to time and place, retention span/recent memory impaired, begins to recall past, consistently follows simple directions, goal directed behavior with assistance.
Level VII-Automatic Appropriate: Minimal Assistance	Performs daily routine in highly familiar environment in non-confused but automatic robot-like manner. Skills noticeably deteriorate in unfamiliar environment. Lacks realistic planning for own future.
Level VIII-Purposeful Appropriate: Stand by Assistance	Consistently oriented to person, place and time. Initiates and carries out steps to complete familiar personal, household, community, work, and leisure routines with stand-by assistance and can modify the plan when needed with minimal assistance.
Level IX-Purposeful, Appropriate: Stand by Assistance on Request	Able to think of consequences of decisions or actions with assistance when requested. Initiates and carries out steps to complete familiar personal, household, community, work and leisure routines independently and unfamiliar personal household, work and leisure tasks with assistance when requested.
Level X-Purposeful, Appropriate: Modified Independence	Able to think about consequences of decisions or actions with assistance when requested.

Figure 7. Ranchos Los Amigos Cognitive Levels of Functioning Scale (Revised) (Hagen, 1997).

Of the support group participants: Two were injured three or four years before the start of the project, four were injured between 8 and 17 years prior to the study, and two were injured more than 25 years prior. Six have survived traumatic brain injuries, and two have survived brain tumors. Participants ranged in age from 40 to 60 years old; five are women and three are men. All are living with disability from brain injury.

For the support group participants, inclusion/exclusion criteria included:

- a. membership in the support group;
- b. interesting in participating;
- c. ability and willingness to adhere to the activity's ethical guidelines;
- d. ability and willingness to commit to attending all support group photovoice meetings.

3. Procedure:

Photovoice has several steps, as illustrated in Figure 8 A Photovoice Path. With individual patients, clinicians will use the first few steps. With support groups, all steps may be used.

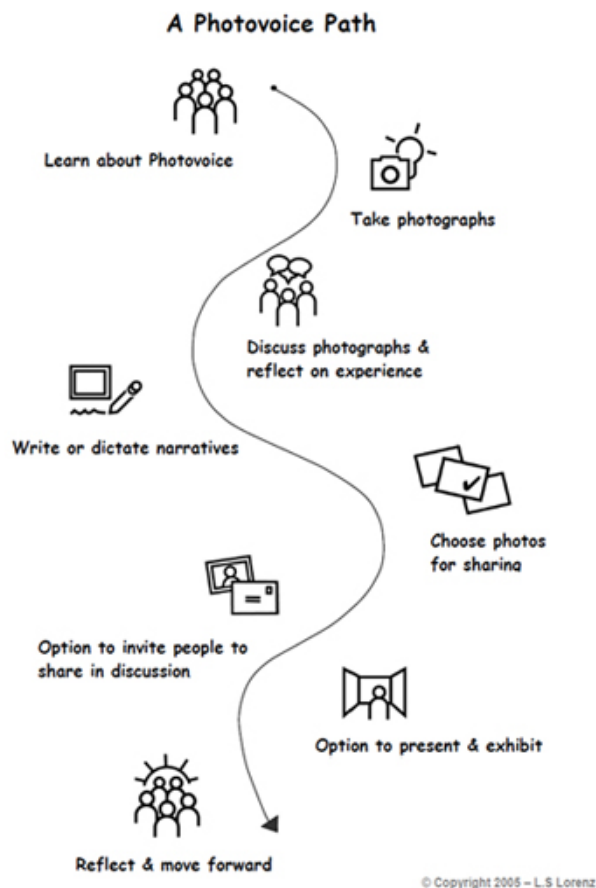


Figure 8. A Photovoice Path (Lorenz, 2010a).

Step 1: Engage the patient in becoming a visual researcher



Figure 9. Icon for learning to be a visual researcher

The goal of this step is to engage the patient in the photo-taking assignment and ensure that the patient understands the ethical parameters of being a visual researcher of their own life.

Explain the assignment. The patient is free to agree to participate or not. Discuss ethical considerations: no pictures of other people without their permission, no pictures of property without the owner's permission, no pictures of illegal activities, no pictures of people in compromising situations. Discuss a question or questions for the patient to answer by taking a photograph or other visual. Sample questions include:

1. What is it like to live with brain injury?
2. What in my life or community has helped me in my recovery from brain injury?
3. What has slowed my recovery from brain injury?
4. What do I want to tell other people about living with brain injury?
5. How is my life different now from how it was before? What is better? What is worse?
6. What are my hopes for the future? What might help me get there?

Explain that the patient can bring in an existing photograph or a picture from a magazine, take a new photograph and bring in a print or a digital file, or create a new drawing, collage, or other artwork that will answer the assignment question or questions from the patient's perspective.

Ask for at least two images: one of something positive in the person's life now, and one of something negative.

Explain that the images can be a concrete problem (e.g., a pile of paperwork or forms to be filled out), or a metaphor for feelings (such as feeling disconnected from a former self or from other people). Discuss an example of each, provided in Figure 10 Sample photo of a concrete topic, and Figure 11 Sample photo of a metaphor for feelings. See also Figure 5 for a sample of a metaphoric image.



Figure 10. Sample photo of a concrete topic.



Figure 11. Sample photo of a metaphor for feelings (Lorenz, 2010c).

Encourage the patient to use a notebook to record possible photo topics and reasons why they are taking a particular photo.

Role-play the picture taking activity. Pretend to be the photographic subject. Ask the patient to explain why they are taking photographs and why they want to take a photo of you. Role play several times as needed.

As seen in Figure 12 Icon of photo-taking assignment, the patient will work on his or her own, taking photographs or otherwise producing two images (one positive and one negative), to discuss in the next session.



Figure 12. Icon of photo-taking assignment

Step 3 Discuss the photo-taking assignment and images



Figure 13. Icon of discussion step

Ask the patient what it was like to take photographs. Was it easy? Was it hard? Did anyone ask why he or she was taking pictures? Did the patient ask anyone permission to take their photo?

Ask the patient to show you his or her two images. Look at each one carefully (Becker 1986). What do you see? What do you think the image might mean?

Ask the patient why s/he took or selected those images. What do they mean to him? What do they signify to her?

Consider your own perspective on the images. Did you see in the images what the patient intended by taking them? In a respectful and curious way, discuss what you see as well. What strengths are illuminated in the image? What weaknesses?

Discuss a possible therapeutic goal raised by the images. Discuss possible strategies to help the patient reach this goal.

Consider asking the patient to bring an image or two in to the next session. Possible questions to answer with the camera could include:

1. How did you feel about this goal once you were back home?
2. What helped you make progress toward your goal?
3. What hindered your progress?
4. What are some strategies might help you to reach your goal?

If the process of taking and discussing images in the clinical setting appears to support building a therapeutic alliance, continue with Steps 2 and 3. Alternately, use them as an occasional way to understand issues the patient is facing and positive things in his or her life as well, over time.

4. Conclusion:

Asking patients to bring visuals of their lives into the clinical setting can help to illuminate gaps in clinical knowledge, forge better therapeutic relationships with patients living with chronic conditions such as brain injury, and identify patient-centered goals and possibilities for healing. The process illustrated in this video article can be used by

- a. primary care physicians working with patients living with chronic conditions;
- b. rehabilitation clinicians such as speech pathologists, occupational therapists, physical therapists, and nurses working with acquired brain injury survivors and others;
- c. neurologists, neuropsychologists, and others working with patients living with potentially chronic conditions such as acquired brain injury;
- d. psychologists and others working with people living with mental illness or other similarly chronic conditions;
- e. leaders of support groups for the types of patients described above and their family members or other caregivers.

Although photography can be seen as a "disruptive technology" challenging beliefs and assumptions, it could become a new clinical methodology. Could patients accounts be seen a cheaper, simpler way to determine how well patients and clinicians are meeting their goals?

Discussion

Respondents become partners and play the role of "co-expert" role in the clinical setting when their lived experience is sought only the patient can really know what it is like to live with brain injury and experience related care. Further, the health care goal for many brain injury survivors appears to be healing, not recovery. Recovery implies a desire to return to a pre-injury status. Newly injured patients may be hoping to recover from their injuries, but long-term survivors have accepted that they will not be able to return to their prior status. They see healing as cognitive, physical, emotional, and even spiritual (Lorenz 2010a). They perceive that they continue to progress over time, even many years after their injury. Discussing photographs of their lives may help patients and clinicians to identify person-centered areas of concern and recognize and appreciate patient progress over time.

Applying fair process to clinical care means the patients are deeply engaged, exploring the way that their experience can be improved, understanding the rationale for all clinical decisions, and accepting their role and responsibility. Fair process activates patient motivation to

adhere to rehabilitation strategies and take action to progress in their healing. When providers apply fair process to clinical care, patient and provider expectations and goals may be better aligned. The photograph becomes the focus of the interaction and engages the professional as well as the patient in exploring experience and building relationships. The therapeutic relationship may be improved. Further, according to the Kim and Mauborgne model, resulting attitude and behavior changes could lead to improved outcomes.

With fair process, power in the clinical interaction may become more balanced as patients feel that they are being heard. Discuss photographs and their meaning can help patients to become 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 every patient or every clinician. It is a tool and methodology to engage patients, improve communication under difficult circumstances, and achieve person-centered care.

Disclosures

The first author provides trainings in photovoice and photo-elicitation through medical schools and other educational venues. The second author has nothing to disclose.

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