



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



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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

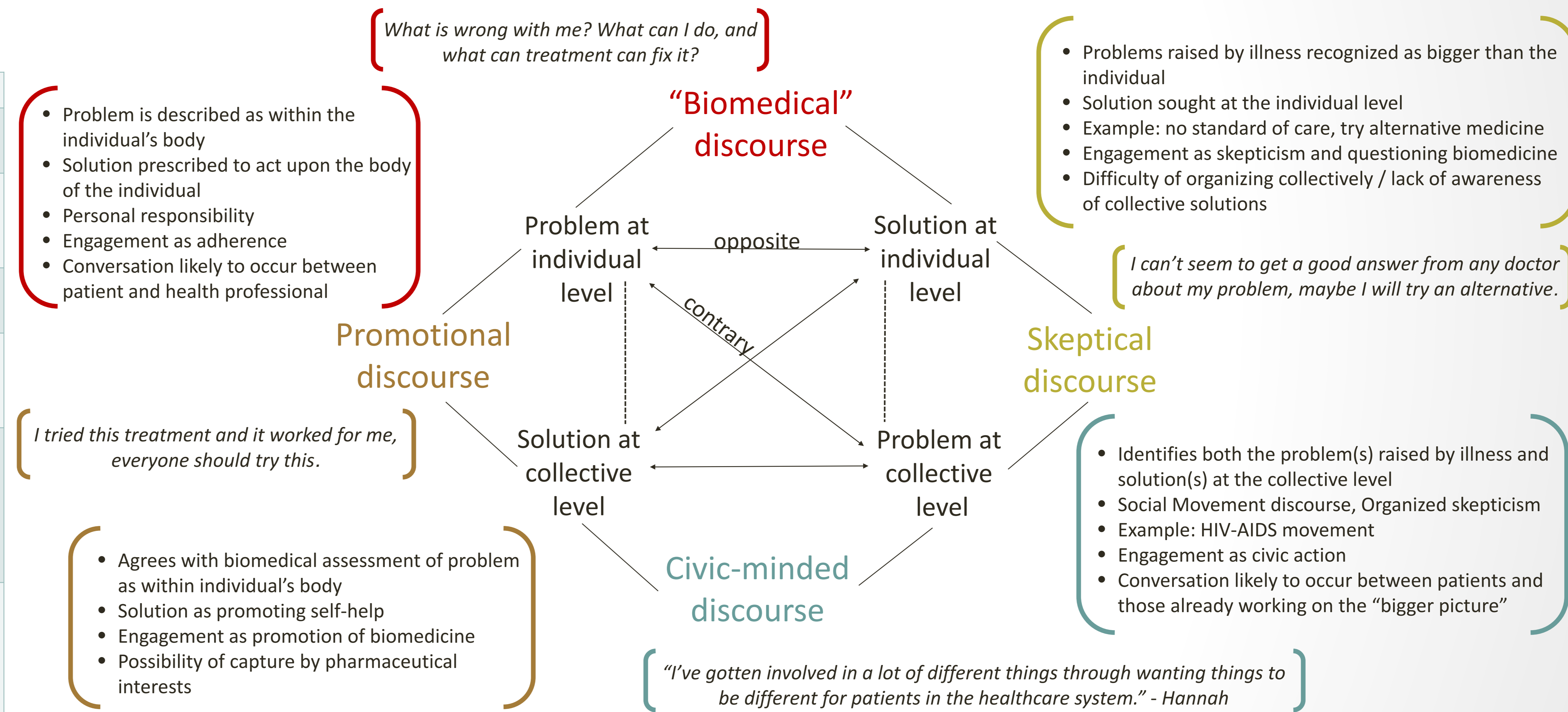
- Study was co-developed and conducted with patient partners.
- Eligible participants were current or past members of Arthritis Patient Advisory Board at Arthritis Research Canada in Vancouver
- Semi-structured, hour-long interviews
- Thematic “constant comparison” analysis, “Semiotic square” model
-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

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

N= 22	
Age Range	26 – 68 (median = 60)
Years of experience (range)	1 month to 10 years
Gender	21 (95%) female, 1 male
Education	14 (64%) with 1+ university degree(s)
Occupational Status	12 (55%) employed fulltime, 9 (41%) retired, 2 (9%) students, 2 (9%) on disability benefits
Diagnosis	12 (55%) inflammatory arthritis, 5 (23%) osteoarthritis, 4 (18%) OA and IA

Results

Semiotic Model: Four Problem-Solving Discourses of Patient Engagement



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