

How Patient Stories are changing Dementia Care



Lillian Hung RN PhD Candidate
Jenifer Tabamo RN MSN

SPRING CEANing
Storytelling for the Health of It
Saturday, April 22nd, 2017



What did we want to learn from patient stories?

2

What are the views of patients with dementia about the hospital environment?



What can stories do?

3

“Stories offer a plot that makes some particular future not only plausible but also compelling”
(Frank, 2011)



Person-centred care

4

- Knowing the person
- Authentic relationship
- Understanding, trust and respect
- People with dementia have entitlement, power, status and responsibilities



Authentic Dialogue & Partnership

5



Critical Social Theory (Habermas, 1984)

- Communicative action
- Power relation
- Research 'with'


Stories create and act

6



- **Stories create fuel for engagement**
- **connect the hearts and the heads**
- **Moral compass**

“Little things matter!” Exploring the perspectives of patients with dementia about the hospital environment

Lillian Hung MA, RN, PhD Candidate ¹  | Alison Phinney PhD, RN, Professor ¹ |
Habib Chaudhury PhD, Professor ² | Paddy Rodney PhD, RN, Associate Professor ¹ |
Jenifer Tabamo MSN, RN, Clinical Nurse Specialist ³ | Doris Bohl BSN, Clinical
Nurse Educator ³

¹School of Nursing, University of British Columbia, Vancouver, BC, Canada

²Simon Fraser University, Vancouver, BC, Canada

³Vancouver Coastal Health, Vancouver, BC, Canada

Correspondence

Lillian Hung, School of Nursing, University of British Columbia, Vancouver, BC, Canada.

Background: Recognising demographic changes and importance of the environment in influencing the care experience of patients with dementia, there is a need for developing the knowledge base to improve hospital environments. Involving patients in the development of the hospital environment can be a way to create more responsive services. To date, few studies have involved the direct voice of patients with dementia about their experiences of the hospital environment.

Design and method: Using an action research approach, we worked with patients with

Conclusion & Implications

8

- Patient engagement should not be regarded as a “*Project*” or “*One-off thing*”
- Ongoing process, embedded in culture & practice
- Grounded in values of person-centredness



- A culture nourished by education, awareness, regular reflection at all levels of the organization

Discussion

9

- How do we avoid tokenism and unethical practice in using patient stories inside and outside the organization?
- How we may ensure people with dementia have a voice and meaningful opportunities to regularly participate in research for service development?