INSTITUTIONAL BETRAYAL IN THE MEDICAL SYSTEM:
DEVELOPMENT, RELIABILITY, AND VALIDITY OF A SELF-REPORT
QUESTIONNAIRE

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By
Andreea Tamaian
Regina, Saskatchewan
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Andreea Tamaian, candidate for the degree of Master of Arts in Clinical Psychology, has presented a thesis titled, *Institutional Betrayal in the Medical System: Development, Reliability, and Validity of a Self-Report Questionnaire*, in an oral examination held on August 26, 2015. The following committee members have found the thesis acceptable in form and content, and that the candidate demonstrated satisfactory knowledge of the subject material.

External Examiner: Dr. Robin Evans, Faculty of Nursing

Supervisor: Dr. Bridget Klest, Department of Psychology

Committee Member: Dr. Heather Hadjistavropoulos, Department of Psychology

Committee Member: *Dr. R. Nicholas Carleton, Department of Psychology

Chair of Defense: Prof. Wes Pearce, Faculty of Fine Arts

*via Teleconference
Abstract

Betrayal trauma, a type of psychological trauma that occurs when the people or institutions a person depends on for survival violate that person’s trust (Freyd, 2008), has been shown to further intensify the negative effects of trauma (Martin, Cromer, DePrince, & Freyd, 2013). A recent extension of this concept, which can cause additional psychological harm to victims, is institutional betrayal (IB), an institutional failure to respond supportively to a traumatic event (Smith & Freyd, 2013). The medical system is an important, but as of yet unstudied institution with regard to betrayal. The frequency of medical errors, ineffectiveness of their disclosure, and the lack of clarity in clinical informed consent may give rise to feelings of betrayal. The current research aimed to develop a psychometrically sound questionnaire that assesses patients’ perceptions of IB. A qualitative study completed by 14 participants investigated the kind of experiences that lead to feelings of IB in the medical system. Content analysis was used to analyze the data, and the overall themes of doctor and system level betrayal guided the development of the IB questionnaire. A quantitative study completed by 352 participants tested the reliability and validity of the measure. An exploratory factor analysis and reliability statistics found three stable and reliable factors of IB: negative healthcare experiences, cognitive-affective reactions, and systemic responses to these experiences. Subsequent correlations and hierarchical multiple regressions found evidence supporting the validity of the IB questionnaire. As expected, IB predicted poorer mental health functioning even after controlling for demographics, and previous traumatic experiences.
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Dedication

I dedicate my thesis work to my family and friends, who have provided me with the greatest support throughout my graduate experience. My loving parents, Ileana and Alex, have been there for me through the good and the bad times of this journey. I am extremely grateful for their unconditional love, understanding, and patience. In addition, I would like to thank my sister, Oana, who has been my greatest supporter ever since we were little and has always provided me with unconditional acceptance and love. Lastly, I would like to express my sincere gratitude to my dear colleagues who have been an essential part of the graduate experience and have become friends very close to my heart.
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CHAPTER ONE

Introduction

1.1 Overview

Traumatic stress represents a major public health concern (Goldsmith, Barlow, & Freyd, 2004), yet its effects are greatly dependent on an individual’s subjective appraisal of the experience. Traumatic events can take a variety of different forms, such as exposure to violence, threatened or actual physical or sexual assault, and serious injury or illness (American Psychiatric Association, 2013). Experiencing one or more traumatic events has been associated with various negative long-term effects, including post-traumatic stress disorder (PTSD), anxiety, and depression. Feelings of unpredictability, uncontrollability, and perceived life threat accompany a psychological trauma (Weathers & Keane, 2007). Individuals who have experienced a stressful event in their lives have an increased risk of being retraumatized at a later point, as researchers found the childhood trauma and adult victimization experiences are strongly correlated (Roodman & Clum, 2001).

Survivors of trauma struggle with both mental (e.g., depression) and physical (e.g., somatic symptoms, pain) long-term consequences. Betrayal trauma is a type of psychological trauma that occurs when the people or institutions a person depends on for survival violate that person’s trust (Freyd, 2008), and it can further intensify the negative psychological and physical effects of experiencing a traumatic event (Freyd, Klest, & Allard, 2005). These individuals tend to have frequent contact with primary care providers (Green et al., 2011). In the medical system, patients’ reliance on their providers’ judgment and expertise and their willingness to take their doctor’s advice lead to recent increased efforts in measuring trust and the potential reasons for mistrust or
disappointment with the medical system (Hall, Camacho, Dugan, & Balkrishnan, 2002). To date, no such measure directly investigates feelings of betrayal within the medical system. Primary care providers sometimes view patients with multiple, complex, and vague physical complaints and chronic pain as “difficult,” and often feel unprepared to adequately work with these clients (Green et al., 2011). Not only do care providers lack training on working with this group, but the patients may also be non-compliant and reject help from others (Green et al., 2011). A problematic consequence of this is that these patients may thus feel misunderstood, not taken seriously, and alienated from the medical system.

Individuals who have experienced extensive trauma, such as childhood victimization and intimate partner violence in adulthood, tend to utilize the health care and mental health services significantly more frequently than individuals who have not experienced such abuse (Bonomi, Anderson, Rivara, & Thompson, 2009). In addition, the higher the number of betrayal traumas one experiences, such as experiencing both sexual and physical abuse during childhood, the higher the costs for annual health care will be (Bonomi et al., 2008). Serious injury or illness meets the definition of trauma used in diagnosing PTSD (APA, 2013), and a patient's negative experience with the medical system may be perceived as traumatic by some patients. The current study was designed to first determine whether or not institutional betrayal (IB) in the Canadian medical system exists and how it impacts patients’ physical and psychological wellbeing. In addition, the present study investigated whether or not there is something about IB in the medical system that is not captured in existing questionnaires about trust and satisfaction with providers, and a new self-report measure of IB was formulated. Lastly,
this new measure was validated with a clinical population. In the introduction that follows, the concept of betrayal trauma is first introduced. This is followed by a summary of potential instances of betrayal in the medical system (i.e., medical errors, patient-physician communication, trust in the medical system, and dissatisfaction with the system), and then a description of the current study.

1.2 Betrayal Trauma

Betrayal can further intensify the deleterious effects of a traumatic experience (Edwards, Freyd, Dube, Anda, & Felitti, 2012; Freyd et al., 2005; Martin, DePrince, Cromer, & Freyd, 2013). The victim is more likely to dissociate in this situation; not being aware of the traumatic nature of the experience allows for the maintenance of the attachment relationship with the perpetrator, which is necessary for the victim’s survival (Freyd, 2008). DePrince and Freyd (2004) demonstrated that individuals who report experiencing more frequent dissociation also report significantly more betrayal trauma relative to people who report infrequent dissociation. In a directed-forgetting task the “high dissociators” recalled fewer trauma-related and more neutral words than the “low dissociators,” regardless of whether they were asked to remember or to forget the words presented. The results support betrayal trauma theory (Freyd, 2008) in that people experiencing trauma high in betrayal may remember fewer trauma-related details due to the higher level of dissociation. Accordingly, the relationship with the perpetrator thus continues, and, consequently, the victim is more likely to experience victimizations in the future.

The results from DePrince and Freyd (2004) also expand on the definition of the type of dissociation people may experience. High dissociators did not remember less
information overall than low dissociators, but did remember different kinds of information (more neutral than trauma-related words). Therefore, individuals experiencing high betrayal trauma may experience dissociation as a combination of both knowing and not knowing. Specifically, they may be aware of the details of the trauma, but may dissociate solely from the emotionality and implications of its consequences. Sexual or physical abuse by a caregiver is associated with less persistent memories of the abuse, while age and duration of the abuse does not predict memory impairment (Freyd, Deprince, & Zurbriggen, 2001). Although this unawareness of trauma may initially be adaptive to maintain a vital relationship with the perpetrator, the absent awareness has been linked to intergenerational transmission of trauma and its effects in the long-term (Goldsmith et al., 2004).

Betrayal can be conceptualized as a subjective appraisal of an objective aspect of a trauma (Kelley, Weathers, Mason, & Pruneau, 2012). Furthermore, situational appraisals affect whether or not a person experiences betrayal (Kelley et al., 2012). The perception of the importance of the relationship with the perpetrator may be more pivotal than the type of trauma itself in determining feelings of betrayal. The subjective appraisal of betrayal may also be important in determining the effectiveness of support-seeking. Foynes and Freyd (2013) found evidence that the relationship between a person disclosing a trauma and the person listening to the disclosure is more important to the post-traumatic psychological outcomes of the discloser than are third-person observer reports on this interaction. Specifically, the appraisal the person disclosing the trauma makes of the relationship with the person listening to the disclosure is a better predictor of the psychological outcomes than are objective observer reports on the quality of the
listener’s support towards the person disclosing (based on verbal and non-verbal support). As such, the quality of the existing relationship with the person he or she is disclosing a trauma to affects the discloser’s appraisal of the interaction (Foyes & Freyd, 2013).

Victims of high betrayal trauma report poorer physical functioning and mental health than victims of low betrayal trauma (Edwards et al., 2012; Freyd et al., 2005). Importantly, childhood abuse predicts the development of poor health mediators such as unhealthy habits (e.g., smoking, substance abuse); these mediators are, in turn, risk factors for future physical health problems (Freyd et al., 2005). High betrayal trauma victims, in comparison to those who suffer low betrayal traumas, experience significantly higher levels of depression, panic attacks, anger problems, and suicide attempts (Edwards et al., 2012). In addition, the number of high betrayal traumas an individual is exposed to predicts not only the psychological outcomes previously discussed, but also the number of days the individual was sick in the previous month, the number of physical health complaints, and self-reported levels of alexithymia, anxiety and dissociation; however, the number of low betrayal traumas experienced does not predict any of these outcomes when controlling for the effects of high betrayal traumas (Goldsmith, Freyd, & DePrince, 2012). High betrayal trauma is positively associated with avoidant and anxious attachment styles (Owen, Quirk, & Manthos, 2012). Therefore, betrayal trauma plays a significant role in the formation of new relationships, and these maladaptive attachment styles can be reinforced in future relationships (Owen et al., 2012).
Betrayal accounts for variance in PTSD symptoms above and beyond injury, trauma type, and perceived level of threat (Kelley et al., 2012). Importantly, negative childhood experiences appear to exacerbate the effect of betrayal trauma on negative psychological outcomes (Edwards et al., 2012). Retraumatization may then increase the effects of betrayal trauma. In addition, individuals exposed to childhood trauma experiences high in betrayal not only display high levels of self-blame regarding that particular incident, but also blame themselves for experiencing intimate partner violence as adults (Babcock & DePrince, 2012). Posttrauma appraisal significantly predicts trauma-related distress even after accounting for the characteristics of the trauma itself (DePrince, Chu, & Pineda, 2011).

The relationship between childhood and adult victimization appears stronger among individuals living in high poverty communities (Klest, 2012). Experiencing childhood trauma predicts higher likelihood of having a low socioeconomic status, which further leads to the adult living in a higher poverty area (Klest, 2012). Therefore, socioeconomic factors may place individuals who have had traumatic experiences at further risk of revictimization. In addition, socioeconomic factors such as education and employment status appear to predict self-rated general health (Klest, Freyd, Hampson, & Dubanoski, 2013). Both traumatic experiences and socioeconomic factors appear to play a role in an individual’s overall health. These individuals may then be more likely to be active users of the health care system, but they may lack effectiveness in their use due to existing expectations and situational appraisals.

Some researchers have distinguished between chronic and new victimizations. A history of intimate partner abuse by multiple perpetrators is associated with passive
avoidance and arousal PTSD symptomology (such as inability to recall aspects of the trauma, feelings of detachment, and restricted affect; APA, 2000), whereas chronic victimization by one partner predicted active avoidance PTSD symptoms (such as efforts to avoid thoughts, feelings or conversations associated with the trauma; Matlow & DePrince, 2013). Due to the dynamic nature of different types of intimate partner violence experiences, victims appear to show different PTSD symptoms. Thus, the nature of a victim’s relationship with his or her perpetrator appears to impact psychological outcomes for the victim (Matlow & DePrince, 2013). Individuals who have experienced childhood abuse by a parental figure reported stronger current feelings of betrayal compared with those who have experienced abuse by a non-parental figure (O’Rinn, Lishak, Muller, & Classen, 2013). However, these individuals’ perceptions of betrayal by the non-abusing parental figure were positively correlated with dissociation (O’Rinn et al., 2013). The relationship to the perpetrator, along with appraisals or perceptions of betrayal, appear to relate to different types of adaptive coping. While experiencing feelings of betrayal towards the non-abusing parental figure for not stopping the abuse, individuals displayed a high level of dissociation in order to maintain the relationship with the non-abusing parental figure.

1.2.1 Institutional betrayal. Trust may also be compromised by relied upon institution. Therefore, IB is an increasingly important area of interest. Smith and Freyd (2013) define IB as institutional failure to prevent or respond supportively to a traumatic event. Inadequate or inappropriate responses by organizations to disclosures of an assault can cause additional psychological harm to sexual assault victims (Smith & Freyd, 2013). Experiences of institutional abuse in childhood, defined as abuse by adults...
working in institutions serving children, appear to increase the rates of mental health problems in adulthood, particularly anxiety, mood, and substance use disorders (Carr et al., 2010). Research on institutional abuse in the military has found similar results. Military sexual trauma is associated with increased rates of depression, alcohol abuse, PTSD, number of physical complaints, and chronic health problems in veterans (Suris & Lind, 2008).

Given the findings that institutional abuse exacerbates both physical and mental health problems in the context of other establishments, the medical system is an important institution to consider. There are a limited number of studies investigating abuse in the medical system. Abuse in health care has been defined as “patients’ subjective experiences of encounters with the health care system, characterized by events that lack care, where patients suffer and feel they lose their value as human beings” (Brüggemann, Wijma, & Swahnberg, 2012). Even when the abuse is unintentional, the patients suffer negative outcomes (Brüggemann et al., 2012). The concept of abuse is subjective and relies on the patient’s perspectives and interpretation. Abuse in the health care system is associated with post-traumatic symptoms for patients, as well as distrust and avoidance of the health care system (Brüggemann et al., 2012). At the same time, staff involved in the concealment of abuse and in allowing it to take place have been seen to experience guilt and shame (Brüggemann et al., 2012). While the concept of abuse in the health care system refers more specifically to instances of emotional, sexual, or physical abuse (Brüggemann et al., 2012), the concept of IB encompasses more diverse and subtle factors that may lead health care users to experience feelings of betrayal.
IB encompasses system-level characteristics that may aid in normalizing trauma, and thus precipitating revictimization (Smith & Freyd, 2014). An institution’s (or doctor’s) prestige and priorities may be a factor affecting the way a traumatic healthcare experience is handled (Smith & Freyd, 2014). When investigating IB, there are many dimensions to be considered: failure to prevent abuse, normalizing abusive contexts, making it difficult to report negative experiences, inadequate responses to negative experiences or disclosures of trauma, covering up traumatic experiences, and punishing victims (Smith & Freyd, 2014). These dimensions differ in importance between institutions based on the institution’s characteristics and priorities. Thus, the impact of IB on individuals’ overall psychological and physical well-being may differ depending on the system at play.

1.3 Betrayal and the Medical System

As of yet, the medical system has not been studied in terms of IB. Patients are highly dependent on and trusting of the medical system, and this arises from the patients’ need for medical providers (Hall, Dugan, Zheng, & Mishra, 2001). In other words, patients’ vulnerability in the face of either the unknown or a known medical condition increases their need for a physician, and therefore this may also increase the potential for trust of that physician (Hall et al., 2001). A medical injury may impact patients differently than other forms of trauma. In these situations, patients are unintentionally harmed by professionals in whom they have instilled a considerable amount of trust and they may also be cared for by the same professionals that have been involved in the initial injury (Vincent & Coulter, 2002). Therefore, a medical error, described as a preventable event that may cause a patient harm (Gokhman, Seybert, Phrampus, Darby,
may be similar to the experiences of betrayal trauma. Additionally, patients’ dissatisfaction and mistrust with the medical system, along with their communication patterns with their providers, may lead to feelings of IB.

1.3.1 Medical errors. Medical errors are quite common, ranging between five and 80 error reports per 100,000 consultations according to a recent literature review (Sandars & Esmail, 2003). The review found that across studies, diagnostic errors were the most frequently identified, ranging from 26 to 78% of errors. Errors related to treatment, either delayed or inappropriate, were the second most common category of error type, varying from 11 to 42% of errors in primary care (Sandars & Esmail, 2003). A recent European study found that 42% of the reported errors from healthcare providers are concerned with diagnostic procedures, while 20% are related to communication difficulties between providers and patients (Källberg, Göransson, Östergren, Florin, & Ehrenberg, 2013). Another systematic review of the literature found that medication errors are also common (Tam et al., 2005). A total of 3755 patients in 22 studies were reviewed. Between 27 and 57% of patients reported at least one medication error. Among these, 10 to 67% of errors were regarding medication prescription, while 27 to 83% of patients reported at least one error related to nonprescription drugs. Some errors were commission errors (administering a drug not required) and some were omission errors (not administering a drug that is required given the patient’s condition).

Pucher and colleagues (2013) analyzed a total of 169 preventable errors from 96 patients who had experienced traumatic events. The researchers identified that 3.6% of the errors resulted in an unnecessary procedure or injury, and that 30.2% of the errors placed patients at risk of harm. The majority of the errors occurred in the domain of the
emergency room (Pucher et al., 2013). While structural failures such as staffing issues or failure of equipment were only found in 12.1% of the errors, 87.9% of errors were due to process issues, such as a misdiagnosis, technical or communication error. The majority of errors (62%) were due to omission and only 38% to commission. Some reasons for omission errors are preventable, such as mental lapses and failures in attention (Pucher et al., 2013). The preventable nature of these errors could enhance feelings of betrayal a patient may experience since the provider’s behaviour led to the error, which ultimately led to patient suffering.

Medical errors are common regardless of age; however, different age groups may experience varying kinds of errors. Patients over the age of 65 have a higher incidence rate of both preventable and non-preventable adverse events during medical procedures than younger patients (Merten, Zegers, de Bruijne, & Wagner, 2013). In addition, older adults with various comorbid conditions also had higher instances of adverse events compared to younger adults with comorbid conditions (Merten et al., 2013). Older adults experienced more adverse events related to medication than younger adults, but the younger group experienced significantly more adverse events related to surgical procedures than the older clients (Merten et al., 2013).

Medical errors are an important cause of both patient morbidity and mortality, yet patients’ expectation of full disclosure of errors is often unmet (Lu, Guenther, Wesley, & Gallagher, 2013). 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 and trust with the medical system (Mazor et al., 2006). In the
face of medical errors, oftentimes physicians do not provide the information or the emotional support that patients need (Gallagher, Waterman, Ebers, Fraser, & Levinson, 2003). Both physicians and patients state that, although inevitable, medical errors are quite frightening (Gallagher et al., 2003). Patients want errors to be disclosed as this would enhance their trust in the physician and would reassure them that they are receiving complete information about their care. Although physicians also believe errors that cause harm should be disclosed, withholding information about minor errors is seen as acceptable (Gallagher et al., 2003). Physicians and patients differ in their emotional response to the disclosure of an error. While patients tend to feel sad, anxious, and traumatized, physicians feel upset, guilty, disappointed, and fearful about a possible lawsuit (Gallagher et al., 2003). Patients’ emotional experience after the disclosure is also affected by the way in which the error was disclosed to them. Honesty, compassion, and an apology decreased patients’ distress, while incomplete explanations of errors increased distress (Gallagher et al., 2003).

The vulnerability a patient experiences when he or she needs to rely on the medical system can also lead to a distrust of the physician or the system if an error is not dealt with in a way that will alleviate both uncertainty and suffering for the patient. Although communicating errors improves patients’ autonomy, health care providers oftentimes lack training in disclosing this information. Lu et al. (2013) found that amongst a group of EMS workers, only 10% received formal instruction on error disclosure. There is also a discrepancy between patient complaints and the incident reports by health care professionals in diagnostic-related medical errors (de Feijter, de Grave, Muijtjens, Scherbier, & Koopmans, 2012). Providers do not appear to always
Providers may be aware of the errors and choose not to report them due to fear of a possible lawsuit, or they may be initially unaware of the wrong diagnosis. Health care providers may experience anxiety regarding disclosing errors as a result of this, and they may be communicating this information to the patient ineffectively.

While most studies have focused on errors reported by physicians, a recent study investigated the differences in what medical errors doctors, office staff or patients report (Phillips, Dovey, Graham, Elder, & Hickner, 2006). Out of 717 reported events containing at least one error, staff made 53% of the reports, physicians 38%, and patients 6%. A third of the client’s error reports revolved around waiting times (Phillips et al., 2006). Due to longer waiting times and the inability to access their health provider, patients suffered further dissatisfaction. Additionally, clients reported the longer waiting times led to errors due to mistaken identity and to being given inappropriate or inaccurate information (Phillips et al., 2006). Clinicians reported more errors related to medications, laboratory investigations and diagnostic imaging, while staff reported more errors related to communication with patients and appointments. Clinicians and staff reported a risk for harm in 49% of the errors, while 33% of the errors resulted in patients or their families becoming upset (Phillips et al., 2006).

Misdiagnosis is a type of medical error that could lead to decreased access to appropriate treatment, inadequate treatment, and more patient suffering. Therefore, an individual who has been misdiagnosed may experience feelings of betrayal. Some argue, however, that an accurate medical diagnosis is not sufficient in providing the proper treatment (Mulley, Trimble, & Elwyn, 2012). Specifically, Mulley and colleagues argue
that when patients are seeking guidance, they should be given enough information that they can choose the treatment they prefer given the circumstances. They claim that by solely focusing on the medical diagnosis at hand, a physician may miss the unique circumstances of that individual and thus be biased to only see a limited view of the issue. Therefore, physicians should provide their patients with all the possible options and the risks and benefits of each of them (Mulley et al., 2012). Providing options is especially important in chronic conditions since patient preferences and decisions are constantly evolving and the patient’s health and priorities may change (Mulley et al., 2012).

1.3.2 Communication in the medical system. Communication between health providers and patients may improve the way the medical system is utilized. Communication not only allows for a positive and open physician-patient relationship, but it is also essential for the exchange of information. Health providers need information from patients in order to provide an accurate diagnosis, while patients need information from physicians about treatment procedures (Ong, De Haes, Hoos, & Lammes, 1995). Patients who adopt a more active role experience higher general satisfaction, better treatment outcomes, and a reduction in overall physical symptoms than patients whose decision-making is paternalistic (Ashraf et al., 2013).

Patient engagement in medical decision-making is associated with higher-quality care, fewer medical errors, and more positive views of the health care system (Osborn & Squires, 2012). Osborn and Squires (2012) combined three dimensions to capture patient engagement: time spent with physician, clear explanations by health provider to ensure that the patients understand, and encouraging patients to ask questions. In Canada,
patients of lower economic status appear less likely to be engaged in their own medical care, and are less likely to have conversations with providers about treatment plans than patients with higher incomes (Osborn & Squires, 2012). Across countries, 20% to more than 40% of patients stated that they could not easily contact their health care providers between visits to ask questions or get advice, and thus they felt additional stress in managing their condition and having to be alert to any medical changes (Osborn & Squires, 2012). Patient satisfaction appears to significantly increase if physicians contact patients after an emergency department visit (Patel & Vinson, 2013). The pattern of communication between patients and providers can influence the development of feelings of IB. Patients who have not been engaged in decision-making and who feel that they were not able to openly discuss diagnosis and prognosis with their provider may experience feelings of IB. The patient may feel that his provider, and potentially the medical system itself, has not offered adequate support and information in the face of the stressful situation of a medical condition or emergency.

Another area in which individuals may experience IB in the medical system relates to negative outcomes of treatment. Informed consent before medical procedures may not be sufficient to prevent IB. Patients often lack recollection of major portions of the informed consent process (Cassileth, Zupkis, Sutton-Smith, & March, 1980), opening the door for perceptions of betrayal when unexpected outcomes occur. Cassileth et al. (1980) found that two of the major factors contributing to this poor recall are medical status and the care with which patients believed that they had read the consent before signing. Hopper, TenHave, and Hartzel (1995) found that clinical informed consent, especially for surgical procedures, may be too complex for patients, resulting in patients
paying less attention to the content of the forms. If patients do not fully understand the risks of a treatment or intervention and believe that the healthcare provider has not provided them with complete informed consent, they may feel betrayed by the system, and subsequently be less willing to trust the medical system in the future.

A recent systematic review of the literature investigated the effectiveness of various interventions to improve patient understanding of the informed consent for medical procedures (Schenker, Fernandez, Sudore, & Schillinger, 2011). The researchers found that additional written information and extended discussions between the physician and the patient improved comprehension of informed consent. Jefford and Moore (2008) further recommend the use of plain language and the importance of a discussion between the provider and the patient to ensure that the patient understood the implications of the procedure he or she will undergo. Research also showed that improving the informed consent process, specifically ensuring that patients receive an adequate amount of information about a medical procedure, decreases anxiety in patients, especially in those who have accessed the Internet previously to gather information (Betti, Sironi, Saino, Ricci, & Bonavina, 2011). In addition, Betti and colleagues found that patient comprehension of the informed consent process was influenced by age, such that older individuals appeared to have more trouble retaining the information.

Patients who are well informed about the risks and benefits of a treatment may be more likely to adhere to that treatment, but may also be less likely to accept risky procedures (Vincent & Coulter, 2002). Research suggests that while even routine procedures can produce post-traumatic symptoms in patients, difficulties in
understanding the diagnosis or treatment can further intensify these stresses and adverse consequences for the patient (Vincent & Coulter, 2002).

An increased emphasis has been placed on patients taking a more active role in their health care needs. However, this could potentially exacerbate the poor understanding and confusion that patients may feel in the face of medical documents or medical conversations. A recent study tested 80 healthy volunteers on their ability to comprehend and relay the content of two documents containing clinical information, one describing a clinical trial and one representing a typical visit note (Keselman & Smith, 2012). In the clinical trial document, 31% of participants made errors of incorrectly explaining some clinical concepts or confusing chemical substances discussed in the document, while 51% of the participants incorrectly explained the purpose of the trial. Errors regarding the visit note were made by 19% of participants and revolved around misconceptions in explaining diabetes concepts and misunderstanding the role of insulin in diabetes. The percentages may be inflated given that this study only used healthy university students, faculty and staff, the participants were not intrinsically motivated to remember all this information (Keselman & Smith, 2012).

Health care providers should be cognizant of the fact that the average person is not familiar with medical language in order to ensure effective communication (Ong et al., 1995). While patients have a better understanding when everyday language is used during medical encounters, physicians may struggle with clearly differentiating between the two different languages and this may lead to a more ineffective pattern of communication (Ong et al., 1995). Research shows that many patients do not recall or understand all the information a physician has provided them about the diagnosis and
prognosis of their condition; however, patients’ understanding of the information received improves with the amount of time spent talking to the medical provider during a consult (Ong et al., 1995).

1.3.3 Trust in the medical system. Hall and colleagues (2001) claim that trust in one’s medical provider is necessary in order to maintain the professional relationship and ensure adherence to treatment. Ultimately, trust affects patients’ willingness to seek medical care. Hall et al. (2001) define trust as an “optimistic acceptance of a vulnerable situation;” the higher the relative risk of a situation, the greater the potential for either trust with the medical system or distrust. These researchers distinguish between trust and trustworthiness; a patient may trust a physician that is not deserving of that trust and may distrust a physician that should be trusted. Individual trust differs from system trust, but these can reciprocally influence one another. Hall et al. (2001) indicated that one’s distrust in an individual physician may affect his or her level of trust with the hospital, or the medical system more generally. In addition, one’s trust of the medical institution can affect his or her trust of an individual provider. Hall and his colleagues described different characteristics that predict trust. Physician personality and behaviour, such as communication style and interpersonal skills, appear to strongly predict a patient’s trust level in the medical system, while patient characteristics do not reliably predict trust. In terms of situational factors predictive of trust, the length of a provider-patient relationship is only weakly related to trust (Hall et al., 2001). Patients’ perceived choice in selecting a provider and the circumstances around this choice (i.e., recommendation versus convenience) are stronger predictors of trust (Hall et al., 2001).
Survivors of high betrayal trauma have a lower willingness to trust others in interpersonal situations (Gobin & Freyd, 2013). Therefore, they may be less likely to trust individuals who could be important for their well-being, such as health care providers (Gobin & Freyd, 2009). In addition, they may be less likely to switch providers when they should be doing so in order to receive better services, as they may overlook minor betrayals and continue the relationship with their current provider (Gobin & Freyd, 2009).

1.3.4 Dissatisfaction with the medical system. Satisfaction and dissatisfaction with the medical system has been frequently assessed in the literature. The number of complaints received by health organizations has increased throughout the last decades, suggesting a willingness of health users to express their dissatisfaction (Coyle, 1999). However, Coyle (1999) argues that formal complaints are not a common expression of dissatisfaction. Coyle interviewed 41 health service users with different types of problems. She found that women were more likely than men to accuse health practitioners of being uncaring and of failing to provide adequate information or offer emotional support. Participants also described practitioners as self-interested, commenting on the length of waiting times. Over half of the respondents associated the discomfort they experienced during treatment to misdiagnosis, ineffective or inappropriate medication or treatment, and the physician’s lack of competency. Nurses were also seen as lacking training and being unsympathetic. Women and ethnic minorities in this sample also commented on being dissatisfied with their experience due to being treated according to negative stereotypes. Overall, participants wanted caring, understanding and sympathetic nurses, and doctors who are empathic listeners and
respectful, who provide adequate information, treat each patient as an individual who is uniquely valued, and attend to their emotional need (Coyle, 1999).

Clinically, participants want their physicians to ask questions and obtain a detailed history of the patient, conduct thorough investigations and refer the patients to someone else when necessary (Coyle, 1999). Patients indicated that they seek medical attention when they are uncertain about their symptoms, or if they feel the condition is serious and beyond their expertise. Participants with chronic conditions appeared to endure their illnesses for some time before seeking services (Coyle, 1999). In terms of personal factors of the providers influencing dissatisfaction with the system, participants indicated that over-work and tiredness may cloud physicians’ judgments and cause misdiagnosis and other errors. However, 24% of the respondents claimed that they themselves may have been partly responsible for being dissatisfied with the medical experience and perceiving it as negative (Coyle, 1999). Some participants indicated that their expectations may have been too high, while others claimed that their complicated medical history and susceptibility to pain may have contributed to the negative experience. Some participants believed they may not have explained the symptoms sufficiently clearly to the doctor in order to allow him or her to make a correct diagnosis (Coyle, 1999). Individuals with a history of trauma tend to exhibit non-secure attachment styles, which may impact their experiences with medical providers (Green et al., 2012). In one study, women with unresolved attachment styles and a history of trauma reported more negative experiences and dissatisfaction with their medical providers that those with other attachment styles (Green et al., 2012). Therefore, a combination of patient
factors and provider factors appear to contribute to patient dissatisfaction with medical encounters.

An early meta-analysis on patient satisfaction found that being given more information during a medical encounter is associated with greater satisfaction (Hall, Roter, & Katz, 1988). The meta-analysis also found that giving more information to participants significantly predicts greater recall and understanding of the procedure and treatment. Surprisingly, the frequency of the physicians asking questions regarding the patients’ understanding and their suggestions was not significantly related to patient satisfaction. There was, however, a tendency for more questions to be associated with poorer recall and understanding (Hall et al., 1988). Greater technical competence and a more cooperative relationship with the patient were associated with higher satisfaction and increased patient participation. More physician non-verbal immediacy (more forward lean, closer distance, more eye contact), more positive talk and less negative talk were also significantly correlated with satisfaction, recall and understanding (Hall et al., 1988). Satisfaction was best predicted by the amount of information provided by the provider; however, medical providers often underestimate the patients’ desire for information (Ong et al., 1995).

Other researchers argue that a patient’s expectations may be the best predictor of satisfaction (Hsieh & Kagle, 1991). Results from a survey of 401 university faculty and staff members showed that individuals with more positive expectations of the medical system expressed more satisfaction with the services they received (Hsieh & Kagle, 1991). The researchers did not find sociodemographic factors to be strong predictors of patient satisfaction, but due to the fact that the participants were all university faculty
and staff (and thus sociodemographic factors may not vary widely in this group), the results may not be broadly generalizable. However, even though participants in this study were on average younger and better educated than the general population, the results showing that one’s expectations in an encounter with the medical system influence satisfaction are still important.

Data from 2841 patients who had undergone cholecystectomy (surgical removal of the gallbladder) revealed that patients with better surgical outcomes expressed greater satisfaction with medical care (Kane, Maciejewski, & Finch, 1997). Patient satisfaction was influenced more by current medical status than by how much they had improved since before the medical procedure. Previous expectations explained only a small percentage of the variance in patient satisfaction (Kane et al., 1997). These results suggest that a patient’s current situation affects the patient’s satisfaction with the quality of care he or she received.

Patient satisfaction has a strong positive relationship with loyalty to the physician (Platonova, Kennedy, & Shewchuk, 2008). Dissatisfied users are more likely to switch providers frequently, which could strengthen the negative expectations they may have of the medical system and further intensify potential feelings of IB. Platonova and colleagues found that trust has a significant direct effect on both loyalty and satisfaction. Therefore, having a good, trusting relationship with a health care provider may enhance both satisfaction and loyalty to that provider.
CHAPTER TWO

The Current Research Project

If actual or perceived IB within the medical system has consequences similar to those of other types of betrayal trauma, such experiences may contribute to poorer mental health status and physical functioning. In turn, poor overall well-being may lead to greater use of the medical system. Individuals who experience IB in the medical system may also use medical services ineffectively. For example, they may be less willing to switch providers when the situation at hand warrants a change or may switch providers frequently due to feelings of mistrust. IB has not been studied in the Canadian health care system, in part due to lack of available instruments with which to survey patients about these types of experiences. The present study was designed to determine if IB exists in the Canadian medical system, and investigate how IB impacts patients’ physical and psychological well-being. The present study inquired about whether or not the concept of IB in the medical system is captured in existing questionnaires about trust and satisfaction with providers and investigated what additional factors fully explain IB. A psychometrically sound questionnaire to test this concept was developed after surveying patients’ experiences with the medical system. The new measure was validated with a clinical population.

The construct of IB in the medical system was hypothesized as being related to the concepts of satisfaction, trust, previous betrayal trauma, patients’ active role in decision-making, and previous expectations of their encounters with the health care system. In addition, the new measure of IB in the medical system was hypothesized to correlate positively with current PTSD symptoms, previous trauma, depression, anxiety, and dissociation, and correlate negatively with social support, general tendencies to trust.
others, trust in the medical profession, satisfaction with healthcare relationships and with patient-physician communication.

The current research included two separate studies. The first study was a qualitative study that queried beliefs about medical errors, reasons for patient dissatisfaction with the medical system, and types of patient experiences that might result in feelings of betrayal. The results of this study were used to develop a questionnaire testing IB in the medical system. Phase two was a study testing the validity and reliability of the new measure.
CHAPTER THREE

Study 1

3.1 Methods

3.1.1 Participants. The study was approved by the Research Ethics Board at the University of Regina on June 19, 2014 (see Appendix A). To be eligible for this study, participants: 1) self-identified as experiencing a chronic health condition; 2) were 18 years or older; 3) currently resided in Canada; 4) were able to read and accurately respond to questions in English; 5) had an interaction with the medical system where they felt the medical system or provider let them down, betrayed them, or did not act in their best interests. A total of 42 participants expressed interest in the study, but only 14 met the inclusion criteria. All 14 participants completed the study. Saturation for a qualitative study is typically reached with 10-12 participants (Guest, Bunce, & Johnson, 2006) and 14 was an adequate sample size to reach saturation in this study.

3.1.2 Measures. An open-ended survey (Appendix B) was completed by participants online through the FluidSurveys website. Questions in this survey 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 patients. The Healthcare Experiences Interview (Green et al., 2012) and the Institutional Betrayal Questionnaire (IBQ; Smith & Freyd, 2011) were modified and aggregated to be used with a medical population. The modified version appears in Appendix B. The authors of both measures were contacted and permission was acquired to use and modify the measures for the purposes of the present study.
The original 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). Statistical reliability and validity have not been established for this interview. The measure is made up of 24 open-ended questions. Each of the questions contains additional probing questions if the participant does not elaborate on her answer. The original IBQ was created to investigate whether IB in a university setting exacerbates feelings of trauma resulting from sexual assault in a sample of college women (Smith & Freyd, 2013). Statistical reliability and validity have not been established yet for this measure. The original IBQ is made up of 14 questions. For ten 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 their situation and three of the questions are open-ended (Smith & Freyd, 2011). The IBQ was modified to fit the medical setting and the questions were reformatted to be open-ended.

3.1.3 Procedure. Advocacy groups for various chronic conditions across Canada were contacted via email 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. Interested participants were asked to contact the Social Context, Health, and Trauma Lab at the University of Regina via email. Eligible participants were provided a link to access the qualitative questionnaire on FluidSurveys. Additionally, participants were also recruited through a database at the University of Regina of past participants with chronic medical conditions who agreed to be contacted with future research from the University of Regina. Information about the study (see appendix C)
was provided on the first page of the survey and informed consent was implied by the
participants’ decision to complete 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).

3.1.4 Analysis. Inductive content analysis was conducted independently by two
independent raters (principal investigator A. T. and three undergraduate research
assistants independent to this study). The raters deduced the main themes and subthemes
directly from the data, and each question was 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. The
researchers coded the data separately and then compared the themes. Results were
discussed amongst the researchers and any discrepancies were resolved.

3.2 Results

3.2.1 Participants. A total of 14 participants completed the online survey, one
male and 13 females. Given the much larger proportion of women, the gender will not be
identified in the quotes used to further support the qualitative themes. Participants’ ages
ranged from 27 to 62, the average age being 49. Two participants reported being single
and never married, one participant was dating, two reported they were in a long-term
relationship, seven were married or common law, and two participants reported being
divorced. Two participants reported having an income under $20000 a year, five
participants reported an income between $30000 to $69999, and half the sample reported
an income of over $70000 a year. The majority of participants ($n = 11$) experienced a significant decrease in income as a results of their chronic medical condition. This sample was highly educated, with nine out of the 14 participants having a Bachelor’s degree or higher postsecondary education. Recruited from across Canada, seven participants reporting residing in Ontario, two in Nova Scotia, two in Alberta, one in Manitoba, one in Saskatchewan and one in Quebec. When asked about their living situation, participants could check all situations that apply to them. Three participants reported living alone, seven with a spouse or partner, one with children under 18, four with other family members, one in assisted living, one with parents who take care of him or her and provide assisted living, and one with roommates or friends. Similarly, participants could check all situations that apply to their employment status. Four participants were employed for pay, three indicated they were out of work but not currently looking for work, eight indicated they were currently unable to work, seven that they were disabled related to the chronic medical condition, one that he/she was disabled related to another condition, three that they were on temporary leave with plans to return to work, two were homemakers, two were retired and two were students.

Participants reported on their specific medical condition, and were instructed to check all the conditions that apply to them: one participant indicated 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 are currently struggling with respiratory problems (i.e., chronic bronchitis, asthma), and one participant said he struggled with them in the past. One participant reported being diagnosed with diabetes type 1 and one with diabetes type
2. In terms of arthritis, one participant indicated they are currently struggling with rheumatoid arthritis, and seven said they have another arthritis related disease. Additionally, 10 participants mentioned they are currently struggling with a neurological disorder. Seven participants reported current chronic back pain, while four said they struggled in the past of it. 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. Some individuals reported other types of health concerns: current \((n = 5)\) and past \((n = 1)\) digestive problems, past gallbladder disease \((n = 4)\), past kidney disease \((n = 1)\), past stroke \((n = 1)\), Parkinson’s disease \((n = 1)\), fibromyalgia \((n = 4)\), interstitial cystitis \((n = 3)\), and multiple sclerosis \((n = 2)\). 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 8 participants reported struggling with six or more conditions.

3.2.2 Thematic analysis. The identified higher-order themes and sub-themes that emerged are summarized in Figure 1 below. Participants described feelings of IB on two different levels: 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.
Figure 1. Qualitative results: higher-order themes and sub-themes.
3.2.2.1 Doctor level IB – Inadequate medical care. Three themes emerged regarding inadequate medical care: (a) Failure to provide effective care, (b) Unwillingness to consider alternative treatments, and (c) Lack of training.

3.2.2.1.1 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 be on the same page” and “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].” Another common concern regarding the lack of continuity of care was that sometimes physicians “discontinued care without notice.” One participant noted: “doctor discontinued care without notice which is extremely dangerous, refused to give me time to find another doctor or supervise a safe decrease in [medication] over time.” Additionally, individuals were concerned about the hesitation physicians may have to refer patients to other doctors, indicating that they “should have been referred to a specialist” much sooner than they had been. Lastly, participants commented on the lack of continuity of care regarding record keeping and information gathering. One individual noted: “I tried for eight 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 he or she was “misdiagnosed for [three] years,” while another
one said he or she was misdiagnosed “and underwent a surgery that [wasn’t] needed and only made … symptoms worse.” The following quote describes this issue further:

[ Twelve] years ago the neurologist suspected Multiple Sclerosis but did not put me on a Disease Modifying Drug (DMD) and as a result I did not get the benefits of being on this treatment that may have helped delay or prevent the symptoms of MS that I have today.

Many participants commented on the reluctance of doctors to engage in a thorough examination, which could further delay treatment. Participants often commented on doctors not doing “the exams they were supposed to,” or not “examining [their] pain complaints with tests and examinations.” Additionally, doctors are reportedly dismissive of complaints presented by patients and do not address them through exams. One participant suggested that “[the doctor should] Check out my complaints […] He could have run tests or trusted my complaints and descriptions of what was hurting.”

This concern is further illustrated in the following quote:

Every time I had a complain about pain the doctor would blame it on my fibromyalgia without examining me […] When the pain became too unbearable I went to another doctor for another opinion and […] was diagnosed with needing to have hip surgery and the pain was due to torn cartilage.

Patients felt that doctors also delayed care by not referring the patients to the appropriate specialist. Some participants indicated that “despite years of requests,” their “family doctor refused to give [them] a referral to a chronic pain management center.” One participant commented on the delay in referral, indicating that he or she “should have been referred to a specialist long before I was.” Moreover, a participant indicated that at times family doctors “…don’t know all they should and become roadblocks to the specialists who could help.” Another participant specified that “the system needs to recognize chronic pain as a legitimate and severely disabling medical condition and start providing timely access to multidisciplinary health services.” Some participants also
commented on doctors’ “reluctance in giving a diagnosis.” This is clearly illustrated in
the following quote:

[Doctor] refuses to tell me what my diagnosis is. To this day all she tells me is I
have pain that will get better. It’s been over 3.5 years since the car accident I was
involved in. I am still in pain.
Not completing the right documentation or receiving the right medication has
also been reported as leading to delay in care, as one participant mentioned that a doctor
“did not fill out medical forms required for Long Term Disability and Canada Pension,”
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.”

3.2.2.1.2 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” and would have liked to hear about “alternative suggestions, not just drug.”

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],” while 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 health care providers and there are no options, I am stuck between a rock and a hard place.”

A number of participants expressed concern about doctors’ tendency to “just prescribe drugs for the symptom without determining the root cause.” One participant indicated that his or her doctor “keeps giving me more and more pharmaceuticals to take,” while another stated that “all the doctor wanted to do was throw pills at me and leave.” The frustration people described regarding the lack of answers provided by drugs and a doctor’s failure to consider clients on an individual basis resonates with the following quotation: “[I]t happens again and again [and doctors] just want to throw pharmaceuticals at [the patients’ concerns] without properly determining the cause, only treat the symptoms.” Additionally, another participant added: “[O]ne doctor went so far
as to say that in [the emergency department] they see many people that are regulars and are mostly looking for drugs. I am not looking for drugs but a solution to my problem.”

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 due to the position the doctor might have taken on the subject, as one participant indicated that the “doctor could have provided more details about […] treatment options […] I could have gotten more information and taken a more active role in learning about treatment options.” 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.

3.2.1.3 Lack of training. Inadequate medical care was often described to be 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 the 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.” Others discussed the lack of training in specific areas such as complex medical concerns, such as not having “enough knowledge to work with chronic pain” and a concern that “there doesn’t appear to be any medical specialists out there in the area of [fibromyalgia].”
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,” while another expressed a wish for doctors to be “better able to diagnose causes of symptoms.” Moreover, participants commented on the fact that “our health care 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 for doctors to fall back on the treatments they know when they are faced with an unfamiliar situation, as one participant mentioned that “fibromyalgia is an uncharted territory and it seems that has been the same excuse I have been given for the past 5 years.”

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 said that his or her doctor “was supportive but could not offer more suggestions for solutions,” and another expressed frustration at the “long waiting periods to only waste time and not get real answers.” One participant further described his 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.” Additionally, another individual expressed concern about doctors “refus[ing] investigation into potential reasons for my pain and trying to find the root of the problem.”

Some participants indicated that more “exposure to research, [and] an interest in getting answers” by their doctors would have improved their interactions with medical providers, while others mentioned even after discussing various treatment options with
the provider they were “told there are none or that no research has been done to prove
treatment methods or options.” As such, a participant advocated for more training and
education in order for doctors to be “better at diagnosing issues to the individual and not
just [use] a blanket approach” and more “appropriate training in dealing with chronic
pain,” as well as a need for “the system […] to recognize chronic pain as a legitimate and
severely disabling medical condition…” One participant did, however, recognize the
lack of information in the literature about some of the complex conditions and advocated
for “more research,” while another mentioned that doctors often have no solutions, and
the patient keeps “getting sheepish looks and [the doctors] say the same thing, until
further research is done their hands [are] tied.”

3.2.2.2 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.

3.2.2.2.1 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.

Feeling dismissed. Some participants indicated that doctors are often “dismissive about [their] symptoms,” or that they are “quick to dismiss [them] because [they are]
returning with the same problems.” One participant stated that they “have heard it
referred to as being ‘chronic visitor syndrome.’” Some participants also commented on
doctors dismissing their ideas, such that one participant stated that the “doctor did not
agree with me that I had Cervical Dystonia,” or the doctor “did not believe me when I
told him what I had.” 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.” A number of participants expressed a fear that doctors will “just shut you out,” as one individual reported that he or she “felt like [the doctor] was saying, ‘oh, it can’t be that bad,’” and another stated that he or she “was never taken seriously.” The most difficult part about doctor visits was often a “fear of being disbelieved, doubted, dismissed, judged, labelled, [and] not helped.” The following quote describes the extent of feeling dismissed by the medical provider:

I am still questioned and doubted. I was recently told by my new doctor that […] doctors are being told to never take on a patient who has ever made any type of complaint, that we are high risk troublemakers and are prone to sue. Feeling unimportant. Most participants expressed a concern regarding “not [being] treated as individuals” by the doctor, medical providers not caring about their patients, and feeling intimated by doctors. One participant indicated that “if he would have done his job as a doctor and examined me and treated me like every other patient, I would not have had to suffer like I did.” 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 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. Sometimes [it’s] not the pain that is the most pressing need.” Yet another participant insisted that the doctor “could have taken [five] minutes to talk to me as a person, not as a ‘case.’”

Some participants also expressed frustration with the lack of empathy shown by doctors, reporting that they don’t “seem to care or understand” and often “forgot they
were dealing with a human being.” One participant reported: “I have been suffering for several years but no one seems to care. Yet everyone reassures me [the pain] will end. No one has an answer as to how.” His or her frustration regarding doctors’ perception of chronic conditions was echoed by other participants, who reported that doctors get desensitized “especially when my problems are not getting resolved,” or “when my doctor keeps seeing me for the same problems she gets desensitized and stops caring.” Moreover, a participant advocated for more “human compassion […] Speaking to the patient as a person who is going through a tough time. Not making [the appointment] feel like it’s about billing time, or having to justify my complaints of my health.”

Many participants also felt that the doctor often “belittled [them] and made [them] feel unimportant and crazy.” Additionally, participants who indicated they have not discussed their concerns with their doctors often would have wanted to, but feared that “they do not care.” A number of respondents advocated for more “human compassion” and for doctors to “take more initiative to care and listen.” One participant commented on having “been through so much because of the years of neglect.” Many participants ultimately discussed a desire to “be helped,” and indicated that they “have [the] right to be heard and taken seriously with a complex case.” Another reason that medical patients may feel unimportant is due to 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 [MS] on an emotional level.”
Participants sometimes described a reluctance to seek care or to report or verbalize their concerns about their experiences with their doctor due to feeling “intimidated” by healthcare providers. One participant indicated that doctors “have so much power and I feel so intimidated.” Similarly, some stated they hold “doctors in high regard” and thus find it difficult to doubt their opinion, as one participant reported: “I did keep going back and saying ‘this can’t be my Fibromyalgia.’ I did feel like he was intimidating and I held doctors in high regard so I didn’t second guess him at that time.”

### 3.2.2.2 Poor communication

Most participants talked about an overall poor physician-patient relationship, and specifically indicated a desire for a 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 labelled 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 “anxiety! Wondering if they will listen or just brush me off,” as well as a fear that the “doctor will not take my suggestions seriously” or patient’s concerns will be “ignored.” A main concern with communication is feeling that the medical provider does not take into consideration the patients’ suggestions regarding treatment. Some participants talked about doctors “not communicating with the patient[s] all the information they need to take control and be active in their health.” 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.”

This is illustrated in the following quote:

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. Some patients discussed feeling “tired of constantly fighting to be believed and medically helped” and of “convincing [the doctors] that the pain I feel is real.” Many of them suggested an improvement in the system could be made in terms of doctors “listening to what is being said” and treating patients “with respect at all times.”

Additionally, a participant advocated for an improvement in communication such that doctors should “explain options clearly and allow me to have a voice in my care or treatment,” while another one suggested a better interaction with the medical providers would be “when they listen to what I have to say about a complaint and then physically check it out and then explain their findings and suggest what to do […] It’s all about communication.”

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, since he or she “work[s] in the medical field and didn’t know what to do or how to do it without […] being label[led].” 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.” Additionally, one participant acknowledged that he or she “didn’t like confrontation.” Another participant stated that he or she was “afraid that
I will then [lose] my family doctor” if he or she was to address the negative experience, and that was described as one of the most difficult parts of interacting with doctors.

3.2.2.2.3 **Strong emotional reactions.** In general, participants expressed strong emotional reactions with regards to their interactions with medical providers, specifically feeling hurt, distrustful, angry, and helpless.

**Hurt.** Many participants commented on feeling “upset,” “very hurt” and “betrayed” by their interactions with medical providers. One participant stated: “I felt very sad about how I was treated,” while another indicated that he or she “felt hurt…sad… depressed.” Moreover, some participants commented on feeling “betrayed and that no one cares.” Receiving “no respect” from the provider or the medical system was a comment shared by most participants. One individual shared that “many, many times over the years I have been disbelieved, dismissed, insulted, [and] disrespected.” Another added that “not only [did the doctor not] help but [he or she] was insulted as well.” Yet another participant felt disrespected by the doctor through discrimination, as he stated: “I was discriminated against because I am a gay male.” Overall, participants advocated that doctors “could show kindness and respect,” as well as “patience and empathy.”

**Distrustful.** When unexpected outcomes occur, participants indicated that they lose significant trust in their providers. One person stated: “I trusted this physician with my life. He had me on dangerous levels of narcotics…” Another participant indicated that he or she felt “disappointed” in how doctors have treated him or her, and yet another indicated that he or she is “afraid to trust them” due to previous negative experiences.
Additionally, one respondent said that his or her doctor “made me feel more anxious rather than […] reassure me.”

The following quote depicts the lack of trust a participant felt after his experience with the medical system:

I was suppose[d] to be able to trust this professional that 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 complain I had. I feel so let down and hate how much I didn’t matter! 

Angry. 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.” Another participant indicated feeling “very frustrated and hurt, especially since it had been such a long time for the appointment.” Individuals also commented on lingering feelings of anger, as one mentioned he or she is “still angry and frustrated, still dealing with the pain,” and another mentioned that he or she “was very angry but in too much pain to do anything about it.” Yet another participant stated: “I am still very angry. I will eventually make a complaint to the Collège des Médecins du Quebec.”

Helpless. 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 he or she feels like there is “no one to complain to,” while another one talked about other patients who “complain about the same things and they are no further ahead.” Therefore, some of the participants felt that even when they bring up concerns with their doctors, they are just as helpless as there issues do not get resolved and they do not receive the psychological support they desire. Many patients indicated feeling “terrified,” and one
person indicated he or she “still has a fear of going to the Emergency.” Patients often talked about feeling “abandoned,” “helpless,” “worthless,” “discouraged,” “desperate,” “anxious […] nervous,” “panicked,” and “confused.” More specifically, one participant indicated that he or she “needed help dealing with the Chronic Pain,” and felt very alone when it wasn’t received. Another participant stated: “I feel betrayed. I feel like I had to diagnose myself.” Additionally, 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.”

### 3.2.2.3 System level IB

Many patients emphasized the issue of a system level betrayal where 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.

#### 3.2.2.3.1 Doctor knows best culture

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

*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 [since] they are trained in ethics and patient care,” and another commented on not “second guess[ing]” the doctor since 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.” Additionally, 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. A participant further elaborated on this issue by stating that “[d]octors are not god yet some of them think they have that status. [There] is a clear power hierarchy especially within the hospital setting which is not helpful when you have a doctor with a distorted attitude.”

*Lack of accountability.* Responses focused on a tendency for doctors not only to not take accountability for errors they may have made, but also not admit when they do not know the right answer. In regards 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 where 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.” Additionally, 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.” Participants’ frustration is illustrated by the following quotes: “Even now, with proof of my medical disabilities, his lies are being believed and I am not.”

When I finally (out of desperation) filed a complaint with the Ontario CP&S he destroyed my records. He would rather have gotten in trouble for a records violation than be in bigger trouble if another doctor saw my records and his treatment of me.

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

*Time constraints.* The “long wait for [an] appointment” and the “limited appointment times” have been frequently cited as system barriers in care. Participants often indicated they feel “rushed” during their appointments and “feel like [they are] taking up [the doctor’s] time.” Additionally, 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 since “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 advocated for doctors to “take time with visits” and “actually want to help. The pressure to perform according to strict guidelines is too much.” Additionally, one patient stated he or she would like to “not be rushed during visits, not have to wait weeks, months, or even years to see specialists,” while another advocated for the medical system to “start providing timely access to multidisciplinary health services.” Some participants also expressed frustration with the “long waiting periods to only waste time and not get real answers.” Lastly, 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.” Moreover, one participant discussed this concern further by raising awareness to the issue of the shortage of doctors impacting who gets treatment, such that “[d]octors are often focused on the most sick, the most disabled, etc. and when you are not the sickest or the most disabled they can be dismissive, even if you do have real medical needs and problems.”
3.2.2.3 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 due to 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.” Some participants commented on the doctor’s “reputation for being ignorant/uncaring,” and indicated that doctors often “all say the same thing” when dealing with patients. One participant stated that his or her doctor “was careless with prescribing practices [and] had myself and many other patients on dangerous levels of narcotics.” Another participant indicated he or she “filed a complaint [about the doctor and] he was found to have done this to many patients.” Yet another participant comments on the fact that “others diagnosed with Fibromyalgia […] get the same type of treatment very often from medical professionals.”

3.3 Qualitative Discussion

The purpose of the qualitative portion of this research was to investigate the presence of IB in the Canadian medical system and capture specific instances that lead to perceptions of IB in a sample of patients with chronic medical conditions. Overall,
patients described IB in varying degrees of betrayal, specifically at the doctor level (including poor medical care and lack of psychological support) and at the system level. In their responses, participants not only described ways in which the medical system and their doctors either responded inadequately in the face of a negative healthcare experience or failed to prevent such events, but also indicated experiencing many negative cognitions and strong emotional reactions directly related to the concept of IB and their interactions with the medical system. Therefore, the way participants think about the negative healthcare experience and perceive the extent of the betrayal experienced are important aspects of IB in the medical system that patients felt were important to address in their responses. These negative cognitions often appeared linked to the lack of psychological support, as patients mainly expressed strong negative emotions related to the way they felt they were treated by the medical providers and the medical team. Thus, psychological support appears to be a major component that affects patient satisfaction with the healthcare system.

This finding echoes 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 controlling for mental health status (Kirby, Dunwoody, & Millar, 2009). Kirby and colleagues 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 specifically in terms of a need for validation, understanding, and improved communication. Individuals suffering from chronic conditions may require additional psychological support compared to others due to the chronicity and nature of
their condition (Kirby et al., 2009). Thus, these patients may see their provider more often, and may also not experience a reduction in symptoms, which may thus increase their need for support from the medical provider.

A qualitative study conducted in Lithuania regarding dissatisfaction with the medical system found similar main categories: 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 the 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). Interestingly, these similarities in the reasons for dissatisfaction were not linked to specific medical conditions, as Bankauskaite and Saarelma used a sample of individuals from the general population, while 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 found themes at the systemic level that specifically relate to the Lithuanian healthcare system (such as the changing health care reform and the high cost of services), which do not generalize to other medical systems, such as the Canadian one. The latter relies on a public healthcare 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 which may cater their services based on ability to pay rather than need.

As predicted, patients expressed dissatisfaction when they were not actively involved in their own treatment. Research has shown that patients who are more active in their own care tend to experience more satisfaction and better outcomes and symptom reduction (Ashraf et al., 2013). Moreover, involving patients in decision-making also appears to be associated with higher-quality care and fewer medical errors (Osborn & Squires, 2012). Thus, quality of care and psychological support can be considered malleable in their relative importance during a negative healthcare experience. The present study mirrors these findings, as the doctor level betrayal theme is comprised of both inadequate care and lack of psychological support. Thus, 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 inadequate given the circumstances.

The strengths of the current study include using qualitative measures to inquire about potential experiences that may lead to feelings of IB in the Canadian medical system. The majority of previous studies have focused on quantitative methods to study satisfaction with healthcare systems, which forces participants to only answer the questions asked and may thus miss specific concerns about different aspects of care that individuals may have (Bankauskaite & Saarelma, 2003). The qualitative method in the present study allowed Canadian participants to openly express their most pressing concerns with the medical system in their own words. A chronic medical sample may be different than a general sample in both their satisfaction with the system and their needs.
They may require more psychological support from providers, and may also be less satisfied with the care they receive due to the nature of their conditions. Thus, all results may not generalize to all medical patients in Canada, but the major themes appear to be similar to those in other countries and systems, specifically the difference between doctor level and system level betrayal, and the differentiation between quality of care and psychological support received.

The principal investigator’s role in the analysis requires some consideration, as suggested by Malterud (2001) and by Tong, Sainsbury, and Craig (2007). The limited amount of experience of the principal investigator and the research assistants with qualitative methods may have negatively impacted results. Although having two raters helped improve reliability of results, discussing the themes and subthemes between raters was an iterative process given the difference in some of the major categories between raters. Preconceptions about IB may have affected the way raters categorized responses. Additionally, the majority of the questions used in the qualitative study came from the original IBQ, which may have created a preconception of what kind of items and factors should describe the concept of IB. The wording of the questions may have therefore been tailored to specifically ask about such factors and could have potentially missed other aspects of IB that have not been studied yet. Lastly, given the online administration of this study, the researcher did not have any direct interactions with the participants. This could have prevented further bias from affecting participants’ responses or the analysis of these responses.

A potential limitation of this research may be the use of online surveys instead of face-to-face interview in order to receive qualitative feedback regarding individual
perceptions about the medical system. In a face-to-face interview, an individual may be more likely to further elaborate on his or her answers and thus provide a richer description of healthcare experiences. However, while doing phone interviews may allow for more probing and ensure that participants both understand the question, and answer it adequately, phone interviews are costly and lengthy. The online format of the present study allowed a more efficient way to collect and analyze the data. Additionally, 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). The main difference between the two qualitative methods was that participant responses were more succinct and specific to the topic at hand in the online group than the face-to-face one (Synnot et al., 2014). Therefore, even though doing the survey online 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 experiences of other medical samples and other demographics (males, different ethnicities, low economic status) with the medical system.
CHAPTER FOUR

Study 2

4.1 Methods

4.1.1 Participants. The study was approved by the Research Ethics Board at the University of Regina on November 20, 2014 (Appendix D). The aim of the study was to test the reliability and validity of a new measure of IB. Specifically, an exploratory factor analysis investigated the dimensions of the IBQ-MS, and correlations and hierarchical multiple regressions tested the convergent and discriminant validity of the scale. Based on the requirements of conducting a factor analysis (Gaundagnoli & Velicer, 1988; Osborne & Costello, 2004), the goal was to recruit over 300 participants to complete a survey that includes the new measure of IB in the medical system (i.e., IBQ-MS). Participants were recruited using Qualtrics. Services such as Qualtrics have access to thousands of individuals who have expressed interest in research participation and who are being compensated (directly by Qualtrics) for each questionnaire they complete. The eligibility criteria required participants to be at least 18 years of age, live in Canada, be able to accurately respond to questions in English, and self-identify as currently having a chronic health condition. Patients with chronic conditions were recruited for this study because they are likely to have had extensive interactions with the medical system. IBQ-MS measure was validated in this study with a population of individuals with chronic medical conditions, as this measure is most likely to be relevant to them and their interactions with their health providers. A total of 376 individuals met inclusion criteria and started the study, and 352 of these completed it. Twelve participants chose to withdraw, while the other twelve who were not included in analyses did not complete the
survey. From those who choose to withdraw, most indicated that they did so due to the length of the survey. Less than 5% of respondents indicated that the survey was more distressing than they had expected. Therefore, this study had an attrition rate of less than 7%.

4.1.2 Measures. The new questionnaire derived from study 1, IBQ-MS, was used along with other measures of health and well-being in order to assess discriminant and convergent validity. SPSS 21.0 was used in all the analyses for this study.

Demographics. The demographic questionnaire (Appendix E) inquired about age, sex, education level, income, ethnicity, and presence of disability.

IBQ-MS. Using information obtained in Study 1, the IBQ-MS was developed (Appendix F). To begin, the wording of the IBQ by Smith and Freyd (2013) was modified so that it applied specifically to the medical system. Additionally, the response format was changed from a dichotomous (yes/no) to a 5-point Likert scale in order to assess extent of IB experienced by individuals. An additional 33 items were formulated based on the themes from the qualitative study after consulting with the thesis committee, creating a scale with a total of 46 items. Five research assistants analyzed the questions for clarity and content validity, and changes to the wording were made accordingly. The completed 42-item questionnaire after item reductions (see study 2 results section for details) can be found in Appendix F.

The measure was designed to capture: 1) negative experiences in the medical system that may be perceived as betrayal, 2) doctor and system-specific instances of betrayal, 3) doctor and system responses to such negative experiences, and 4) negative cognitions and emotions related to healthcare interactions. Each item was rated on a 5-
point Likert scale either from “never” to “almost always” for questions asking about specific experiences, and from “not at all” to “extremely” for questions investigating feelings, cognitions, and reactions to negative healthcare experiences. The overall score indicated the extent of IB reported by participants. The mean of each factor derived from the factor analysis was used in order to create the subscales of IBQ-MS, in order to account for the varying number of items in each subscale.

**Brief Betrayal Trauma Survey (BBTS).** A version of the BBTS (Goldberg & Freyd, 2006a) appears in Appendix G. The BBTS investigates betrayal trauma instances both in childhood and adulthood (Goldberg & Freyd, 2006b). The measure assesses the occurrence of 14 specific traumatic events in the individual’s life both before and after the age of 18, and assesses the severity of betrayal. Participants indicated whether or not each of the events has occurred to them both during their childhood and in adulthood. The response format is dichotomous (yes/no), and the sum of all items represents the overall level of betrayal trauma experienced by an individual. The test-retest stability of indices is fairly high: 83% for childhood events and 75% for events in adulthood, which is similar to other self-report measures of trauma (Goldberg & Freyd, 2006b). The BBTS was used to establish convergent validity for the IBQ-MS.

**Adverse childhood experiences (ACE) survey.** The ACE survey (Appendix H) is based on questions used in the Adverse Childhood Experiences Study (Felitti et al., 1998). The ACE survey asks about the occurrence of different adverse exposures (neglect, abuse, and household dysfunction) an individual may have experienced in childhood. The ACE survey contains 17 questions, and the response options are “yes” or “no.” The overall score on the ACE is calculated based on how much exposure a participant reports.
in each of the 10 categories of the measure (Felitti et al., 1998), for a total score of 10.
Statistical reliability and validity have not been established for this measure, but it was
used in a medical population to show that there is a long-term relationship between
childhood adverse experiences and later health problems (Felitti et al., 1998). In the
proposed study, individuals who have experienced more adverse events in childhood
were expected to display higher levels of IB in adulthood.

**PTSD checklist-5 (PCL-5).** The PCL was originally introduced by Weathers,
Litz, Herman, Huska, and Keane (1993) to assess symptoms of PTSD based on the DSM
IV diagnostic criteria and has been widely used in different versions. The PCL-Civilian
Version shows adequate reliability (total scale \( \alpha = .94 \); Ruggiero, Del Ben, Scotti, &
Rabalais, 2003), and test-retest reliability varies from \( r = .92 \) for participants asked to take
the test again immediately, and \( r = .68 \) for participants retested two weeks later (Ruggiero
et al., 2003). The PCL-5 (I), created by Weathers et al. (2013), is an adaptation of the
original PCL that includes items that fit the DSM-5 symptom criteria for PTSD (Biehn et
al., 2013). The 20 questions in the PCL-5 inquire about symptoms the participant has
been bothered by in the past month in relation to an identified stressor. The extent of
distress the participant experiences in relation to each of the twenty symptoms is rated on
a 5-point Likert scale, ranging from “not at all” to “extremely.” This measure is scored
by summing each of the questions for a total score of maximum 100 representing
extreme levels of posttraumatic symptoms. The PCL-5 was used to establish convergent
validity for the IBQ-MS.

**Medical outcomes study (MOS) social support survey.** The MOS social
support survey (Appendix J) measures the perceived availability of functional social
support (Sherbourne & Stewart, 1991). The participant is first asked for the number of close friends and relatives he or she has, after which he/she is asked to answer the remaining 19 questions about the frequency different kinds of support are available to him or her when needed. The responses are rated on a 5-point Likert scale, ranging from “none of the time” to “all of the time.” The MOS score is calculated by summing all responses for a total score representing the amount of perceived social support. The scale displays high internal consistency ($\alpha=.97$; Sherbourne & Stewart, 1991), as well as a fairly high one year stability coefficient ($r=.78$; Sherbourne & Stewart, 1991). Participants who have less social support were expected to display higher levels of IB in the medical system.

**Dissociative experiences scale II (DES-II).** The DES-II (Appendix K) is a self-report measure investigating the continuum of dissociative experiences (Bernstein & Putnam, 1986). The original DES has an appropriate test-retest reliability coefficient ($r=.84$; Bernstein & Putnam, 1986). With the original DES, respondents were asked to place a tick on a line to indicate what percentage of time they have each of the 28 experiences (Wright & Loftus, 1999). The DES-II has the same 28 items that investigate degree to which participants experience dissociative symptoms on a daily basis, but its response system is easier to code and administer. The items were summed for a total score representing the level of dissociation experienced by each individual. Responses are coded on a continuum, with answers ranging from 0% of the time to 100% of the time in 10% increments (Wright & Loftus, 1999). Participants who displayed higher levels of dissociation were expected to report more feelings of IB in the medical system.
**General trust scale.** The general trust scale (Appendix L) is a brief, 6-item measure that inquires about general tendency to trust others (Siegrist, Gutscher, & Earle, 2005). Its internal consistency is satisfactory ($r=.67$; Siegrist et al., 2005). Responses are rated on a 5-point Likert scale ranging from “don’t agree at all” to “agree absolutely.” The mean of all responses for each individual represented the total score for the respondent’s willingness to trust others. It was used to determine whether or not a difference exists between participants who have a low general tendency to trust in comparison to those whose willingness to trust is mediated by the interpersonal nature of a situation in terms of the extent of IB they experience.

**Trust in the medical profession scale.** This 11-item questionnaire (Appendix M) assesses four dimensions of trust in physicians: fidelity, competence, honesty, and global trust (Hall et al., 2002). This measure has good internal consistency (Cronbach’s alpha = .89; Hall et al., 2002). Responses are rated on a 5-point Likert scale from “strongly agree” to “strongly disagree.” The mean of all responses for each individual represented the total score for the respondent’s willingness to trust doctors and the medical profession. This measure was expected to correlate with feelings of IB, but the concept of IB in the medical system is expected to explain more than just distrust in the medical profession.

**Patient continuity of care questionnaire (PCCQ) – revised for a chronic conditions.** The revised PCCQ (Appendix N) is 20-item measure investigating patients’ perceptions of factors related to continuity of care: relationships in hospital, information received by patient, relationships in community, management of healthcare forms, management of follow-up, and management of communication among providers.
The PCCQ has subscales analyzing the relationship between patients and their providers and quality of the patient-physician communication. The original PCCQ was developed for patients who are being discharged from the hospital. The revised version does not include specific information about hospital stays, but rather inquires about whether participants felt that their physicians provided them with adequate information about their diagnosis and prognosis. Responses are given on a 5-point Likert scale, with an option to choose “not applicable” if the particular question does not apply to the participant; higher scores reflect more positive perceptions of care (Hadjistavropoulos et al., 2008). Two factors from the original PCCQ (“relationships with providers in hospital” and “information transfer to patients;” Hadjistavropoulos et al., 2008) were used to create the variables of healthcare relationships and patient-physician communication in the present study. Moderate correlations were found among the PCCQ subscales, ranging from $r = .23$ to $r = .52$ (Hadjistavropoulos et al., 2007). Participants’ positive perceptions of continuity of care were expected to correlate negatively with feelings of IB.

**The Hospital Anxiety and Depression Scale (HADS).** This 14-item questionnaire (Appendix O) was developed to assess depression and anxiety in a medical outpatient population (Zigmond & Snaith, 1983). Responses are given on a 5-point Likert scale, ranging from “most of the time” to “not at all.” Each scale score was made up of the sum of each item in that scale. The anxiety and depression subscales demonstrated moderate internal consistency (Spearman correlations between 0.30 and 0.76; Zigmond & Snaith, 1983), and both subscales are adequate measures of symptom severity (Spearman correlation for anxiety is 0.74 and for depression 0.70; Zigmond &
Snaith, 1983). The HADS is a reliable and valid measure of global psychological distress in medical populations (Zigmond & Snaith, 1983). The HADS was used in the present study to draw comparisons between this population and other clinical populations in terms of their symptoms of depression and anxiety. However, a second measure of depression was also used, as previous research found that the subscale of HADS designed to measure depressive symptoms mainly investigates dimensions of anhedonia (Martin, 2005) and therefore may not be a reliable measure of depression.

**Center for Epidemiologic Studies Depression Scale Revised (CESD-R).** This questionnaire is a 20-item measure of depressive symptoms (Appendix P). The variable for depression using this scale was computed by summing of all items. The original CESD (Radloff, 1977) has been revised to the CESD-R in order to reflect the changes made in the diagnostic criteria for major depression (Eaton, Muntaner, Smith, Tien, & Ybarra, 2004). A recent study validated this measure for depression (Van Dam & Earleywine, 2011), and the review by Eaton et al. (2004) found the scale to have strong psychometric properties.

**4.1.3 Procedure.** Participants were recruited through Qualtrics panels. Eligible participants were at least 18 years of age, living in Canada, and currently suffering from a chronic medical condition. The IBQ-MS from study 1 was used in this online study, along with other measures. In-depth information about the study was provided to the participants on the main page of the survey (see appendix Q) and informed consent was implied by their decision to complete the online survey. The questionnaire took about 1 hour to complete, and participants were compensated through Qualtrics.
4.1.4 Analyses. Coefficient alphas were used to test the measure’s reliability, and hierarchical multiple regression analyses were used to assess validity. A factor analysis determined the main components of the concept of IB in the medical system. The analyses are herein described in more detail.

Descriptive statistics. Descriptive statistics were calculated for demographic variables.

Coefficient alpha. The internal consistency and reliability of the scale was determined using coefficient alpha calculations.

Factor analysis. An exploratory factor analysis was conducted based on Costello and Osborne’s recommendation (2005) to determine a good fit for the IBQ-MS and to conceptualize the main components of the questionnaire. IB in the medical system was expected to be a multidimensional concept that encompasses experiences, interpretations, trust, and emotional responses during and after interactions with health care providers. Item reductions were also performed in order to eliminate questions that do not significantly load on any of the factors derived.

Multiple regressions. Hierarchical multiple regression analyses were conducted to evaluate convergent and discriminant validity. Importantly, these analyses were used to determine the relationship between IB and other trauma, health, and well-being factors.

4.2 Results

4.2.1 Demographics. A total of 352 participants from across Canada completed the validation study. About half of the sample was from Ontario (49.7%), 20.7% from British Columbia, 8.8% from Alberta, 0.9% from Saskatchewan, 4.3% from Manitoba,
7.1% from Quebec and 8.5% from the Maritime provinces (4.0% Nova Scotia, 1.1% Newfoundland and Labrador, 0.3% Prince Edward Island, and 3.1% New Brunswick). Participants’ ages ranged from 18 to 88, with a mean age of 47.8, and median of 49. Approximately 57.1% of participants identified as female, and 42.3% as male. Two individuals (0.6%) identified their gender as “other.” Most of the sample identified as “White” (81%), while 11.6% identified as “Asian,” 1.7% as “First Nations,” 1.4% as “Black,” 1.4% as “Hispanic,” and 2.8% as “other,” which mainly indicated being multiracial. Given the high percentage of white participants, a new variable was created for race to investigate the differences between white people versus non-white people (visible minorities) in all subsequent analyses. Over half of the sample identified as being in a long-term relationship (58.1%), 23% as single never married, 2% dating, 2.8% separated, 9.7% divorced, and 4.3% widowed.

The participants’ living situation was reported as follows: 25.3% living alone, 56.8% living with spouse or partner, 15.6% living with other family members, 4% with roommates or friends, 17.3% with children under age 18, and 2% living with others, which most clarified as being with children over the age of 18. In terms of income, 4.3% reported making less than $10000 a year, 7.7% between $10000 and $19999, 8.2% between $20000 and $29999, 9.7% between $30000 and $39999, 6.5% between $40000 and $49999, 8.8% between $50000 and $59999, 6.5% between $60000 and $69999, 4.8% between $70000 and $79999, 6.3% between $80000 and $89999, 4% between $90000 and $99999, 8.5% between $100000 and $149999, and 2% reported a total income of over $150000. A total of 54% of participants indicated the home they live in is owned by them, while 38.1% were renting.
The sample who completed this study were highly educated: 10.5% completed a graduate or professional degree (e.g., MA, MD), 21.3% had a bachelor’s degree, 17.6% had an associate or technical degree, 28.7% completed some college or post-secondary education, 17.3% completed high school or GED, and only 4% indicated their education was less than high school. Individuals reported on their employment status in the past month: 36.4% said they worked full time, 16.5% part time, 2.8% indicated they were out of work and looking for work, 1.1% that they were out of work and not looking for work, 4% said they were unable to work, 12.5% said they were disabled related to their chronic condition, 2.8% disabled due to another condition, 1.7% indicated they were on temporary leave, 4.8% identified as homemakers, 6.5% as students, and 21.9% indicated they were retired. Compared to the Canadian population (Statistics Canada, 2011), this sample had a somewhat higher proportion of females, a much higher proportion of people who self-identified as Caucasian, a higher proportion of people living in Ontario and none from the territories, and participants were more educated and had a higher income than the national average.

Participants were required to self-identify as experiencing a chronic medical condition in order to be eligible to participate in this study. Table 1 below displays these results. A total of 15.6% of participants reported suffering from one condition, 21.6% from two, 14.5% from three, 15.3% from four, 8.0% from five, and 20.2% reported suffering from six or more health conditions. There was less than 5% of missing data for this variable.

Table 1: Chronic conditions summary

<table>
<thead>
<tr>
<th>Chronic condition</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart problems</td>
<td>12.3</td>
</tr>
<tr>
<td>Condition</td>
<td>Percentage</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>Heart attack</td>
<td>4.3</td>
</tr>
<tr>
<td>Coronary artery bypass surgery</td>
<td>2.6</td>
</tr>
<tr>
<td>Angina</td>
<td>5.1</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>3.1</td>
</tr>
<tr>
<td>Coronary artery disease</td>
<td>4.0</td>
</tr>
<tr>
<td>Cancer</td>
<td>5.4</td>
</tr>
<tr>
<td>Breast</td>
<td>1.4</td>
</tr>
<tr>
<td>Prostate</td>
<td>3.1</td>
</tr>
<tr>
<td>Colorectal</td>
<td>1.4</td>
</tr>
<tr>
<td>Other types</td>
<td>2.3</td>
</tr>
<tr>
<td>Respiratory problems</td>
<td>27.8</td>
</tr>
<tr>
<td>Emphysema</td>
<td>2.3</td>
</tr>
<tr>
<td>Chronic Bronchitis</td>
<td>6.5</td>
</tr>
<tr>
<td>Asthma</td>
<td>19.0</td>
</tr>
<tr>
<td>Diabetes</td>
<td>20.5</td>
</tr>
<tr>
<td>Type 1</td>
<td>3.7</td>
</tr>
<tr>
<td>Type 2</td>
<td>17.9</td>
</tr>
<tr>
<td>Arthritis related diseases</td>
<td>24.7</td>
</tr>
<tr>
<td>Rheumatoid arthritis</td>
<td>8.5</td>
</tr>
<tr>
<td>Other forms (e.g., osteoarthritis)</td>
<td>13.4</td>
</tr>
<tr>
<td>Neurological disorders (e.g., multiple sclerosis, fibromyalgia, neuropathy)</td>
<td>7.7</td>
</tr>
<tr>
<td>Chronic pain</td>
<td>43.8</td>
</tr>
<tr>
<td>Back pain</td>
<td>42.3</td>
</tr>
<tr>
<td>Migraines</td>
<td>25.9</td>
</tr>
<tr>
<td>Other forms (e.g., endometriosis, degenerative disk disease)</td>
<td>16.5</td>
</tr>
<tr>
<td>Digestive problems</td>
<td>21.9</td>
</tr>
<tr>
<td>Ulcerative colitis</td>
<td>3.4</td>
</tr>
<tr>
<td>Chron’s disease</td>
<td>3.1</td>
</tr>
<tr>
<td>Gallbladder disease</td>
<td>2.6</td>
</tr>
</tbody>
</table>
Liver problems (e.g., cirrhosis) 1.7
Kidney disease 2.3
Stroke 2.3
HIV/AIDS 0.6
Other health problems 23.9
(e.g., high blood pressure, high cholesterol, hepatitis C, allergies, sleep difficulties, mental health disorders, hypothyroidism)

About a quarter of participants (24.7%) reported being misdiagnosed before receiving a correct diagnosis, and 38.1% said they experienced delay in receiving medical care for their condition (either due to wrong diagnosis, provider being unavailable, or financial or medical system barriers). Out of these individuals, 71.6% said that the delay resulted in new or worsening symptoms. Overall, 5.7% reported that their general health is excellent, 21.3% very good, 34.7% good, 29% fair, and 9.4% poor. Most of the sample (88.4%) indicated that they have a family doctor, and almost half of the participants (47.4%) said they have regular contact with healthcare providers other than their family doctors. Individuals reported on their behaviours related to non-adherence to their medical care over the past 12 months: 36.1% said they did not take a doctor’s advice, 29.8% that they did not seek medical care when needed, 19.9% that they did not fill a prescription that the doctor ordered, and 35.8% that they postponed or delayed seeking care that they felt was needed.

4.2.2 Missing Data. Less than 1% of the demographic data was missing. Similarly, less than 1% of the data on traumatic experiences (BBTS), childhood adverse experiences (ACES), PTSD symptoms (PCL), social support (MOS), general health,
nonadherence variable, symptoms of dissociation (DES), general trust, doctor trust, depression and anxiety symptoms (HADS and CESD-R). Less than 2% of the IBQ-MS data was missing. The measure of healthcare relationships and patient-physician communication (PCCQ) had over 5% of missing data, but less than 1% of this referred to actual missing values; specifically, most of the missing values involved participants choosing to respond with “not applicable.” Therefore, the two variables using the PCCQ measures (healthcare relationships and patient-physician communication) were constructed by creating the mean of the items that were answered by participants.

4.2.3 Factor Analysis. An exploratory factor analysis (EFA) was conducted on the items of the IBQ-MS. Table 2 below shows the main statistical results of the factor analysis.

<table>
<thead>
<tr>
<th>Statistic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Determinant</td>
<td>$1 \times 10^{-13}$</td>
</tr>
<tr>
<td>KMO measure</td>
<td>.974</td>
</tr>
<tr>
<td>Chi-square</td>
<td>20831.27</td>
</tr>
<tr>
<td>Degrees of freedom</td>
<td>1035</td>
</tr>
<tr>
<td>Significance</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

The determinant is very low, showing that there was adequate multicollinearity amongst variables, and thus the variables were highly correlated with each other. Bartlett’s test of sphericity was significant $\chi^2(1035)=20831.27, p<.001$; thus, the correlation matrix was significantly different from an identity matrix. The KMO statistic is of adequate magnitude for a factor analysis (.974), as KMO values larger than .6 show that the correlations between variables can be explained by other variables. The KMO
The statistic summarizes how small the partial correlations are in relation to the original correlations between variables.

According to the method described by Costello and Osborne (2005) for parallel analysis, the EFA was conducted by using the method of Principal Axis Factoring, extracting three factors and doing a promax rotation. Three items did not load significantly (over .40) on any of the factors and were thus removed from the analysis (“these experiences made me feel more trusting of the medical system,” “have you had an experience not mentioned above where you felt the medical system or provider let you down, betrayed you, or did not act in your best interests?” and “medical professionals responded inadequately to these experiences, if reported”). Another item cross-loaded on two of the factors (loading of .43 on one and .36 on the other), and was also removed from the analysis (“The medical system created an environment in which these types of experiences seemed to be accepted as appropriate”). Table 3 below shows the total variance explained by the three factors extracted.

Table 3: Total variance explained by each factor

<table>
<thead>
<tr>
<th>Component</th>
<th>Eigenvalue</th>
<th>% Variance</th>
<th>Cumulative %</th>
<th>Rotation sums of squared loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>26.11</td>
<td>61.57</td>
<td>61.57</td>
<td>23.76</td>
</tr>
<tr>
<td>2</td>
<td>3.38</td>
<td>7.33</td>
<td>68.90</td>
<td>18.86</td>
</tr>
<tr>
<td>3</td>
<td>2.26</td>
<td>4.79</td>
<td>73.68</td>
<td>19.14</td>
</tr>
</tbody>
</table>

Tables 4-6 below present the pattern matrix for each of the three factors.
Table 4: Pattern matrix for Factor 1

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1 loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Made me feel betrayed.</td>
<td>.717</td>
</tr>
<tr>
<td>2. Made me feel cautious about seeking care.</td>
<td>.750</td>
</tr>
<tr>
<td>3. Made me feel reluctant to seek further medical care.</td>
<td>.656</td>
</tr>
<tr>
<td>4. Made me feel angry</td>
<td>.911</td>
</tr>
<tr>
<td>5. Made me feel sad</td>
<td>.918</td>
</tr>
<tr>
<td>6. Made me feel hurt</td>
<td>.926</td>
</tr>
<tr>
<td>7. Made me feel disrespected</td>
<td>.972</td>
</tr>
<tr>
<td>8. Made me feel ignored</td>
<td>.946</td>
</tr>
<tr>
<td>9. Made me feel dismissed</td>
<td>.919</td>
</tr>
<tr>
<td>10. Made me feel disappointed</td>
<td>.944</td>
</tr>
<tr>
<td>11. Made me feel helpless</td>
<td>.938</td>
</tr>
<tr>
<td>12. Made me feel desperate</td>
<td>.904</td>
</tr>
<tr>
<td>13. Made me feel humiliated</td>
<td>.853</td>
</tr>
<tr>
<td>14. Made me feel ashamed</td>
<td>.785</td>
</tr>
<tr>
<td>15. Made me feel like the medical providers didn’t really care about me</td>
<td>.925</td>
</tr>
<tr>
<td>16. Made me feel scared/terrified</td>
<td>.783</td>
</tr>
<tr>
<td>17. Made me feel lonely/alone</td>
<td>.834</td>
</tr>
<tr>
<td>18. Made me feel guilty</td>
<td>.661</td>
</tr>
<tr>
<td>19. Made me feel disempowered</td>
<td>.911</td>
</tr>
<tr>
<td>20. Made me feel less trusting of the medical system</td>
<td>.779</td>
</tr>
</tbody>
</table>
Table 5: Pattern matrix for Factor 2

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 2 loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Medical professionals fail to provide appropriate treatment (e.g., did not provide a solution to the problem).</td>
<td>.725</td>
</tr>
<tr>
<td>2. The medical system fails to efficiently administer care (e.g., lack of continuity of care, delay in care).</td>
<td>.723</td>
</tr>
<tr>
<td>3. Doctors provide inadequate information about risks and procedures of various treatments.</td>
<td>.749</td>
</tr>
<tr>
<td>4. Medical providers do not communicate effectively with patients.</td>
<td>.894</td>
</tr>
<tr>
<td>5. Medical providers do not listen to patients’ concerns.</td>
<td>.871</td>
</tr>
<tr>
<td>6. Medical providers are not open to patients’ input.</td>
<td>.810</td>
</tr>
<tr>
<td>7. Medical professionals are not open to alternative treatments (e.g., place emphasis on pharmaceuticals).</td>
<td>.888</td>
</tr>
<tr>
<td>8. Medical providers lack appropriate training for some complex cases.</td>
<td>.751</td>
</tr>
<tr>
<td>9. Medical professionals are not held accountable or sanctioned for their actions.</td>
<td>.727</td>
</tr>
<tr>
<td>10. The medical system creates barriers to care (e.g., not enough time spent with patients, long wait times, financial issues, shortage of doctors).</td>
<td>.872</td>
</tr>
<tr>
<td>11. The medical system did not take proactive steps to prevent these experiences.</td>
<td>.525</td>
</tr>
<tr>
<td>12. The medical system created an environment in which these types of experiences seemed common.</td>
<td>.505</td>
</tr>
<tr>
<td>13. The medical system created an environment in which these experiences seemed more likely to occur.</td>
<td>.452</td>
</tr>
<tr>
<td>14. The medical system made it difficult to report the experiences.</td>
<td>.446</td>
</tr>
</tbody>
</table>
Table 6: Pattern matrix for Factor 3

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 3 loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The system mishandled your report of a problem with a medical professional and/or the medical system, or failed to take disciplinary action.</td>
<td>.807</td>
</tr>
<tr>
<td>2. The medical system covered up these experiences.</td>
<td>.837</td>
</tr>
<tr>
<td>3. The medical system denied your experiences in some way.</td>
<td>.818</td>
</tr>
<tr>
<td>4. The medical system punished you in some way for reporting these experiences (e.g., loss of privileges or status).</td>
<td>.960</td>
</tr>
<tr>
<td>5. The system or medical professionals suggested your experiences might affect the reputation of the institution.</td>
<td>.953</td>
</tr>
<tr>
<td>6. The medical system created an environment where you no longer felt like you were valued within the system.</td>
<td>.691</td>
</tr>
<tr>
<td>7. The medical system created an environment where seeking future medical care was difficult for you.</td>
<td>.631</td>
</tr>
<tr>
<td>8. The medical system created an environment that promoted further negative experiences.</td>
<td>.741</td>
</tr>
</tbody>
</table>

Given the content of the questions that load on each of the factors, the following conclusions are drawn. Factor 1 refers to negative cognitive-affective reactions that patients experienced in response to their interactions with healthcare providers and the medical system. Factor 2 refers to doctor and system factors that may lead to negative healthcare experiences and ultimately feelings of betrayal (e.g., doctor communication, systemic barriers to care, inappropriate treatment). Factor 3 refers to system factors in response to a negative healthcare experience that contribute to feelings of IB (e.g., punishing individuals for their experience). Each of these factors contributes to explaining individual differences in the experience of IB.
4.2.4 Reliability Statistics. A reliability analysis was run on the entire IB scale, as well as each of the three subscales.

Total scale reliability. The Cronbach’s alpha for the entire scale (42 items) is .99. Therefore, the items as a single scale appear to have strong internal consistency.

Factor 1: cognitive-affective reactions. The Cronbach’s alpha for factor 1 (20 items) is .99. This subscale has similar internal consistency to the total scale. Item-total statistics revealed that if any item is removed from this factor, the internal consistency would decrease or remain the same.

Factor 2: negative healthcare experiences. The Cronbach’s alpha for factor 2 (14 items) is .96. Item-total statistics revealed that if any item is removed from this factor, the internal consistency would decrease, and thus the subscale would be less reliable.

Factor 3: systemic response. The Cronbach’s alpha for factor 3 (8 items) is .96. Item-total statistics revealed that if any item is removed from this factor, the internal consistency would decrease, or remain the same.

4.2.5 Correlations. Table 7 below presents the means and standard deviations of all the variables used in the analyses that follow.
Table 7: Means and standard deviations of all variables of interest

<table>
<thead>
<tr>
<th>Variable</th>
<th>Minimum Score</th>
<th>Maximum Score</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nonadherence</td>
<td>0</td>
<td>5</td>
<td>1.42</td>
<td>1.62</td>
</tr>
<tr>
<td>PTSD symptoms</td>
<td>19</td>
<td>100</td>
<td>40.28</td>
<td>21.21</td>
</tr>
<tr>
<td>Dissociation</td>
<td>28</td>
<td>308</td>
<td>75.47</td>
<td>57.72</td>
</tr>
<tr>
<td>Depression (CESD measure)</td>
<td>20</td>
<td>80</td>
<td>33.91</td>
<td>14.69</td>
</tr>
<tr>
<td>Social support</td>
<td>19</td>
<td>95</td>
<td>65.53</td>
<td>22.06</td>
</tr>
<tr>
<td>High betrayal trauma</td>
<td>0</td>
<td>11</td>
<td>1.65</td>
<td>2.23</td>
</tr>
<tr>
<td>Low betrayal trauma</td>
<td>0</td>
<td>14</td>
<td>2.16</td>
<td>2.79</td>
</tr>
<tr>
<td>Doctor trust</td>
<td>1</td>
<td>5</td>
<td>3.31</td>
<td>.66</td>
</tr>
<tr>
<td>General trust</td>
<td>1.67</td>
<td>5</td>
<td>3.87</td>
<td>.46</td>
</tr>
<tr>
<td>Healthcare relationships</td>
<td>1</td>
<td>5</td>
<td>3.74</td>
<td>1.04</td>
</tr>
<tr>
<td>Patient-physician communication</td>
<td>1</td>
<td>5</td>
<td>3.83</td>
<td>.99</td>
</tr>
<tr>
<td>Adverse experiences</td>
<td>0</td>
<td>10</td>
<td>2.54</td>
<td>2.70</td>
</tr>
<tr>
<td>IB total</td>
<td>41</td>
<td>210</td>
<td>99.32</td>
<td>42.38</td>
</tr>
<tr>
<td>IB cognitive-affective reactions</td>
<td>1</td>
<td>5</td>
<td>2.28</td>
<td>1.24</td>
</tr>
<tr>
<td>IB negative experiences</td>
<td>1</td>
<td>5</td>
<td>2.70</td>
<td>.91</td>
</tr>
<tr>
<td>IB systemic response</td>
<td>1</td>
<td>5</td>
<td>1.99</td>
<td>1.09</td>
</tr>
</tbody>
</table>

**IB factors.** Pearson correlations were conducted to investigate the strength of the relationship between the three factors of the IB scale and the total system scale. Given the difference in the number of items for each factor, the average of each scale was obtained when computing the factor variables. The correlation matrix is presented in table 8 below.
Table 8: Intercorrelations among the total IB and the three subscales

<table>
<thead>
<tr>
<th>Variable</th>
<th>Cognitive-affective reactions</th>
<th>Healthcare experiences</th>
<th>Systemic response</th>
<th>Total system</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive-affective reactions</td>
<td>1</td>
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<td>.865***</td>
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Notes: ***p < .001, **p < .01, *p < .05

IB and demographics. Pearson correlations were conducted to investigate whether a significant relationship exists between overall IB and demographic variables, specifically age, gender, education, income, and race (white versus non-white). Age was significantly correlated with IB ($r = -.31, p < .001$), such that younger individuals reported higher rates of IB. Additionally, race was significantly correlated with IB ($r = -.13, p = .02$), such that people who are of a visible minority (i.e., non-white) were more likely to experience higher levels of IB. Gender ($r = .10, p = .06$) had a tendency to be correlated with IB; specifically, females tended to experience higher levels of IB than men. Education ($r = .05, p = .31$) and income ($r = -.07, p = .22$) were not significantly correlated with IB. People who reported being misdiagnosed were significantly more likely to experience feelings of IB ($r = .35, p < .001$). Similarly, individuals who experienced delay in medical care also were more likely to report feelings of IB ($r = .44$, $p < .001$).
Of these, people who also reported that the delay resulted in worsening of symptoms had significantly higher levels of IB ($r = .17, p = .05$). Individuals who engaged in more behaviours related to non-adherence also reported higher levels of IB ($r = .31, p < .001$). Overall, people who experienced more IB reported significantly poorer self-rated health ($r = .22, p < .001$). The correlation results supported known groups validity.

**IB, trauma, and mental health.** Pearson correlation analyses were conducted to investigate whether a significant relationship exists between overall IB and variables of mental health status. Individuals who reported higher levels of IB also reported significantly higher levels of PTSD ($r = .55, p < .001$), dissociation ($r = .47, p < .001$), anxiety ($r = .44, p < .001$), depression (using CESD $r = .54, p < .001$; using HADS $r = .47, p < .001$). Of note, depression symptoms as measured by the CESD and the HADS measures are strongly correlated ($r = .58, p < .001$). IB was also significantly correlated with both total high betrayal trauma ($r = .34, p < .001$) and total low betrayal trauma ($r = .37, p < .001$). People who reported more feelings of IB also reported significantly more adverse childhood experiences ($r = .30, p < .001$).

**IB and interpersonal variables.** Pearson correlations were conducted to investigate whether a relationship exists between IB and interpersonal variables. Participants who reported higher levels of IB had significantly less social support ($r = -.18, p < .01$). They also reported significantly less general trust than others ($r = .30, p < .001$) and less trust in doctors ($r = -.38, p < .001$). In terms of their interactions with their healthcare providers, people who experienced more IB reported less satisfaction with the quality of their healthcare relationships ($r = -.51, p < .001$) and with the patient-
physician communication and information transfer ($r = -.48, p < .001$). Of note, satisfaction with healthcare relationships is strongly correlated with satisfaction with the patient-physician relationship ($r = .85, p < .001$).

### 4.2.6 Hierarchical multiple regressions.

Hierarchical multiple regression analyses were conducted to investigate whether IB predicts a variety of health outcomes (both mental and physical health variables) after controlling for demographics in the first block (i.e., age, gender, race, income, education), previous traumatic experiences in the second block (i.e., total low betrayal trauma, total high betrayal trauma, total adverse childhood experiences), and interpersonal variables in the third block (i.e., doctor trust, general trust, satisfaction with healthcare relationships, satisfaction with patient-physician communication, social support). None of the main assumptions for conducting multiple regressions were violated. Specifically, multicollinearity was tested using the Variance Inflation Factor in SPSS; results indicated no multicollinearity issues in any of the regression analyses, as the VIF values were less than 5. Tests of skewness and kurtosis revealed adequate normality for most variables of interest (with values less than 1), with the exception of the variables for previous trauma (low and high betrayal) and adverse childhood experiences, which were positively skewed. This pattern of responses is expected given the nature and format of these questionnaires. No transformations were done to this data in order to preserve meaningful interpretability and remain more conservative in the analyses. Linearity and homoscedasticity were tested visually by using scatterplots for bivariate correlations. These assumptions were not violated in the present sample.
**IB and mental health.** Hierarchical multiple regression analyses were conducted to investigate whether IB predicts a variety of mental health outcomes: PTSD, anxiety, depression (as measured both by the HADS and the CESD), and dissociation. The first regression investigated whether or not IB significantly predicted PTSD symptoms (table 9 below). Results revealed a significant model that predicts PTSD, $R = .72$, $F(16, 321) = 21.53$, $p < .001$. PTSD symptoms were predicted by a younger age, a lower income, more high betrayal trauma, more adverse childhood experiences, less general trust, and more negative cognitions regarding IB. Adding IB to the model explained an additional 9% of the variance in PTSD symptoms, such that the total adjusted $R^2$ after adding IB was .49.
Table 9: Hierarchical regression analysis for variables predicting PTSD symptoms

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Notes: ***$p < .001$, **$p < .01$, *$p < .05$, $\beta$ represents the part correlation
The second regression investigated whether or not IB predicted anxiety symptoms after controlling for the other variables of interest. The model predicting anxiety symptoms was significant ($R = .64$, $F(16, 321) = 13.81, p < .001$). Symptoms of anxiety were predicted by a younger age, a tendency to have a lower education ($\beta = -.08$, $p = .07$), less general trust, having poorer healthcare relationships, experiencing better systemic response to healthcare experiences but having more negative cognitions regarding the medical system. Results (table 10) showed that while IB did significantly predict anxiety symptoms, this is not a meaningful finding since the IB variables only explain 3% of the variance, with the adjusted $R^2$ after adding IB being .38.
Table 10: Hierarchical regression analysis for variables predicting anxiety symptoms

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**Notes:** ***p < .001, **p < .01, *p < .05, β represents the part correlation
The third regression investigated whether or not IB predicted depression symptoms (as analyzed by the HADS measure) after controlling for the other variables of interest. The model predicting depressive symptoms was significant, $R = .64$, $F(16, 321) = 13.55, p < .001$. Symptoms of depression as assessed using the HADS measure were predicted by being male, exhibiting less general trust, being of visible minority, having less social support, and experiencing more negative cognitions towards IB. Results (table 11) showed that IB significantly predicted depressive symptoms after controlling for all other factors, but this finding should be interpreted with caution since IB only explained an additional 5% of the variance (adjusted $R^2 = .37$).
Table 11: Hierarchical regression analysis for variables predicting depressive symptoms using the HADS questionnaire

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82
The fourth regression also investigated whether or not IB predicted depressive symptoms (as analyzed by the CESD measure) after controlling for the other variables of interest. The model predicting depressive symptoms was significant ($R = .67$, $F(16, 321) = 16.16, p < .001$). Symptoms of depression as assessed using the CESD measure were predicted by exhibiting less general trust, a tendency to be younger ($\beta = -.08, p = .07$), experiencing more adverse childhood experiences, experiencing more negative cognitions towards the medical system and a tendency towards experiencing better systemic response to negative experiences ($\beta = -.07, p = .09$). Results (table 12) showed that IB significantly predicted depressive symptoms after controlling for all other factors, with IB explaining an additional 13% of the variance (adjusted $R^2 = .42$).
Table 12: Hierarchical regression analysis for variables predicting depressive symptoms using the CESD-R questionnaire

<table>
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<td>.26***</td>
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</table>

Adjusted R²: .07 .22 .29 .42
The fifth regression investigated whether or not IB predicted symptoms of dissociation after controlling for the other variables of interest. The model was significant ($R = .66, F(16, 321) = 15.30, p < .001$). Dissociation was predicted by a younger age, being of a visible minority (i.e., not white), being male, a tendency to experience more high betrayal trauma ($\beta = .08, p = .06$), experiencing higher levels of doctor trust, experiencing lower general trust, perceiving the patient-physician communication positively, experiencing poorer systemic responses to negative experiences and experiencing more negative cognitions regarding the medical system. Results (table 13) showed that IB significantly predicted dissociative symptoms after controlling for all other variables, with IB explaining an additional 12% of the variance (adjusted $R^2 = .40$).

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*notes:***$p < .001$, **$p < .01$, *$p < .05$, $\beta$ represents the part correlation*
Table 13: Hierarchical regression analysis for variables predicting dissociation

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<th>Model 3</th>
<th>Model 4</th>
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</table>

Notes: ***p < .001, **p < .01, *p < .05, β represents the part correlation.
**IB, self-rated health and health behaviours.** Hierarchical multiple regression analyses were also conducted to investigate the effect of IB on self-rated health and health behaviours (i.e., nonadherence). The same blocks were retained as in the above analyses with mental health variables as predictors.

The next regression (see table 14) investigated whether or not IB significantly predicted nonadherence behaviours after controlling for the other variables as described previously. Results revealed a significant model that predicts nonadherence ($R = .50$, $F(16, 321) = 6.64, p < .001$). Nonadherence was predicted by a younger age, a higher level of low betrayal trauma, more adverse childhood experiences, more willingness to trust others (general trust), better patient-physician communication, less social support, and more negative experiences with the medical system. IB significantly predicted nonadherence after controlling for all other factors, but this was not a meaningful finding. Adding IB to the model explained an additional 2% of the variance, for a total adjusted $R^2$ after adding IB of .21.
Table 14: Hierarchical regression analysis for variables predicting nonadherence

<table>
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<th>Model 3</th>
<th>Model 4</th>
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Notes: ***p < .001, **p < .01, *p < .05, β represents the part correlation
The last regression investigated whether or not IB predicted self-rated health after controlling for the other variables of interest. This model was significant \(R = .44, F(16, 321) = 4.67, p < .001\). Poorer self-rated health was predicted by an older age, a lower education, more low betrayal trauma, poorer systemic response to negative healthcare experiences, and more negative cognitions regarding the medical system. Results (table 15 below) revealed that IB significantly predicted self-rated health, but only explained 3% of the variance, with the adjusted \(R^2\) after adding IB being .15. Therefore, this finding may be arbitrary and thus is not meaningful.
Table 15: Hierarchical regression analysis for variables predicting self-rated health

<table>
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</tbody>
</table>

Adjusted $R^2$ | .02 | .07 | .12 | .15

$F$ | 2.34*** | 4.21*** | 4.59*** | 4.67***

Notes: ***$p < .001$, **$p < .01$, *$p < .05$, $\beta$ represents the part correlation
4.3 Quantitative Discussion

The second study was designed to validate the IBQ-MS and capture the impact of IB on patients’ physical and psychological well-being. Results indicated that the IBQ-MS (42 items) is a psychometrically sound self-report questionnaire that reliably measures IB in the medical system. According to the regression analyses, the IBQ-MS also appears to have good convergent and discriminant validity. Results supported three major components of the measure: negative experiences in the medical system, systemic responses to healthcare experiences, and negative cognitive-affective response to the medical system. Supporting the validity of the measure, individuals who experienced more trauma in adulthood and childhood also experienced more feelings of IB in their interactions with medical providers and the system. Additionally, people who have experienced misdiagnoses or a delay in care were more prone to reporting IB. Other factors that predicted higher levels of IB in the medical system were poorer self-reported health, nonadherence with doctor advice, lower social support, less general and doctor trust, and less satisfaction with healthcare relationships and patient-physician communication. IB appeared to be more prevalent amongst individuals who were younger and those who self-identified as being of visible minority. Women also had a tendency to experience more IB in the medical system than men did.

As predicted, IB had a negative impact on patients’ overall well-being; however, the factors of IB affected mental and physical health differently. IB predicted PTSD and depression after controlling for demographics, previous trauma, and interpersonal factors. Specifically, the IB factor that reliably predicted these mental health variables was having more negative cognitive-affective responses towards the medical system. IB
did not reliably predict anxiety. Dissociation, on the other hand, was significantly predicted by both experiencing poorer systemic responses to negative healthcare experiences and by having more negative cognitions towards the medical system. In terms of general health and health behaviours, IB did not reliably predict nonadherence or self-rated health.

The results of the current study indicate that negative interactions with the medical system and thus feelings of IB only strongly and reliably affect patients’ psychological well-being when individuals conceptualize the experience as having been traumatic, distressing, and as having had a negative overall impact on their health and well-being. The negative cognitions about medical interactions are the most reliable factor of IB that predicts poorer mental health functioning. Other researchers have also emphasized the necessity of investigating the subjective appraisal of an objective trauma when discussing betrayal trauma (Kelley et al., 2012). The current study further supports the importance of appraisal by clearly showing the greater impact of the subjective appraisal on an individual’s well-being compared to the objective trauma, which was reflected in two of the three factors of IB: negative healthcare experiences and systemic responses to such experiences.

These results are similar to those conveyed by Smith and Freyd (2013), who found that women who experienced IB after reporting an unwanted sexual experience to their university also experienced significantly more PTSD, dissociation and anxiety symptoms. The current study did not replicate the finding regarding anxiety, which may be in part due to the different sample of participants. In the instance of unwanted sexual assaults, which are more isolated and may require immediate assistance and support
from the institution, anxiety may become a factor when the institution does not respond appropriately as the individual may feel at a higher risk of having this experience in the future. In the chronic medical sample on the other hand, depression appeared to be a more common correlate of IB. This may be due to the nature of chronic conditions, and the potential commonality of negative interactions with the medical system. In this sample, about a quarter reported having been misdiagnosed before receiving a correct diagnosis, and 38.1% reported a delay in care, most of whom indicated that the delay in care resulted in worsening of their symptoms. Therefore, anxiety symptoms may be less of a concern after their interactions with the medical system, and they may instead experience more feelings of helplessness, which relate more to symptoms of depression than anxiety. Other research on betrayal trauma also found that high betrayal trauma victims, in comparison to those who suffer other kinds of trauma, experience more depression and suicidal thoughts and attempts (Edwards et al., 2012).

IB, mental health, and trauma variables are correlated, but not interchangeable. Therefore, experiencing IB, especially the negative cognitions factor, does not automatically mean that an individual will also be experiencing poorer mental health. Additionally, IB does not equate to poorer general trust, doctor trust, or healthcare relationships and patient-physician communication. IB is, therefore, a different concept altogether that appears to incorporate many of these factors. As betrayal trauma theory posits (Freyd, 2008), higher levels of dissociation allow for the maintenance of attachment relationships. In the present study, dissociation was predicted by more doctor trust, less general trust, a positive perception of the patient-physician communication, poorer systemic responses to negative experiences, and more negative cognitions.
regarding IB. Individuals who trusted their doctor more and perceived their interactions (specifically related to information transfer and communication style) positively, but had less general trust overall also tended to experience more mental health issues than others. In line with betrayal trauma theory, those who experience individual or institutional types of betrayal have lower willingness to trust others generally, yet they may dissociate in the face of trauma in order to preserve the relationship with the betraying institution or individual (Gobin & Freyd, 2013). This explains the finding individuals who experience a lot of system commission errors tend to exhibit more symptoms of dissociation. The high levels of doctor trust can be explained by the necessity for an individual to consider the relationship with the betraying individual or institution important enough to be significantly affected by it (Foynes & Freyd, 2013). Thus, when an individual places a lot of trust in the healthcare provider and the medical system and perceives the patient-physician communication positively, he or she may perceive the betrayal as much more intense when unexpected outcomes occur than one who does not trust the system as much. Ultimately, these exacerbated negative cognitions that arise may further drive the connection between IB and PTSD.

An unexpected result of the current research was evidence that women tend to experience more IB symptoms, but men who experience IB in the medical system exhibit higher levels of dissociation. Future research should further investigate these relationships and associated variables. Gender roles may play a role in the interactions men have with the medical system compared to those women have, and the cognitions that may follow negative experiences with the medical system.
Previous researchers found evidence that individuals with experiences of high betrayal trauma also report poorer physical health and functioning (Goldsmith et al., 2012). Additionally, research on institutional abuse in the military implicates betrayal trauma is associated with increased chronic health problems in veterans (Suris & Lind, 2008); however, the results were not replicated in the current study. A potential explanation for this discrepancy is the high socioeconomic status of the sample in the present study. Participants were highly educated and reported high incomes, which may have affected the results. Socioeconomic factors often place individuals at an increased risk of revictimization (Klest, 2012) and ultimately predict poor self-rated general health (Klest et al., 2013). Over half of the participants of the current study (61.7%) rated their overall health as excellent, good, or very good. Socioeconomic status, and more specifically income, appears to be one of the strongest and most stable predictors of self-rated health (Santiago, Wadsworth, & Stump, 2011); as such, the small, potentially trivial, relationship between self-rated health and IB may be much stronger in a different sample, such as one of a lower socioeconomic status.

Generalizability may be a key limitation of the current study. The participants were recruited from across Canada, but the sample had a higher proportion of women, was mainly Caucasian, had a higher proportion of individuals living in Ontario, but none from the territories or rural areas, and participants reported a high socioeconomic status compared to the national average (Statistics Canada, 2011). The results may thus not only fail to be generalizable to the average Canadian, but may also not be generalizable to non-medical patients. A chronic medical population may be significantly different in their interactions with the medical system than an acute medical population. One of the
main differences may be regarding which factors of IB affect the patients’ overall well-being, as acute medical patients may have less negative experiences to draw on when perceiving a particular interaction with the medical system as distressing or traumatic. Lastly, future studies should be conducted to confirm if these factors hold as separate factors in a different population.
CHAPTER FIVE

Conclusion

The present research significantly contributed to the literature through the construction of a measure of IB that is psychometrically sound and has now been validated in a chronic medical population. The qualitative study ensured that patients’ own experiences were used to formulate some of the items of the IBQ-MS, while conducting the current study online allowed for efficient qualitative analysis to be able to validate the measure in a timely manner. The measure of IB appears to have three reliable and stable factors: negative healthcare experiences, systemic responses to such experiences, and negative cognitions regarding the medical system. The quantitative study replicated previous research results that IB can predict mental health status, but the current results did not find that IB reliably predicts self-rated health or health behaviours in the current sample. The main novel finding of this research is that the perception of betrayal (i.e., negative cognitions factor of IB) is the most important factor driving the deleterious effects of IB on patients’ well-being, which provides further concrete support to the concept of betrayal trauma.

Implications of the current research speak to the current state of the Canadian medical system and point to potential avenues for change. Institutional characteristics such as systemic policies and cultures are a part of the precipitation of IB in the medical system, as shown by the qualitative study in this research. These characteristics may help normalize traumatic healthcare experiences (Smith & Freyd, 2014). Future studies should be designed to validate this measure with other populations, such as an acute medical population or a mental health population. Given the effect of gender in several
current analyses, future research should focus on investigating the differences in
cognitions and experiences between men and women. A major limitation in the
construction of the IBQ-MS is that 93% of the participants in the qualitative study were
women; accordingly, the measure may not fully cover the main concerns that may lead
to IB in the medical system for men. Validating the measure with men is vital for
understanding the implications of some of these results.

The measure of IB tailored to the medical system may provide greater knowledge
about the effects of betrayal in the Canadian health care system when used among
patients who suffer from different conditions, are of varying socioeconomic status, and
are of different ethnic backgrounds. In turn, the results of the current study may
influence the effectiveness of the distribution of care and patient satisfaction.
Specifically, individuals experiencing IB may utilize medical care ineffectively, or have
difficulty communicating with health care professionals. A measure to test this concept
may be able to provide the foundation for future studies to further examine this
phenomenon. While being able to identify IB is pivotal, prediction and prevention of IB
will be a vital area for investigation. Future research should identify interventions for
individuals who have experienced IB and examine the prevalence of IB in the Canadian
healthcare system. Further, research should employ longitudinal designs in order to
better understand causal factors of IB (Smith & Freyd, 2014). Interventions that would
best modify the institutional factors and actions that help hide or precipitate negative
healthcare experiences may improve the distribution of care in the Canadian medical
system.
6. References


Four recommendations for getting the most from your analysis. *Practical Assessment, Research & Evaluation, 10*(7), 1-9.


Statistics Canada. 2012. Canada (Code 01) and Canada (Code 01) (table). Census Profile.


7. Appendices

Appendix A: Qualitative Study Research Ethics Board Approval

Research Ethics Board Certificate of Approval

<table>
<thead>
<tr>
<th>Principal Investigator</th>
<th>Department</th>
<th>REB ID</th>
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</thead>
<tbody>
<tr>
<td>Andrea Tamalan</td>
<td>Psychology</td>
<td>2014-102</td>
</tr>
</tbody>
</table>

Supervisor
Dr. Bridget Kiest - Psychology

Funder(s)
Internally Funded – Dr. Kiest Research Start Up Funds

Title
Institutional Betrayal in the Medical System: Development, Reliability, and Validity of a Self-Report Question

Approval of
- Appendix A - Recruitment Poster
- Appendix B - Consent Form
- Appendix C - Demographics Questionnaire
- Health Questionnaire
- Qualitative Questionnaire
- Appendix D - Resource List

Approved on: June 19, 2014
Renewal date: June 19, 2015

Full Board Meeting
- Delegated Review

Certification
The University of Regina Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol, consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

Ongoing Review Requirements
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion.
Please refer to the following website for further instructions: http://www.uregina.ca/research/REB/main.shtml

Dr. Larena Hoeber, Chair
University of Regina
Research Ethics Board

Please send all correspondence to:
Office for Research, Innovation and Partnership
University of Regina
Research and Innovation Centre 109
Regina, SK S4S 0A2
Telephone: (306) 585-4775  Fax: (306) 585-4893  research.ethics@uregina.ca
Appendix B: Qualitative Study Questionnaire

The follow questions will ask you about your experiences in the health care system, with doctors, nurse practitioners, nurses, and about what it has been like seeking and getting help for your physical problems. Answer the questions in as much detail as you feel is necessary.

1. Have you ever had an interaction with the medical system where you felt the medical system or provider let you down, betrayed you, or did not act in your best interests?
   - If yes: How so?
   - If no: Excluded

2. Provide a brief description of this experience.

3. How did you feel about it, or how were you thinking about it in the moment?

4. How do you feel about it or are thinking about it now?

5. What made it feel or seem like a particularly negative experience for you?

9. Do you feel that the doctor/ medical system did not take proactive steps to prevent this negative experience?
   - Why?

10. Do you feel that the medical system creates an environment in which this type of experience seemed common or like no big deal?
    - Why?

11. Do you feel that the medical system creates an environment in which this experience seems more likely to occur?
    - Why?

12. Did you discuss what was bothering you with your doctor or nurse practitioner?

   - If yes: How did the conversation go?

   - If no: Have you wanted to?
     - Why didn’t you bring it up? (Is having enough privacy an issue?)
     - Did you want your doctor to ask about it?
     - Do you feel the medical system made it difficult to report this experience?
13. Did you report the experience to anyone else?

If yes: Who did you tell?

If no: Have you wanted to?

   Why didn’t you bring it up? (Is having enough privacy an issue?)
   Did you want your doctor to ask about it?
   Do you feel the medical system made it difficult to report this experience?

   Why?

14. What do you think could have been done differently in this situation in order for you to feel better about the experience?

Answer the remaining questions about medical providers and medical visits in general.

15. What is the most difficult part of going for a medical visit in general?

16. What is the most difficult part of interacting with doctors in general?

17. Would it be more or less difficult to discuss sensitive or very personal concerns with a nurse in the office, compared to a doctor?

18. Would it matter if the doctor or nurse were a man or woman?

19. What would you find helpful in dealing with doctors or nurse practitioners? In being sure they understood you and were able to help?

20. What would you need from your doctor to feel supported/helped in dealing with your health problems?

21. Is there anything related to your health care system and your interactions to your doctor that you feel is important but has not yet been asked about in this survey?
Appendix C: Qualitative Study Informed Consent

**Project Title:** Institutional betrayal in the medical system: development, reliability, and validity of a self-report questionnaire

**Researcher:** Andreea Tamaian, BSc, University of Regina Department of Psychology, 306-585-4300, tamaiana@uregina.ca, and Bridget Klest, PhD, University of Regina Department of Psychology, 306-585-4214, Bridget.Klest@uregina.ca. The research team includes Andreea Tamaian, Dr. Klest, and some undergraduate students at University of Regina.

**Purpose and Objectives of the Research:**
This is a study of adults living in Canada who have a confirmed chronic medical condition. The primary goals of this research are:

- To understand the experiences and interactions with the Canadian medical system of patients with chronic medical conditions.
- To understand what kinds of things are associated with feelings of institutional betrayal, and patients’ feelings of satisfaction and trust with the medical system.

Information gathered as part of this study will be presented in journal articles and conference presentations.

**What you will be asked to do if you decide to participate:**
- Answer questions about many different aspects of your life, some of which are personal in nature.
- Complete a survey online, which will take about one hour.
  - You will be asked open-ended questions about your experiences in the health care system, with doctors, nurse practitioners, and nurses. You will be specifically asked about what it has been like seeking and receiving services for your chronic medical condition.

**Potential risks to you if you decide to participate:**
Some research participants who are asked about personal experiences and life events will experience a strong emotional response. This may be especially true of people who find they get upset when they think about negative things that have happened in the past, or are ongoing challenges.

- Usually this emotional response goes away quickly. Should you require further assistance, an emergency telephone number in your region can be found at the end of the survey.
- At the end of the survey there will be additional links to online sources of support and referral sources.
- You may want to make sure that a friend, family member, or other support person will be around as you complete the survey, in case you find that it is upsetting.

If you experience any kind of physical discomfort while completing the survey (e.g., muscle soreness, fatigue, headache), you may take a break and return to the survey at a later time. If you wish to complete the survey at a later time, ensure that you click the “save and continue later” button. If you wish to withdraw, click on the “withdraw”
Potential Benefits:
• There are no known benefits directly to you related to participating in this study.
• This research may be helpful in the future to individuals living with chronic medical conditions, as it might help doctors, patients, and others understand patient experiences and potentially understand how to better improve provision of health services.
• It may also contribute to understanding things that contribute to the well-being of individuals living with chronic conditions more generally and how experiences with the medical system may have a direct impact on well-being.

Compensation:
• Each eligible person who participates in the study will receive an online certificate of $20 to the store of their choice from a list of national chains.

Confidentiality:
• This survey is completely confidential. In order to be able to distribute the gift card, your email will be recorded. However, your survey responses will not be linked to your individual email address. Once the gift certificate has been sent, your email address will be deleted.
• All information collected in this survey will be kept confidential – only the researchers will have access to the raw data, and any of your responses presented in journal articles or presentations will be combined with the responses of other participants.
• Security options in FluidSurveys have been set to include data encryption, in order to increase data security and confidentiality.
• When data collection is complete, data will be downloaded from FluidSurveys, and deleted from the FluidSurveys website.
• Data will be stored indefinitely in a password locked file on computers located at the University of Regina, that only the research team members (researchers named above and students under their supervision) have access to.

Right to Withdraw:
• Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.
• Should you wish to withdraw, you may click on the "withdraw from the study and provide feedback" link, which will be on each page of the survey.
• If you click on this link, the survey will end, you will be given the option of whether you would like your responses up to that point to be included in the study, and you will be given the option of providing feedback about why you are choosing to withdraw.
• Eligible participants who complete the survey will be eligible to receive a $20 gift certificate. Participants may choose to skip questions they do not wish to answer and still receive the gift card.
• Your right to withdraw data from the study will apply until you are finished with the study.
survey. Since this survey is anonymous and there will be no identifying information linking you to your survey responses, after you complete the survey it may not be possible to identify and withdraw your responses.

• If you choose to withdraw from the survey, you will not be able to return to it to finish later; there will be a separate option available to save and return later.

Follow up:
• A summary of results from the study will be posted to the website http://uregina.ca/~schtlab/pages/about/aboutComplete.html.

Questions or Concerns:
• You may contact the researchers with any questions, comments, or concerns, using the information at the top this page. This project has been approved on ethical grounds by the U of R Research Ethics Board on June 19, 2014. Any questions regarding your rights as a participant may be addressed to the committee at 306.585.4775 or research.ethics@uregina.ca. Out of town participants may call collect.

Consent: By clicking on “I Agree” below, YOUR FREE AND INFORMED CONSENT IS IMPLIED and indicates that you understand the above conditions of participation in this study. Please print or save a copy of this consent form for your records before proceeding to the survey.
Appendix D: Quantitative Study Research Ethics Board Approval

Research Ethics Board
Certificate of Approval

PRINCIPAL INVESTIGATOR: Andreea Tamalain
DEPARTMENT: Psychology
REB# 2014-189

SUPERVISOR: Dr. Bridget Kiest

FUNDER(S): Saskatchewan Health Research Foundation (SHRF) Establishment Grant – Dr. Kiest

TITLE: Institutional Betrayal in the Medical System: Validation of a Self-Report Questionnaire

APPROVAL OF: Application for Behavioural Ethics Review
• Appendix A – Consent Form
• Appendix B – Demographics
• Appendix C – Questionnaires – Brief Betrayal Trauma Survey; Adverse Childhood Experiences Survey; PTSD Checklist-5; Medical Outcomes Study Social Support Survey; Dissociative Experiences Scale II; General Trust Scale; Trust in the Medical Profession Scale; Patient Continuity of Care Questionnaire – Revised for Chronic Conditions; Hospital Anxiety and Depression Scale; Institutional Betrayal in the Medical System Questionnaire; Centre for Epidemiologic Studies Depression Scale Revised;
• Appendix D – Level of distress assessment
• Appendix E – Resource list
• Appendix F – save e-mails for future contact for studies

APPROVED ON: November 20, 2014
RENEWAL DATE: November 20, 2015

CERTIFICATION
The University of Regina Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol, consent process or documents.

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ONGOING REVIEW REQUIREMENTS
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Dr. Larena Hoeber, Chair
University of Regina – Research Ethics Board

Please send all correspondence to:
Office for Research, Innovation and Partnership
University of Regina
Research and Innovation Centre 109
Regina, SK S4S 0A2
Telephone: (306) 585-4775 Fax: (306) 585-4863 research.ethics@uregina.ca

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Appendix E: Demographics Questionnaire

Are you currently at least 18 years of age?
Yes/No

Are you able to read and accurately respond to questions written in English?
Yes/No

What is your current age? ____

What is your gender?

□ Female  □ Male  □ Other

What is your current relationship status? (please select one)
Single, Never Married
Dating
Long-term Relationship
Married (or equivalent, e.g., Civil Union, Common Law)
Separated
Divorced
Widowed

What is your current living situation? (please select all that apply)
Live alone
Live with spouse/partner
Live with children (ages 0-18)
Live with other family members
Live in assisted living
Live with roommates or friends
Live in a long-term care center
Other: ____________________

What is your total household income?
Less than $10,000
$10,000 to $19,999
$20,000 to $29,999
$30,000 to $39,999
$40,000 to $49,999
$50,000 to $59,999
$60,000 to $69,999
$70,000 to $79,999
$80,000 to $89,999
$90,000 to $99,999
$100,000 to $149,999
$150,000 or more

How many people are supported by this income? _______

Have you experienced a significant decrease in income after your surgery (e.g., due to losing a job)?
Yes/No
If yes, what was your previous household income? ________________

Is the home you currently live in
Owned by you (alone or jointly with someone else)?
Owned by someone else in your household?
Rented?
Occupied without payment of rent?
Other _____________________

What is your highest level of completed education? (please select one)
Less than high school graduate
High school diploma or GED
Some college/post-secondary credit, no degree
Associate or technical degree, or professional program graduate (for example: AA, CNA)
Bachelor's degree
Graduate or professional degree (for example: MA, PhD, MD)
Other, please specify: __________

Which of the following best describes your employment status in the past month?
(please select all that apply)
Employed for pay
full-time/part-time
Out of work and looking for work
Out of work but not currently looking for work
Unable to work
Disabled related to cavernous malformation
Disabled related to another condition
On temporary leave (e.g., medical, parental) with plans to return to work
Homemaker
Student
Retired

Please specify your race.
(please select one. If more than one applies, select the one that you identify most strongly with.)
American Indian, Alaska Native, or Aboriginal
Asian
Black or African American
Hispanic/ Latino
White
Other: ________________

What is your primary nationality (if not Canadian)?
________________________________________
Where were you born?
_________________________

How long have you lived in Canada for?
________________________

Where do you live?
Province ________________
Town/City _____________

What is/are your chronic condition(s)?
_______________

Were you misdiagnosed with a different condition before receiving a correct diagnosis?  
Yes/No

Approximately how many different doctors did you see for this condition before receiving a correct diagnosis (including the doctor who made the correct diagnosis)?
_____________

Approximately how long was it between when you first noticed symptoms related to your condition and when you received a correct diagnosis?  
______years _______ months _______weeks

Have you ever experienced a delay in receiving needed medical care for your condition (due to wrong diagnosis, provider being unavailable, financial or medical system barriers)?  
Yes/No

If yes, did the delay in care result in new or worsening symptoms?  
Yes/No

Approximately how long has it been since you last noticed a significant worsening in any of your symptoms or functional abilities related to your condition?  

Years _____ Months _____

Were you ever given a choice regarding treatment for your chronic condition?  
Yes/No

If yes, How important were each of the following factors in your choice regarding treatment for your chronic condition:
<table>
<thead>
<tr>
<th></th>
<th>Not important</th>
<th>Somewhat important</th>
<th>Very important</th>
<th>Most important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor’s opinion</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Disabling symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Fear of symptoms getting worse or developing new symptoms</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Means to pay for treatment/medication (through insurance or otherwise)</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Availability of social support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**In general, would you say your health is:**
- Excellent
- Very good
- Good
- Fair
- Poor

**Do you have a family doctor?**
- Yes
- No

**Do you have regular contact with a healthcare provider other than a family doctor?**
- Yes
- No

**Approximately how many visits have you made to a healthcare provider in the past month?**
- _____

**In the past twelve months has there been a time when you:**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not take your physician's advice?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not keep a follow-up appointment?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not seek medical care when you felt you needed it?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not fill a prescription that your doctor ordered?</td>
<td></td>
<td></td>
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<tr>
<td>Postponed or delayed seeking care that you felt you needed?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix F: Institutional Betrayal in the Medical System Questionnaire

This questionnaire will ask you to think about your interactions with medical professionals and the medical system. For each of the statements below, rate the extent to which the situation applies to you, from “never” to “almost always”.

Never, rarely, sometimes, often, almost always (0–4)

1. Medical professionals fail to provide appropriate treatment (e.g., did not provide a solution to the problem).
2. The medical system fails to efficiently administer care (e.g., lack of continuity of care, delay in care).
3. Doctors provide inadequate information about risks and procedures of various treatments.
4. Medical providers do not communicate effectively with patients.
5. Medical providers do not listen to patients’ concerns.
6. Medical providers are not open to patients’ input.
7. Medical professionals are not open to alternative treatments (e.g., place emphasis on pharmaceuticals).
8. Medical professionals lack appropriate training for some complex cases.
9. Medical professionals are not held accountable or sanctioned for their actions.
10. The medical system creates barriers to care (e.g., not enough time spent with patients, long wait times, financial issues, shortage of doctors).
11. **Have you had an experience not mentioned above where you felt the medical system or provider let you down, betrayed you, or did not act in your best interests?

If yes, Describe this experience.

Think about the above situations that you have experienced. Rate the extent to which the following statements are true for you (from “never” to “almost always”) related to those experiences.

12. The medical system did not take proactive steps to prevent these experiences.
13. The medical system created an environment in which these types of experiences seemed common.
14. **The medical system created an environment in which these types of experiences seemed to be accepted as appropriate.
15. The medical system created an environment in which these experiences seemed more likely to occur.
16. The medical system made it difficult to report the experiences.
17. **Medical professionals responded inadequately to these experiences, if reported.
18. The system mishandled your report of a problem with a medical professional and/or the medical system, or failed to take disciplinary action.
19. The medical system covered up these experiences.
20. The medical system denied your experiences in some way.
21. The medical system punished you in some way for reporting these experiences (e.g., loss of privileges or status).
22. The system or medical professionals suggested your experiences might affect the reputation of the institution.
23. The medical system created an environment where you no longer felt like you were valued within the system.
24. The medical system created an environment where seeking future medical care was difficult for you.
25. The medical system created an environment that promoted further negative experiences.

Taken together, please rate the extent to which these experiences have impacted you (from “not at all” to “extremely”).

Not at all, slightly, somewhat, moderately, extremely

26. Made me feel betrayed.
27. Made me feel cautious about seeking care.
28. Made me feel reluctant to seek further medical care.
29. Made me feel angry.
30. Made me feel sad.
31. Made me feel hurt.
32. Made me feel disrespected.
33. Made me feel ignored.
34. Made me feel dismissed.
35. Made me feel disappointed.
36. Made me feel helpless.
37. Made me feel desperate.
38. Made me feel humiliated.
39. Made me feel ashamed.
40. Made me feel like the medical providers didn’t really care about me.
41. Made me feel scared/ terrified.
42. Made me feel lonely/ alone.
43. Made me feel guilty.
44. Made me feel disempowered.
45. **Made me feel more trusting of the medical system.**
46. Made me feel less trusting of the medical system.

** the 4 italicized items (11, 14, 17, and 45) were removed after the factor analysis
Appendix G: Brief Betrayal Trauma Survey

For each item below, please mark one response in the columns labeled “Before Age 18” AND one response in the columns labeled “Age 18 or Older”. Have each of the following events happened to you?

<p>|                                                                                  | Before age 18 | Age 18 or after |</p>
<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>You were in a major earthquake, fire, flood, hurricane, or tornado that resulted in significant loss of personal property, serious injury to yourself or a significant other, the death of a significant other, or the fear of your own death.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You were in a major automobile, boat, motorcycle, plane, train, or industrial accident that resulted in similar consequences</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You witnessed someone with whom you were very close (such as a parent, brother or sister, caretaker, or intimate partner) committing suicide, being killed, or being injured by another person so severely as to result in marks, bruises, burns, blood, or broken bones. This might include a close friend in combat.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You witnessed someone with whom you were not so close undergoing a similar kind of traumatic event.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You witnessed someone with whom you were very close deliberately attack another family member so severely as to result in marks, bruises, blood, broken bones, or broken teeth.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You witnessed someone with whom you were not so close deliberately attack a family member that severely.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You were deliberately attacked that severely by someone with whom you were very close.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You were deliberately attacked that severely by someone with whom you were not close.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You were made to have some form of sexual contact, such as touching or penetration, by someone with whom you were very close (such as a parent or lover).</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You were made to have such sexual contact by someone with whom you were not close.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You were emotionally or psychologically mistreated over a significant period of time by someone with whom you were very close (such as a parent or lover)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You were emotionally or psychologically mistreated over a significant period of time by someone with whom you were not close.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You experienced the death of one of your own children.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You experienced a seriously traumatic event not already covered in any of these questions.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix H: Adverse Childhood Experiences Survey

For each item below, please mark whether or not you experienced any of the following while you were growing up during the first 18 years of your life.

<table>
<thead>
<tr>
<th>While you were growing up, during your first 18 years of life:</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did a parent or other adult in the household <strong>often or very often</strong> swear at you, insult you, put you down, or Humiliate you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did a parent or other adult in the household <strong>often or very often</strong> act in a way that made you afraid that you might be physically hurt?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did a parent or other adult in the household <strong>often or very often</strong> push, grab, slap, or throw something at you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did a parent or other adult in the household <strong>often or very often ever</strong> hit you so hard that you had marks or were injured?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did an adult or person at least 5 years older than you <strong>ever</strong> touch or fondle you or have you touch their body in a sexual way?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did an adult or person at least 5 years older than you <strong>ever</strong> attempt or actually have oral, anal, or vaginal intercourse with you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you <strong>often or very often</strong> feel that no one in your family loved you or thought you were important or special?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you <strong>often or very often</strong> feel that your family didn’t look out for each other, feel close to each other, or support each other?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you <strong>often or very often</strong> feel that you didn’t have enough to eat, had to wear dirty clothes, and had no one to protect you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you <strong>often or very often</strong> feel that your parents were too drunk or high to take care of you or take you to the doctor if you needed it?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Answer</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>--------</td>
<td></td>
</tr>
<tr>
<td>Were your parents <strong>ever</strong> separated or divorced?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was your mother or stepmother <strong>often or very often</strong> pushed, grabbed,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>slapped, or had something thrown at her?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was your mother or stepmother <strong>sometimes, often, or very often</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>kicked, bitten, hit with a fist, or hit with something hard?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was your mother or stepmother <strong>ever</strong> repeatedly hit at least a few</td>
<td></td>
<td></td>
</tr>
<tr>
<td>minutes or threatened with a gun or knife?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you live with anyone who was a problem drinker or alcoholic or who</td>
<td></td>
<td></td>
</tr>
<tr>
<td>used street drugs?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was a household member depressed or mentally ill, or did a household</td>
<td></td>
<td></td>
</tr>
<tr>
<td>member attempt suicide?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did a household member go to prison?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix I: PTSD Checklist-5

Instructions: Below is a list of problems that people sometimes have in response to a very stressful experience. Please read each problem carefully and then circle one of the numbers to the right to indicate how much you have been bothered by that problem in the past month. Make sure to base your answers on problems that started or got worse after the event.

The event you experienced was ______________ in ______________.

<table>
<thead>
<tr>
<th>In the past month, how much were you bothered by:</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Repeated, disturbing, and unwanted memories of the stressful experience?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Repeated, disturbing dreams of the stressful experience?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Suddenly feeling or acting as if the stressful experience were actually happening again (as if you were actually back there reliving it)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Feeling very upset when something reminded you of the stressful experience?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Having strong physical reactions when something reminded you of the stressful experience (for example, heart pounding, trouble breathing, sweating)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Avoiding memories, thoughts, or feelings related to the stressful experience?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
7. Avoiding external reminders of the stressful experience *(for example, people, places, conversations, activities, objects, or situations)*?

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
</table>

8. Trouble remembering important parts of the stressful experience *(for some reason besides a head injury or alcohol or drug use)*?

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
</table>

9. Having strong negative beliefs about yourself, other people, or the world *(for example, having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)*?

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
</table>

10. Blaming yourself or someone else *(who didn’t directly cause the event or actually harm you)* for the stressful experience or what happened after it?

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
</table>

11. Having strong negative feelings such as fear, horror, anger, guilt, or shame?

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
</table>

12. Loss of interest in activities that you used to enjoy?

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
</table>

13. Feeling distant or cut off from other people?

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>14. Having trouble experiencing positive feelings <em>(for example, being unable to feel happiness or have loving feelings for people close to you)</em>?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. Feeling irritable or angry or acting aggressively?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. Taking too many risks or doing things that could cause you harm?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. Being “superalert” or watchful or on guard?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. Feeling jumpy or easily startled?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. Having difficulty concentrating?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. Trouble falling or staying asleep?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Appendix J: MOS Social Support Survey

Next are some questions about the support that is available to you.

1. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?

Write in number of close friends and close relative: ______

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

(Circle One Number on Each Line)

<table>
<thead>
<tr>
<th>Question</th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Someone to help you if you were confined to bed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Someone you can count on to listen to you when you need to talk</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Someone to give you good advice about a crisis</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Someone to take you to the doctor if you needed it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Someone who shows you love and affection</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Someone to have a good time with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Someone to give you information to help you understand a situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Someone to confide in or talk to about yourself or your problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Someone who hugs you</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Someone to get together with</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relaxation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>12. Someone to prepare your meals if you were unable to do it yourself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. Someone whose advice you really want</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. Someone to do things with to help you get your mind off things</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. Someone to help with daily chores if you were sick</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. Someone to share your most private worries and fears with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. Someone to turn to for suggestions about how to deal with a personal problem</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. Someone to do something enjoyable with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. Someone who understands your problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. Someone to love and make you feel wanted</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Appendix K: Dissociative Experiences Scale II

This questionnaire consists of 28 questions about experiences that you may have in your daily life. We are interested in how often you have these experiences. It is important, however, that your answers show how often these experiences happen to you when you are not under the influence of alcohol or drugs. To answer the questions, please determine to what degree the experience described in the question applies to you and check the box with the answer that corresponds to the percentage of the time you have the experience. The left of the scale corresponds to 0% of the time, while the right side of the scale corresponds to 100% of the time; the range covers 0% to 100% in 10% increments.

1. Some people have the experience of driving a car and suddenly realizing that they don’t remember what has happened during all or part of the trip.

2. Some people find that sometimes they are listening to someone talk and they suddenly realize that they did not hear part or all of what was just said.

3. Some people have the experience of finding themselves in a place and having no idea how they got there.
4. Some people have the experience of finding themselves dressed in clothes that they don’t remember putting on.

5. Some people have the experience of finding new things among their belongings that they do not remember buying.

6. Some people sometimes find that they are approached by people that they do not know who call them by another name or insist that they have met them before.

7. Some people sometimes have the experience of feeling as though they are standing next to themselves or watching themselves do something and they actually see themselves as if they were looking at another person.

8. Some people are told that they sometimes do not recognize friends or family members.

9. Some people find that they have no memory for some important events in their lives (for example, a wedding or graduation).
10. Some people have the experience of being accused of lying when they do not think that they have lied.

11. Some people have the experience of looking in a mirror and not recognizing themselves.

12. Some people sometimes have the experience of feeling that other people, objects, and the world around them are not real.

13. Some people sometimes have the experience of feeling that their body does not seem to belong to them.

14. Some people have the experience of sometimes remembering a past event so vividly that they feel as if they were reliving that event.

15. Some people have the experience of not being sure whether things that they remember happening really did happen or whether they just dreamed them.
16. Some people have the experience of being in a familiar place but finding it strange and unfamiliar.

17. Some people find that when they are watching television or a movie they become so absorbed in the story that they are unaware of other events happening around them.

18. Some people sometimes find that they become so involved in a fantasy or daydream that it feels as though it were really happening to them.

19. Some people find that they sometimes are able to ignore pain.

20. Some people find that they sometimes sit staring off into space, thinking of nothing, and are not aware of the passage of time.

21. Some people sometimes find that when they are alone they talk out loud to themselves.
22. Some people find that in one situation they may act so differently compared with another situation that they feel almost as if they were two different people.

![Percentage Chart](image)

23. Some people sometimes find that in certain situations they are able to do things with amazing ease and spontaneity that would usually be difficult for them (for example, sports, work, social situations, etc.).

![Percentage Chart](image)

24. Some people sometimes find that they cannot remember whether they have done something or have just thought about doing that thing (for example, not knowing whether they just mailed a letter or have just thought about mailing it).

![Percentage Chart](image)

25. Some people find evidence that they have done things that they do not remember doing.

![Percentage Chart](image)

26. Some people sometimes find writings, drawings or notes among their belongings that they must have done but cannot remember doing.

![Percentage Chart](image)
27. Some people sometimes find that they hear voices inside their heads that tell them to do things or comment on things that they are doing.

28. Some people sometimes feel as if they are looking at the world through a fog so that people and objects appear far away or unclear.
Appendix L: General Trust Scale

Please rate how much you agree with these statements on a scale of 1 (‘don’t agree at all’) to 5 (‘agree absolutely’).

1. If given a chance, most people would try to take advantage of you.
2. Most people are too busy looking out for themselves to be helpful.
3. You can’t trust strangers anymore.
4. When dealing with strangers, one is better off using caution before trusting them.
5. Most people are basically honest.
6. Most people tell a lie when they can benefit doing so.
Appendix M: Trust in the Medical Profession Scale

For each of the statements below, rate the extent of your agreement or disagreement (strongly disagree, disagree, neutral, agree, strongly agree).

1. Doctors in general care about their patients’ health just as much or more as their patients do.
2. Sometimes doctors care more about what is convenient for them than about their patients’ medical needs.
3. Doctors are extremely thorough and careful.
4. You completely trust doctors’ decisions about which medical treatments are best.
5. Doctors are totally honest in telling their patients about all of the different treatment options available for their conditions.
6. Doctors think only about what is best for their patients.
7. Sometimes doctors do not pay full attention to what patients are trying to tell them.
8. Doctors always use their very best skill and effort on behalf of their patients.
9. You have no worries about putting your life in the hands of doctors.
10. A doctor would never mislead you about anything.
11. All in all, you trust doctors completely.
INSTRUCTIONS: These statements are designed to assess the care you have received from medical providers with regard to your chronic condition. Read each statement and circle a number between 1 and 5 to indicate whether you 1 (strongly disagree), 2 (somewhat disagree), 3 (cannot decide whether you agree or disagree), 4 (somewhat agree), or 5 (strongly agree) with the statement. If the item does not apply to your care, please circle Not Applicable.

Please answer the following questions as they pertain to DOCTORS and other MEDICAL PROVIDERS you have seen related to your chronic condition(s):

<table>
<thead>
<tr>
<th>How strongly do you agree or disagree with this statement?</th>
<th>Strongly Disagree</th>
<th>Somewhat Disagree</th>
<th>Cannot Decide</th>
<th>Somewhat Agree</th>
<th>Strongly Agree</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have been provided with clear information on my diagnosis.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>NA</td>
</tr>
<tr>
<td>2. I have been provided with clear information on my prognosis.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>NA</td>
</tr>
<tr>
<td>3. I have been told about non urgent symptoms that may occur and how I should cope with these.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>NA</td>
</tr>
<tr>
<td>4. I have been given information on symptoms that may signal a need to seek urgent medical attention &amp; whom to contact for these symptoms (e.g. specialist, family physician).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>NA</td>
</tr>
<tr>
<td>5. I have been given complete information on my medications, including medication restrictions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>NA</td>
</tr>
<tr>
<td>How strongly do you agree or disagree with this statement?</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Cannot Decide</td>
<td>Somewhat Agree</td>
<td>Strongly Agree</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>----------------------------------------------------------</td>
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</tr>
<tr>
<td>6. I have been provided with information on recommendations and restrictions in activities and exercises.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>NA</td>
</tr>
<tr>
<td>7. I have been informed of ongoing treatment that may be required (e.g., purpose, how, when).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>NA</td>
</tr>
<tr>
<td>8. I have been informed of patient resources/supports and educational material (e.g., peer support, websites) that may be available.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>NA</td>
</tr>
<tr>
<td>9. Providers have understood my expectations, beliefs and preferences.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>NA</td>
</tr>
<tr>
<td>10. I have felt “known” (e.g. current clinical condition and events) by the providers involved in my care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>NA</td>
</tr>
<tr>
<td>11. I have confidence in the providers involved in my care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>NA</td>
</tr>
<tr>
<td>12. I have been satisfied with the information from the providers involved in my care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>NA</td>
</tr>
<tr>
<td>13. I have been satisfied with the emotional support from the providers involved in my care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>NA</td>
</tr>
<tr>
<td>14. I have been satisfied with the opportunity to talk and raise questions with the providers involved in my care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>NA</td>
</tr>
</tbody>
</table>
How strongly do you agree or disagree with this statement? | Strongly Disagree | Somewhat Disagree | Cannot Decide | Somewhat Agree | Strongly Agree | Not Applicable
---|---|---|---|---|---|---
15. The different providers involved in my care have appeared to communicate well with each other. | 1 | 2 | 3 | 4 | 5 | NA

Please answer the remaining questions as they pertain to other sources of information and support (e.g., a website, forum, or support group) you have sought out related to your chronic condition:

16. I have obtained information relevant to my care from sources other than medical providers (e.g., a website). | 1 | 2 | 3 | 4 | 5 | NA
17. I have confidence in these other sources of information. | 1 | 2 | 3 | 4 | 5 | NA
18. I have been satisfied with these other sources of information. | 1 | 2 | 3 | 4 | 5 | NA
19. I have obtained support related to my care from sources other than medical providers (e.g., online support forum). | 1 | 2 | 3 | 4 | 5 | NA
20. I have been satisfied with these other sources of support. | 1 | 2 | 3 | 4 | 5 | NA
Appendix O: Hospital Anxiety and Depression Scale

Rate each of the following statements in terms of the frequency with which you experience each of the given situations. Responses are: “most of the time”, “some of the time”, “from time to time, occasionally”, and “not at all”.

**Anxiety subscale**

1. I feel tense or “wound up”
2. I get a sort of frightened feeling as if something awful is about to happen
3. Worrying thoughts go through my mind
4. I can sit at ease and feel relaxed
5. I get a sort of frightened feeling like “butterflies” in the stomach
6. I feel restless as I have to be on the move
7. I get sudden feelings of panic

**Depression subscale**

8. I still enjoy the things I used to enjoy
9. I can laugh and see the funny side of things
10. I feel cheerful
11. I feel as if I am slowed down
12. I have lost interest in my appearance
13. I look forward with enjoyment to things
14. I can enjoy a good book or radio or TV program
Appendix P: The Center for Epidemiologic Studies Depression Scale Revised

Below is a list of the ways you might have felt or behaved. Please select how often you felt this way in the past week or so.

<p>| Below is a list of the ways you might have felt or behaved. Please check the boxes to select how often you have felt this way in the past week or so. | Last Week |  |
|---|---|---|---|---|
| | Not at all or less than 1 day | 1-2 days | 3-4 days | 5-7 days | Nearly every day for 2 weeks |
| 1. My appetite was poor. | 0 | 1 | 2 | 3 | 4 |
| 2. I could not shake off the blues. | 0 | 1 | 2 | 3 | 4 |
| 3. I had trouble keeping my mind on what I was doing. | 0 | 1 | 2 | 3 | 4 |
| 4. I felt depressed. | 0 | 1 | 2 | 3 | 4 |
| 5. My sleep was restless. | 0 | 1 | 2 | 3 | 4 |
| 6. I felt sad. | 0 | 1 | 2 | 3 | 4 |
| 7. I could not get going. | 0 | 1 | 2 | 3 | 4 |
| 8. Nothing made me happy. | 0 | 1 | 2 | 3 | 4 |
| 9. I felt like a bad person. | 0 | 1 | 2 | 3 | 4 |
| 10. I lost interest in my usual activities. | 0 | 1 | 2 | 3 | 4 |
| 11. I slept much more than usual. | 0 | 1 | 2 | 3 | 4 |
| 12. I felt like I was moving too slowly. | 0 | 1 | 2 | 3 | 4 |
| 13. I felt fidgety. | 0 | 1 | 2 | 3 | 4 |
| 14. I wished I were dead. | 0 | 1 | 2 | 3 | 4 |
| 15. I wanted to hurt myself. | 0 | 1 | 2 | 3 | 4 |
| 16. I was tired all the time. | 0 | 1 | 2 | 3 | 4 |
| 17. I did not like myself. | 0 | 1 | 2 | 3 | 4 |</p>
<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. I lost a lot of weight without trying to.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. I had a lot of trouble getting to sleep.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. I could not focus on the important things.</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>
Appendix Q: Quantitative Study Informed Consent

**Project Title:** Institutional betrayal in the medical system: Validation of a self-report questionnaire

**Researcher:** Andreea Tamaian, BSc, University of Regina Department of Psychology, 306-585-4300, tamaiana@uregina.ca, and Bridget Klest, PhD, University of Regina Department of Psychology, 306-585-4214, Bridget.Klest@uregina.ca. The research team includes Andreea Tamaian, Dr. Klest, and some undergraduate students at University of Regina.

**Purpose and Objectives of the Research:**
This is a study of adults who have a confirmed chronic medical condition. The primary goals of this research are:

- To validate a self-report questionnaire that assesses experiences with healthcare providers and the medical system in Canada.
- To understand how these interactions with healthcare providers and systems affect medical patients’ perceived health, psychological well-being, and overall adjustment.

Information gathered as part of this study will be presented in journal articles and conference presentations, and will be used in a Master’s thesis project.

**What you will be asked to do if you decide to participate:**

- Answer questions about many different aspects of your life, some of which are personal in nature.
- Complete a survey online, which will take about one hour.
  - You will be asked to answer a series of questions about your interactions with medical professionals, trust, satisfaction, demographics, psychological and physical adjustment, and previous stressful life experiences.

**Potential risks to you if you decide to participate:**
Some research participants who are asked about personal experiences and life events will experience a strong emotional response. This may be especially true of people who find they get upset when they think about negative things that have happened in the past, or are ongoing challenges.

- Usually this emotional response goes away quickly.
- At the end of the survey there will be links to online sources of support and referral sources. You may also report your concerns to the research team by calling 306-585-4300 or by emailing schtlab@uregina.ca.
• You may want to make sure that a friend, family member, or other support person will be around as you complete the survey, in case you find that it is upsetting.

If you experience any kind of physical discomfort while completing the survey (e.g., muscle soreness, fatigue, headache), you may take a break and return to the survey at a later time. If you wish to complete the survey at a later time, ensure that you click the “save and continue later” button. If you wish to withdraw, click on the “withdraw” button.

**Potential Benefits:**
• There are no known benefits directly to you related to participating in this study.
• This research may be helpful in the future to individuals living with chronic medical conditions, as it might help doctors, patients, and others understand patient experiences and potentially understand how to better improve provision of health services.
• It may also contribute to understanding things that contribute to the well-being of individuals living with chronic conditions more generally and how experiences with the medical system may have a direct impact on well-being.

**Compensation:**
• Each eligible person who participates in the study will be entered to win an online certificate of $50 to the store of their choice from a list of national chains.

**Confidentiality:**
• This survey is completely confidential. In order to be able to distribute the gift card, your email will be recorded. However, your survey responses will not be linked to your individual email address. Once the gift certificate has been sent, your email address will be deleted.
• All information collected in this survey will be kept confidential – only the researchers will have access to the raw data, and any of your responses presented in journal articles or presentations will be combined with the responses of other participants.
• Security options in Qualtrics have been set to include data encryption, in order to increase data security and confidentiality.
• When data collection is complete, data will be downloaded from Qualtrics, and deleted from the Qualtrics website.
• Data will be stored indefinitely in a password locked file on computers located at the University of Regina that only the research team members (researchers named above and students under their supervision) have access to.

**Right to Withdraw:**
• Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.
• Should you wish to withdraw, you may click on the "withdraw from the study and provide feedback" link, which will be on each page of the survey.
If you click on this link, the survey will end, you will be given the option of whether you would like your responses up to that point to be included in the study, and you will be given the option of providing feedback about why you are choosing to withdraw.

Participants who complete the survey will be eligible to enter the draw for a $50 gift certificate. Participants may choose to skip questions they do not wish to answer and still be entered into the draw receive the gift card.

Your right to withdraw data from the study will apply until you are finished with the survey. Since this survey is anonymous and there will be no identifying information linking you to your survey responses, after you complete the survey it may not be possible to identify and withdraw your responses.

If you choose to withdraw from the survey, you will not be able to return to it to finish later; there will be a separate option available to save and return later.

Follow up:
- A summary of results from the study will be posted to the website http://uregina.ca/~schtlab/pages/about/aboutComplete.html

Questions or Concerns:
- You may contact the researcher with any questions, comments, or concerns, using the information at the top this page. This project has been approved on ethical grounds by the U of R Research Ethics Board on [DATE]. Any questions regarding your rights as a participant may be addressed to the committee at 306.585.4775 or research.ethics@uregina.ca. Out of town participants may call collect.

Consent: By clicking on “I Agree” below, YOUR FREE AND INFORMED CONSENT IS IMPLIED and indicates that you understand the above conditions of participation in this study. Please print or save a copy of this consent form for your records before proceeding to the survey.