



Using patient stories for organizational learning and improvement

Carol Fancott, PhD

G. Ross Baker, PhD

Whitney Berta, PhD

Ayelet Kuper, MD, DPhil

Stories are everywhere.....

FACES OF
HEALTH
CARE

HOME ABOUT MORE FACES SUPPORTERS
HEALTHY DEBATE



Patient Stories



Mayo Clinic provides the best care to every patient every day. Patient stories are the story of Mayo Clinic. Patients tell that story best.

The truth of it

HEALTHY MEDIA LAB, THE TRUTH OF IT features interviews with Canadians diagnosed with cancer who were asked to share their story so others could learn from their experience. By providing candid accounts of the personal impact of cancer, the video series will serve as an educational resource for health care professionals as well as patients, survivors and others with a personal connection to cancer.

To view the full series, visit www.cancerview.ca/thetruthofit



Clean Care is Safer Care

Inventory of patient stories

On this page you can see web sites featuring videos and stories of patients affected by health care-associated infection and/or involved in hand hygiene promotion. These can be very powerful for health-care workers' training and patients' awareness raising and empowerment. If you know of any good videos of patient stories on health care-associated infection and patient participation in hand hygiene, please send us the

Patient Stories

Help us improve healthcare

We value your healthcare experiences, as they inform us on

- Services patients and families receive - or don't receive
- What constitutes 'patient and family-centred care'
- Ways to improve the patient experience



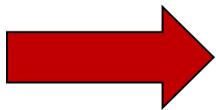
Make your
experience
count

Learning from stories

We work with your stories to identify key areas for change in the healthcare system from the patient perspective. To learn more about how your stories can lead to change, [click here](#).

“At first it was kind of sexy to use a patient story because everybody was talking about it.” (Leader)

The problem



Little nuanced understanding of what type of stories, told by who, for what purposes, and with what impact

The Story of **GRACE**

Research objectives

- To explore and to understand the use of patient stories in healthcare organizations that are leaders in the systematic and deliberate use of patient stories for learning and improvement
 - What types of stories and for what purpose(s)?
 - Who tells their stories and in whose interest(s)?
 - In what context?
 - With what impact on learning and improvement?

Theoretical perspectives on storytelling and learning

- Bringing together social theory with organizational learning theory
 - Thinking *with* vs. thinking *about* stories
(Frank, 2010)
 - Multilevel learning at individual, team/group, and organizational levels
(Chuang et al., 2007; Crossan et al., 1999)

Methodology

- Case study methodology using four North American healthcare organizations known to be leaders in their use of patient stories for learning and improvement
 - Selection of organizations via feedback from seven key informants, environmental scan, and review to literature
 - 3 acute care academic healthcare institutions (2 in Canada, 1 in US)
 - 1 national health organization (non-service delivery)

Study Design

- **Data generation strategies** (Bowen, 2009; Handley, 2002; Kvale, 1996; Patton, 2002)
 - 38 individual interviews (7 patients, 9 family members, 22 leaders)
 - Non-participant observations of patient stories told within organizations
 - Document retrieval of publically available documents and organization-specific documents referred to in interviews

- **Data analysis** (Clark, 2005; Mauthner & Doucet, 1998)
 - Interpretivist approach using situational maps and layered reads

Findings

- The story
- The storytellers
- The organization

What kinds of stories were told?

“We assume we know, but we don’t know. We are not the experts. We are the experts in clinical care, best practice, but we are not knowledge holders of experience.” (Leader)

The stories

□ The co-construction of patient stories

- Moving chaos narratives to quest narratives

“And we try and end every story on a message of hope...” (Leader)

□ Stories as strategic actors

□ Stories as connectors

“So they came to me not as health care professionals but they came to me as sisters and brothers, and wives and daughters.”

(Family member)

Who are the storytellers?

“You just hear those moments in people’s lives and ...you feel like you’re right there with them. And you just look at these beautiful people, who have so much courage to go on and to share their stories and to try and change the system.” (Leader)

The storytellers

- ❑ The ‘gatekeeper’ function: ensuring the “right fit”, at the “right time” and to be “solution-focused”
- ❑ Authenticity: Stories matter, but *how* the story is told is also important
- ❑ Patient stories or stories **of** patients

“The goal is to be constructive and make positive change.” (Leader)

What enables stories to be told and acted upon in these organizations?

“If nobody wanted to hear the story, then we wouldn’t be able to tell it.” (Family member)

“I think they made the choice to make sure our voices are very important.” (Family member)

The organization

- ❑ Symbiotic relationship: PFCC and patient stories

“When you look at PFCC, the patient and family being at the centre, I think the real anchor to it all is the stories...” (Patient)

- ❑ Leaders are key enablers of PFCC

- ❑ Structures to support patient stories

- Purposeful gathering of stories
- Explicit linkages to improvement and learning

“I think if you’re going to have people tell their stories, you need to have a system that’s set up that is doing something about those stories, right?” (Leader)

BUT.....

“Stories are great, [but] stories can be used and abused...” (Leader)

Emerging tensions with stories

- ❑ Tension 1: Whose story is it? The 'patient story' or the story **of** the patient
- ❑ Tension 2: In whose interests are these stories told?
- ❑ Tension 3: Who gets to tell their story?
The hegemonic power to story

SO WHAT?

“....the stories create the thinking about wow, we might have an opportunity here...it’s a catalyst, but I don’t think it creates different outcomes. I think its taking the patient with you and giving people the skills and tools to improve something...its giving the legs to stories.”

(Leader)

Implications for theory

- ❑ Results in this study highlight the need to consider issues of culture and power for learning
 - Patient stories as legitimate forms of knowledge
 - Expert by experience
 - Professional hierarchies in healthcare
 - Hegemonic power to story

How do we effectively use patient stories for learning?

- Stories have power – but we need ***“to give legs to stories”***
 - Stories are not ‘stand-alone’ vehicles for change
 - Need for explicit structures and processes that support stories and storytellers and make links to learning

How do we effectively use patient stories for learning?

- A cautionary tale: the need for reflexive storytelling practices
 - Recognition of authorized stories and authorized storytellers
 - What voices are silenced?
 - Consider what is the purpose of telling stories – supporting existing structures or disrupting them?



Acknowledgements:

- Healthcare organizations and participants
- Thesis committee

Grant funding:

- AMS Phoenix Project

Fellowship funding:

- CIHR-funded Knowledge Translation in Patient Safety
- Ontario Training Centre for Health Services Research
- Ontario Graduate Scholarship
- Team Optimize – Toronto Rehabilitation Institute-UHN
- Institute of Health Policy, Management and Evaluation