

Patient experiences of institutional betrayal in the Canadian medical system

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Introduction

- ▶ Extensive trauma
 - ▶ frequent utilization of healthcare services
- ▶ Psychological and physical consequences
 - ▶ Betrayal trauma

Introduction

- ▶ Trauma has a cumulative effect on health
 - ▶ Interactions with the medical system may further traumatize individuals with chronic conditions
 - ▶ “difficult” patients
- ▶ Patients may reject help due to previous negative experiences
- ▶ Institutional betrayal?

Purpose

- ▶ Study queried beliefs about medical errors, reasons for patient dissatisfaction with the medical system, and types of experiences that might result in feelings of IB
- ▶ Results were used to develop a questionnaire testing IB in the medical system

Methods

▶ Participants:

- ▶ 14 participants from across Canada who self-identified as having a chronic medical condition

▶ Measures:

- ▶ Healthcare Experiences Interview (Green et al., 2012)
- ▶ Institutional Betrayal Questionnaire (Smith & Freyd, 2013)

Methods

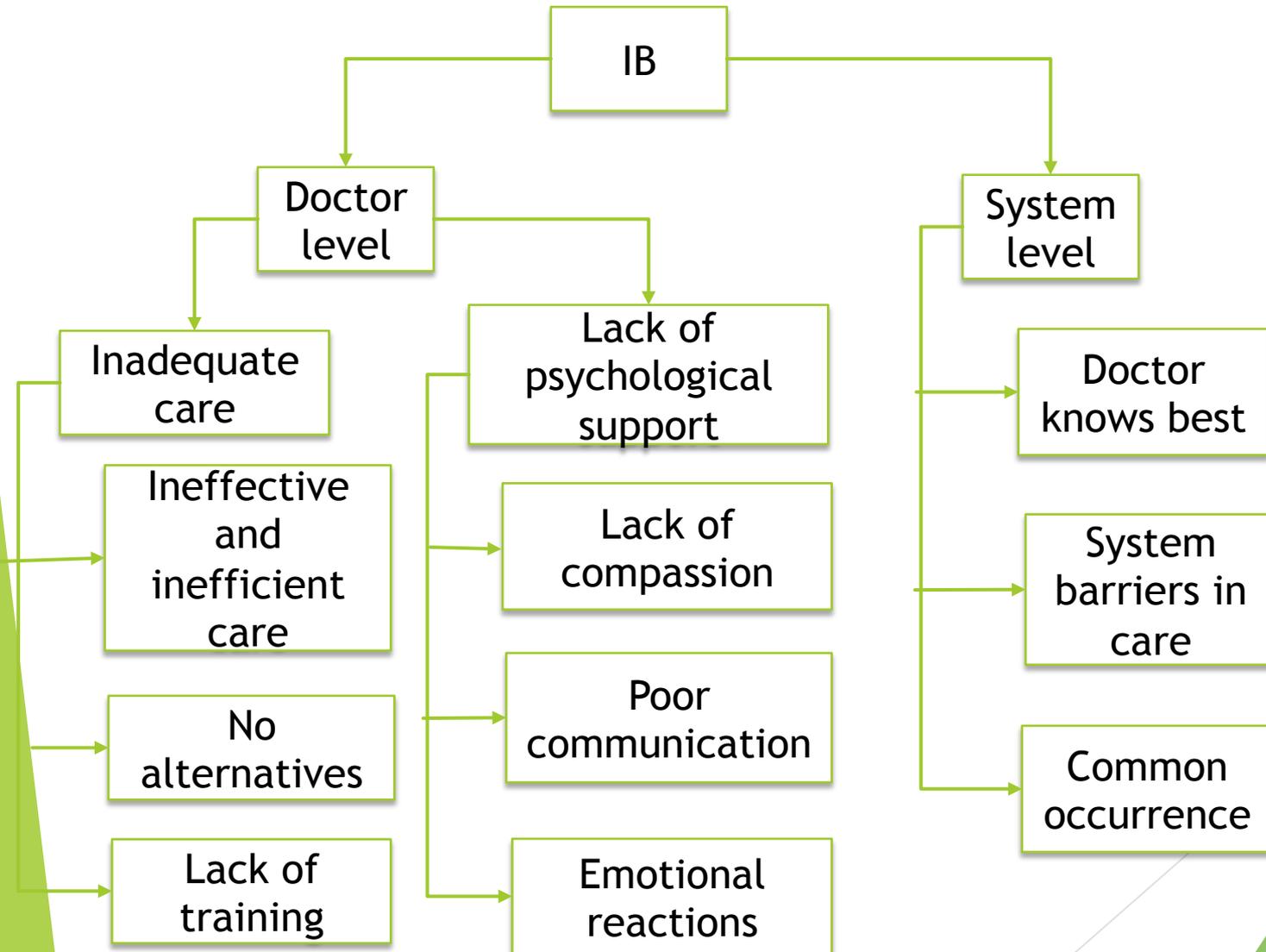
▶ Procedure:

- ▶ Advocacy groups
- ▶ Online open-ended survey on FluidSurveys

▶ Analysis:

- ▶ Inductive content analysis

Results



Doctor level betrayal

Inadequate care

- ▶ Inefficient and ineffective care
 - ▶ Lack of continuity of care
 - ▶ Delay in care
 - ▶ Lack of informed consent

Doctor level betrayal

Inadequate care

- ▶ No alternative treatments
 - ▶ Emphasis on pharmaceuticals
- ▶ *“It happens again and again [and doctors] just want to throw pharmaceuticals at [the patients’ concerns] without properly determining the cause, only to treat the symptoms”*

Doctor level betrayal

Inadequate care

- ▶ Lack of training and education
 - ▶ Poor doctor training
 - ▶ More research
 - ▶ No solutions to patient concerns
- ▶ *“Everyone reassures me the suffering will end. No one has an answer as to how. They refuse to admit they don’t know”*

Doctor level betrayal

Lack of psychological support

- ▶ Lack of compassion
 - ▶ Feeling dismissed
 - ▶ Unimportant
- ▶ *“Every time I had a complaint about pain [...the doctor] told me to suck it up and live with it”*

Doctor level betrayal

Lack of psychological support

- ▶ Poor communication
 - ▶ Desire for a more active involvement in decision making
 - ▶ Need for validation, understanding, empowerment
- ▶ *“I wanted to talk to my doctor about all the different drugs and what it was doing to me. She did not want to listen to anything I had to say. She got angry that I wanted to discuss these issues”*

Doctor level betrayal

Lack of psychological support

- ▶ Strong emotional reactions
 - ▶ Hurt
 - ▶ Distrustful
 - ▶ Angry
 - ▶ Helpless
- ▶ *“I was supposed to be able to trust this professional and he would have my best interests at hand but he had a doctor diagnose me as having Fibromyalgia and used that diagnosis as a scapegoat for every complaint I had. I feel so let down and hate how much I didn't matter”*

System level betrayal

- ▶ Doctor knows best culture
 - ▶ Doctors are always right
 - ▶ Lack of accountability
 - ▶ No sanctions
- ▶ *“nothing is done on behalf of advocating for the patient”*

System level betrayal

- ▶ System barriers in care
 - ▶ Time constraints
 - ▶ Shortage of doctors
- ▶ *“system encourages that not much time should be spent on complex cases”*
- ▶ *“doctors are often focused on the most sick, most disabled, etc. and when you are not the sickest or the most disabled they can be dismissive, even if you have real medical needs and problems”*

System level betrayal

- ▶ Negative experiences are common occurrences
 - ▶ *“happened more than once”*
 - ▶ *“many friends and colleagues have told [me] similar stories”*

Discussion

- ▶ Varying degrees of betrayal
 - ▶ Patients described ways in which the medical system responded inadequately in the face of a negative healthcare experience or failed to prevent such events
 - ▶ Negative cognitions and strong reactions related to interactions with the healthcare system

Discussion

- ▶ Psychological support
 - ▶ Particularly important for a chronic medical population
- ▶ Canadian vs. other medical systems
 - ▶ Public healthcare platform of universality and accessibility

Future direction

- ▶ Results were used to revise the original Institutional Betrayal Questionnaire for the Canadian medical system
- ▶ Validation study results for this measure will be posted on the SCHAT lab website
- ▶ Future studies should validate the measure with acute medical and non-medical populations

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Social Context, Health and
Trauma Lab

<http://uregina.ca/~schtlab/>

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