Research, Knowledge Translation and the Arts: Using Digital Stories to Explore the Experiences of Breast Cancer Patients

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(Downfall, 2017)
Overview

- Background
- Why digital stories?
- Overview of study
- Key findings
- Considerations
Breast cancer is the most frequently diagnosed cancer in Canadian women.

Combination of age, income and travel time can influence variations in treatment options.

Challenges with making an informed decision: identified gaps in delivery, format and timing of information about options.

(Being my own advocate, 2017)
DIGITAL STORYTELLING

Honouring individual voices while recognizing shared experiences.
WHY DIGITAL STORYTELLING?

The NL Health Care Paradox
- Two-year participatory health research study
- Three phases:
  - Digital story workshops
  - Organized KUs screenings with questionnaires
  - Knowledge users focus groups
- Team members included a patient advisor and knowledge users
Under the knife
Key findings

1. Determinants influence treatment decisions
   - Life stages
   - Personal circumstances
   - Personal values
   - Previous experiences (family, self, others)
   - Sense of control
   - Sexual health
   - Medical advice
   - Information received /sought out
   - Doctor-patient dynamic

(The Detour, 2017)
Key findings

Patient priorities focused on:

2. Minimizing emotional distress
3. The role of patient navigators
4. A whole person care approach is needed

5. Creating and viewing digital stories:
   Overall impact

Upcoming site:
www.patientstories.ca
digital stories
digital stories
focus groups
community
theatre production
survey screenings
Considerations

- Time commitment
- Resources
- Responsibility

(My Story, 2017)
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For more information about NL SUPPORT and the kind of research they fund, please visit: www.nlsupport.ca
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