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## Using Fair Process to Cross the Quality and Healthcare Chasm:

### Eliciting the Perspective of Brain Injury Survivors



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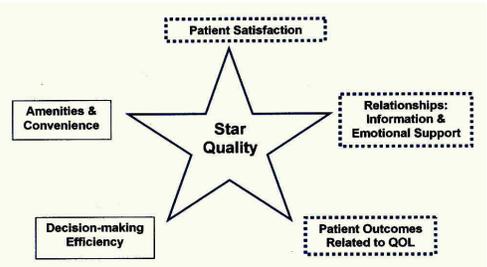
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## Background

- TBI is a serious public health problem in the U.S.
  - 1.4 million new injuries diagnosed each year
  - 80,000 to 90,000 new long-term disabilities
- IOM Report calls for providing patient-centered care that reflects patients' preferences and expressed needs
- TBI can affect cognitive functioning, self-esteem, and perception of self
- These consequences pose challenges to including the TBI survivor's perspective

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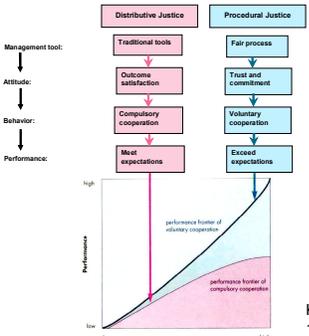
## A Patient-Centered View of Quality: Satisfaction, Relationships, & Outcomes



(Chilingerian 2004)

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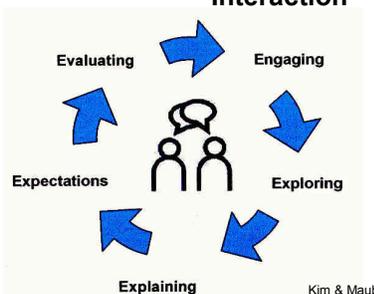
## Two Complementary Paths to Performance



Kim & Mauborgne 1997

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## Fair Process & the Patient-Provider Interaction



**Look at people as individuals**

**Individually tailored plans**

**Give and take**

**Activate patient motivation**

Kim & Mauborgne 1997; Van der Heyden et al 2005; Chilingerian 2006

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## Study Purposes

- Provide an opportunity for participants to:
  - reflect on living with brain injury and their progress in dealing with this major life change
  - use their brains in new ways
  - employ a variety of cognitive skills
- Raise awareness about brain injury
- Help professionals and policymakers understand ways to support healing from brain injury
- Explore the value of using visual research methods with brain injury survivors

### Study Population



- 8 ABI survivors who are members of a brain injury support group
- 2 ABI co-facilitators

### Action Research Using Photovoice

- Photovoice is action research that asks participants to represent their lives, point of view and experience using photographs and narratives (Wang et al, 1996)
- Action research involves scholar-practitioners integrating science and practice in a dynamic group setting (Adelman, 1993).
- Action research is systematic investigation carried out in collaboration with people affected by a particular issue.

### Photovoice Applied in this Context

- Participants learned about ethical issues related to being visual researchers of their own lives
- Using disposable cameras, took photos of living with brain injury from their perspective
- Selected some for discussion with group and wrote narratives
- Created an exhibit of 50 photos and narratives grouped into 9 categories, from The Journey to Chaos, Strategies, and Hope for the Future

### The Journey



It's a muddy, ratty, 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....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.....

### 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 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.

### Challenges



...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.

### 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.

### My Advocacy Story



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.

### Comfort and Support



With TBI 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 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.

### Acceptance



Whose grave is this? Surely it's not mine. This is not my fate, is it? I need to make the best of this situation, but how? It's all suddenly complicated...This was not my doing, nor my choice! I'm trying to be gracious. 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 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

- Participants played a participant-expert role in this study (Balcazar et al, 1998)
- Their rehabilitation goal is healing, not recovery
- Their experience resists current policies for b.i. rehabilitation: they feel their healing has progressed over time, even years
- This study is an example of fair process in action
- For this study, the camera is an instrument of justice



## Policy Implications of Fair Process

- Creates opportunities to gain an insider's perspective on living with disability
- Brings the environment and 'real lives' into the health care interaction and health policy
- Can promote interactional justice and a balance of power in professional-patient interactions
- May activate patient motivation to heal
- Promote a model of health care founded on justice and treating patients (not diseases)