Patient engagement in research as transformation in problem-solving: A semiotic model of patient partner narrative and discourse

Graham G. Macdonald1,2, Jenny Leese1,2, Bao Chau Tran1,2, Lianne Gulka3, Alison Hoens1,3, Sheila Kerr3, Wendy Lum3, Linda Li1,2


Background

- Patient engagement in research seeks collaboration and inclusion of patients in all stages of research
- Different ideas as to what “engagement” entails
- Many motivating factors, ideas, & values animate “engagement”
- Engagement as a problem-solving endeavor that follows the interests and awareness of patients

Objective

To understand how patient partners’ experience of problem-solving with their condition relates to their engagement with health research

Methods

- Study was co-developed and conducted with patient partners
- Eligible participants were current or past members of Arthritis Patient Advisory Board at Arthritis Research Canada in Vancouver
- Semi-structured, hour-long interviews
- Thematic “constant comparison” analysis, “Semiotic square” model
- Secondary study of original dataset

In 2015-16, 22 participants were interviewed in Vancouver, British Columbia, Canada

<table>
<thead>
<tr>
<th>N=22</th>
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<tbody>
<tr>
<td>Age Range</td>
<td>26 – 68 (median = 60)</td>
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<td>Years of experience (range)</td>
<td>1 month to 10 years</td>
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<tr>
<td>Gender</td>
<td>23 (95%) female, 1 male</td>
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<tr>
<td>Education</td>
<td>14 (64%) with 1+ university degree(s)</td>
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<td>Occupational Status</td>
<td>12 (55%) employed fulltime, 9 (41%) retired, 2 (9%) students, 2 (9%) on disability benefits</td>
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<td>Diagnosis</td>
<td>12 (55%) inflammatory arthritis, 5 (23%) osteoarthritis, 4 (18%) OA and IA</td>
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Results

Semiotic Model: Four Problem-Solving Discourses of Patient Engagement

- Problem is described as within the individual’s body
- Solution prescribed to act upon the body of the individual
- Personal responsibility
- Engagement as adherence
- Solution at individual level
- Problem at collective level
- Example: no standard of care, try alternative medicine
- Engagement as skepticism and questioning biomedicine
- Difficulty of organizing collectively / lack of awareness of collective solutions

- I tried this treatment and it worked for me, everyone should try this.

- I can’t seem to get a good answer from any doctor about my problem, maybe I will try an alternative.

I’ve gotten involved in a lot of different things through wanting things to be different for patients in the healthcare system.” - Hannah

Implications

- Build hands-on knowledge, from patient perspective, of how involvement in research relates to real-world problems, interests, and awareness
- Understand that awareness and interests do not always overlap in problem solving -- need not only to raise awareness, but to articulate interests
- Provide clarity for what kind of discourse patient organizations are looking to engage in and promote
- Demonstrate how “organized skepticism” of patients is a critical feedback mechanism for research/medicine/policy