How Patient Stories are changing Dementia Care



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SPRING CEANing

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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)

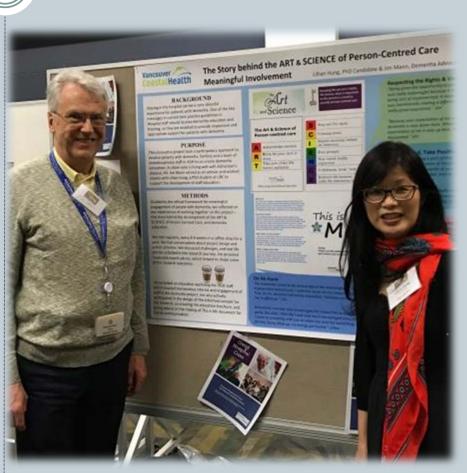




Person-centred care

4

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



Authentic Dialogue & Partnership



Critical Social Theory (Habermas, 1984)

- Communicative action
- Power relation
- Research 'with'

Stories create and act



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

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ORIGINAL ARTICLE

WILEY

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

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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

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Conclusion & Implications

- 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?