How Risk Ideology Creates Patient Work in a Secondary Stroke Prevention Clinic: Findings from an Institutional Ethnography in Canada

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BACKGROUND

- As a nurse, I was trained and educated in a biomedical model
- My personal musings about health and health care were challenged by exposure to a ‘social determinants of health’ conference while I was working as a Nurse Practitioner with an Acute Stroke Team in Toronto
- Question: How is stroke prevention care socially organized?
PATIENT “DOT”

73 year old divorced woman
Single mother for years
House keeper
Social exclusion
Low socioeconomic status
Life long smoking habit
High blood pressure
THEORY & METHODS: INSTITUTIONAL ETHNOGRAPHY

- Developed by Dr. Dorothy Smith, feminist sociologist who countered theory-driven sociological research.
- Smith argued for research that began from the actualities and standpoint of people.
- Developed a “method of inquiry” that examines relations of power and knowledge.
- Claimed ruling relations of knowledge erase the ‘knowing’ of those excluded from power.
- Two materialist concepts drove data collection and analysis:
  - Texts link local to extra-local.
  - ‘generous concept of work’.
DATA COLLECTION DESIGN, METHODS & SETTING

- “Local” secondary stroke prevention clinic
- Observation of patient appointments, interviews with patients and health professionals, textual analysis
- Texts provided empirical link to extra-local settings
- “Extra-local” interviews with informants from Ontario Heart and Stroke Foundation, Ontario Ministry of Health and Long Term Care in Canada
## INFORMANTS

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Status</th>
<th>Cultural Group</th>
<th>Co-morbidities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helen</td>
<td>81</td>
<td>Widow</td>
<td>German</td>
<td>Arthritis, hearing</td>
</tr>
<tr>
<td>Walter</td>
<td>85</td>
<td>Widower</td>
<td>Guyanese</td>
<td>Alzheimer's</td>
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<tr>
<td>Tom</td>
<td>72</td>
<td>Married</td>
<td>German</td>
<td>Cardiac, hearing</td>
</tr>
<tr>
<td>Nancy</td>
<td>~70's</td>
<td>Married</td>
<td>Chinese</td>
<td>Diabetes, BP</td>
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<tr>
<td>Ivy</td>
<td>~70's</td>
<td>Married</td>
<td>Jewish</td>
<td>Fabry’s, Atrial fibrillation</td>
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<tr>
<td>Amy</td>
<td>82</td>
<td>Single</td>
<td>English</td>
<td>Atrial fibrillation</td>
</tr>
<tr>
<td>Bert</td>
<td>54</td>
<td>Married</td>
<td>Canadian</td>
<td>Obesity, BP, migraines</td>
</tr>
<tr>
<td>Caroline</td>
<td>80</td>
<td>Widow</td>
<td>Filipina</td>
<td>Thyroid, BP</td>
</tr>
</tbody>
</table>
FINDINGS: CONTEXT

- Through local interviews I found texts which made visible links from the clinic to the Heart and Stroke Foundation, the pharmaceutical and technological industries and the Ontario government.
- The Ontario Stroke Strategy was founded using risk ideology:
  - an Empire Club speech
  - an article published about the origins of the Ontario Stroke Strategy authored by Heart and Stroke Foundation executives
  - the ICES data collection forms
FINDINGS: SOCIAL MARKETING

- Patients were activated by texts: HSFO magnets and commercials
- These texts are social marketing products
- Problem: ambiguity
FINDINGS: PATIENT ENCOUNTERS

- Prevention understood by patients as lifestyle changes, HOWEVER....
- Prevention identified by the neurologist as ‘secondary prevention’
- For the neurologist, stroke damage was minimized through a risk formula, the number needed to treat (NNT)
- Patients were not participants in NNT discussions, rather, seemed to trust that clinical decisions made for them were for the best
- The referral form, triage form and appointment observations show the privileging of certain physical variables as risk factors that ‘count’
- These variables are mined from the body through patient work: blood tests, examination, investigations, self- monitoring (eg: blood pressure)
- Blood pressure is example of ‘certain’ variable with ambiguous elements
SUMMARY OF PATIENT WORK

- Stroke warning sign/symptom detection
- Health care solicitation and navigation of health care system
- Managing health care response to their symptom
- Traveling to, undergoing and coordinating investigations within “life’s calendar”
- Taking, monitoring and managing medications and blood pressure
- Remembering and providing history and/or taking notes along the journey
- Managing ambiguity regarding symptom
- Participating in expert: patient relationship
- Financially integrating health related expenses
- Managing co-morbid health concerns
RISK IDEOLOGY

- Risk is connected to “lack of knowledge”
- Risk ideology authorizes the creation of certainty in ambiguous unknown situations
- The goal of Secondary Stroke Prevention is to make sure your “chance” of having a stroke is low.
- Chance is not explained to patients, who engage in substantial work and at times, risky treatments
- Stroke has moved from being known as ‘fate’ and ‘stroke down by the gods’ to ‘risk ideology’ to provide the illusion of certainty and control
Questions, queries, inquiries?

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