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ARTICLE

Patient dissatisfaction and institutional betrayal in the Canadian medical system: A qualitative study

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ABSTRACT

Individuals who struggle with chronic medical conditions frequently use medical services and may depend on the medical system to ensure their overall well-being. As a result, they may be at a greater risk of feeling betrayed by the medical system when their needs are not being met. The current study aimed to qualitatively assess patients' negative experiences with the medical system that may lead to feelings of institutional betrayal. A total of 14 Canadian adults struggling with various chronic conditions completed an online open-ended questionnaire. Results indicated that institutional betrayal is composed of doctor-level betrayal (inadequate medical care and lack of psychological support) as well as system-level betrayal. The findings are discussed in the context of betrayal trauma theory; specifically, patients' appraisals of their negative health care experiences may play a vital role when one is considering the impact of institutional betrayal on an individual's overall well-being.

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Betrayal trauma; chronic medical illness; medical system; qualitative methods

Trauma survivors often struggle with long-term mental and physical health consequences. These effects are further intensified when the trauma experience is associated with feelings of betrayal by a group in which the individual had instilled trust (Martin, Cromer, DePrince, & Freyd, 2013). Betrayal trauma theory (Freyd, 1996) states that when people or institutions a person depends on for survival violate that person's trust, the negative psychological and physical effects of experiencing trauma are exacerbated (Freyd, Klest, & Allard, 2005). One specific type of institution that individuals depend on for survival is the medical system. Individuals with chronic medical conditions have frequent interactions with a variety of health care providers due to the chronicity of their conditions. Therefore, this population may be more likely to have an encounter with the health care system that violates their instilled trust, leading to feelings of betrayal.

Betrayal trauma theory suggests that the importance of the relationship with a perpetrator determines the negative impact of a trauma to a greater

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extent than the type of trauma the victim has been exposed to (Freyd, 1996). If individuals experience betrayal by someone they are very close to or are dependent on (e.g., a partner), this would be considered a high betrayal trauma (Freyd, 2008). *Institutional betrayal* (IB) is defined as an institution's failure to prevent or respond effectively to unexpected or negative experiences (Smith & Freyd, 2013) and appears to exacerbate both physical and mental health problems (Smith & Freyd, 2013). Individuals suffering from chronic medical conditions are dependent on health care providers and systems and may experience feelings of betrayal when the care they receive does not meet their expectations. IB has been researched in a variety of contexts, including universities' responses to sexual assault, military sexual assault, and abuse in religious institutions (Smith & Freyd, 2013). Currently, IB has not been researched in the context of the medical system, but this is an important institution to consider when conceptualizing IB. Dissatisfaction with the medical system has been extensively researched, but not in the context of betrayal theory. In the medical system, patients' trust and reliance on their providers may lead to increased mistrust in or disappointment with the system when they are betrayed (Hall, Camacho, Dugan, & Balkrishnan, 2002).

IB theory has been discussed as occurring in two specific ways: as isolated or systemic betrayals (Smith & Freyd, 2014). Isolated incidents are betrayals that appear to occur to only one or very few individuals in the system. Systemic betrayals are types of betrayals that happen regularly within the institution. IB theory also states that there are two ways in which IB can occur: through acts of omission and commission (Smith & Freyd, 2014). Acts of omission are ones in which the institution has a system in place that ignores or does not respond appropriately to members' complaints (Smith & Freyd, 2014). Acts of commission are betrayals that occur when the institution responds to a complaint with retaliatory actions (Smith & Freyd, 2014). In the medical system, both isolated and systemic betrayals may be occurring, and the actions taken by an institution following a negative experience may further intensify feelings of betrayal (Smith & Freyd, 2014).

A medical error is described as a preventable event that may cause a patient harm (Gokhman, Seybert, Phrampus, Darby, & Kane-Gill, 2012) and is a type of isolated betrayal that may occur in the medical system. Medical errors may be similar to the experience of betrayal trauma if patients perceive the error as an intentional or preventable harm by professionals in whom they have instilled a considerable amount of trust. Diagnostic errors are the most frequently identified medical errors in the medical system, ranging from 26% to 78% of errors (Sandars & Esmail, 2003). Pucher and colleagues (2013) analyzed a total of 169 preventable errors from 96 patients who had experienced traumatic events. The researchers identified that 87.9% of errors were due to process issues, such as a misdiagnosis, technical error,

or communication error. Additional research has also indicated that patients feel dissatisfied during treatment because of misdiagnosis, ineffective or inappropriate medication or treatment, and the physician's lack of competency (Coyle, 1999).

Patients and their families suffer not only from the physical effects of medical errors or misdiagnoses but also from how the incident is handled after the error occurs (Vincent & Coulter, 2002). Nondisclosure of medical errors is associated with reduced patient satisfaction with and trust in the medical system (Mazor et al., 2006). Although physicians appear to believe that errors that cause harm should be disclosed, Gallagher, Waterman, Ebers, Fraser, and Levinson (2003) found that physicians view withholding information about errors as acceptable. Withholding information may be perceived as an act of omission, leading to feelings of IB.

Research has found that even when problems with medical care are unintentional, patients suffer negative outcomes (Brüggemann, Wijma, & Swahnberg, 2012). Oftentimes physicians view patients with complex complaints and chronic conditions as difficult and may not be comfortable working with these clients (Green et al., 2011). A problematic consequence is that these patients may feel misunderstood, not taken seriously, and alienated from the medical system. Abuse in the health care system is associated with posttraumatic symptoms for patients as well as distrust and avoidance of the health care system (Brüggemann et al., 2012). Acts of omission and commission in the realm of IB by the medical system appear to be having a negative effect on the lives of patients.

To date, no research has examined the possibility of betrayal trauma in interactions between patients and the medical system. Patients may feel betrayed by the system when they experience errors that could have been prevented or are in some way perpetuated by the system itself. In addition, the way in which the medical system prevents or responds supportively to medical errors will exacerbate or prevent feelings of IB (Smith & Freyd, 2013). Patients with chronic medical conditions have more opportunities to experience IB because of their frequent interaction with medical professionals and because of the complexity and chronicity of their conditions.

Because patients with chronic medical conditions tend to utilize medical services more often (Bonomi, Anderson, Rivara, & Thompson, 2009) and delay seeking health services (Coyle, 1999), their negative experiences may lead to higher levels of IB, exacerbating their psychological and physical complaints. Given a patient's vulnerability and reliance on the medical system, unexpected medical outcomes as well as an institutional failure to prevent or respond supportively to such events (Smith & Freyd, 2013) may create feelings of IB for patients. A previous study found that patients suffer various negative consequences when their health care provider or the system devalues them as human beings or does not offer psychological support

(Brüggemann et al., 2012). Therefore, the patient's subjective appraisal and interpretation of a health care interaction appears to be particularly important when one is investigating feelings of IB.

The current study aimed to investigate participants' negative experiences with medical providers and the medical system in Canada that may lead to feelings of betrayal. To our knowledge, no such study has been conducted in Canada using a qualitative approach. The purpose of the current research was to explore the experiences of patients that lead them to feel that the medical system or providers let them down, betrayed them, or did not act in their best interests.

Method

Participants

To be eligible for this study, participants (a) self-identified as experiencing a chronic health condition; (b) were 18 years or older; (c) currently resided in Canada; (d) were able to read and accurately respond to questions in English; and (e) had an interaction with the medical system in which they felt that the medical system or provider let them down, betrayed them, or did not act in their best interests. A total of 14 participants completed the online survey, one male and 13 females. Participants ranged in age from 27 to 62, with the average age being 49. Recruited from across Canada, seven participants reported residing in Ontario, two in Nova Scotia, two in Alberta, one in Manitoba, one in Saskatchewan, and one in Quebec.

Participants reported on their specific medical condition: One participant indicated that he had a current heart problem, one reported previously suffering from breast cancer, another reported previously experiencing prostate cancer, and two reported other types of cancer. Five participants indicated that they were currently struggling with respiratory problems (i.e., chronic bronchitis, asthma), and one participant said that he had struggled with them in the past. One participant reported being diagnosed with Type 1 diabetes and one with Type 2 diabetes. In terms of arthritis, one participant indicated that he or she was currently struggling with rheumatoid arthritis, and seven said that they had another arthritis-related disease. In addition, 10 participants mentioned that they were currently struggling with a neurological disorder. Seven participants reported current chronic back pain, whereas four said that they had struggled with it in the past. Migraines were current concerns for five participants and past concerns for three. Participants also reported current other forms of chronic pain ($n = 12$), and one indicated a past struggle with such. One participant reported only having struggled with one condition either in the past or currently, one participant reported two conditions, one reported four, three participants

reported five conditions, and the remaining eight participants reported struggling with six or more conditions.

Procedure

The current study was the first phase of a larger project aiming to create a psychometrically sound measure of IB in the Canadian medical system. Advocacy groups for various chronic conditions across Canada were contacted via e-mail about the study. The recruitment poster was then uploaded on the following websites: Crohn's and Colitis Canada, Canadian Cancer Society, and Chronic Pain Canada. Eligible participants were provided a link to access the qualitative questionnaire on FluidSurveys. In addition, participants were also recruited through a database of past participants with chronic medical conditions who had agreed to be contacted for future research. Informed consent was implied by participants continuing on with the survey. The study took an hour to complete, and participants were compensated with an online certificate of \$20 to the store of their choice from a list of national chains (Amazon, Chapters, Starbucks).

Measures

An open-ended survey was completed by participants online through the FluidSurveys website (www.fluidsurveys.com). The first part of the survey asked questions about demographics, and the second part contained an open-ended questionnaire (21 questions) asking about participants' experiences in the health care system with doctors, nurses, and nurse practitioners. The questionnaire permitted respondents to extensively discuss their satisfaction with the medical system, beliefs about instances that may elicit feelings of betrayal, and what providers could do in order to improve the delivery of health care and meet the needs of a chronic medical population.

The Healthcare Experiences Interview (Green et al., 2012) and the Institutional Betrayal Questionnaire (Smith & Freyd, 2011) were modified and aggregated to be used with a medical population. The Healthcare Experiences Interview was created for a qualitative study that examined low-income women with a history of trauma and their relationship with their health providers (Green et al., 2012). The questions that were relevant to a medical population were used in the current study and modified to ask specifically about this population's experience with the medical system. The original Institutional Betrayal Questionnaire was created to investigate whether IB in a university setting exacerbated feelings of trauma resulting from sexual assault in a sample of college women (Smith & Freyd, 2013). For 10 of the questions the response format is dichotomous (yes or no), one of the questions requires the participant to choose as many of the options as are

appropriate for his or her situation, and three of the questions are open ended (Smith & Freyd, 2011). The Institutional Betrayal Questionnaire was modified to inquire about the medical system specifically, and the questions were reformatted to be open ended. Two additional clinical psychologists not involved with the current project reviewed and suggested improvements to the newly created qualitative questionnaire before the survey was deployed.

Analysis

Three raters conducted content analysis independently. Because the questionnaire was created from existing measures investigating experiences in the medical system and IB, the analysis was conducted within the framework of betrayal trauma theory, and participant responses aided in developing themes of betrayal specific to the medical system. The raters deduced the main themes and subthemes directly from the data, and questions were coded based on the content of the participants' responses (Elo & Kyngas, 2007). Categories were generated from these codes and grouped under themes (Elo & Kyngas, 2007). Responses were categorized as subthemes if more than one participant mentioned the overall content. Combining and summarizing subthemes that conveyed similar ideas created higher order themes. We coded the data separately and then compared the themes. We discussed results, and any discrepancies were resolved.

Results

The identified higher order themes and subthemes that emerged are summarized in [Figure 1](#). Given the much larger proportion of women, gender is not identified in the quotes used to further support the qualitative themes. Participants described feelings of IB on two different levels: the doctor level and system level. Two higher order themes in relation to doctor-level IB emerged: (a) inadequate medical care and (b) lack of psychological support. The system-level betrayal theme reflected systemic dysfunction that promotes further negative experiences.

Doctor-level IB—Inadequate medical care

Three themes emerged regarding inadequate medical care that may lead to feelings of IB: (a) failure to provide effective care, (b) unwillingness to consider alternative treatments, and (c) lack of training.

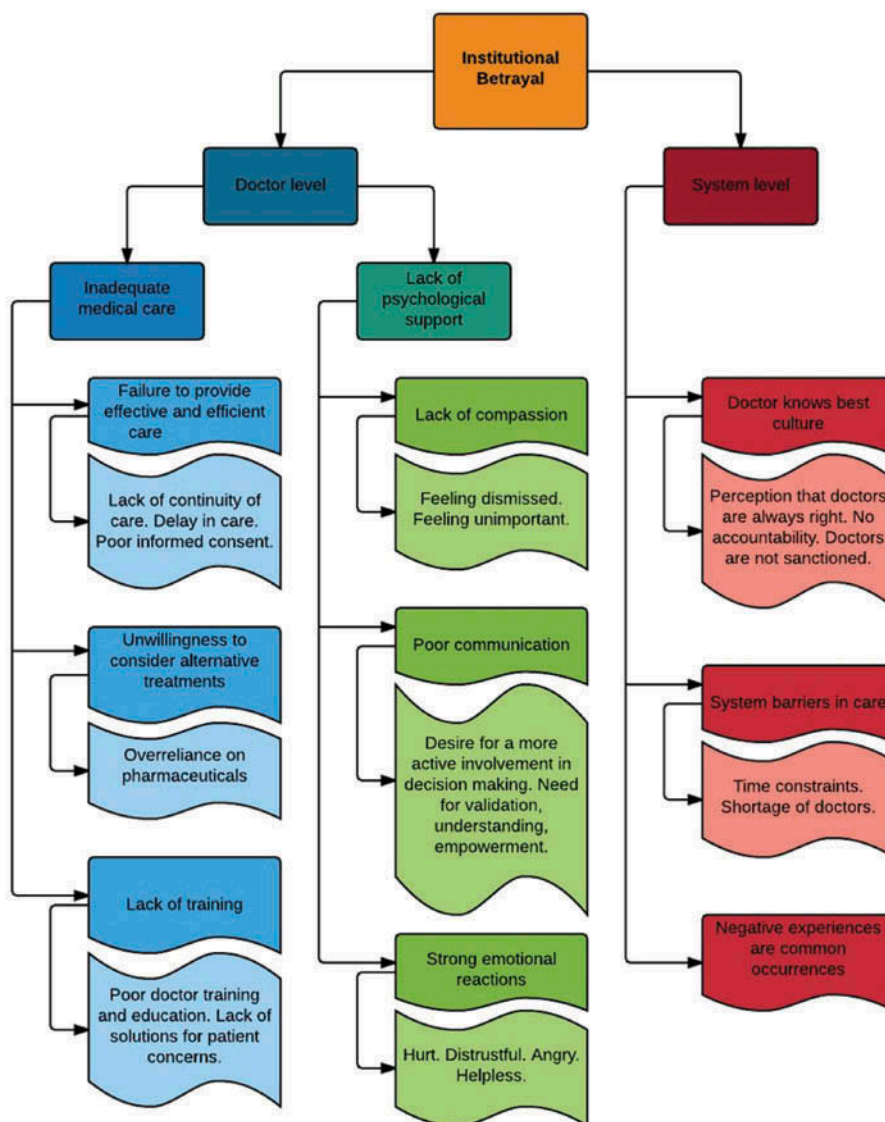


Figure 1. Qualitative results: higher order themes and subthemes.

Failure to provide effective and efficient care

Participants commonly reported on (a) the lack of continuity of care between doctors, (b) a frequent delay in care, and (c) the lack of informed consent regarding risks and procedures.

Lack of continuity of care. A number of patients complained that “doctors don’t stay on the same path” and urged physicians to “read your records and communicate with previous [doctors].” One participant reported that he or she “... went to another doctor for another opinion and [...] was diagnosed with [something different].” In addition, individuals were concerned about

the hesitation physicians may have referring patients to other doctors, indicating that they “should have been referred to a specialist” much sooner than they had been. Last, participants commented on the lack of continuity of care regarding record keeping and information gathering. One individual noted, “I tried for 8 years to get my records through seven different doctors.”

Delay in care. Participants frequently commented on the impact delay in care has had on their health, specifically related to a delay in “starting the right symptom medication.” One of the most cited concerns was the issue surrounding misdiagnosis. One participant indicated that he or she was “misdiagnosed for [3] years,” whereas another one said that he or she was misdiagnosed “and underwent a surgery that [wasn’t] needed and only made . . . symptoms worse.” Not completing the right documentation or receiving the right medication was also reported as leading to a delay in care, as one participant mentioned that a doctor “did not fill out medical forms required” and another would have liked his or her doctor to have been “proactive [. . . and] fill out the paperwork that I paid to have completed.” At times, these delays in paperwork resulted in financial struggles for clients, as one participant reported that his or her “income depended on forms being completed by a certain date and went 3 months with no income due to this.”

Lack of information about risks and procedures. Doctors’ failure to provide adequate information about risks and procedures was often mentioned as a concern by patients. One participant indicated that his or her negative experience with the medical system was due to “not being provided with all the information about the risks to watch out for and protocol to follow.” Another concern was regarding doctors failing to “explain their findings and suggest what to do.” The following quote encompasses these main concerns: “Doctor could have provided more details about the situation, treatment options and risks for the future [. . .] I could have gotten more information and taken a more active role in learning about treatment options.”

Unwillingness to consider alternative treatments

Another major theme surrounding inadequate medical care was doctors’ unwillingness to consider alternative treatments, placing a specific emphasis on pharmaceutical treatment. Patients advocated that the doctors “should at least give you options of support groups you can go to” and discuss “multiple options to work on treating chronic pain” or other concerns patients may have. One patient indicated that doctors “are not open to alternatives to treat the root cause because that takes too much time.” A large majority of patients complained about their doctor’s refusal “to consider any other treatment beside drugs.”

Overall, many participants expressed a dissatisfaction with drug efficacy and side effects. One participant indicated he or she does “not like all the meds [the doctor] keeps giving [him or her],” whereas another stated that doctors “prescribe things [...] without knowing all the side effects.” Yet another participant raised the issue of finances in paying for medication, stating that “the medication I am on is not covered by province or healthcare providers and there are no options, I am stuck between a rock and a hard place.”

Related to the lack of alternatives, one participant reported taking on a more active role and “find[ing] more information myself and try[ing] to discuss alternatives; sometimes [I’m successful] but most times not.” Patients also commented on the difficulty of taking on a more active role in decision making because of the position the doctor might have taken on the subject. The following quote further illustrates this concern:

I tried 4 different anti depressants. The last one had made me suicidal. I was terrified of taking more anti depressants. I wanted to use alternative therapies or talk to [the doctor] about all the different drugs and what [they were] doing to me [...]. She said if I wasn’t going to take the drugs t[h]en she couldn’t help me.

Lack of training

Inadequate medical care was often described as being due to a lack of doctor training and education, which ultimately tended to lead to a lack of solutions to patient concerns. Some patients commented on perceived doctor incompetence, and one participant indicated that he or she “felt like I had to diagnose myself.” Moreover, another patient indicated that his or her doctor “didn’t have openness to other options,” and as a result the patient “followed all of those treatments I tried due to my own research and trials.”

A concern raised by one participant was about doctors not fully “understand[ing] the risks of certain prescription and the adverse side effects.” One participant advocated for “better education to the staff,” whereas another expressed a wish for doctors to be “better able to diagnose causes of symptoms.” Moreover, participants commented on the fact that “our healthcare system seems to be a cookie cutter system,” so that “if you are outside the mold you don’t fit.” Thus, responses also reflected a tendency of doctors to fall back on the treatments they know when they are faced with an unfamiliar situation.

No solutions. Participants advocated for “more research” in this area as they recognized the lack of solutions to many complex health problems. They often described “run[ning] out of options” and being “genuinely in need of medical help” without receiving any. One participant further described his or her frustration by indicating that “everyone reassures me [the suffering] will

end. No one has an answer as to how. They refuse to admit they don't know. The general physician [...] should know better than that.”

Doctor-level IB—Lack of psychological support

Three themes emerged regarding a lack of psychological support: (a) lack of compassion, (b) poor patient–physician communication, and (c) strong emotional reactions.

Lack of compassion

The majority of participants reported that medical providers lacked compassion in their interactions with patients. Specifically, they commented on feeling dismissed and unimportant. Some participants indicated that doctors are often “dismissive about [their] symptoms.” One participant mentioned that “every time I had a complain[t] about pain [...] the doctor] told me to suck it up and live with it.” The most difficult part about doctor visits was often a “fear of being disbelieved, doubted, dismissed, judged, labelled, [and] not helped.” Participants discussed feeling “sad that [they were] never treated as [...] human[s]” and expressed a particular concern about doctors only seeing a person’s medical condition instead of focusing on the whole person. This concern regarding the difficulty of doctor visits was illustrated by a patient’s comment regarding “not examining me and just treating me as a ‘Fibromyalgia’ patient instead of a human” and another participant’s wish “to be treated as a whole person, often doctors just focus on the physical.”

Some participants also expressed frustration over the lack of empathy shown by doctors, reporting that they do not “seem to care or understand” and often “forgot they were dealing with a human being.” Many participants also felt that the doctor often “belittled [them] and made [them] feel unimportant and crazy.” Another reason why medical patients may feel unimportant is because of the lack of human interaction during their medical visits. One participant expressed frustration “with doctors who spend the whole appointment typing into their computers, often with their backs to the patient without even looking up.” Another participant indicated that “very few [doctors] have made [him or her] feel that they understand what [it’s] like to live with [multiple sclerosis] on an emotional level.”

Poor communication

Most participants talked about an overall poor physician–patient relationship and specifically indicated a desire for more active involvement in decision making and a need for validation, understanding, and empowerment from the provider. Some participants also commented on a reluctance to communicate their concerns to the medical provider due to a concern that they would be labeled or considered a nuisance.

A number of respondents advocated for more “human compassion, people skills, [and] listening skills” from their providers. The lack of listening skills often leads to fear that the “doctor will not take my suggestions seriously” or patients’ concerns will be “ignored.” A main concern with communication is feeling that the medical provider does not take into consideration patients’ suggestions regarding treatment. Some patients indicated that it would be helpful for medical providers “to listen to me,” to “confirm that they have heard my concerns correctly,” and to “take into account my feelings about what will work for me.”

A number of participants described a “fear of [. . .] being labelled” as one of the most difficult parts of going for a medical visit. One participant indicated a reluctance to discuss his or her concerns regarding a negative experience with the doctor due to a fear of being labelled, as he or she “work[s] in the medical field and didn’t know what to do or how to do it without [. . .] being label[l]ed.” Another common worry preventing patients from discussing their concerns with the medical provider appeared to be not wanting to be seen as a nuisance, as one participant indicated that he or she does not “want to be seen as a complainer.” Another participant stated that he or she was “afraid that I will then [lose] my family doctor” if he or she were to address the negative experience, and that was described as one of the most difficult parts of interacting with doctors.

Strong emotional reactions

In general, participants expressed strong emotional reactions with regard to their interactions with medical providers, specifically feeling hurt, distrustful, angry, and helpless. Many participants commented on feeling “upset,” “very hurt,” and “betrayed” by their interactions with medical providers. Moreover, some participants commented on feeling “betrayed and that no one cares.” One individual shared that “many, many times over the years I have been disbelieved, dismissed, insulted, [and] disrespected.” Overall, participants advocated that doctors “could show kindness and respect” as well as “patience and empathy.”

The majority of participants described feeling “frustrated [and] angry” about how they have been treated and their interactions with medical providers. One participant specified feeling “angry and in a bit of shock [because of the discriminating] comments [made] by the nurse.” Some participants talked about feeling helpless in their interactions with the medical system and feeling like they have no one to turn to. One participant indicated that he or she feels like there is “no one to complain to,” whereas another one talked about other patients who “complain about the same things and they are no further ahead.” Many patients indicated feeling “terrified,” and one person indicated that he or she “still [has] a fear of going to the Emergency.” In addition, one participant commented on feeling

that specific issues are not important enough to discuss with providers or send in a formal complaint: “not something to go to the Medical Society with.”

System-level IB

Many patients emphasized the issue of a system-level betrayal in which the medical system promotes negative experiences through various types of dysfunctional actions and practices: (a) doctor-knows-best culture, (b) barriers in care, and (c) negative experiences are common occurrences.

Doctor-knows-best culture

A number of participants commented on the perception that doctors are always right as well as doctors' lack of accountability when errors occur and the system not sanctioning those who do make significant errors in their practice.

The perception that doctors are always right. Many participants talked about both an expectation that doctors should be the experts as well as a sometimes false perception that doctors are always right when the evidence shows otherwise. One participant indicated that “we hold our doctors to a higher standard [because] they are trained in ethics and patient care,” and another commented on not “second guess[ing]” the doctor because he or she “held doctors in high regard.” At the same time, respondents discussed the “culture of ‘doctor knows best’” and their perceptions that the system is “always taking a doctor’s word over a patient.” In addition, one participant said that “physicians are automatically given credibility, while patients are doubted.” One individual stated that “doctors are being told to never take on a patient who has ever made any type of complaint, that [they] are high risk troublemakers and are prone to sue.” This perception adds to the “hierarchy of power” and the fact that patients’ opinions are often not taken into consideration by the medical system or providers.

Lack of accountability. Responses focused on a tendency for doctors to not only not take accountability for errors they may have made but also not admit when they do not know the right answer. In regard to not taking accountability for errors, a participant indicated that the doctor “had me on dangerous levels of narcotics, when it looked like he was going to get in trouble he ditched me, destroyed my records early and illegally, and now he is lying about it . . .” Many participants indicated that “hearing, ‘I don’t know what I can do to help you,’ would have been better than dismissing my symptoms.” Doctors sometimes “refuse to admit they don’t know,” and participants advocated “for them to be held accountable for their attitudes

and actions.” One participant even stated that “family [doctors] who don’t know all they should [...] become roadblocks to the specialists who could help.” Doctors’ negative or unhelpful attitudes were also seen as an area in which doctors did not take full responsibility. One participant indicated that in his or her interactions with the doctor “there was no acknowledgement of her having done anything wrong.”

Doctors not sanctioned. Some participants complained about a system failure to sanction doctors when they should be doing so given the circumstances, especially given the fact that “doctors [are] policing doctors” and thus “never get disciplined.” In addition, some participants indicated that issues are “brushed off, nothing is ever done on behalf of advocating for the patient” and that the medical system could ameliorate these types of negative experiences by having someone who “would have any power to discipline the rogue doctor in an attempt for this not to happen again.”

System barriers in care

Respondents frequently commented on time constraints and the shortage of doctors as system barriers in care.

Time constraints. The “long wait for [an] appointment” and the “limited appointment times” were frequently cited as system barriers in care. Participants often indicated that they feel “rushed” during their appointments and “feel like [they are] taking up [the doctor’s] time.” In addition, one participant stated that “the system encourages that not much time should be spent on complex cases.” Moreover, a number of participants felt that the system encourages “that we should be booking multiple appointments that the doctor can bill so we can have time with the doctor.” Therefore, multiple appointments may be needed if a participant has a complex case because “the family doctors want to get the patients in and out as quick[ly] as possible” and are “too busy trying to rush the appointment.”

Some participants talked about how doctors “are paid by how many patients they see and how many drugs they [prescribe]” and insisted that they should not make appointments “feel like it’s about billing time, or having to justify my complaints of my health . . . I have the right to be taken seriously with a complex case.” Some participants also expressed frustration with the “long waiting periods to only waste time and not get real answers.” Last, a participant expressed feeling “rush and need[ing] to get straight to [the point] or the [doctor] will get impatient; so I go in with written lists [...] then I feel like they feel annoyed that they have to read something.”

Shortage of doctors. Some respondents commented on the “shortage of doctors and not enough time to help” as a major system barrier to care.

They felt that “doctors have limited appointment times, or work short hours,” which thus prevents them from effectively accessing care. One participant commented on not being able “to switch doctors as there [are] not enough doctors to be able to get a second opinion.”

Negative experiences are common occurrences

The majority of participants commented on the commonality of the negative experiences they were faced with in the medical system not just for themselves but also for others. One participant indicated that his or her experience “happened more than once,” and another indicated that because of his or her previous negative interactions with the medical system, he or she is “now reluctant to go to the hospital for any reason, and it has been under force that [he or she] go[es].” Similarly, another participant talked about his or her numerous negative experiences with the medical system and stated, “I did not go to see [my doctor] for 5 months. I suffered worse pain and depression. The only reason I returned was because my mother dragged me to a doctor to be seen.” Other participants talked about “many friends and colleagues [who] have told [. . .] similar stories.” Another participant indicated that he or she “filed a complaint [about the doctor and] he was found to have done this to many patients.”

Discussion

The purpose of the present study was to capture specific instances that may lead to perceptions of IB in a sample of Canadian patients with chronic medical conditions. Overall, participants described varying degrees of betrayal in their interactions with medical providers and the medical system, specifically at the doctor level (including poor medical care and lack of psychological support) and at the system level. In their responses, participants discussed ways in which the medical system and their doctors either responded inadequately in the face of a negative health care experience or failed to prevent such events, which reflects IB as defined by betrayal trauma theory. In addition, participants indicated experiencing many negative cognitions and strong emotional reactions directly related to instances of betrayal. Betrayal trauma theory suggests that the perception of the importance of the relationship with the perpetrator is more imperative than the type of trauma in determining feelings of betrayal (Freyd, 1996). Because all participants had chronic medical conditions, the relationship with their doctor was presumably important for their well-being. The way in which participants perceived negative health care experiences and the extent of the betrayal was an important aspect of their interactions with the medical system. Negative cognitions often appeared to be linked to the lack of psychological support, as patients expressed strong negative emotions related to the way they felt they were treated by the medical providers and the medical team. Psychological support appeared to be a major component that affected patient satisfaction with the health care system.

Individuals suffering from chronic conditions may require additional psychological support compared to others because of the chronicity and nature of their condition (Kirby, Dunwoody, & Millar, 2009). The current findings echo results of a previous study of people with chronic pain, who appeared to require more emotional support from their medical provider than did no-pain patients even after mental health status was controlled (Kirby et al., 2009). Kirby and colleagues (2009) found that patients suffering from chronic pain needed to feel understood by their providers and wanted doctors to act empathetically in their interactions with these patients. Similarly, the present study found a great need for psychological support in this sample, especially in terms of a need for validation, understanding, and improved communication. Patients with chronic conditions may see their provider more often, while never experiencing a reduction in symptoms, which may increase their need for support from the medical provider. Because patients rely heavily on their doctors, not receiving the psychological support needed is a violation of the patient–physician relationship and instilled trust. Such feelings of IB are due to an omission on the part of the doctor to satisfy the patients’ needs for support.

The present study found inadequate medical care to be another emerging theme of doctor-level betrayal. Participants indicated that doctors failed to provide effective and efficient care through a lack of continuity of care, delay in care, and lack of information made readily available. Participants most commonly reported misdiagnosis, errors pertaining to medication, poor patient–provider communication, and a delay in care due to wait times. Given the chronic and complex nature of the health conditions in the present study, it may be possible that physicians did not realize that they were making a medical error. One participant indicated that he or she was “misdiagnosed for [3] years,” which could have been the result of a very complex, hard to diagnose condition. Although this error may not have been directly the fault of the health care provider, IB may be present if the patient conceptualizes this error as traumatic or as a betrayal of the trust that he or she has placed in the physician. IB theory suggests that when a system does not respond appropriately to a betrayal, and instead tries to cover up the betrayal, this can lead to further feelings of betrayal (Smith & Freyd, 2014). Providers who are willing to admit a medical error when it occurs and to disclose that information to the patient not only may ensure that the patient receives the required treatment but also may foster better communication and health care relationships, which may ultimately create a buffer that could prevent feelings of IB.

Patients expressed feelings of being let down by their providers when they were not actively involved in their own treatment. Previous research has found that when patients are seeking guidance about their treatment options, they should be given enough information regarding the risks and benefits of

each in order for them to choose the treatment they prefer (Mulley, Trimble, & Elwyn, 2012). Providing options is especially important for chronic conditions because patients' preferences about their health may change (Mulley et al., 2012). Moreover, involving patients in decision making also appears to be associated with higher quality care and fewer medical errors (Osborn & Squires, 2012). Quality of care and psychological support can be considered malleable in their relative importance during a negative health care experience. The present study mirrored these findings, as the doctor-level betrayal theme was composed of both inadequate care and lack of psychological support. As support and communication improve, the perception of quality of care may also improve. Alternatively, as the quality of care improves, patients may need less psychological support or may perceive the support they receive as adequate given the circumstances.

The themes of inadequate care and lack of psychological support, as viewed through the lens of betrayal trauma theory, provide an additional factor to consider that is separate from satisfaction with the medical system. In this sample of patients with chronic medical conditions, not receiving the support and care needed from an individual (i.e., doctor) or the medical system, both of which an individual depends on for survival, can be significantly more harmful than instances that do not rely on a trusting relationship (Smith & Freyd, 2014). Experiencing feelings of IB may be highly correlated with dissatisfaction in the system, as feeling betrayed by an institution could also cause individuals to feel dissatisfied. However, unlike feelings of dissatisfaction with a particular service received, IB occurs when an institution actually causes harm to the individual (Smith & Freyd, 2014) and the individual appraises that harm as a violation of trust. IB is inherently more detrimental than dissatisfaction with the medical system because it involves a loss of trust in a physician or an institution due to harm having been done through an action or inaction of the medical system.

Many participants in the current study stated that doctors were not willing to consider alternative treatments. A study of Canadian gastroenterologists found that only 8% of doctors reported initiating a conversation about alternative treatments with their patients, and 51% of the sample reported that they avoided conversations about other treatments because of a lack of knowledge about such (Gallinger, Bressler, Devlin, Plamondon, & Nguyen, 2014). In addition, Mildren and Stokols (2004) found that 61% of the medical professionals they surveyed did not feel that they had sufficient knowledge about alternative treatments. It is possible that although Canadian medical professionals may be open to alternative treatments, they do not have adequate knowledge to communicate about these alternatives with patients. Physicians have extensive training in pharmaceuticals, which may be why they are much more open to discuss these as treatment options. Medical training should include information about alternative treatments for

individuals with chronic conditions who appear to be open to and in need of other treatment options.

Some participants felt that medical professionals lacked training, specifically in chronic conditions. Previous research has found that health care providers may view patients with multiple, complex, and chronic symptoms as difficult and may also feel unprepared to adequately work with these clients (Green et al., 2011). It may be possible that primary care doctors do not want to get involved in chronic cases because of their complexity, or they may not be trained to effectively care for these patients. Therefore, it is important that physicians provide efficient referrals for these patients so that they receive the care they need.

A qualitative study conducted in Lithuania regarding dissatisfaction with the medical system found similar main categories as the present study: shortcomings in the health system, poor quality of services, and poor doctor attitudes (Bankauskaite & Saarelma, 2003). Overall, subthemes overlapped with the ones from the current sample of Canadians, such that Lithuanians were dissatisfied with long wait times; inadequate service quality, doctors' lack of competency, indifference, and rudeness, the lack of accountability, and the lack of information provided to patients regarding treatment or the course of disease (Bankauskaite & Saarelma, 2003). It is interesting that these similarities were not linked to specific medical conditions, as Bankauskaite and Saarelma (2003) used a sample of individuals from the general population, whereas the present study used a sample of Canadians with chronic medical conditions and found comparable results.

There were, however, some differences in the findings of the two studies. Bankauskaite and Saarelma (2003) found themes at the systemic level that specifically relate to the Lithuanian health care system (such as the changing health care reform and the high cost of services) that do not generalize to other medical systems, such as the Canadian one. The latter relies on a public health care platform of universality and accessibility. Therefore, the organization and bureaucracy of a medical system impacts individuals' satisfaction with it. In the present study, individuals commented on specific system barriers to care, such as long wait times and shortages of doctors, which may reflect the bureaucracy of the Canadian medical system and may not generalize to private medical systems that may cater their services based on ability to pay rather than need. It could be argued that the results of this study would also not generalize to a chronic medical patient sample from the United States. The American medical system differs from the Canadian one in that it is privatized, such that consumers rely on insurance in order to access services. Experiences with the medical system may be different in a middle-class compared to a lower socioeconomic status American sample. Specifically, lower income patients may experience similar delays in being able to access care to Canadians, whereas individuals who can afford

insurance may deal with other concerns that could lead them to experience feelings of IB.

The major strength of the current study involves using qualitative measures to inquire about potential experiences that may lead to feelings of IB in the Canadian medical system. The qualitative method in the present study allowed this sample of Canadian participants to openly express their most pressing concerns with the medical system in their own words. A potential limitation of this research may be the use of online surveys instead of a face-to-face interview in order to receive qualitative feedback regarding individual perceptions of betrayal by the medical system. The online format of the present study allowed for a more efficient way to collect and analyze the data. In addition, a recent study found comparable results between online qualitative methods and face-to-face methods in a sample of individuals with multiple sclerosis (Synnot, Hill, Summers, & Taylor, 2014). Therefore, even though an online survey may have prevented individuals from expanding on their experiences, the responses did appear to reach saturation and the results are comparable with other similar studies. An additional limitation of this study is the high percentage of female respondents. Future studies should further investigate the potential experiences of IB with the medical system in other medical samples and other demographics (males, different ethnicities, low economic status).

Overall, the results of this study seem to reflect IB as defined by betrayal trauma theory (Smith & Freyd, 2014), as the various dimensions of IB were captured by the themes of participants' responses. Specifically, participants indicated both isolated instances of betrayal in the medical system (under the theme of doctor-level betrayal) as well as systemic instances of betrayal (under the theme of system-level betrayal). In addition, the type of institutional action described by respondents reflected both acts of commission (such as system barriers in care, or negative experiences being common) and acts of omission (such as a failure to provide efficient care and a lack of compassion). A follow-up study using patients with chronic medical conditions who did not experience betrayal would be beneficial in order to further examine this conceptualization of problems in the medical system as IB. Future research should also investigate the consequences of IB in the medical system for medical patients. Longitudinal designs should be used to better understand the causal factors of IB (Smith & Freyd, 2014) and implement interventions to modify the institutional factors that help hide or precipitate negative health care experiences.

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References

- Bankauskaite, V., & Saarelma, O. (2003). Why are people dissatisfied with medical care services in Lithuania? A qualitative study using responses to open-ended questions. *International Journal for Quality in Health Care*, 15(1), 23–29. doi:10.1093/intqhc/15.1.23
- Bonomi, A. E., Anderson, M. L., Rivara, F. P., & Thompson, R. S. (2009). Health care utilization and costs associated with physical and nonphysical-only intimate partner violence. *Health Services Research*, 44(3), 1052–1067. doi:10.1111/j.1475-6773.2009.00955.x
- Brüggemann, A. J., Wijma, B., & Swahnberg, K. (2012). Abuse in health care: A concept analysis. *Scandinavian Journal of Caring Sciences*, 26(1), 123–132. doi:10.1111/j.1471-6712.2011.00918.x
- Coyle, J. (1999). Understanding dissatisfied users: Developing a framework for comprehending criticisms of health care work. *Journal of Advanced Nursing*, 30(3), 723–731. doi:10.1046/j.1365-2648.1999.01137.x
- Elo, S., & Kyngas, H. (2007). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115. doi:10.1111/j.1365-2648.2007.04569.x
- Freyd, J. J. (1996). *Betrayal trauma: The logic of forgetting childhood abuse*. Cambridge, MA: Harvard University Press.
- Freyd, J. J. (2008). Betrayal trauma. In G. Reyes, J. D. Elhai, & J. D. Ford (Eds.), *Encyclopedia of Psychological Trauma* (pp. 76). New York, NY: John Wiley & Sons.
- Freyd, J. J., Klest, B., & Allard, C. B. (2005). Betrayal trauma: Relationship to physical health, psychological distress, and a written disclosure intervention. *Journal of Trauma & Dissociation*, 6(3), 83–104. doi:10.1300/J229v06n03_04
- Gallagher, T. H., Waterman, A. D., Ebers, A. G., Fraser, V. J., & Levinson, W. (2003). Patients' and physicians' attitudes regarding the disclosure of medical errors. *Journal of the American Medical Association*, 289(8), 1001–1007. doi:10.1001/jama.289.8.1001
- Gallinger, Z., Bressler, B., Devlin, S. M., Plamondon, S., & Nguyen, G. C. (2014). A survey of perceptions and practices of complementary alternative medicine among Canadian gastroenterologists. *Canadian Journal of Gastroenterology & Hepatology*, 28(1), 45–49. doi:10.1155/2014/632627
- Gokhman, R., Seybert, A. L., Phrampus, P., Darby, J., & Kane-Gill, S. L. (2012). Medication errors during medical emergencies in a large, tertiary care, academic medical center. *Resuscitation*, 83(4), 482–487. doi:10.1016/j.resuscitation.2011.10.001
- Green, B. L., Kaltman, S. I., Chung, J. Y., Holt, M. P., Jackson, S., & Dozier, M. (2012). Attachment and health care relationships in low-income women with trauma histories: A qualitative study. *Journal of Trauma & Dissociation*, 13(2), 190–208. doi:10.1080/15299732.2012.642761
- Green, B. L., Kaltman, S., Frank, L., Glennie, M., Subramanian, A., Fritts-Wilson, M., & Chung, J. (2011). Primary care providers' experiences with trauma patients: A qualitative study. *Psychological Trauma: Theory, Research, Practice, and Policy*, 3(1), 37–41. doi:10.1037/a0020097
- Hall, M. A., Camacho, F., Dugan, E., & Balkrishnan, R. (2002). Trust in the medical profession: Conceptual and measurement issues. *Health Services Research*, 37(5), 1419–1439. doi:10.1111/1475-6773.01070
- Kirby, K., Dunwoody, L., & Millar, R. (2009). What type of service provision do patients with chronic pain want from primary care providers? *Disability and Rehabilitation*, 31(18), 1514–1519. doi:10.1080/09638280802639137
- Martin, C. G., Cromer, L. D., DePrince, A. P., & Freyd, J. J. (2013). The role of cumulative trauma, betrayal, and appraisals in understanding trauma symptomatology. *Psychological Trauma: Theory, Research, Practice, and Policy*, 5(2), 110–118. doi:10.1037/a0025686

- Mazor, K. M., Reed, G. W., Yood, R. A., Fischer, M. A., Baril, J., & Gurwitz, J. H. (2006). Disclosure of medical errors: What factors influence how patients respond? *Journal of General Internal Medicine*, *21*(7), 704–710. doi:10.1111/j.1525-1497.2006.00465.x
- Milden, S. P., & Stokols, D. (2004). Physicians' attitudes and practices regarding complementary and alternative medicine. *Behavioral Medicine*, *30*(2), 73–84. doi:10.3200/BMED.30.2.73-84
- Mulley, A. G., Trimble, C., & Elwyn, G. (2012). Stop the silent misdiagnosis: Patients' preferences matter. *BMJ*, *345*, e6572. doi:10.1136/bmj.e6572
- Osborn, R., & Squires, D. (2012). International perspectives on patient engagement: Results from the 2011 Commonwealth Fund Survey. *Journal of Ambulatory Care Management*, *35*(2), 118–128. doi:10.1097/JAC.0b013e31824a579b
- Pucher, P. H., Aggarwal, R., Twajj, A., Batrick, N., Jenkins, M., & Darzi, A. (2013). Identifying and addressing preventable process errors in trauma care. *World Journal of Surgery*, *37*(4), 752–758. doi:10.1007/s00268-013-1917-9
- Sandars, J., & Esmail, A. (2003). The frequency and nature of medical error in primary care: Understanding the diversity across studies. *Family Practice*, *20*(3), 231–236. doi:10.1093/fampra/cm301
- Smith, C. P., & Freyd, J. J. (2011). *Institutional Betrayal Questionnaire (IBQ)*. Retrieved from <http://dynamic.uoregon.edu/jjf/institutionalbetrayal/ibq.html>
- Smith, C. P., & Freyd, J. J. (2013). Dangerous safe havens: Institutional betrayal exacerbates sexual trauma. *Journal of Traumatic Stress*, *26*(1), 119–124. doi:10.1002/jts.21778
- Smith, C. P., & Freyd, J. J. (2014). Institutional betrayal. *American Psychologist*, *69*(6), 575–587. doi:10.1037/a0037564
- Synnot, A., Hill, S., Summers, M., & Taylor, M. (2014). Comparing face-to-face and online qualitative research with people with multiple sclerosis. *Advancing Qualitative Methods*, *24*(3), 431–438. doi:10.1177/1049732314523840
- Vincent, C. A., & Coulter, A. (2002). Patient safety: What about the patient? *Quality and Safety in Health Care*, *11*(1), 76–80. doi:10.1136/qhc.11.1.76