

Abstract. Purpose—In health care, quality of care is critical to patient well-being and organizational accountability. This paper used visual and narrative methods to elicit and understand quality of care from the patient's perspective. **Methodology**—14 acquired brain injury (ABI) survivors took photographs of their lives and explored the meaning of their images in photo-elicitation interviews. Narrative analysis methods were used to analyze visuals and interview texts. A patient case study was selected to illustrate study methods and findings. **Findings**—The patient's visual illness account challenges policies and practices of health care providers, organizations, and systems. The account shows a brain injury survivor's difficulty adhering to physician-recommended treatment, and provides a vivid depiction of her efforts to advocate for appropriate care. Her narrative resists current health care payer policy, which limits provision of brain injury rehabilitation services to six to 12 months post-injury. **Practical implications**—Photo elicitation and narrative analysis methods could encourage clinicians and organizations to view illness and quality of care through patients' eyes. Listening to brain injury survivor accounts could help to improve the quality of care for persons suffering with chronic conditions. The methods encourage provision of holistic, patient-centered care that addresses patients' real lives. **Relevance to policy**—This study contributes to the organization and management literature by translating patient accounts of their lived experience with illness and care in terms of quality of care. The findings demonstrate the potential for incorporating patient perspectives into health care policies and practices that support long-term healing for persons with chronic conditions, address quality of care from patients' perspectives, and promote innovation and learning. **Funding and other support**—This study benefited from the collaboration of R. Richard Sanders, Sr. Speech Pathologist, Spaulding Rehabilitation Hospital, Boston, MA and the Brain Injury Survivor Support Group, Framingham, MA. Support was provided by the Brain Injury Association of Massachusetts and the Massachusetts Rehabilitation Commission. **Keywords**—Accountability health research, patient accounts, performance audits, qualitative research audits, patient-provider relationship, quality of care, visual illness narratives, chronic conditions, brain injury.

Judy's Visual Illness Narrative

In the 2.5 hour interview, Judy talked about just 8 of her 52 photos taken for the study. She spoke about each one for up to 14 minutes. Her visual illness narrative is presented in the order in which her photographs were discussed. Each photo depicts an aspect of her identity. The summary narrative below, provides 4 photos and a structured summary of what she said about it (Gee, 1991). Each narrative excerpt provides a title that describes the image and places it in context using Judy's own words.

Discovering a New Identity

1) Cookbooks: "Identity lost"



"My work as a chef ended with my brain tumor. I didn't have a life separate from my work. It was always Judy the Chef, not ever Judy. I had to find who I was besides being a chef. I've still got over a hundred cookbooks. That was part of making the picture."

3) Garden: "The new Judy"



"I thought, 'Oh, I can do that.' I started experimenting. So I have something new. I'm in the roses now. The identity of the chef is no longer the focus of my life."

2) Pill Box: "These are all my brain injuries"



"This is my pill box for the week. It would start to become very confusing. I started coordinating with my doctors."

4) Keys in the Freezer: "What do I make out of that, that I want?"



"We as brain injured people put things in weird places. Maybe I was getting a glass of water with some ice cubes. I make things out of nothing. I can do that because I was a chef."

Discussion. Brain injury survivors were traditionally expected to plateau in their recovery 6 months post-injury—a rationale used by health insurance payers to limit funding for rehabilitation services (Thomas and Pollio, 2002). Judy's narrative of healing over time aligns with current neuroscience research on the ability of the adult brain to generate new pathways (plasticity), and resists current payer and provider policies for rehabilitation for brain injury. Judy's visual account reveals that health care providers, organizations, and systems are not providing quality care.

Uncovering Hidden Information about Quality: A Detailed Account

We use one excerpt to 1) illustrate the methods used to elicit patient accounts and understand patient perspectives, and 2) illuminate a health care adherence challenge that Judy faced. The excerpt title is followed by the image and its interview text parsed into lines and grouped into parts, each with a line using Judy's own words (Gee, 1991). Any text said by the interviewer is italicized; all other text was said by Judy. A period indicates a full stop, a comma indicates a brief pause, and a series of dots indicates a longer pause.

Pill Box: "These are all my brain injuries"



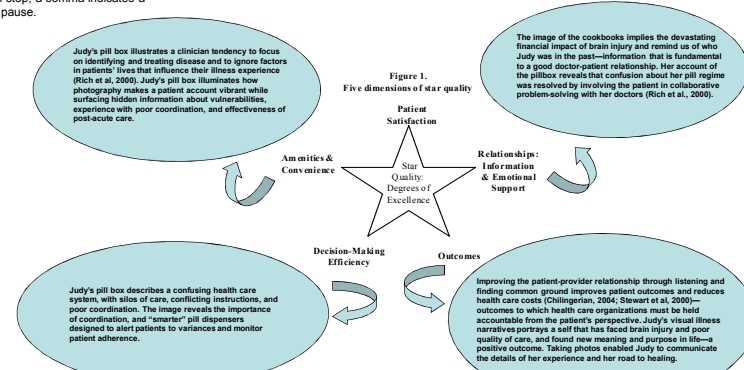
Part 1: This is my pillbox for the week. Now, are those related to your brain injury?
 Oh, yes, these are all my brain injuries. This is my pill box for the week. So you'd know if you'd taken the dose? Right, because I used to forget, and I still do forget. I'll forget to take morning ones or night ones. But at least if I don't remember if I took it or not, I can look and see I took it or didn't take it.

Part 2: It would become very confusing.
 That's what used to confuse me *hmm*. Did I take it, did I not take it? And so I got things down to just morning and night. There were other pills that I used to have to take...four times in a day *wow*. Morning, midday, late afternoon and then evening. So it would become very confusing. And if I didn't have it laid out in front of me, did I take it, did I not take it? *Hm hmm*

Part 3: I started coordinating with my doctors.
 And then I started coordinating with my doctors. To get it down to just, let's just get it down to twice, two times a day. Oh, good. So you advocated for yourself with your doctors? Right. Sounds like? Yeah. Because I was getting too confused. And I was missing too many. I would look back on the week and say, "Oh, my god, I totally missed all week. I missed the nighttime one." Right? So that's when we started working on getting it down to twice a day.

Connecting Patient Accounts to Quality

Patient-centered care implies that the care provided is of better quality. From an organizational perspective, quality is frequently tied to costs. From a clinician's perspective, quality is "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge (Chassin and Glavin, 1998). From a patient's perspective, however, quality is best understood in terms of the five dimensions illustrated in the Star Quality Model in Figure 1 (Chilingirian, 2004).



Conclusions. Visualizing quality of care from a patient's perspective could prove to be an excellent technique for evaluating outcomes, effectiveness, and patient experiences.

Patient-physician accountability

The constructive use of detailed patient accounts for "attention-directing" could become a tool to facilitate patient-centered care, by engaging both patients and physicians to develop a balanced allocation of effort and shared responsibilities for patient satisfaction and technical outcomes.

Clinical practice

Study findings suggest that photography and voice can make important contributions to patient-centered care, but they also raise clinical practice questions. Can visual patient accounts test the premises of care being delivered? Are clinical assumptions consistent with patient visual accounts and clinical evidence?

Bringing visual into medical records raises issues for future accountability research. Where should visual accounts be stored, and what should be done with photos that are not discussed? Can visual tools become part of clinician training to realize the value of the patient's perspective?

Images alone are not necessarily useful as records of illness experience. They need text to make their meaning known. Further, future audiences need to be aware that the patient's perceptions of experience do not remain frozen, like the image, but likely change from day to day and context to context (Chamaz, 1991; Lorenz, 2008).

With visual accounts, perhaps clinicians can begin to comprehend the patient's lived experience in a way that could unite patient and provider in a more collaborative effort to better achieve the goals of care and rehabilitation. It is hoped that the research presented here will stimulate further accountability research using photography and narrative techniques to capture patients' stories of illness as patient record.

Table 1.2: A Listing of Judy's Photos Topics by Camera

Camera #1	Camera #2	Camera #3		
Photo Topic	#	Photo Topic	#	Photo Topic
Perennial garden	1	Keys in freezer	4	Books of puzzles
Container garden	2	Living room in chaos	1	Sky
Bags blocking door	2	Scrambled eggs	5	Alternative therapies
Copper pots and chef's apron	2	Bricks on a board	2	Strengthening exercises
Cookbooks	1	Outside garden	4	Driving in car
Keys in freezer	1	Potted herbs	2	Countryback road
Ceiling (mistake)	1	Cookbooks and nameplate	2	Subtotal
Subtotal	12	Bags blocking door	3	
		Back of head	3	
		Subtotal	26	
		Grand total	53	