## FIRST, DO NO HARM:

## INSTITUTIONAL BETRAYAL IN HEALTHCARE

by

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## A DISSERTATION

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#### DISSERTATION ABSTRACT

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Title: First, do no harm: Institutional betrayal in healthcare

Seeking healthcare is an act of trust: patients reveal private information, pain, and vulnerability to physicians who have specialized knowledge and skills. Patients may endure risk and uncertain treatment outcomes based on the assurance of a trusted physician. Physicians' professional oaths compel them to protect patients' welfare first, and the power imbalance in these relationships is tolerable precisely because of the bond of trust. When this trust is protected, it is a powerful tool: patients are more engaged, benefit more from medical interventions, and are healthier overall. Yet these healthcare relationships are contained within larger institutions – hospitals, insurance companies, government programs – that may circumscribe physicians' abilities to protect patients' trust to the fullest and even contribute to negative medical experiences. Because trust and vulnerability characterize patients' interactions with healthcare institutions, institutional actions and inactions that contribute to negative medical experiences constitute institutional betrayal. In this dissertation I address this largely unexamined issue in health care research by drawing on research and theory in trauma psychology.

I report the results of a study based on the survey responses of 707 American adults. Institutional betrayal in healthcare was reported by two-thirds of the participants and predicted lower trust in participants' own physicians, doctors in general, and

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healthcare organizations. These negative effects were more pronounced for patients who reported higher levels of trust in healthcare institutions prior to the betrayal and did not seem to be influenced by a general tendency to trust others. However, the effects of institutional betrayal on trust in healthcare organizations were buffered by trust in one's own physician. Institutional betrayal also predicted worse physical health and increased symptoms of depression, dissociation, and post-traumatic distress – both directly and through disengagement from healthcare. Consistent with betrayal trauma theory, participants who experienced institutional betrayal and negative medical experiences. This unawareness may allow patients to continue to seek necessary medical care, even in the presence of institutional betrayal. In order to understand what contributes to patient trust and engagement in healthcare and why some patients experience worse mental and physical health outcomes, institutional betrayal must be taken into account.

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- Rosenthal, M. N., & Smith, C. P. (2014). Harnessing hearts and minds: The power of activism in academia. *Center for the Study of Women in Society, 2014 Annual Review,* 8-9.
- Smith, C. P. & Freyd, J. J. (2014). Institutional betrayal. *American Psychologist*, 69, 575-587.

- Smith, C. P., & Freyd, J. J. (2014). The courage to study what we wish did not exist. Journal of Trauma & Dissociation, 15, 521-528. doi: 10.1080/15299732.2014.947910
- Smith, C. P., Gómez, J. M., & Freyd, J. J. (2014). The psychology of judicial betrayal. *Roger Williams Law Review, 19,* 451-475.
- Gómez, J. M., Smith, C. P., & Freyd, J. J. (2014). Zwischenmenschlicher und institutioneller verrat [Interpersonal and institutional betrayal]. In R. Vogt (Ed.), Verleumdung Verrat bei dissoziativen Traumafolgestörungen. Roland, Germany: Asanger Verlag.
- Goldsmith, R. E., Gamache-Martin, C., & Smith, C. P. (2014). Systemic trauma. Special Issue of the Journal of Trauma & Dissociation: Systemic Trauma. 15, 117-132. doi: 10.1080/15299732.2014.871666
- Smith, C. P. & Birrell, P. J. (2014). Holding and being held: Review of *Treating Trauma* with Plain Old Therapy. Journal of Traumatic & Dissociation.
- Smith, C. P. (2013, April 15). Institutional betrayal and sexual violence. [Web Log Post]. SAFERcampus.org
- Smith, C. P. (2013). Review of the book *Revictimization*. *Journal of Trauma & Dissociation*.
- Smith, C. P. & Freyd, J. J. (2013). Dangerous safe havens: Institutional Betrayal exacerbates traumatic aftermath of sexual assault. *Journal of Traumatic Stress*, 26, 119-124. DOI: 10.1002/jts.21778
- Smith, C. P. & Birrell, P. J. (2012). The trauma of institutional betrayal. *Traumatic Stress Points*, *26*(5), 4-5.
- Smith, C. P. (2012). Review of the book Surviving the Shadows: A journey of hope into post-traumatic stress. Journal of Trauma & Dissociation, 13, 494-496. DOI:10.1080/15299732.2012.672393

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To Sam, my right-hand man.

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#### First, do no harm: Institutional betrayal in healthcare

What would eventually become the Patient Protection and Affordable Care Act was first introduced during the 2008 U.S. presidential election and signed into law in the spring of 2010. As the nation discussed the Affordable Care Act – the biggest change to healthcare since the implementation of Medicare and Medicaid in the 1960's – millions of uninsured Americans could imagine living without the uncertainty that had marked their access to care (Quealy & Sanger-Katz, 2014), while others worried for the first time about losing the ability to choose or keep their own doctor (Sundby, 2013). Healthcare systems were tasked with providing adequate and safe care under the potential strain of a sudden influx of patients who might now seek care regularly, rather than wait for an emergency (Goodnough, 2013). Woven through this national discussion of healthcare policy were themes of need, dependency, and trust – all focused on healthcare systems that provide services to improve, and in some cases save, lives. Need for care and dependency on healthcare institutions to meet that need – both sources of vulnerability – could be uncomfortable if the source of that care is untrustworthy (Hall, Dugan, Zheng, & Mishra, 2001). Discussions of trust already marked personal experiences with and research related to healthcare, but the sudden shift in the way the United States attempted to meet the healthcare needs of its citizens brought these issues back to the forefront. What do we know about the ways healthcare institutions gain and keep our trust? What happens when that trust is betrayed?

#### **Purpose and Organization of Dissertation**

This dissertation is meant to add to the national healthcare discussion by clarifying the role of trust in healthcare. In it, I first discuss a broad range of research in

order to understand why trust may be so fundamental to the experiences of individuals in the U.S. healthcare system. Trust has long been a focus of medical researchers, as a metric of patient satisfaction and perceptions of physicians (Peabody, 1927). However, very little research has focused on the types of healthcare experiences that are likely to degrade trust. Similarly, healthcare research has not examined whether some patients' characteristics or past experiences might make them more vulnerable to these types of experiences or their ill effects. Less still is known about the institutional characteristics that predict trust. The question of trust, or broken trust (which sometimes, but not always, is the result of a betrayal), *has* been addressed in research on interpersonal and institutional trauma and this research is brought to bear on this discussion, with an emphasis on institutional betrayal.

This literature review establishes the need for an empirical examination of a broad range of individuals' healthcare experiences in a new way. Specifically, the medical and trauma literatures are synthesized to generate testable hypotheses about the roles of negative medical experiences, institutional betrayal, and individual characteristics and experiences in predicting outcomes related to trust in healthcare systems, physical health, and emotional well-being. Next, I describe the methods and report the results of a study designed to test these hypotheses, including the creation of a novel scale to measure negative medical experiences and the adaptation of an existing scale to measure institutional betrayal in healthcare. Finally, these results are discussed in terms of their contribution to the existing literature as well as potential applications for healthcare institutions and professionals.

#### **Trust and Healthcare**

**Defining trust.** Patients' trust in their individual healthcare provider (e.g., doctor, nurse, etc.) encompasses several distinct but related concepts. Most closely aligned with the definition of trust used in the current study is *fiduciary trust* (derived from *fidelity*), which has been defined as the belief that healthcare providers will act in patients' best interests and not take advantage of their vulnerability (Hall et al., 2001). This is critically different from *confidence*, which involves a calculated prediction of a positive outcome based on measurable characteristics (e.g., specialized training, past success; Heimer, 2001). Fiduciary trust, in contrast, is primarily about the patients' beliefs regarding their physicians' motivation and intention rather than concrete outcomes of treatment (Hall et al., 2001). It is perhaps unsurprising that a central tenet of medical ethics is the principle *beneficence*, which instructs physicians to provide for the welfare of their patients and is aimed at intention rather than outcome. Trust is also readily distinguished from satisfaction, although the two are related (e.g., patients who trusts their doctor are more likely to be satisfied with their care; Hall et al., 2001). The primary difference here is that trust captures a belief about an on-going relationship and optimism about future interactions, whereas satisfaction is limited to describing past interactions (Murray & Holmes, 1997). Although trust, satisfaction, and confidence in a physician may be aligned, they can also be independent: patients may believe their physicians to be competent in general but doubt their physician's personal commitment to their own care (Mechanic, 1996).

Because trust, in its most basic fiduciary form, has a strong emotional component, it is not always easily changed by experiences that might otherwise affect more cognitive

qualities like confidence and satisfaction (Murray & Holmes, 1997). Trust influences perceptions of treatment, such that patients who trust their physicians more describe treatment more positively, regardless of the objective quality of that treatment (Mechanic & Schlesinger, 1996). Patients who distrust their physicians describe their treatment experiences more negatively, also independent of outcomes (Hall et al., 2001). This is consistent with prior research on the role of trust in attribution of positive or negative intent in relationship research (Rempel, Ross, & Holmes, 2001). When patients realize their physician has acted counter to their best interests or taken advantage of them (a betrayal of fiduciary trust), their reaction is likely to have a strong emotional component akin to moral outrage and indignation (Hall et al., 2001). This reaction is stronger than disappointment at an unexpected outcome (Mechanic, 1998). Yet trust plays an insulating role in that it allows for mistakes or errors to be made in the provision of healthcare without disastrous consequences. Patients can tolerate doubt about a physician's competence or infallibility without necessarily having to adjust their beliefs about the physician's motivations and intentions towards them – fiduciary trust can remain intact (Hall et al., 2001; Mechanic, 1998).

The *realization* that trust has been betrayed is not actually a given, even in the presence of evidence that a physician has acted counter to a patient's best interests. Yet this does not explain why these types of experiences are not discussed in healthcare research. Although dissociation and outright forgetting can obscure concrete knowledge of the betrayal if acknowledgment would be too threatening to the relationship (Freyd, 1996), it is not impossible to measure these types of experiences via self-report. Individuals are often able to report behaviors of trusted individuals or institutions that

constitute a betrayal (e.g., being abused by a parent, having a report of sexual harassment covered up at a workplace) without necessarily identifying these actions as betrayals (Freyd & Birrell, 2013; Smith & Freyd, 2014). Additionally, even if the memory for an event had been obscured for a time, individuals are often report both the experience and that they had once (or still do) have some trouble remembering it at a later time (Freyd, DePrince, & Zurbriggen, 2001).

*Attitudes vs. behavior.* Although self-report is the primary way trust in healthcare professionals and systems is measured, it is important to consider the degree to which healthcare-related behavior also reveals trust. This is another way that awareness of betrayal may play out – patients may indicate that they trust their doctor, but delay care or cancel appointments, subconsciously protecting themselves from further exposure to betrayal. Seeking care requires at least a minimal level of vulnerability (e.g., admitting limitations or pain that are beyond one's ability to manage alone) and trusting behaviors (e.g., submitting to physical examination or invasive treatments). In theory, a patient could bear this vulnerability and engage in these behaviors while maintaining an attitude of distrust. Yet this would involve a degree of cognitive dissonance unlikely to be tolerated by most individuals (Hall et al., 2001). Specific behaviors may indicate the possibility for trust to develop or signal a potential lack of trust, but they cannot stand as absolute markers of a patient's trust (Hall et al., 2002).

*Individuals to institutions.* Trust in an individual physician and trust in a larger healthcare institution may be interrelated; patients may generalize their trust in a physician to doctors in general or the healthcare system in which the physician is located (Hall et al., 2001; Mechanic, 1996), or patients may base their trust in a physician on their

trust in the healthcare system or their attitudes about doctors in general (more likely in new treatment relationships; Buchanan, 2000). Patients may vary in how well they distinguish their individual doctor from the system in which they work. Some systems are highly visible and distinct from individual providers (e.g., the Veterans Health Administration), which may make systemic limitations on physicians' behaviors more clear and serve to create a "common foe" against which both doctor and patient must petition for adequate services (Budzi, Lurie, Signh, & Hooker, 2010). In other cases, individual physicians may be very strongly identified with their institution. For example, the reputation of prestigious medical centers like the Mayo Clinic may inform patients' attributions of competence and, by extension, trustworthiness of an individual physician, even if they are unknown to the patient (Mechanic, 1998). Organizations' understanding of this bi-directional influence can be seen in public assurances of their personnel selection process or advertising prestigious awards of their staff (Mechanic, 1996).

With experience, trust in different parts of a healthcare system may be refined and further differentiated; patients may trust their physician but distrust their insurance company or a larger healthcare system that they find unresponsive (e.g., Armstrong et al., 2006). Beginning nearly 20 years ago, Mechanic (1996) argued that public discussions of healthcare reform were creating increasing differentiation between doctors and the healthcare systems in which they worked, particularly as Health Maintenance Organizations (HMOs) became more common and access to care became less certain because some physicians or treatments were not covered by these policies. Although trust in individual providers and healthcare institutions appear to share some common

features (Hall et al., 2001), it is not entirely clear how closely linked they are nor whether they predict similar behavioral or health outcomes.

**Patient characteristics.** Much medical research has focused on patient qualities that may predict trust in physicians and healthcare systems. This research has by and large produced inconsistent and moderated effects. This may be due, at least in part, to searching for an explanation within patients that may well reside in the healthcare systems themselves. Yet this discussion is relevant to understand potential mediators in any new research on trust in healthcare. So, what does and does not predict trust?

*Personality.* Although it would seem intuitive that personality would predict a patient's willingness or even tendency to trust, research has repeatedly found little to no support for this prediction. It appears that the trust a patient has in healthcare providers is a unique quality reserved for a defined relationship. A weak correlation (r = .08, p = .02) was observed between tendency to trust people in general and a measure of trust in one's physician (Thom, Ribisl, Stewart, & Luke; 1999). Measures of cynicism also do not predict trust in physicians (Kao, Green, Davis, Koplan, & Cleary, 1998). More recently, neuroticism was found be associated with a passive medical decision making style, which could be indicative of higher trust in physicians (at least behaviorally), as recommendations by doctors are accepted passively or without discussion (Flynn & Smith, 2007). Another study found that neuroticism did not predict the quality of relationship with a physician when controlling for health problems (Noyes, Kukoyi, Longley, Langbehn, & Stuart, 2011). Yet optimism, in some ways an indicator of low neuroticism, has been found to predict trust in interpersonal relationships more generally

(Murray & Holmes, 1997), which suggests patients' broader attitudes may influence their trust in specific relationships.

*Race.* A study of patients receiving care for HIV/AIDS found that black participants were more likely to hold beliefs about systemic mistreatment of minorities pertaining to AIDS, including believing that the government had created AIDS to kill minorities and that their healthcare providers withheld information from them (Whetten et al., 2006). To some healthcare providers (and researchers), these beliefs may appear naive or even paranoid. Yet, it was not long ago that this exact behavior was not only occurred but was publically justified (e.g., Tuskegee Syphilis Study; Black slaves were sold as subjects in medical experiments; and bodies of Black Americans were exhumed and sold without their or their families' consent; Dula, 1996; Thomas & Quinn, 1991; Corbie-Smith, Thomas, & St. George, 2002). In Whetten et al. (2006), Black participants reported lower levels of trust in their individual doctors and clinics compared to White participants and did not believe that their health was a main priority for their providers. For both Black and White participants, lower trust in healthcare providers was associated with poorer physical and mental health. The mechanism explaining poorer health was only revealed for Black participants: for them, distrust also translated into a lower likelihood of visiting their provider regularly enough to receive sufficient care (i.e., 3 times within the 9 month study period). As striking as these results are, they are not always replicated and several studies have not found a racial difference in trust in either healthcare providers (Hall et al., 2002) or healthcare systems (Armstrong et al., 2006).

*Poverty.* Structural barriers to care (e.g., lack of insurance, transportation, childcare, or ability to take time off work) are most often cited as the link between

poverty and lack of engagement with healthcare (e.g., Mollborn et al., 2005). However, lack of trust in healthcare providers may also play a role. A study of women diagnosed with Post-traumatic Stress Disorder who were living in extreme poverty (i.e., typically homeless) found that these women trusted their doctors less, found medical staff to be more rude, indicated that healthcare providers did not understand their problems, were more concerned that they did not get good medical care, and waited longer before seeing a doctor compared to women who were not homeless (Bassuk, Dawson, Perloff, & Weinreb, 2001). In this case, it was not entirely possible to disentangle childhood abuse history from adulthood poverty as the women who were classified as living in extreme poverty also had more severe abuse histories than their less impoverished counterparts. Other researchers have attempted to understand the interaction between poverty and trauma history in healthcare relationships and have found that distrust in healthcare providers most often manifests in disengagement from these relationships following perceived mistreatment (Green et al., 2012; Rheingold, Acierno, & Resick, 2004). While this is intuitive (i.e., past experience may suggest that leaving a relationship is the best strategy for avoiding further mistreatment), it also creates a real dilemma because many survivors of abuse have complicated health problems that are likely to require medical care (Banyard, 2009). Not all studies that have examined the relationship between socioeconomic status and trust have found a negative relationship. For instance, a study of the experiences of sickle-cell patients found that trust was higher among patients with less education and lower household income (Haywood et al., 2010).

*Health Status.* Health status appears to differentiate between trust in healthcare systems and trust in physicians, in that the relationship between health and trust in

institutions tends to be consistent (and positive) whereas trust in physicians seems to be more complex. In one study, individuals with poorer physical health also reported lower trust in healthcare systems, even controlling for income and access to healthcare, but did not differ in their trust in physicians from healthier participants (Armstrong et al., 2006). This is consistent with a paradox described by Hall et al., (2001): although the vulnerability associated with health problems would seem to predict self-protective wariness of physicians, what actually tends to happen is that sicker patients display *more* trust in their physicians. Hall et al. (2001) theorized that this alleviates some dissonance about the uneven needs and vulnerability in these healthcare relationships, particularly for chronically ill patients (e.g., Thorne & Robinson, 1988). Yet other studies reveal that healthier patients tend to trust their physicians more (perhaps due to successful treatment; Thorne & Robinson, 1988).

**Building trust in healthcare.** Trusting a physician or healthcare system is not a passive process that grows from a belief that caregivers are infallible (Mechanic, 1998), but instead arises at least in part from a predictable set of physician characteristics and behaviors. These qualities arise repeatedly in discussions of trust in physicians (e.g., Anderson & Dedrick, 1990; Bowling et al., 2012; Hall et al., 2001). These are *fidelity* (e.g., expressing caring, respect, advocacy, and avoiding conflicts of interest), *competence* (not technical skill, necessarily, which can be hard for a patient to assess, but rather expressed through behaviors such as gathering medical history with attention to detail, giving patients information they need to feel informed, overall communication skills), *honesty* (e.g., admitting mistakes, avoiding dishonesty either by commission or omission), and *confidentiality* (e.g., protection and proper use of patient information).

These qualities are more readily apparent in individual physicians than institutions, but institutions can embody these trustworthy traits as well. For example, insurance plans that provide a choice in doctors promote fidelity because patients' treatment preferences are respected and they are able to change providers if they are not getting the care they need (Mechanic, 1996). At other times, these institutional characteristics may become suddenly clear when there is a break down in functioning (e.g., a data breach at an insurance company that exposes many patients' personal information). In fact, it appears that one reason patients are more aware of potential conflicts of interest that exist in their healthcare systems is due to increased media exposure of healthcare system failings (Mechanic, 1996; Mechanic, 1998). More informed patients may push healthcare systems to be more responsive, but, taken to an extreme, skepticism may tip to suspicion and undermine the trust necessary to hold healthcare relationships together.

In this context, healthcare marketing has begun emphasizing the trustworthiness of their providers (e.g., comparing a treatment team to a family; e.g., see Figure 1). Advertising healthcare services has only been legal since 1980, when a court ordered the American Medical Association (AMA) to lift the ban on healthcare advertising established in the mid-1800's due to ethical concerns (American Medical Association v. Federal Trade Commission, 1980). Healthcare advertising, although regulated by the Federal Trade Commission like consumer product advertising, is different from advertising for consumer goods in part because consumers (patients) do not always have the expertise necessary to evaluate the quality of the "product" (healthcare) as they do with other services (Mechanic, 1998; Schenker, Arnold, & London, 2014). Instead, they

look to qualities they can evaluate such as a sense of connection to providers or feeling like a valued participant in healthcare decisions (Schenker et al. 2014). One healthcare marketing firm reminds providers that potential patients are interested in whether a doctor provides safe care, has their best interests in mind, and is trusted by their patients (Garland, 2013). Yet, organizational undertakings to improve trust are more often slightly off-target from building fiduciary trust and instead focus on building up perceived expertise and competence (see Figure 2). Organizations might advertise where their doctors received their medical training (*expertise*) or share hospital "report cards" detailing patient satisfaction (*competence*), but fall short on presenting physicians as caring or motivated to promote the welfare of their patients. The harm from these advertising strategies may arise when patients' experiences in these systems do not match the experience advertised, which in turn undermines trust even further (Schenker et al., 2014). As more healthcare marketing begins to focus on promising a safe experience in trustworthy healthcare institutions, it is critical to understand what happens when these promises are not met.

A potentially promising development is the increasing emphasis on patientcentered care, which underscores the importance of building and maintaining trust in healthcare relationships (Rickert, 2012). Many healthcare institutions have implemented programs such as those designed to involve patients in treatment decision-making; provide mediation for dispute resolution about healthcare events and ombudspersons for patient representation; and provide formal support and education for patients and their families – all operating under the belief that these programs were initially developed and

implemented without clear empirical support that they would improve patient trust in physicians or organizations (Mechanic, 1996), research has begun to accrue that indicates they do have positive impacts on trust in healthcare (e.g., Lee & Lin, 2010).

It is in the best interest of healthcare systems that patients trust their physicians because trust predicts outcomes that directly benefit these systems. Trust in physicians is associated with following treatment recommendations (Altice, Mostashari, & Friedland, 2001) and seeking care in a timely manner (Mollborn, Stepanikova, & Cook, 2005) – both of which are associated with reduced healthcare costs (Tidikis & Strasen, 1994) and faster recovery (Bowling et al., 2012). Trust is, in and of itself, powerful; it may mediate clinical outcomes such as placebo effects and explain some of the variance in responses to non-traditional treatments (Branch, 2000; Hall et al., 2001). Establishing trust seems to create a feedback loop where trust begets better care, which increases trust and satisfaction (Mollborn et al., 2005).

Undermining forces in healthcare. Healthcare systems that operate as marketplaces carry the implicit message that patients need to be "savvy consumers" and undertake some risk in choosing among competing plans (Mechanic, 1996). In some ways, the new emphasis on "self-advocacy" or "patient-empowerment" in medicine reveals this shift. Encouraging patients to seek information on their own, speak up when something about their treatment seems amiss, ask questions, or get a second opinion to obtain optimal treatment suggests that not doing so will somehow result in sub-optimal care (Lee & Lin, 2010). This is only the case if one assumes that the physician treating the patient is not inherently inclined to provide the best care possible. More troubling still is that this view suggests that sub-optimal care is somehow at least partially the fault

of the patient, ignoring the incredible imbalance of power and expertise between physician and patient.

Managed care systems (e.g., Medicare) offer the clearest example of the competing needs of doctors and patients as well as doctors and insurance companies. In these systems, a patient's preference for a longer appointment in order to understand a new treatment is in conflict with a doctor's need to meet scheduling demands; similarly, doctors may need to weigh their treatment recommendations against an insurance system that incentivizes reduced healthcare utilization (Mechanic, 1996). These systems may operate entirely un-ironically along with the programs that purport to increase the agency of patients described above (Davies & Rundall, 2000). In fact, the notion of well-informed patients often stops short of them understanding the incentives or even restrictions imposed on their healthcare providers that may limit their treatment options (Buchanan, 2000). Some research suggests that patients' trust in healthcare systems is changing independently of their trust in physicians (Rose, Peters, Shea, & Armstrong, 2004), which implies that patients are able to distinguish institutional barriers to ideal care from physician qualities.

#### **Institutional Betrayal in Healthcare**

The role of adverse events. A study released by the Institute of Medicine (IOM) in 1999 reported that medical errors are responsible for between 44,000 to 98,000 deaths annually. This report defined medical errors as the failure of a planned action to be taken or the use of the wrong plan to achieve an aim. The IOM also listed the most common types of errors as described in Leape et al., (1993), including diagnostic errors (e.g., wrong or delayed diagnosis), treatment errors (e.g., pertaining to operations, treatments,

tests, or medications), preventative errors (e.g., failing to provide prophylactic treatment or monitoring), and other errors (e.g., related to facilities, equipment). The report further notes that 90% of these errors were due to system failures, rather than individual provider error. The IOM reports that, in spite of the huge financial costs associated with these errors, healthcare systems are resistant to change and cite the medical liability system as an impediment to understanding and preventing medical errors. Perhaps unsurprisingly, IOM linked these errors to reduced patient trust in physicians and healthcare systems; patients' mental and physical health declines; and frustration and lost morale for healthcare providers.

Yet the relationship between medical errors and trust is not as direct as one might assume. The first indication of this is that patients' perceptions of when an error has occurred do not always match a physician's. One study found that patients tend to underidentify technical errors (more commonly identified by physicians) but do report errors they attribute to sub-standard care arising from communication difficulties or perceived discrimination (Suurmond, Uiters, Bruijne, de Stronks, & Essink-Bot, 2011). In this study, only the errors attributed to communication problems and discrimination (as opposed to technical errors) were associated with decreased trust and confidence in a physician. Another indication that some types of errors might not directly decrease trust comes from research of patients' willingness to report errors when they occur and how they label those errors. Researchers found that more reports of adverse medical events are elicited with open-ended questions and when those events are referred to as "mistakes" rather than "errors" (King et al., 2010). Together, these results point to the resiliency of trust itself and the positive bias trust may create in reframing errors as

"mistakes" (Hall et al., 2001). However, as more systemic factors arise – such as communication problems and discrimination – patients are increasingly able to recognize medical errors and are willing to report them. These systemic issues were identified in the IOM report as well and may be necessary to understand when negative medical experiences lead to decreased trust.

Another framing of medical errors and trust may clarify their relationship. Mattox (2010) shares several vignettes about medical errors linked to patient characteristics that are known to be risk factors for miscommunication or non-standard care, both of which contribute to medical errors (e.g., limited English proficiency interfering with accurate symptom assessment; infection requiring isolation leading to fewer visits from physicians). Although the author purports to explain risk factors for errors, what follows is as much about maintaining patient trust as it is about preventing medical errors. For example, in a vignette where a patient notes his intravenous medication is being administered at a higher rate than usual, the patient's nurse apologizes for the error, acknowledges the risk this dosage posed, and thanks the patient for calling for help. This follows the recommendations Maddox gives to nurses to acknowledge and evaluate patient's concerns and provide meaningful feedback in order to establish a trusting partnership with patients.

**Recognizing institutional betrayal.** As described above, the impact of adverse medical experiences on trust and health may be buffered by existing trust in a physician or healthcare system. What types of experiences may puncture the protective barrier of this trust? One potential explanation may be the co-occurrence of institutional action or inactions that contribute to these experiences: institutional betrayal in healthcare. For

institutional betrayal to occur, there must first exist trust in or dependency upon an institution (Smith & Freyd, 2014). In the case of healthcare systems, both of these are likely to exist – it is in a state of vulnerability that patients seek healthcare (Hall et al., 2001). Furthermore, although the review of trust in healthcare institutions suggests there are many reasons patients might distrust these institutions, mean levels of trust are actually quite high (LaVeist et al., 2009).

In order to measure institutional betrayal, it is also necessary that the institution itself is clearly identifiable and has a defined purpose that organizes its functioning. This feature allows for individuals to consider interactions they may have with individual representatives of the institution (e.g., a claims processor at an insurance company) as indicative of broader institutional values (e.g., declining to cover an expensive but effective medication due to its price reflects prioritizing profits over patient health). Awareness around how healthcare systems function has been growing over the previous decades. Most recently, public discussion of the Affordable Care Act meant that – even though unrelated to their own personal experiences as patients – Americans began taking note of the behaviors of healthcare systems and how they responded to the new legislation. Well before the Affordable Care Act, however, a series of national news exposés in the 1980's and 1990's detailed faulty oversight of physicians, insurers, and medical boards; cover-ups of malpractice and inconsistent or ineffective disciplinary boards; and conflicts of interest and outright medical fraud (Horowitz, 2013). Motivation for understanding these systems is also clear. When patients seek healthcare, it is increasingly through accessing a healthcare institution (e.g., a medical practice, a
hospital) rather than the more traditional model of seeing an individual physician who is thought of as a primary provider (Buchanan, 2000; LaVeist et al., 2009; Mechanic, 1996).

There are at least two compelling reasons to incorporate institutional betrayal into healthcare research. First, it is a largely unexamined dimension of healthcare relationships, which are typically defined as occurring only between individual patients and physicians, without recognition of institutional influences on those interactions. Examining institutional factors may not only add a new dimension to understanding trust in healthcare but also clarify why some negative medical experiences impact patients' trust in healthcare providers and organizations while others do not – it may be that the initial error is not necessarily harmful but institutional responses to these errors is where the problem lies (e.g., Mattox, 2010). This is particularly important as trust in organizations and individual physicians has been described as interrelated (e.g., Hall et al., 2001; Mechanic, 1996), so even if the primary impact of institutional betrayal in healthcare is on trust in organizations, it may affect trust in physicians. A second reason for incorporating institutional betrayal into healthcare research is that it is theoretically and structurally consistent with the existing framework of how trust operates in healthcare. Specifically, the framework of describing fiduciary trust in physicians and organizations – each aspect of fidelity, competence, honesty, and confidentiality – is represented on the Institutional Betrayal Questionnaire (IBQ; Smith & Freyd, 2013), as detailed below:

*Fidelity.* The main characteristic of fidelity in regards to trust in healthcare is that patients' needs are clearly prioritized and physicians and organizations actively advocate for the best possible care. Should conflicts of interest occur that threaten those needs

(e.g., the financial, professional, or personal needs of the physician or institution), those conflicts are disclosed and, when possible, avoided. Relevant items on the IBQ that assess institutional betrayals of fidelity:

- Suggesting your experience might affect the reputation of the institution (e.g., your experience was contrasted with the "typical" one, you were discouraged from seeking a second opinion or sharing your experiences with others).
- Creating an environment where you no longer felt like a valued member of the institution (e.g., you had to repeatedly remind providers of your identity or treatment history, your primary identity was your medical condition rather than a person, you were discriminated against due to a personal characteristic).
- Creating an environment where continuing to seek care was difficult for you (e.g., your appointments were repeatedly changed or cancelled at short notice, seeking healthcare was financially or personally difficult and not supported by the institution).

*Competence.* Avoiding mistakes when possible and producing the best possible results are the hallmarks of competence that patients may be unable to assess without technical knowledge (Hall et al., 2001; Suurmond et al., 2011). Instead, competence is usually evaluated by a physician's competent "bedside manner" (Cvengros, Christensen, Cunningham, Hillis, & Kaboli, 2009; Hall et al., 2001) and communication (e.g., Haywood et al., 2010). This includes giving patients information they need to understand their treatment and to listen to concerns they bring. Relevant items on the IBQ that assess institutional betrayals of competence:

- Not taking proactive steps to prevent unpleasant healthcare experiences (e.g., by *explaining procedures, side effects, etc.*).
- Creating an environment in which unpleasant healthcare experiences seemed common or normal (*e.g., minimizing your concerns, delivering serious news in a casual way*).
- Creating an environment in which a negative experience seemed more likely to occur (e.g., an apparent lack of communication between providers, lack of clear or consistent policies).
- Making it difficult to report a negative experience or share concerns (e.g., difficulty contacting provider, not being given a chance to ask questions, no clear avenue for sharing dissatisfaction).
- Responding inadequately to your concerns or reports of a negative experience, if shared (e.g., you were given incorrect or inadequate information or advice that was not feasible for you to follow).

*Confidentiality.* The protection and proper use of sensitive and private medical information becomes more of a concern at an institutional level as multiple individuals may encounter information about a patient. As distance grows between a provider or professional and a patient, breaches of confidentiality may include disclosures of information without authorization or casual discussion of private information among medical professional in a public space (Hall et al., 2001). The item on the IBQ that assesses institutional betrayal of confidentiality:

• Mishandling your protected personal information (e.g., unauthorized release of medical history, losing records, not keeping track of complaints or concerns).

*Honesty.* Dishonesty can be displayed through acts of omission (e.g.,

withholding information) or commission (e.g., inaccurately attributing blame to a patient) and can often be identified by its benefit to either the physician or the institution, both of which may benefit from avoiding blame or revealing systemic problems. The intent of dishonesty does not always have to be malicious; for example, physicians may withhold information from anxious patients about some risks of a procedure in order to convince these patients to undergo a treatment they think will be beneficial. Relevant items on the IBQ that assess institutional betrayals of honesty:

- Covering up adverse medical events (e.g., not immediately informing you of a mistake in treatment, withholding information about healthcare coverage, or not disclosing prior records of known risks for a treatment).
- Denying your experience in some way (e.g., your concerns were treated as invalid, your prior history was dismissed as unimportant).
- Punishing you in some way for reporting a negative healthcare experience (e.g., you were labeled as problematic or responsible for a lack of recovery or timely healthcare delivery).

# **Impact of Institutional Betrayal on Physical Health**

Studies linking physical health to trust in physicians often use global measures of health and health-related quality of life such as the Short-Form 36 Health Survey (Ware, Snow, Kolinski, & Gandeck, 1993). Both interpersonal (Klest & Freyd, 2007) and institutional betrayal (Smith, 2014) have been related to poorer physical health measured via symptom inventories such as the Pennebaker Inventory of Limbic Languidness (PILL; Pennebaker, 1982). In order to understand the impact of institutional betrayal in healthcare on health-related outcomes, both direct and indirect effects of institutional betrayal must be examined.

**Direct effect.** Institutional betraval, particularly for the chronically ill or those with frequent exposure to healthcare systems, may represent a form of chronic stress that directly impacts physical health. For example, Haywood et al. (2010) found that patients with sickle-cell disease who found their physician's communication styles dismissive or disrespectful (a potential form of institutional betrayal if patients were to identify systemic problems with communications) reported lower trust in medical professionals as their number of yearly visits increased (i.e., with increased exposure). Over time, being in a state of chronic stress begins to impact immune functioning and increased vulnerability to disease and injury. Hormones associated with inflammation (e.g., cortisol) occur at higher levels and remain in circulation longer when under stressful conditions (Grissom, Iyer, Vining, & Bhatnagar, 2007). These hormones are released in response to direct threat (e.g., being exposed to violence) as well as reminders of those threats (McEwen, 2012). More recently, stress has been understood as an environmental toxin, including environmental stressors such as poverty and dangerous neighborhoods (Sexton & Linder, 2011). This research indicates that the ability to leave an environment negatively predicts how toxic it may be to physical health; dependence on healthcare may make leaving quite difficult, particularly in the middle of a course of treatment. A similar role of dependency is seen in elder care research. Elder abuse in institutions (nearly certainly a form of institutional betrayal given patients' utter dependence upon staff) is associated with increased morbidity and mortality (Dong, 2012). The degree to which older individuals are dependent upon a facility (e.g., availability of other nearby options,

involvement of family members in care) predicts willingness to report abuse experience in these contexts (Ziminski-Pickering & Rempusheski, 2014).

Indirect effect. If it is the case that institutional betrayal following negative healthcare experiences may account for at least some variance typically assigned to trust in physicians and healthcare systems, then some of the outcomes attributed to lower trust in physicians and healthcare may in fact be due to institutional betrayal. Disengagement from healthcare and lack of compliance with medical treatment, delayed care, inappropriate use of emergency rooms, and medication non-compliance have all been associated with lower trust in physicians and decreased health functioning (Altice et al., 2001; Armstrong et al., 2006; Haywood et al., 2010). When institutional betrayal is considered as an explanation of this disengagement, withdraw from healthcare systems begins to make sense – why would patients continue to engage with a system that had betrayed them?

### **Impact of Institutional Betrayal on Mental Health**

Institutional betrayal has been associated with a range of mental health outcomes that are initially due to effects of traumatic experiences but then exacerbated by institutional betrayal (e.g., increased symptoms of PTSD and dissociation following a sexual assault; Smith & Freyd, 2013). Additionally, institutional betrayal may operate as a unique risk factor for mental health problems like depression and suicidal ideation, given the disruption to institution-related social support networks it creates and the potential for withdrawal and isolation (Glass, 2009; Monteith, Bahraini, Matarazzo, Sobery, & Smith, under review). Although it is likely that many mental health problems may be associated with institutional betrayal in healthcare settings, the current study will

begin the investigation into the effects of institutional betrayal on three main types of psychological distress: post-traumatic distress, depression, and dissociation.

Intensive treatment can, in and of itself, be traumatizing, and estimates of PTSD diagnoses following hospitalization for respiratory failure, heart attack, and cancer range from two to near 30 percent (Wade, 2011). In part, these treatments can be frightening (e.g., insertion of a breathing tube is painful, simulates choking, and patients' hands are often restrained to prevent them from touching the tube). However, treatments may interfere with the very means by which patients establish trust in their physician. To follow the example of a breathing tube, a qualitative study by Russell (1999) found that intubated patients reported feeling unable to express their wishes about treatment and felt that nurses did not attempt to communicate with them about their treatment. This lack of communication was associated with anxiety, depression, and withdrawal in these patients. Other research in the area of mental health functioning following difficult experiences in intensive care found that although physical quality of life improved in the months following discharge, mental health often continued to suffer (Dowdy et al., 2005).

The degree to which a physician engages in collaborative care (i.e., an interaction style that is open, communicative, and likely to lead to patient trust) has been shown to predict patient satisfaction (also an indicator of trust), lower depression, and treatment adherence for patients with depression (Deen, Fortney, & Pyne, 2011). What is key about this finding is that prior research had also indicated that depression itself was a predictor of disengagement from treatment and lack of adherence to recommended treatment (in this case, antidepressant medication). Non-supportive healthcare behaviors (e.g., making it difficult to contact providers with worries or questions) predicted PTSD

in a sample of patients who had defibrillators implanted, even after controlling for variables such as patients' worries about being shocked by their defibrillators (Morken et al., 2014).

The mental health impact of betrayal, broadly speaking, and institutional betrayal follow predicted patterns based on the distinct impact of experiencing abuse in a context that was expected to be safe (Freyd, 1997; Freyd & Birrell, 2013; Smith & Freyd, 2013; 2014). Smith and Freyd (2013) found that institutional betrayal exacerbates the psychological impact of sexual violence, predicting increased dissociation, anxiety, and trauma-related symptoms such as nightmares. A recent study of veterans indicated that institutional betrayal, above and beyond military sexual trauma, predicted symptoms of PTSD, depression, and suicide attempts (Monteith et al., under review). As suggested before, the role of past traumatic experiences is hard to disentangle from the physical and mental health of patients who experience institutional betrayal in healthcare, as both trauma and institutional betrayal would seem to predict many of the same outcomes. Wade (2011) noted that all types of past trauma (e.g., war, child abuse) seemed to be a risk factor for developing PTSD following hospitalization, as did current factors such as other life stress and a lack of social support, which is consistent with other trauma research (Brewin, Andrews, & Valentine, 2000).

Although a diagnosis of PTSD may include dissociative symptoms, betrayal in particular is associated with dissociation and difficulty remembering traumatic events (Freyd, 1996; Freyd et al., 2001). Relationship closeness predicts forgetting in interpersonal abuse (Freyd et al., 2001), consistent with Betrayal Trauma Theory, which indicates that forgetting and/or dissociating during abuse high in betrayal operates as a

survival mechanism that allows necessary relationships to be maintained. Institutional betrayal has been shown to similarly predict dissociation (Smith & Freyd, 2013). One study found that continued membership with a betraying institution predicted higher rates of dissociation compared to individuals who leave an institution following betrayal (Smith, 2014). This is consistent with Betrayal Trauma Theory in that dissociation may be necessary for individuals to continue to interact with an institution that has harmed them (Freyd & Birrell, 2013).

## Hypotheses of the Current Study

The goal of the current study is to understand the role of institutional betrayal in healthcare. Given the existing literature, there is a range of hypotheses to test – from basic descriptive (e.g., establishing the rate and form of institutional betrayal in healthcare) to testing multivariate models that clarify the role of institutional betrayal in trust in healthcare professionals and systems. In keeping with the literature reviewed above, the following hypotheses are tested:

- Institutional betrayal will occur in healthcare settings related to, but as a distinct construct from, negative medical experiences (i.e., not all participants who report negative medical experiences will also report institutional betrayal related to those experiences).
- Race and socio-economic status will be predictors of negative medical experiences, institutional betrayal, and trust in healthcare professionals and systems.
- 3. Institutional betrayal will mediate the relationship between negative medical experiences and decreased trust in healthcare systems and professionals, even

controlling for variables such as race, socioeconomic status, and medical history (e.g., hospitalization) found to covary with either predictors or outcomes in these models.

- a. These effects will be distinct from individuals' general tendency towards viewing others as trustworthy.
- 4. Institutional betrayal will predict lower compliance with healthcare advice and both these variables will predict worse mental and physical health.
  - a. Dissociation will be significantly higher for individuals who are still associated with the institution than for those who are no longer associated.
  - Individuals who experience institutional betrayal will report a less consistent memory for negative medical experiences (e.g., they will have experienced at least some difficulty in remembering the events).
- The effects of institutional betrayal will be more harmful for individuals who 1) have higher initial trust in healthcare institutions and 2) have existing histories of interpersonal betrayal.

## Method

# Participants

A total of 759 individuals, recruited through Amazon's Mechanical Turk, participated in the study. Of these, 707 provided valid responses (see validation items section below for screening procedure). The final sample was 73% Caucasian, 10.3% Black or African American, 6.2% Asian American, 2.7% Native American, 6.5% Hispanic or Latino/a, and 1.3% Mixed race. Many of these demographics are within five percentage points of the 2013 U.S. Census figures representing the United States

(exception was Hispanic or Latino/a, which was 17.1% in 2013 Census). The sample was 42.2% male, 56.8% female, and 1% indicated they were genderqueer or gender nonconforming. Nearly 10% of the sample (9.8%) identified as non-heterosexual. The median age fell between 18-35 years; participants reported their age by choosing a tenyear increment beginning at 25-35 years (exceptions were the spans from 18-25 years and 76 and older). Nearly all of participants (99.3%) were below 65 years of age (compared to 75.9% of the population of the United States; U.S. Census, 2013) and many (91.6%) were below 55 years of age. The sample was relatively well-educated, with 47.2% holding a bachelor's degree or higher (compared to a national average of 28.5%; U.S. Census, 2013). In keeping with literature on Amazon's Mechanical Turk, the median individual income of participants (approximately \$1500/month) was lower than the national median of \$2300/month (Paolacci, Chandler, & Ipeirotis, 2010). Healthcare workers represented 7.8% of the total sample. See Tables 1 and 2 for full demographic information.

All participants had exposure to U.S. healthcare systems and a range of healthcare experiences and needs. Most reported choosing healthcare professionals who were covered by insurance (75.5%) or near to their home (52.5%). Almost half (46.5%) reported taking a prescribed medication daily. Nearly all (93.2%) had been hospitalized fewer than 7 times in their life. Most (95.1%) reported visiting the doctor once per month or less. Most participants reported being generally compliant with medical advice or seeking care when they felt they needed it. See Tables 3 and 4 for more healthcare descriptives.

# Materials

**Consent form.** The consent form provided information about the purpose of the study, participation details, researcher information (including contact information), and institutional review board contact information. The purpose of the study was generally described as increasing understanding of healthcare experiences. Participation eligibility was limited to individuals who were at least 18 years old and who had used healthcare in the United States. The consent form also stated that only complete participation would result in compensation of \$5, which included spending sufficient time on each page to ensure instructions and items could be read and answered. Additionally, the use of participants' Mechanical Turk worker ID numbers was explained as only being used for compensation and not to gather additional information about participants nor included as a variable in any publically available dataset. This information was included given recent research indicating the Mechanical Turk worker IDs can be connected to an individual's Amazon shopping history, and, at times, names (Lease et al., 2013). Participants chose a single item that read, "I agree to participate," in order to proceed to the survey. See Appendix A for full form.

**Healthcare use.** This was the first section participants encountered and general instructions oriented them to the nature of the survey (see Appendix B for these instructions and the items for this section). They were instructed to think flexibly about the terms "healthcare" and "doctor" (e.g., the one they have seen most often, most recently, or are able to report upon most accurately). Respondents were asked several different questions about their use of U.S. Healthcare that assessed their exposure to healthcare. Respondents reported how often they need to see a doctor (choosing among

six items ranging from *Less than once per year* to *Daily*), indicated how many statements about healthcare needs described them (e.g., *I take prescribed medication every day, I currently have a serious health condition*), indicated how many times in their life they had been hospitalized (on a four point scale, with response options ranging from *0-3* to *12 or more times*). Respondents indicated whether they had ever accessed healthcare in a country other than the United States and, for those who indicated they had, a follow-up question asked them to compared these experiences, in general, to healthcare in the United States, using a five-point scale that ranged from *Much worse than U.S. Healthcare*.

Respondents were asked to indicate how they chose their current doctor/healthcare system, choosing as many of seven items that applied to them. Responses included, "*My insurance covered it,*" "*They were recommended to me,*" "*I was referred by another healthcare provider,*" and "*They were the only option, I did not choose among others.*" Respondents were also asked how far, on average, they travel to reach their healthcare provider, choosing one of five options ranging from 0-5 miles to 20 *or more miles.* These items are also included in Appendix B.

**Demographics.** Respondents provided information about their personal characteristics, including age range (e.g., *18-25*, *26-35*, to *76 or older*), range of approximate individual monthly income (e.g., *\$0-500*, *\$501-1000*, to >*\$3000*), sexual orientation (options included *Heterosexual*, *Lesbian*, *Gay*, *Bisexual*, and an *Other* option with a text box), and gender (mutually exclusive options included *Man*, *Woman*, *Genderqueer/non-conforming*, and *Transgender*). Respondents were asked to indicate their race by checking as many boxes as applied of a list of six races identified on the

U.S. Census, including *Asian, American Indian or Alaska Native, Black or African American, Native Hawaiian or Pacific Islander, White, Hispanic/Latino/a, Mixed Race,* and an *Other* option with a text box. Finally, respondents indicated the highest level of education they had completed among 13 options (see Appendix C for full list). Although not technically a demographic item, respondents were asked (about halfway through the survey) whether they worked in the healthcare industry or a related industry. This question was followed by the note that this information would not change their eligibility for the survey in any way. Response options were *Yes* and *No*.

**Medical history.** Respondents' reasons for seeking healthcare over their lifetime was assessed by presenting common surgeries (eight items, e.g., Bone or joint replacement, Tissue removal, Cesarean delivery), injuries or emergencies (six items; e.g., Broken bones, Stroke, Heart attack), illness or chronic conditions (26 items, e.g., Cancer, Asthma, Diabetes), and preventative care (three items, Reproductive, Cancer screening, *Vaccination*). Each category also had a text box labeled "*Other*" with the category name (e.g., *Other preventative care*). The directions at the start of this section indicated the four categories they would be asked about and noted that they would have the option to write in other experiences (see Appendix D). This section also allowed the use of the "back" page navigation buttons if participants wished to change their responses. The options in each category were not meant to be exhaustive but represented commonly assessed medical conditions as following a review of physician office screening tools (e.g., the American Medical Association's Family Medical History Form). The purpose of these sections was not necessarily to obtain a health history for respondents but to 1) get a general metric of health problems and exposure to healthcare systems that might

serve as a control in statistical models, and 2) help participants recall a wider range of healthcare experiences beyond recent or particularly memorable ones, essentially by priming their memory with specific medical terms (Conway & Pleydell-Pearce, 2000).

**Healthcare behavior.** Underutilization, disengagement, and non-compliance related to healthcare in the past 12 months were measured using a checklist that included five items used in previous studies. Each of these items has been previously found to be associated with mistrust of healthcare institutions (e.g., *A physician gave me advice that I did not take; I did not seek medical care at all even when I felt I needed it;* LaVeist, Isaac, & Williams, 2009; *I delayed seeking healthcare that I thought I needed;* Mollborn et al., 2005). See Appendix E for full scale.

**Trust of healthcare professionals and systems.** Trust in healthcare was assessed via several different scales. These scales tapped various aspects of trust (e.g., fidelity, competence, honesty, confidentiality, physician dependability, confidence in physician knowledge and skills, reliability of information received from the physician, and global trust; Hall et al., 2002). Multiple measures were included in order to examine the validity of new measures introduced in this study as well as replicate and extend previous findings regarding the role of trust in healthcare. Reliability information and descriptive statistics are available in Table 5.

*Wake Forest Trust in Physician Scale.* This scale contains five items that assess agreement with positively and negatively worded statements about trusting one's own physician (e.g., *I completely trust my doctor's decisions about which medical treatments are best for me*) with response options on a five-point scale ranging from *Strongly disagree* to *Strongly agree*. Responses on this scale are averaged to create a composite

variable representing trust in one's own physician (range = 1 - 5). This scale has demonstrated good internal consistency (alpha > .90) and validity via positive correlations with other measures of trust, physician competence, and compliance with medical advice (Hall et al., 2002). See Appendix F for full scale.

**Primary Care Assessment Survey – Trust Scale.** The trust subscale of the larger Primary Care Assessment Survey contains eight items that assess agreement with positively and negatively worded statements about trusting one's own physician (e.g., *My doctor would always tell me the truth about my health, even if there was bad news*) with response options on a five-point scale ranging from *Strongly disagree* to *Strongly agree*. Responses on this scale are averaged to create a composite variable representing trust in one's own physician (*range* = 1 - 5). This scale has demonstrated good internal consistency (*alpha* > .80) and validity via positive correlations with patient satisfaction and treatment adherence (Safran et al., 1998). See Appendix G for full scale.

*Trust in Physician Scale.* The Trust in Physician Scale was one of the first published scales of trust in healthcare providers (Anderson & Dedrick, 1990). The scale contains nine items that assess agreement with positively and negatively worded statements about trusting one's own physician (e.g., *I trust my doctor's judgments about my medical care*) with response options on a five-point scale ranging from *Strongly disagree* to *Strongly agree*. Responses on this scale are averaged to create a composite variable representing trust in one's own physician (*range* = 1 - 5). This scale has demonstrated good internal consistency (*alpha* > .90) and validity via positive correlations with other measures of trust, continuity of care, adherence to prescribed

medication, and overall satisfaction with care (Anderson & Dedrick, 1990). See Appendix H for full scale.

*Wake Forest Trust in Doctors Scale.* This scale contains five items that assess agreement with positively and negatively worded statements about trusting doctors in general (e.g., *Doctors are extremely thorough and careful*) with response options on a five-point scale ranging from *Strongly disagree* to *Strongly agree*. Responses on this scale are averaged to create a composite variable representing trust in doctors in general (*range* = 1 - 5). This scale has demonstrated good internal consistency (*alpha* > .90) and validity via positive correlations with other measures of trust in healthcare systems and healthcare engagement (Hall, Dugan, Zheng, & Mishra, 2001). See Appendix I for full scale.

*Wake Forest Trust in Medical Researchers Scale.* This scale contains four items that assess agreement with positively and negatively worded statements about trusting medical researchers (e.g., *Doctors who do medical research only care about what is best for each patient*) with response options on a five-point scale ranging from *Strongly disagree* to *Strongly agree*. Responses on this scale are averaged to create a composite variable representing trust in medical researchers (*range* = 1 - 5). This scale has demonstrated good internal consistency (*alpha* > .90) and validity via positive correlations with other measures of trust in individual physicians and willingness to follow medical advice (Hall, Dugan, Zheng, & Mishra, 2001). See Appendix J for full scale.

*Wake Forest Trust in Insurer Scale.* This scale contains five items that assess agreement with positively and negatively worded statements about trusting one's own

insurance company (e.g., *I believe my insurance company will pay for everything it is* supposed to, even really expensive treatments) with response options on a five-point scale ranging from *Strongly disagree* to *Strongly agree*. Responses on this scale are averaged to create a composite variable representing trust in one's own insurance company (*range* = 1 - 5). This scale has demonstrated good internal consistency (*alpha* > .90) and validity via positive correlations with other measures of trust in individual physicians and healthcare systems (Hall, Dugan, Zheng, & Mishra, 2001). See Appendix K for full scale.

*Medical Mistrust Inventory.* This scale contains 17 items that assess agreement with positively and negatively worded statements about mistrust of medical institutions (e.g., *When healthcare organizations make mistakes, they usually cover it up*) with response options on a five-point scale ranging from *Strongly disagree* to *Strongly agree* (LaVeist et al., 2009). Responses on this scale are averaged to create a composite variable representing mistrust medical institutions (*range* = 1 - 5). This scale has demonstrated good internal consistency (test-retest correlation coefficients ranging from 0.35 to 0.70) and validity via positive correlations with underutilization of healthcare (e.g., failure to keep a healthcare appointment, failure to fill a prescription, failure to take medical advice). To facilitate comparison with other scales of trust, the negatively worded items were reverse scored so the composite score reflects the degree to which a respondent trusts medical organizations. See Appendix L for full scale.

Medical Errors, Adverse Consequences, Unexpected or Lasting Pain Assessment (MEACULPA). The 15-item MEACULPA was created for this study in order to assess negative medical experiences that are notable but not necessarily egregious (i.e., most people were expected to have experienced at least one of the items at some point). The items themselves were drawn from examples in the medical literature of commonly experienced adverse medical events (e.g., King, Daniels, Cochrane, Taylor, & Ansermino, 2010). Examples of medical errors included receiving an incorrect diagnosis or being prescribed the wrong dose of a medication; adverse consequences included developing an infection following a procedure or needing to return to the hospital for emergency care; and unexpected or lasting pain included having a procedure that was more painful than expected or having post-surgical complications. The items are presented as a checklist that encompasses a participant's lifetime experiences of healthcare systems. Respondents are also given the option to write in an experience. See Appendix M for full scale.

Institutional Betrayal Questionnaire – Healthcare (IBQ-H). The IBQ-H is a 15-item modified version of the IBQ (Smith & Freyd, 2013) that assess institutional betrayal specifically in healthcare settings. Presented directly following the MEACULPA to respondents who endorsed one or more items, respondents were asked to consider the MEACULPA items they endorsed (which were listed within the instructions via display logic within Qualtrics) and indicate whether a healthcare institution played a role in their experiences. The instructions orient respondents to the range of institutions that would be appropriate to consider, from the U.S. healthcare system as a whole to a staff within a single doctor's office. Additionally, they are instructed to report on any institutional betrayal they have experienced, even if it means reporting about different institutions. The main content of the items (e.g., *Not taking proactive steps to prevent, Responding inadequately to*, etc.) mirrors the original IBQ, but "negative" or

"unpleasant" healthcare (rather than the more general "experience" of the original scale) experiences are referred to throughout and the examples provided for each item are healthcare related (e.g., *Not taking proactive steps to prevent unpleasant healthcare experiences* was followed by the example *by explaining procedures, side effects, etc.*). Following a checklist of 12 such items, respondents are asked to identify the healthcare institution or institutions involved in these experiences by typing into a field, to indicate the degree to which they trusted this institution prior to their experience (on a four-point scale from *Not at all* to *Very much*), and to indicate whether they have continued to seek healthcare from this institution following these experiences (response options are *Yes* or *No*). See Appendix N for full scale.

The original Institutional Betrayal Questionnaire has previously been used to measure individuals' experiences with a variety of institutions following interpersonal violence (e.g., Smith & Freyd, 2013). Previous analyses of the scale have indicated that it is a unidimensional construct, reliable when used as a Likert scale, and not an indicator of severity of traumatic experiences (i.e., individuals who experience more violent sexual assaults do not endorse more items on the IBQ; Smith & Freyd, 2013). The IBQ was developed with Freyd's (1996) Betrayal Trauma Theory in mind; as such, indicators of the validity of the IBQ would be positive correlations between the IBQ (and IBQ-H) and dissociation, anxiety, and post-traumatic stress indices, which had been demonstrated with the IBQ (Smith & Freyd, 2013).

**Memory of events.** Respondents' memory for the events endorsed on the MEACULPA and the IBQ-H was assessed via a single memory persistence item from the Betrayal Trauma Inventory (Freyd, DePrince, & Zurbriggen, 2001), which measures

memory for abusive experiences. Respondents were instructed to consider the events on the MEACULPA and the IBQ-H and indicated whether any of six statements applied to their memory of the events. Items differed in the degree of forgetting experienced from none at all (I have a good memory of the event/s and always have) to complete forgetting (Someone told me that the event/s happened, but I have no memory of them). On this scale, five of the six response options indicate some degree of forgetting. These five items are summed to indicate the degree of total memory impairment experienced, with scores ranging from zero to five. In Freyd et al.'s study, they presented this memory item for each type of abuse individually and assigned a score of zero (no memory impairment) or one (any memory impairment as indicated by endorsing any of the five items describing some forgetting) in order to test their hypothesis that abuse higher in betrayal would be more likely to result in at least some forgetting. Because this item was used in reference to all the items in the MEACULPA and IBQ-H at once and participants could select as many of the responses as they wished, summing the five items seemed the best way to capture the degree to which forgetting was present as it related to institutional betrayal. See Appendix O for full scale.

**Brief Betrayal Trauma Survey.** Respondents' lifetime trauma history was assessed via a slightly modified version the Brief Betrayal Trauma Survey (Goldberg & Freyd, 2006). Respondents were presented with two low betrayal items (i.e., natural disasters, accidents), four medium betrayal items (i.e., physical abuse, emotional abuse, neglect, and sexual abuse by someone with whom the respondent was not close), and four high betrayal items (i.e., physical abuse, emotional abuse, someone with whom the respondents reported whether each

event had happened to them both before and after they were 18 years old. Responses on this scale can be combined to indicate low, medium, and high betrayal at these two age points or summed to indicate lifetime trauma in each category. See Appendix P for full scale.

**Post-Traumatic Stress Disorder Checklist – Civilian (PCL-C).** Respondents' experience of psychological symptoms typically associated with traumatic or stressful events was assessed with the PCL-C (Weathers, Litz, Herman, Huska, & Keane, 1993). The PCL-C asks respondents to rate 17-items describing symptoms of re-experiencing (e.g., *Repeated, disturbing memories, thoughts, or images of a stressful experience from the past*), numbing/avoidance (e.g., *Loss of interest in activites you used to enjoy*), and hyperarousal (e.g., *Being "super-alert" or watchful or on guard*) on a five-point scale ranging from "*not at all*" to "*extremely*" to indicate the degree to which they have been bothered by that particular symptom over the past month. Scores can be summed within these subscales to represent the degree to which each symptom is experienced, or the total scale score can be used to indicate the degree to which trauma-related symptoms are causing distress (*range* = 0 - 68). See Appendix Q for full scale.

Although the PCL-C can be used to support a diagnosis of PTSD (along with history and interview), the current study does not use it as such because other supporting information was not available (e.g., interview information about the experience). When used in a non-clinical civilian sample to assess general trauma-related symptoms, the PCL-C has demonstrated strong reliability (*alpha* > .90, and test-retest correlations >.80; Blanchard, Jones-Alexander, Buckley, & Forneris, 1996). It has also demonstrated validity in non-clinical uses, with strong positive correlations with measures of traumatic

symptom checklists such as the TSC-40 as well as demonstrating discriminant validity with other symptom inventories measuring depression and social anxiety (Coneybeare, Behar, Solomon, Newman, & Borkovec, 2012). Reliability information and descriptive statistics are available in Table 6.

**World Assumptions Questionnaire (WAQ).** Respondents' beliefs related to the degree to which the world is predictable and trustworthiness of others were measured with the World Assumptions Questionnaire (WAQ; Kaler, 2009). The WAQ is a 22-item scale that has four subscales measuring the controllability of events (5 items, e.g., *I don't feel in control of the events that happen to me*), comprehensibility and predictability of people (5 items, e.g., *People often behave in unpredictable ways*), the trustworthiness and goodness of people (6 items, e.g., *Other people are usually trustworthy*), and one's sense of personal safety and vulnerability (6 items, e.g., *Anyone can experience a very bad event*). Respondents rate their agreement with positively and negative worded items on a four-point scale ranging from *Strongly disagree* to *Strongly Agree*. Responses are averaged to indicate overall agreement with these statements (*range* = 0 - 3). See Appendix R for full scale.

The WAQ is a relatively new questionnaire that was designed to address the limitations of previous scales assessing world assumptions, which were found to have questionable validity and temporal stability (Kaler et al., 2008). The WAQ has demonstrated strong reliability (*alpha* > .70; test-retest correlations > .68; Kaler, 2009). The validity of the WAQ has been supported by positive correlations between WAQ scores and proximity to traumatic events such as bombings (Freh, Chung, & Dallos, 2013), the Post-Traumatic Stress Disorder Checklist, and measures of general distress

(Kaler, 2009). The WAQ has been used to measure the impact of traumatic experiences that are expected to have a moral component that may change an individual's beliefs about the world or their "world schema," which includes how controllable, predictable, and safe they perceive the world to be. Scores on the WAQ have been found to predict the impact of traumatic events on trauma symptoms (Freh et al., 2013). Reliability information and descriptive statistics are available in Table 4.

Wessex Dissociation Scale. Respondents' tendency to have dissociative experiences was assessed with the Wessex Dissociation Scale (Kennedy et al., 2004). The Wessex Dissociation Scale is a 40-item scale that assess a broad range of dissociative experiences including cognitive (e.g., *I remember bits of past experiences, but cannot put them together*), affective (e.g., *I just feel numb and empty inside*), behavioral (e.g., *I talk to myself as if I were another person*), and physiological/perceptual (e.g., *I do not seem to feel physical pain as much as other people; I feel touched by something or someone that is not there*). Respondents rate each item on a six-point scale with response options ranging from *Never* to *All the time*. See Appendix S for full scale.

Responses are averaged to represent the degree to which these experiences occur (range = 0 - 5). The Wessex Dissociation Scale has demonstrated strong reliability with both clinical and non-clinical populations (alphas > .90). The Wessex Dissociation Scale has also demonstrated validity, with positive correlations with other measures of dissociation (e.g., the Dissociative Experiences Scale) as well as theoretically related symptom inventories (e.g., for PTSD, somatization, alcohol dependence, and Borderline Personality Disorder; Kennedy et al., 2004). Reliability information and descriptive statistics are available in Table 4.

**Patient Health Questionnaire – Depression (PHQ-9).** Respondents' experience of depression symptoms over the past two weeks was assessed with the PHQ-9, a nineitem self-report measure that assesses DSM-IV criteria for depression (Spitzer et al., 1994). Respondents indicated the degree to which they have been bothered by symptoms (e.g., *Feeling down, depressed, or hopeless*) on a four-point scale ranging from *Not at all* to *Nearly every day.* See Appendix T for full scale.

Scores on the PHQ-9 are summed (*range* = 0 - 27) and can be interpreted as indicating severity of depression (scores of 5, 10, 15, and 20 represent cutpoints for mild, moderate, moderately severe and severe depression, respectively). Although the PHQ-9 was initially developed as one of several subscales that appeared as part of a larger screen for common mental health problems, it has been frequently used as a stand-alone measure of depressive symptoms and found to have good reliability (*test-retest correlation over* 48 hours = .84) and validity, demonstrating positive correlations with sick days, clinic visits, and symptom-related difficulty (Kroenke, Spitzer, & Williams, 2001). Reliability information and descriptive statistics are available in Table 4.

**RAND 36-Item Short-Form Health Survey (SF-36).** The RAND 36-Item Health Survey (Version 1.0; Tsai, Bayless, & Ware, 1997) is a self-report measure that assesses eight health-related concepts: physical functioning (10 items), bodily pain (2 items), role limitations due to physical health problems (4 items), role limitations due to personal or emotional problems (3 items), emotional well-being (5 items), social functioning (2 items), energy/fatigue (4 items), and general health perceptions (5 items). It also includes a single item that provides an indication of perceived change in health over the past year (see Appendix U for full scale, including labels indicating to which

subscale an item corresponds). The SF-36 includes both positively and negatively worded items (i.e., higher scores indicating better or worse health, respectively) but ultimately the subscales are compiled such that higher scores indicate better health. Therefore, scoring requires a two-step process of first assigning a score to each response on a 0 to 100 scale with the response indicating the least optimal health state assigned a score of 0 and the most optimal assigned a 100. For example, the responses to the item, *"In general, would you say your health is"* would be scored as follows: *Excellent* (100), *Very Good* (75), *Good* (50), *Fair* (25), *Poor* (0). After these scores are assigned, items on the same scale are averaged together (*range* = 0 - 100). Scores represent the percentage of total possible score received. Items that are left blank are not taken into account when calculating the scale scores.

The SF-36 was originally designed to be a general measure of health for use across a variety of patient samples (i.e., not with a specific disease or population in mind). To date, the SF-36 has been used in over 4,000 published studies of disease burden, quality of life, and intervention evaluation. The validity of the physical health scales has been supported by their sensitivity to changes in physical functioning following joint replacements (e.g., Kantz et al., 1992; Lansky, Butler, & Waller, 1992), and the validity of the mental health scales by their sensitivity to changes in the severity of depression (e.g., Beusterien et al., 1996, Coulehan, Schulberg, Block, Madonia, & Rodrigues, 1997). Reliability information and descriptive statistics are available in Table 7.

**Pennebaker Illness and Limbic Languidness Scale (PILL).** In order to measure general physical health complaints, respondents completed the PILL

(Pennebaker, 1982). The PILL is a 54-item measure that lists common physical illness symptoms and sensations (e.g., *Coughing, Indigestion, Back pain, Headaches*) and asks respondents to indicate how frequently they have experienced each symptom overt the course of the preceding year on five-point scale ranging from *Have never or almost never experienced the symptom* to *More than once every week*. See Appendix V for full scale. Responses can be averaged (*range* = 0 - 4) to indicate the overall frequency at which respondents are experiencing these symptoms or examined at an item level to identify patterns of symptoms related to different experiences or individual differences. The PILL demonstrates good reliability (*alpha* = .96) and validity, correlating positively with healthcare center visits (Pennebaker, 1982). Reliability information and descriptive statistics are available in Table 7.

**Validation Items.** Throughout the survey, five items checked for attention. They appeared in the medical experiences section ("*Check this box to indicate you are reading each item*" appeared among a list of illness), in the Primary Care Assessment Survey (*My response to this item will be agree if I am reading carefully*"), in the Medical Mistrust Scale ("*I will choose neutral for this item if I am reading each item on this list fully*"), in the SF-36 ("*I will indicate I am not limited on this item*"), and on the PILL ("*Leave this item blank*"). Inclusion of such items has been demonstrated to reduce "noise" of careless or inattentive responding and increase the validity of self-report data (Oppenheimer, Meyvis, & Davidenko, 2009). Removing participants who do not pass these instructional manipulation checks increases power, particularly where small effects are concerned. Correctly responding to four of five of these items was required in order to "pass" the validation check.

# Procedure

**Recruitment.** The study was advertised on the Mechanical Turk as a Human Intelligent Task (HIT) titled "Healthcare Survey" that would take approximately 45 minutes to complete. Potential participants first saw a brief description of the study that read, "Describe your personal experiences accessing healthcare along with information about your health." To learn more about the study, the Mechanical Turk worker had to meet certain requirements that are built into their worker account. These included having registered as living in the United States, having an approval rating of at least 95% for previous HITS, having completed more than 500 HITS, and having not participated in this survey already.

Mechanical Turk workers who met these requirements could preview the HIT and read a more detailed description of the study and what a "successful" completion of the HIT would require. This description was as follows:

We are conducting an academic survey about experiences in healthcare systems and how those experiences may be related to personal history, mental and physical health, and opinions about healthcare systems. This HIT involves describing experiences that may be sensitive and as such we do not collect your worker ID as part of your responses. It also involves several somewhat detailed questionnaires and we ask at several points for you to verify you are paying attention by instructing you to respond a certain way to an item. Your survey is automatically scored as you complete it and the code you are given corresponds to a valid or invalid response style. You many not miss more than 1 of these items and still receive a valid score.

Please consider this HIT only if you have accessed healthcare in the United States and are able to describe those experiences (e.g., experiences from your very early life may be hard to recall and describe accurately). Select the link below to complete the survey. At the end of the survey, you will receive a code to paste into the box below to receive credit for taking our survey. Make sure to leave this window open as you complete the survey. When you are finished, you will return to this page to paste the code into the box.

Compensation and Correspondence. Growing research on Mechanical Turk as a source of social science participants has indicated that participation rates are affected by compensation, participation time (e.g., length of a survey or complexity of a task), and likelihood that their work may be rejected (Buhrmester, Kwang, & Gosling, 2011). Participants were paid a flat rate of \$5 credited to their Mechanical Turk account for completing the survey, regardless of how long it took them in order to reduce the possibility that respondents would endorse more items on the survey instruments in an attempt to stay in the survey longer. In the Mechanical Turk marketplace, \$5 for a 45minute survey is quite generous (typical rates are closer to \$3/hour; Fort, Adda, & Cohen, 2011), which led to rapid recruitment and completion of posted HITs. However, some research indicates that generously compensated tasks are sometimes viewed with suspicion among Mechanical Turk workers as they may be used by unscrupulous Requesters to recruit a large number of workers whose work will be arbitrarily rejected and thus not compensated (Chilton, Horton, Miller, & Azenkot, 2010). Mechanical Turk workers have little recourse in these cases; they are able to email the Requester for

clarification or they can discuss specific requesters on message boards hosted outside of Amazon.com in order to track requesters or HITs that seem to be associated with unfairly rejected work.

For the first 100 HITs posted, respondents received an "invalid" code if they missed any of the five validation items or spent less than 10 minutes in the survey. This initially led to a rejection rate of nearly 12% of work. Although some research indicates this is an expected rate of rejection due to "quality assurance items" like those used to assess attention in the current survey (Oppenheimer et al., 2009), correspondence from Mechanical Turk workers suggested that even respondents who were paying attention to the survey items were getting marked as invalid (including screenshots of correctly answered validation items). Upon examination of the patterns of the invalid responses in these first 100 responses, the most frequent reasons for being marked invalid was not checking the box that appeared within a list of illnesses followed by having a response to a PILL item that requested respondents to leave it blank (about which several Mechanical Turk workers emailed to report they could not "unclick" once they had clicked any of the Likert options). Much fewer (closer to 5%) of respondents missed two or more validation items. Therefore, the formula for generating valid or invalid codes for participation was modified to allow for missing one validation item for the remaining data collection. Additionally, the workers who had previously been rejected for missing one item were retroactively approved and compensated for their work. It is likely that this action, and the perceived "righting of a wrong," had a measurable impact on participation rates as this process was detailed on Mechanical Turk message boards. The current study name for the HIT and researcher's name was included in all posts and the

initial discussion of the unfair rejections turned to accounts of email exchanges where the process was explained and corrected. The ratings of the HIT and the researcher remained very high for the duration of data collection.

# Results

#### **Data Analysis Plan**

Perhaps as a testament to the investment of Mechanical Turk workers, there was very little missing data. Therefore, the data analysis plan will begin with an examination of the reliability and descriptive statistics for measures (reported in Table 5 – Table 11). Second, potential group differences based on demographics are examined (tested via omnibus ANOVAs, post-hoc contrasts, and Chi-square tests of independence) and zeroorder correlations are computed among variables in order to inform more complex models. Because of the many comparisons computed, particularly when examining group differences across variables such as trust (which includes seven different scales) Bonferroni family-wise corrections in alpha are used to lower the critical value required to determine whether group differences may be observed by chance (Simes, 1986). Additionally, groups where less than 10 participants were included were excluded from between group analyses (e.g., six individual identified as multi-racial, thus multi-racial is not one of the categories in the analysis of racial differences in trust in healthcare; similarly seven individuals did not identify as male or female alone, and thus were not included in between-gender analyses). Relevant hypotheses and aims at this step include: 1) racial differences in trust in healthcare institutions and professionals, and 2) evidence of the impact of both negative medical experiences as assessed by the MEACULPA and institutional betrayal as assessed by the IBQ-H via negative correlations between these

measures and mental health, physical health, and trust in healthcare institutions and providers (i.e., providing evidence of the validity of the MEACULPA and IBQ-H). Third, models of multiple linear regression are tested to determine the degree to which negative medical experiences and institutional betrayal uniquely account for outcomes, with a particular focus on the degree to which institutional betrayal explains variance above and beyond negative medical experiences.

Finally, more complex multivariate models are tested that allow for the analysis of multiply mediated and moderated pathways. These path analyses are tested using ordinary least squares regression via PROCESS software, a macro available in SPSS that is designed to test complex models of multiple mediation and moderation, where each direct and indirect pathway is specified and tested (see Hayes, 2013). PROCESS differs from traditional mediational process (e.g., Baron and Kenny's popular four-step process that uses multiple regression) in two important ways. First, it does not depend upon the assumption that any variable (much less the combined effects of two or more variables) is normally distributed in the population. This assumption is necessary in standard regression models, which must generate standard errors from the sample data in order to, for example, conduct a Sobel test of an indirect pathway. PROCESS does not depend upon this assumption and instead uses bootstrapping to estimate standard error, which in effect creates an empirical distribution by repeatedly "sampling" the data with replacement (10,000 times in the current study). This distribution is then used to test inferential hypotheses by computing regression coefficients and 95% confidence intervals that indicate the likelihood that the observed effects differ from zero. The second difference arises from this method: because the sample data are not expected to conform

to normal assumptions, irregularly distributed variables are not as disruptive to inferential tests and thus real indirect effects are more likely to be observed – yielding higher powered tests.

### **Negative Medical Experiences and Institutional Betrayal**

Negative medical experiences were reported by 80.1% of participants (see Table 8 and Table 9) and the average number of MEACULPA items endorsed was 3.35 (*SD* = 2.53). The most common experiences were being prescribed an unnecessary medication (28% of participants), being given an incorrect diagnosis (27%), not being notified of test results (24.6%), having an allergic reaction to medication (24.5%) and under-going an unnecessary procedure or test (22.5%). Each item on the MEACULPA was endorsed by at least 50 respondents, indicating that this construct assessed meaningful and relatively common negative medical experiences.

Institutional betrayal was reported by 66.1% of participants (see Table 10 and Table 11) and the average number of IBQ-H items endorsed was 3.01 (SD = 2.23). The most common types of institutional betrayal reported were failure to take steps to prevent an unpleasant healthcare experience (31.5% of participants), responding inadequately to concerns or reports of a negative experience (24.8%), denying negative medical experiences (24.8%), making it difficult to report a negative healthcare experience or share concerns (21.4%), and creating an environment where negative experiences seemed more likely to occur (21.1%). Reporting institutional betrayal was only an option for individuals who indicated experiencing at least one item on the MEACULPA, so examining the correlation between the MEACULPA and IBQ-H or discussing the independence of these two constructs is not entirely appropriate. However, institutional

betrayal does not appear to be a given following or leading up to negative medical experiences as 17.5% of participants who reported such an experience did not report institutional betrayal.

# **Group differences**

**Race.** The familywise error rate was determined by computing alpha/number of comparisons or 0.05/7 = .007, indicating that a group difference would be considered significant at p < .007. Omnibus tests of between-group differences across all trust scales by race were non-significant with the exception of one scale, that measuring trust in insurance companies (see Table 12). Post-hoc examination of means for trust in insurance companies suggests that this difference was driven by Native American participants, who reported significantly lower trust in insurance companies (M = 2.12, SD = 0.88) compared to other racial groups combined; *contrast* = 2.23, SE = 0.90, t(693) = 2.45, p = .014. These results should be interpreted with some caution as the number of participants represented within each racial category differed a great deal (e.g., 516 in Caucasian compared to 19 in Native American). Examination of group means suggest that Caucasian participants were routinely reporting lower trust than participants who identified as racial minorities.

A similar pattern held when group differences were examined in MEACULPA and IBQ-H scores (see Table 13). The omnibus ANOVA testing group differences in negative medical experiences reported on the MEACULPA was not significant at p <.007, F(4, 693) = 2.73, p = .028. The omnibus ANOVA testing group differences between experiences of institutional betrayal reported on the IBQ-H was not significant, F(4, 693) = 1.58, p = .177. Chi-square tests of independence also indicated that race did

not predict whether an individual would be more likely to experience institutional betrayal,  $X^2(4, N = 698) = 0.99$ , p = .91. Racial identity does not appear to be an appropriate covariate for mediational models predicting trust or with institutional betrayal as a mediator.

Socio-economic status. No correlation was found between monthly individual income (on the seven-point Likert scale corresponding to different income brackets: M = 3.82, SD = 2.03) and negative medical experiences, institutional betrayal, compliance with healthcare advice, or any trust scale (see Table 15). Socio-economic status does not appear to be an appropriate covariate for mediational models predicting trust or with institutional betrayal as a mediator.

**Gender**. No gender differences across trust scales were significant at p < .007. Women reported significantly more negative medical experiences on the MEACULPA (M = 2.92, SD = 2.70) than men (M = 2.28, SD = 2.29), t(695) = 3.25, p = .001. Women's total institutional betrayal scores on the IBQ-H (M = 2.16, SD = 2.43) were marginally higher than men's (M = 1.69, SD = 2.03) but did not meet the adjusted criteria for significance, t(695) = 2.71, p = .008. Chi-square tests of independence also indicated that gender did not predict whether an individual would be more likely to experience institutional betrayal,  $X^2(1, N = 697) = 2.69, p = .10$ . Gender will not be included as a covariate in mediational models as the MEACULPA is not used as either a mediator or outcome, thus the gender differences observed do not need to be accounted for in predicting trust or in models where institutional betrayal is a mediator.

### **Bivariate analyses and validation of MEACULPA and IBQ-H**

Negative Medical Experiences and Institutional Betrayal. The family-wise error rate was determined by computing alpha/number of correlations or 0.05/26 = .001, indicating that a group difference would be considered significant at p < .001. Negative medical experiences reported on the MEACULPA and institutional betrayal reported on the IBQ-H strongly predicted lower trust in healthcare organizations and professionals in all seven areas (see Table 14). MEACULPA and IBQ-H scores significantly predicted mental health problems including dissociation, symptoms of post-traumatic distress, depression, and negative assumptions about the world (see Table 16). Participants who had experienced institutional betrayal (n = 467) reported significantly more dissociation (M = 0.82, SD = 0.61) than participants who had not experienced institutional betrayal (n = 235, M = 0.57, SD = 0.58, t(700) = -5.22, p < .001, d = 0.42. For individuals who had experienced institutional betrayal, rates of dissociation did not differ by continued interaction with the institution following betraval, t(561) = .77, p = .44. Institutional betrayal predicted forgetting negative medical experiences  $(X^2(df = 1, N = 707) = 30.09)$  $p < .001, \varphi = .21$ ). People who experienced institutional betraval were five times as likely to say they had trouble remembering negative medical experiences as those who had not experienced institutional betraval (see Figure 3).

MEACULPA and IBQ-H scores were also significantly correlated with measures of physical health including overall number of physical illness symptoms, measures of health-related functioning (all sub-scales as well as total SF-36 scores), and compliance with healthcare behaviors (see Table 17). Finally, it appears the risk for experiencing both negative medical experiences and institutional betrayal increases with increased
exposure to healthcare systems, as indicated by positive correlations between overall number of medical procedures, illnesses requiring medical attention, surgeries, and preventative care visits (see Table 17). In total, these correlations represent the initial validation of both the MEACULPA and IBQ-H.

**Interpersonal Betrayal.** Many of the participants (n = 326, 46.11%) reported at least one experience of interpersonal betrayal perpetrated by someone with whom they were very close (i.e., high betrayal trauma) over their lifetime and on average reported one to two experiences total (M = 1.11, SD = 1.56); see Table 19. Many participants also reported at least one experience of non-interpersonal trauma (i.e., low betraval trauma; n = 230, 32.53%) and interpersonal trauma perpetrated by someone with whom they were not close (i.e., *medium betrayal trauma;* n = 225, 31.82%). However, very few participants experienced only low (12%) or medium betrayal trauma (6.5%). In fact, most of the participants who had experienced high betrayal trauma also experienced either a low betrayal trauma, medium betrayal trauma, or both. Therefore, it is likely that some of the correlation between each low and medium betrayal trauma and mental and physical health outcomes are actually due to these participants' other traumatic experiences. A total of 18 correlations were computed between lifetime trauma (low, medium, and high betrayal) and dissociation, symptoms of post-traumatic distress, depression, negative assumptions about the world, physical illness symptoms, and overall health. In keeping with the multiple trauma explanation, high betrayal trauma was most strongly correlated with each outcome. Both medium and high betrayal trauma were significantly associated with all outcomes and high betrayal exhibited the strongest correlations with the outcomes (see Table 20). In fact, given these observed

relationships, high betrayal trauma history was included as a covariate in the multiple regression models described below.

# Multiple Regression

Several multiple regression models tested the unique (change in  $R^2$ ) and combined  $(R^2)$  effects of interpersonal trauma history, negative medical experiences, and institutional betrayal, each entered individually in a hierarchical multiple regression. Tables including individual standardized beta, standard error, unstandardized beta, and significance information for each predictor are provided (see Table 21). The hypotheses in this study are more complex than these models can fully test; this was an intermediate step to examine how the main predictors behaved in a model together (i.e., whether each appeared to be predicting unique variance). For example, in all but one model (predicting physical health via the PILL; see Table 22), institutional betrayal significantly improved the model (indicated by significant  $R^2$  change values). In models predicting trust in one's own physician, healthcare organizations, and doctors in general, the amount of variance that a history of betrayal trauma explained was overshadowed by negative medical experiences and institutional betrayal (see Table 23).

#### **Path Analyses**

**Trust.** A moderated mediation analysis indicated that the indirect effect of negative medical experiences through institutional betrayal on trust in one's own physician depended upon the initial level of trust in the institution one had prior to experiencing institutional betrayal (as assessed on the IBQ-H). As can be seen in Figure 4 and Table 24, participants who indicated higher initial trust in their healthcare institution (i.e., one SD above the mean) showed a stronger effect of institutional betrayal

on trust in their physicians ( $b_1 = -.09$ ) than individuals who reported lower trust in healthcare systems (i.e., one SD below the mean;  $b_1 = -.04$ ). This effect was observed even after controlling for hospitalization history, which was positively associated with trust in one's own physician. This mediation only partially explained the relationship between negative medical experiences and trust in one's own physician, as a non-zero direct pathway between these two variables remained even with institutional betrayal and initial levels of trust in the model (c' = -.06, p < .001). The same pattern of results held for predicting trust in doctors in general (see Figure 5 and Table 25) and trust in healthcare organizations (see Figure 6 and Table 26).

A moderated mediation analysis indicated that the indirect effect of negative medical experiences through institutional betrayal on trust in healthcare organizations depended upon trust in one's own physician. As can be seen in in Figure 7 and Table 27, participants who reported more trust in their own physician (i.e., one SD above the mean) were more negatively impacted by negative medical experiences ( $c_1 = -.06$ ) than individuals who reported less trust in their own physician (i.e., one SD above the mean;  $c_1 = -.02$ ). However, the effect of institutional betrayal on trust in healthcare organizations did not depend upon trust in one's own physician ( $a_{21} = .01$ ) and biascorrected bootstrap confidence intervals based on 10,000 bootstrap samples were all entirely below zero for the indirect effect of negative healthcare experiences through institutional betrayal ( $a_1b_1 = -.03$ ). There was no evidence that negative medical experiences predicted trust in healthcare organizations independent of their effects on institutional betrayal and their interaction with trust in one's own physician ( $c_1 = .02$ , p = .34).

A moderated mediation analysis indicated that the neither the direct effect of negative medical experiences on trust in physicians nor the indirect effect through institutional betrayal was mediated by a general tendency to trust (measured via the World Assumptions Questionnaire). This model also controlled for hospitalization history and high betrayal trauma history (see Figure 8 and Table 28). Bias-corrected bootstrap confidence intervals based on 10,000 bootstrap samples all contained zero for the interaction between negative healthcare experiences and negative world assumptions predicting institutional betrayal ( $a_3 = .02$ ) and trust in physician ( $c_3$ ' = -.05), and for the interaction between institutional betrayal and negative world assumptions predicting trust in physicians ( $b_2 = .03$ ).

**Physical Health.** A multiple mediation analysis indicated that negative medical experiences indirectly affect health through institutional betrayal and non-compliance with healthcare advice, controlling for hospitalization history and high betrayal trauma history. As can be seen in Figure 9 and Table 29, participants who had negative healthcare experiences were more likely to report non-compliance with healthcare advice  $(a_2 = .17)$ . Both institutional betrayal  $(b_1 = -1.91)$  and non-compliance with healthcare advice  $(b_2 = -2.09)$  uniquely predicted decreased health on the SF-36. Bias-corrected bootstrap confidence intervals based on 10,000 bootstrap samples were all entirely below zero for the indirect effect of negative healthcare experiences through institutional betrayal  $(a_1b_1 = -1.24)$ , through non-compliance with healthcare advice  $(a_2b_2 = -.35)$ , and through both institutional betrayal and non-compliance with healthcare advice  $(a_1d_{21}a_2 = -.12)$ . There was no evidence that negative medical experiences predicted health

independent of their effects on institutional betrayal and non-compliance with healthcare advice (c'=-.23, p=.45).

**Mental Health.** A multiple mediation analysis indicated that negative medical experiences indirectly affect depression, dissociation, and symptoms of post-traumatic stress disorder through institutional betrayal and non-compliance with healthcare advice, controlling for hospitalization history and high betrayal trauma history. As can be seen in Figures 10 to 12 and Tables 30 to 32, participants who had negative healthcare experiences were more likely to report non-compliance with healthcare advice ( $a_2$  paths). Both institutional betraval ( $b_1$  paths) and non-compliance with healthcare advice ( $b_2$ paths) uniquely predicted increased symptoms of depression, dissociation, and posttraumatic stress disorder. Bias-corrected bootstrap confidence intervals based on 10,000 bootstrap samples were all entirely below zero for the indirect effect of negative healthcare experiences through institutional betrayal  $(a_1b_1 \text{ paths})$ , through noncompliance with healthcare advice ( $a_2b_2$  paths), and through both institutional betraval and non-compliance with healthcare advice  $(a_1d_{21}a_2 \text{ paths})$ . There was no evidence that negative medical experiences predicted health independent of their effects on institutional betrayal and non-compliance with healthcare advice (c' paths). In each model, high betrayal trauma history was significantly associated with both institutional betrayal and each mental health outcome, but was not associated with non-compliance.

**Trauma history.** A multiple mediation analysis indicated that high betrayal trauma history indirectly affects institutional betrayal through symptoms of physical illness, doctor visits, and negative medical experiences. As can be seen in Figure 13 and Table 33, participants who experienced high betrayal trauma were more likely to report

physical illness symptoms ( $a_1 = .15$ ), more visits to the doctor ( $a_2 = .05$ ), and more negative medical experiences ( $a_3 = .40$ ). Physical illness symptoms predicted visits to the doctor ( $d_{21} = .18$ ), and visits to the doctor predicted negative medical experiences ( $d_{32}$ = .69). Bias-corrected bootstrap confidence intervals based on 10,000 bootstrap samples were all entirely below zero for the indirect effect of high betrayal trauma history on institutional betrayal through negative medical experiences alone ( $a_1a_3 = .25$ ), through both physical illness symptoms and negative medical experiences ( $a_1d_{31}b_3 = .09$ ), through both visits to the doctor and negative medical experiences ( $a_2d_{32}b_3 = .02$ ), and through physical illness symptoms, visits to the doctor, and negative medical experiences ( $a_1d_{21}d_{32}b_3 = .01$ ). There was still evidence that high betrayal trauma history directly predicts institutional betrayal independent of its effect on physical illness symptoms, visits to the doctor, and negative medical experiences (c' = .11, p = .006).

#### Discussion

This study found robust evidence that institutional betrayal plays an important role in healthcare. Broadly speaking, institutional betrayal appears to be a relatively common experience that is distinct from negative healthcare experiences such as treatment errors. It has a strong effect on patients' trust in individual healthcare providers as well as organizations. Finally, institutional betrayal uniquely predicts physical health functioning, both directly and through disengagement from healthcare. Similarly, institutional betrayal predicts depression, dissociation, and post-traumatic distress, both directly and through disengagement from healthcare are exciting and meaningful findings but not all initial hypotheses were fully supported and further explanation is necessary.

### **Revisiting Hypotheses**

Hypothesis one: I hypothesized institutional betraval would occur in healthcare settings related to, but as a distinct construct from negative medical experiences (i.e., not all participants who report negative medical experiences will also report institutional betrayal related to those experiences). This hypothesis was intended to fill a gap in the literature on trust in healthcare by addressing the possibility that trust may actually be *lost* by physicians or institutions when they act in distinctly untrustworthy ways. Previous literature has explored the rate of negative medical events (e.g., Institute of Medicine, 1999) as well as patients' willingness to and comfort with reporting these events (King et al., 2010; Schwappach, 2008). However, no prior research has explored whether institutional factors surrounding these types of experiences may contribute to decreased trust in healthcare professionals or systems. This hypothesis was supported; two-thirds of the participants reported experiencing at least one item on the IBQ-H (M = 3.01, SD =2.23). Institutional betrayal did appear to be a distinct experience from the events measured on the MEACULPA; both in form (17.5% of individuals who reported negative medical experiences did not report institutional betrayal) and function (institutional betrayal often mediated the relationship between negative medical experience and hypothesized outcomes).

This finding represents an important new application of institutional betrayal. Although institutional betrayal is theoretically possible within any institutional environment where members trust or depend upon the institution (Smith & Freyd, 2014), it has largely been examined in the context of universities and related to sexual violence (Smith & Freyd, 2013). Other applications are underway (e.g., Monteith et al., under

review), and the process of adapting the IBQ to new environments is quite easy and allows for comparisons across contexts (i.e., keeping the same items but adapting the instructions and examples to fit the institution in question). There do appear to be unique aspects of examining institutional betrayal in healthcare. The overall rate of institutional betrayal was higher than observed in college-student samples where sexual assault was the negative experience around which institutional betrayal was assessed (82% of individuals in the current sample reported negative medical experiences also reported institutional betrayal, compared a rate typically around 40% in college samples; Smith & Freyd, 2013) but lower than in military contexts (95% related to military sexual trauma, Monteith et al., under review). The most common types of institutional betrayal reported in the current study (i.e., failure to prevent negative experiences, responding inadequately to reports) also differ from other studies conducted in college and military samples where environmental factors making negative experiences more likely to occur or seemingly common are most often reported. It is not clear without replication whether this pattern will hold, but it is of note as research on institutional betrayal across institutional contexts continues.

**Hypothesis two:** I hypothesized racial and socio-economic status differences would predict negative medical experiences, institutional betrayal, and trust in healthcare professionals and systems. This hypothesis was based on research indicating that both race and socioeconomic status were predictors of variability in healthcare-related trust and utilization of healthcare (e.g., Mollborn et al., 2005; Whetten et al., 2006). Examining group differences in negative medical experiences, institutional betrayal, and trust in healthcare professionals and systems was of interest from a theoretical point of

view alone (i.e., as understanding of institutional betrayal in healthcare develops, it is important to know whether it disproportionately affects disempowered individuals). However, in this study it was also relevant to the statistical models tested; if race or socio-economic status co-varied with any of the predicted outcomes, then these variables would need to be added to models where they could account for variance that would otherwise be attributed to other predictors. This hypothesis was not supported; neither race nor socio-economic status predicted negative medical experiences, institutional betrayal, or trust in healthcare professionals and systems. These variables were not included as covariates in any mediational model. It may be that non-Caucasian participants were too under-represented in the sample such that when organized by racial identity, the variance within each group of participants was too great to reveal differences between groups, particularly given the relatively conservative correction used to determine significant differences. Given the means of collecting data on Mechanical Turk, which at least requires access to a computer and internet, the range for socioeconomic status may have been too restricted to detect differences in the outcomes tested even though the median income was below the national average.

**Hypothesis three:** I hypothesized institutional betrayal would mediate the relationship between negative medical experiences and decreased trust in healthcare systems and professionals, even controlling for variables such as race, socioeconomic status, and medical history (e.g., hospitalization) found to co-vary with either predictors or outcomes in these models. In many ways, this hypothesis represents the crux of the study: Would institutional betrayal operate as the "missing variable" that I imagined it to be when it comes to understanding why some patients seem to trust their healthcare

providers and institutions less? This hypothesis was supported. Institutional betrayal explained meaningful variance in the relationship between negative medical experiences and trust in one's own physician, trust in doctors in general, and trust in healthcare organizations. These models each controlled for medical history via number of hospitalizations (which was found to correlate with healthcare utilization in the form of surgeries, injuries, illnesses, chronic conditions, and physical illness symptoms).

Institutional betrayal appeared to be an equally robust mediator across models predicting trust in individual physicians as well as health organizations. Given the multiple forms of trust measured, it was possible to begin to understand how institutional betrayal might "spread" from physician to institution or vice versa as predicted by previous research (e.g., Armstrong, 2006; Mechanic, 1996). Prior research found that trust in organizations "spreads" to physicians more frequently in newer healthcare relationships (Buchanan, 2000), but the length of the relationships participants had with their current physicians was unknown in the current study. Instead, the degree to which trust in one's own physician predicted trust in a healthcare system (or rather, healthcare organizations in general) was tested. This model indicated that both institutional betrayal and trust in one's own physician mattered. It appears that trust in one's own physician serves as a "buffer" of sorts for the effects of negative medical experiences on trust in healthcare organizations. Although participants with higher trust in their own physician had lower trust in healthcare organizations following negative healthcare experiences, their trust in healthcare organizations decreased less than participants who reported lower trust in their own physicians. This is consistent with the findings that trust may color patients' interpretation of medical experiences more generally, in a manner that matches

their trust in their doctor, relatively independent of the actual quality of care (Hall et al., 2001; Mechanic & Schlesinger, 1996; Rempel, Ross, & Holmes, 2001).

Trust in one's own physician did not affect the relationship between negative medical experiences and institutional betrayal. This is another piece of evidence that differentiates negative medical experiences from institutional betrayal. It is also suggests that institutional betrayal may be undermining some of the potentially protective aspects of trust in healthcare providers as even participants with apparently good relationships with their physicians were vulnerable to the effects of institutional betrayal. This becomes particularly relevant to understanding healthcare utilization behaviors, as discussed in the next hypothesis.

**Hypothesis four:** I hypothesized institutional betrayal would predict lower compliance with healthcare advice and together these variables will interact to predict worse mental and physical health. This hypothesis arose in part from prior research on the effects of trust on healthcare utilization (e.g., Altice et al., 2001; Armstrong et al., 2006; Haywood et al., 2010), particularly linking distrust in medical organizations to underutlization (LaVeist et al., 2009). I expected that institutional betrayal explained at least some of that disengagement (in the current study, captured by compliance with doctor's advice, but also by healthcare-seeking behaviors like getting medical care when it seemed necessary). It was also based on research indicating that delays in seeking care account for both increased healthcare spending, which is often an indicator of more severe mental and physical health problems (Tidikis & Strasen, 1994), as well as delayed recovery from illness or medical procedure (Bowling et al., 2012). Testing this hypothesis was about understanding the potential mechanisms by which institutional

betrayal may operate, as correlations between institutional betrayal and every mental and physical health outcome were significant.

This hypothesis was roundly supported – each of the four models tested indicated that institutional betrayal and non-compliance (as well as their combined effect) accounted for nearly all of the variance in the direct relationship between negative medical experiences and mental and physical health outcomes (i.e., the direct path between the MEACULPA and each outcome was not significant in any model once the mediators were accounted for). This indicates that the initial correlations observed between the MEACULPA and mental and physical health outcomes can be alternatively explained by institutional betrayal and related disengagement behaviors.

I also hypothesized 1) dissociation would significantly differ between individuals who are still associated with the institution and those who are no longer associated, and 2) individuals who experience institutional betrayal will report a less consistent memory for negative medical experiences (e.g., they will have experienced at least some difficulty in remembering the events). Both of these hypotheses would be expected to occur following institutional betrayal, given predictions by Betrayal Trauma Theory and prior research indicating the relationship between dissociation and continued involvement with an institution following betrayal. Betrayal Trauma Theory holds that dissociation during and after abuse and difficultly remembering abuse allow individuals to maintain a necessary relationship, even when it is abusive (Freyd, 1996). The first hypothesis was not supported, as the mean dissociation scores between individuals who indicated they had continued to seek care from the institution following betrayal did not differ from those who left the institution after the betrayal. In part this may be due to the different

time periods addressed between this question (which may be getting at betrayal that happened some time in the past) and the Wessex Dissociation Scale, which asks about experiences in a general time frame (i.e., *"During your daily life"*).

However, consistent with prior research on interpersonal betrayal (Freyd et al., 2001) and my hypothesis, institutional betrayal was associated with disrupted memory for negative medical experiences. Of the participants who had experienced institutional betrayal, 85% had also experienced some difficulty with recalling the negative medical experiences they reported on the MEACULPA. This forgetting ranged from some partial forgetting in the past to current lack of memory to the extent that they are only able to report the events because someone else told them they occurred.

**Hypothesis five:** I hypothesized the effects of institutional betrayal would be more harmful for individuals who 1) have higher initial trust in healthcare institutions, and 2) have existing histories of interpersonal betrayal. This hypothesis was informed by research indicating that interpersonal betrayal has a direct relationship with a variety of mental and physical health outcomes (e.g., Freyd, Klest, & Allard, 2005; Klest & Freyd, 2007). The closeness, dependency, or trust within an interpersonal relationship is thought to contribute to this toxicity of betrayal and I suspected the same would hold for institutional betrayal while still acknowledging the effects of interpersonal betrayal (Freyd & Birrell, 2013). This hypothesis was partially supported. Each of the mediational models described under hypothesis three was also affected by how much initial trust (i.e., the trust they recalled having before the betrayal) a participant reported having in the institution that was the source of the betrayal. Higher initial trust in healthcare institutions (as captured by the item on the IBQ-H, *"Prior to this experience*,

was this an institution you trusted?") also predicted a stronger effect of institutional betrayal on depression and dissociation. Higher trust in the institution that betrayed seemed to increase the toxicity of the betraval. While one interpretation of this finding may be that participants who were more harmed by institutional betrayal were motivated to report that they had initially trusted the institution more, this interpretation is not consistent with research on retrospective reports of trust in romantic relationships (an imperfect proxy for institutions, but one where trust and betrayal have been studied). Not only are individuals able to accurately report on their trust in partners at earlier time points (i.e., retrospective reports are highly correlated with actual previous reports), but the best predictor of bias in these reports is actually the current level of trust – which predicts bias in a *congruent* direction with current trust (Schwarz & Sudman, 2012). Therefore, although asking participants to retrospectively report their trust in institutions for a time previous to betrayal is imperfect, it appears that any bias in these reports is likely to be in a direction that would have weakened the observed effect, rather than created it.

While this is perhaps intuitive, it is not necessarily a given that "cynicism" is purely protective and thus maintaining low trust in institutions will protect patients from the effects of institutional betrayal. Individuals who reported low initial trust in their healthcare institutions were still negatively affected by institutional betrayal and negative medical experiences still significantly predicted all types of trust, even when the indirect paths through institutional betrayal and initial trust in an institution were considered. Furthermore, as previous research indicates, maintaining lower trust in an institution while seeking care is not likely a tenable position (Hall et al., 2001).

The second part of this hypothesis was not as clearly supported. Several different models were tested in which betrayal trauma history was included as a moderator, consistent with the hypothesis that a history of trauma would be associated with stronger effects of institutional betrayal. However, the effects of institutional betrayal were consistent across trauma histories - compared to individuals with no trauma history, individuals who had experienced interpersonal betrayal did not appear to be more impacted by institutional betrayal. A history of betrayal trauma was a significant covariate of institutional betrayal and physical and mental health outcomes (see Tables 27 -32 for covariate coefficients). The mechanism by which a history of betrayal trauma predicts institutional betrayal appears to operate *through* the physical health toll of interpersonal betrayal such that high betrayal trauma predicted physical health symptoms (via the PILL), which predicted visits to the doctor, which predicted negative medical experiences, which in turn predicted institutional betrayal. Given the higher likelihood of physical health problems associated with betrayal trauma, it appears that this increases individuals' exposure to healthcare systems which in turn increases their exposure to institutional betrayal. Even after accounting for this indirect path, the direct relationship between high betrayal trauma history and institutional betrayal was still significant, indicating that there is more to understand about this relationship.

### **Trust in Healthcare**

This study expands the discussion of trust in healthcare beyond individual patient or doctor characteristics by measuring the impact of institutional betrayal. In fact, trust was not correlated with individual patient characteristics except for trauma history and, even then, institutional betrayal was a predictor of all types of trust after controlling for

that trauma history. This differs distinctly from explanations more common in medical literature that look for explanations of patients' trust in doctors in the patients themselves rather than the systems in which healthcare occurs (LaVeist et al., 2009). What this means for healthcare professionals can be considered both good and bad news. The good news is that it is not completely up to doctors alone to establish and protect patients' trust in the broader healthcare system. Furthermore, it appears their relationships with patients are even protective against institutional betrayal, to some degree. The bad news is the broader institutional environment may be undoing some of the hard work that goes into treating patients. This institutional betrayal is occurring both before negative medical experiences and in the aftermath; some of the most common forms of betrayal reported were institutional failure to prevent these negative experiences and responding inadequately to reports of negative experiences. Both point to a lack of responsiveness that does not match the needs of patients who may be at their most vulnerable. Unsurprisingly, this betrayal appears to be a contributor to patient behaviors that undermine treatment effectiveness, including not seeking medical care when it is necessary and not complying with treatment recommendations. This is consistent with previous research on institutional betrayal where withdrawal from the institution was a common outcome of institutional betrayal (Smith & Freyd, 2013). Although this reaction is entirely understandable, one consequence is that these systems do not always get feedback that something they did contributed to a patient's disengagement or even complete departure.

Physicians and others who work in healthcare systems are aware of the constraints placed upon their ability to provide ideal care for all patients (Buchanan, 2000). At first

glance, healthcare institutions have but one primary task: to improve the health of patients. Yet, as with most institutions, this primary task is actually overlaid with many other tasks that may sometimes conflict (Kahn, 2005). Healthcare institutions must also comply with insurance provisions, remain profitable, train new physicians, secure grants and conduct research, attract donors, maintain adequate staff morale, and more. When these tasks appear to conflict, institutions develop predictable dysfunction: communication suffers, rifts develop between organizational levels (e.g., between doctors and administrators), and staff burnout increases (Bloom & Farrgher, 2010; Kahn, 2005). These organizational stressors create an environment that is conducive to institutional betrayal by disrupting the process of fully attending to patient care and limiting the capacity to respond fully to patient concerns.

### **Clinical Implications**

The most important clinical implication from these findings is that asking about negative medical experiences and institutional betrayal – and listening to the answer – is critical. These are not rare occurrences; the majority of participants in this study had experienced both negative medical experiences and institutional betrayal. Although patients may be hesitant to bring up medical errors or institutional betrayal (King et al., 2010), it is likely that the mere act of a physician or healthcare system asking about these experiences could be a means to restore lost trust (Schwappach, 2008). That dissociation and memory problems were both associated with institutional betrayal has implications for relying solely on volunteered patient reports as a barometer of performance (e.g., no news may not be good news), but also may explain why some patients do not report adverse events. Prior research has characterized decisions not to report documented

medical mistakes as a hesitancy to question medical professionals (King et al., 2010; Schwappach, 2008), but the results of this study suggest that patients' reasons may be more complex. It may be threatening to acknowledge that a trusted medical professional or institution has contributed to a negative healthcare experience or it may be difficult voice concerns with an incomplete memory of one's experience. When patients do report negative medical experiences, it is critical to validate and respond to these reports. Many participants reported inadequate responses to their reports or outright denials of their experience. This type of invalidation is particularly harmful coming from a depended upon institution at a time of vulnerability (Kahn, 2005).

What response would be best in these situations? The most basic answer is an apology. Yet this very human reaction is one that many doctors have been implicitly or explicitly advised against given the potential for malpractice suits that may follow an admission of guilt (Knapp, 2009). In the majority of states, however, the framework for encouraging apologies in medical settings is already in place in the form of "I'm Sorry" laws (Ho & Liu, 2010). These laws are based on research on the motivations of patients who file medical malpractice suits – in many cases, the patients reported being motivated not by the medical error itself but by the insensitivity of the physician and a lack of accountability for the mistake (Knapp, 2009). I'm Sorry laws protect doctors who apologize (i.e., including admitting fault, expressing regret for the injurious action, and expressing sympathy for the other's injury) from later having that apology used in litigation. These laws have been associated with fewer lawsuits, lower settlement amounts, and shorter litigation (Ho & Liu, 2010). There is still some risk in apologizing but there is clear risk in having patients lose trust as well. Even when the individual

healthcare provider is not directly responsible, an apology for the pain, distress, or uncertainty the patient has experienced could contribute to restoring trust (Brooks, Dai, & Schweitzer, 2014).

A second clinical implication is related to the finding that trauma was a risk factor for exposure to institutional betrayal via increased exposure to healthcare systems and negative medical experiences. Physicians often fail to ask patients about their trauma histories unless it seems directly relevant to their treatment goals (Baltrushes & Karnik, 2013). Yet the mental and physical health problems associated with experiencing trauma, particularly within a close relationship, put patients into more frequent contact with the healthcare system. While the current study did not address whether these participants' doctors knew about their trauma history, this result indicates that asking patients about these histories might help physicians understand their patients better. One form this could take is trying to protect patients with trauma histories from negative medical experiences such as unnecessary tests, procedures, or medications by understanding the role of trauma in physical health problems (Banyard, 2006). While trauma was not a significant predictor of trust in physicians or healthcare institutions once negative medical experiences and institutional betrayal were accounted for, it may also behoove physicians to recognize the difficulties some individuals with trauma history may have with the vulnerability that accompanies seeking healthcare (Green et al., 2012).

# Limitations

This study is the first to examine the role of institutional betrayal in healthcare. As such, the hypotheses were broad and the primary goals were accomplished by collecting a large number of responses at a single time point. This also represents a

methodological limitation as the temporal precedence of events could not be established. The described models had strong theoretical rationales for testing directional hypotheses (e.g., that institutional betrayal would lead to decreased trust, rather than the other way around), but the manner in which the data were collected did not truly allow for establishing the order of events as all variables were measured at the same time. Future studies could examine the association of negative medical experiences, institutional betrayal, and the outcomes reported in this study in real time quite easily – particularly if researchers are associated with a medical institution with access to patients seeking treatment. Additionally, the results could have been influenced by participants selfselecting into the study based on their interest in the topic – either because they had a strong opinion on healthcare or because they had had particularly egregious experiences they hoped to describe. However, the rapidity with which the HITs were completed suggested that the \$5 payment was motivation enough, but it is still the case that participants knew the topic of the study from the description as well as from potentially communicating with one another. This limitation could be addressed in future studies if these measures were embedded in a larger study or on-going healthcare research that could obscure the research aims more readily, and depend upon debriefing to fully inform participants of the purpose of the research.

### **Future Directions**

There are at least two clear future directions suggested by these results. The first is to assess the effects of institutional betrayal on physicians and other healthcare providers. The way that the current study posed questions about institutional betrayal to participants asked them to consider larger healthcare institutions rather than individual

providers. These are the same institutions in which healthcare providers work and they are likely to also experience institutional betrayal (Kahn, 2005). However, it is not clear that their experiences would be the same ones as patients' or what outcomes (behavioral or emotional) would be associated with working along side of institutional betrayal. It may be that they are aware of *more* institutional betrayal than patients, given their "behind the scenes" access to the workings of the system. However, given that they must work in the institution daily, it could also be that they develop more effective mechanisms to protect themselves from awareness of the institutional betrayal and would report less institutional betrayal. The second future direction is one of intervening on institutional betrayal, either before it happens or addressing and repairing its effects. These interventions could operate at two levels: at a provider level, where individual physicians or other professionals are educated about institutional betrayal and how to prevent or ask about it, and at an institutional level where risk factors contributing to institutional betrayal are addressed.

## Conclusion

Although we are biased to trust those on whom we depend, trust does not remain impenetrable to the effects of betrayal. This has long been understood in the case of interpersonal relationships, and this study added to the evidence that this also holds for the trust patients have in their healthcare institutions. The deleterious effects of institutional betrayal in healthcare are apparent in patients' trust in their physicians and healthcare institutions, their mental well-being, and their physical health. Each of these outcomes is counter to the Hippocratic oath that physicians and healthcare institutions

aim to uphold: to first, do no harm. Recognizing and addressing institutional betrayal in healthcare is critical to achieving this standard.

#### References

- American Medical Association v. Federal Trade Commission. 638 F.2d 443 (U.S. Court of Appeals, 1980).
- Altice, F. L., Mostashari, F., & Friedland, G. H. (2001). Trust and the acceptance of and adherence to antiretroviral therapy. *Journal of Acquired Immune Deficiency Syndromes*, 28, 47–58. doi: 10.1097/00042560-200109010-00008
- Anderson, L., & Dedrick, R. F. (1990). Development of the Trust in Physician Scale: A measure to assess interpersonal trust in patient physician relationships. *Psychological Reports*, 67, 1091-100.
- Armstrong, D. K., Rose, A., Peters, N., Long, J. A., McMurphy, S., & Shea, J. A. (2006).
  Distrust of the health care system and self-reported health in the United States. *Journal of General Internal Medicine*, *21*, 292–297.
  http://doi.org/10.1111/j.1525-1497.2006.00396.x
- Baltrushes, N., & Karnik, N. S. (2013). Victims of military sexual trauma--you see them, too. *The Journal of Family Practice*, 62(3), 120–125.
- Banyard, V. L. (2006). The complexity of links between physical health and trauma: The role of gender. In V. L. Banyard, V. J. Edwards, & K. K. Tackett (Eds.) *Trauma and Physical Health.* (pp. 91-111). New York: Routledge.
- Beusterien, K. M., Steinwald, B., & Ware, J. E. (1997). Usefulness of the SF-36® Health Survey in measuring health outcomes in the depressed elderly. *Journal of Geriatric Psychiatry and Neurology*, 9, 1023-1039. doi: 10.1177/089198879600900103

- Blanchard, E. B., Jones A. J., Buckley, T. C., & Forneris, C. A. (1996). Psychometric properties of the PTSD Checklist (PCL). *Behaviour Research and Therapy*, *34*, 669-673. doi: 10.1016/0005-7967(96)00033-2.
- Bloom, S. L., & Farragher, B. (2010). Destroying Sanctuary. Oxford University Press.
- Bowling, A., Rowe, G., Lambert, N., Waddington, M., Mahtani, K. R., Kenten, C., ...
  Francis, S. A. (2012). The measurement of patients' expectations for health care:
  A review and psychometric testing of a measure of patients' expectations. *Health Technology Assessment*, *16*(30), i–xii, 1–509. http://doi.org/10.3310/hta16300
- Branch, W. T. (2000). Is the therapeutic nature of the patient-physician relationship being undermined? *Archives of Internal Medicine*, 160, 2257-2260. doi: 10.1001/archinte.160.15.2257.
- Brewin, C. R., Andrews, B., & Valentine, J. D. (2000). Meta-analysis of risk factors for posttraumatic stress disorder in trauma-exposed adults. *Journal of Consulting and Clinical Psychology*, 68, 748–766. http://doi.org/10.1037/0022-006X.68.5.748
- Brooks, A. W., Dai, H., & Schweitzer, M. E. (2014). I'm sorry about the rain!
  Superfluous apologies demonstrate empathic concern and increase trust. *Social Psychological and Personality Science*, *5*, 467–474. http://doi.org/10.1177/1948550613506122
- Buchanan, A. E. (2000). Trust in managed care organizations. *Kennedy Institute of Ethics Journal*, 10, 189–212. http://doi.org/10.1353/ken.2000.0018
- Budzi, D., Lurie, S., Singh, K., & Hooker, R. (2010). Veterans' perceptions of care by nurse practitioners, physician assistants, and physicians: A comparison from

satisfaction surveys. *Journal of the American Academy of Nurse Practitioners*, 22(3), 170–176. http://doi.org/10.1111/j.1745-7599.2010.00489.x

- Buhrmester, M., Kwang, T., & Gosling, S. D. (2011). Amazon's Mechanical Turk: A new source of inexpensive, yet high-quality, data? *Perspectives on Psychological Science*, 6, 3–5. doi:10.1177/1745691610393980
- Chilton, L. B., Horton, J. J., Miller, R. C., & Azenkot, S. (2010). Task search in a human computation market. In Proceedings of the ACM SIGKDD Workshop on Human Computation (pp. 1–9). New York: ACM.
- Consumers Union Safe Patient Project. (2009). *To Err is Human, To Delay is Deadly: Tens years later, a million lives lost and a billion dollars wasted.* Retrieved from http://safepatientproject.org/pdf/safepatientproject.org-to\_delay\_is\_deadly-2009\_05.pdf
- Conway, M. A., & Pleydell-Pearce, C. W. (2000). The construction of autobiographical memories in the self-memory system. *Psychological Review*, 107, 261–288. dx.doi.org/10.1037/0033-295x.107.2.261
- Conybeare, D., Behar, E., Solomon, A., Newman, M. G., & Borkovec, T. D. (2012). The PTSD Checklist—Civilian Version: Reliability, validity, and factor structure in a nonclinical sample. *Journal of Clinical Psychology*, 68, 699–713. doi:10.1002/jclp.21845
- Corbie-Smith, G., Thomas, S. B., & St. George, D. M. M. (2002). Distrust, race, and research. Archives of Internal Medicine, 162, 2458–2563. doi:10.1001/archinte.162.21.2458.

Coulehan, J. L., Schulberg, H. C., Block, M. R., Madonia, M. J., & Rodrigues, E. (1997).
 Treating depressed primary care patients improves their physical, mental, and social functioning. *Archives of Internal Medicine*. *157*, 1113-1120.
 doi:10.1017/S1041610208007746

Cvengros, J. A., Christensen, A. J., Cunningham, C., Hillis, S. L., & Kaboli, P. J. (2009). Patient preference for and reports of provider behavior: Impact of symmetry on patient outcomes. *Health Psychology*, 28, 660–667. http://doi.org/10.1037/a0016087

- Davies, H. T. O., & Rundall, T. G. (2000). Managing patient trust in managed care. *Milbank Quarterly*, 78, 609–624. http://doi.org/10.1111/1468-0009.00187
- Deen, T. L., Fortney, J. C., & Pyne, J. M. (2011). Relationship between satisfaction, patient-centered care, adherence and outcomes among patients in a collaborative care trial for depression. *Administration and Policy in Mental Health and Mental Health Services Research*, 38, 345–355. http://doi.org/10.1007/s10488-010-0322-z
- Dong, X. (2013). Elder abuse: Research, practice, and health policy. The 2012 GSA Maxwell Pollack Award Lecture. *The Gerontologist*, 153-162. doi:10.1093/geront/gnt139

Dula, A. (1994). African American suspicion of the healthcare system is justified: What do we do about it? *Cambridge Quarterly of Healthcare Ethics: CQ: The International Journal of Healthcare Ethics Committees*, *3*, 347–357. doi: 10.1017/S09180100005168.

- Flynn, K. E., & Smith, M. A. (2007). Personality and health care decision-making style. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 62(5), 261–267.
- Fort, K., Adda, G., & Cohen, K. B. (2011). Amazon Mechanical Turk: Gold mine or coal mine? *Computational Linguistics*, 37, 413–420. doi:10.1162/COLI\_a\_00057
- Freh, F. M., Chung, M. C., & Dallos, R. (2013). In the shadow of terror: Posttraumatic stress and psychiatric co-morbidity following bombing in Iraq. The role of shattered world assumptions and altered self-capacities. *Journal of Psychiatric Research*, 47(2), 215–225. doi:10.1016/j.jpsychires.2012.10.008
- Freyd, J. J. (1996). *Betrayal Trauma: The Logic of Forgetting Childhood Abuse*. Harvard University Press.
- Freyd, J., & Birrell, P. (2013). Blind to Betrayal: Why We Fool Ourselves We Aren't Being Fooled. New Jersey: John Wiley & Sons.
- Freyd, J. J., Deprince, A. P., & Zurbriggen, E. L. (2001). Self-reported memory for abuse depends upon victim-perpetrator relationship. *Journal of Trauma & Dissociation*, 2(3), 5–15. doi:10.1300/J229v02n03\_02
- Freyd, J. J., Klest, B., & Allard, C. B. (2005). Betrayal trauma: relationship to physical health, psychological distress, and a written disclosure intervention. *Journal of Trauma & Dissociation*, 6(3), 83–104. http://doi.org/10.1300/J229v06n03\_04
- Garland, T. (2013, December 28). Healthcare marketing and the importance of building trust [Web log post]. Retrieved from http://customdentalmarketing.com/healthcare-marketing-building-trust/

Glass, K. (2009). Are coping strategies, social support, and hope associated with psychological distress among Hurricane Katrina survivors? *Journal of Social & Clinical Psychology*, 28, 779–795.

Goodnough, A. (2013, November 28). Medicaid Growth Could Aggravate Doctor Shortage. *The New York Times*. Retrieved from http://www.nytimes.com/2013/11/29/us/lack-of-doctors-may-worsen-as-millionsjoin-medicaid-rolls.html

- Goldberg, L. R., & Freyd, J. J. (2006). Self-reports of potentially traumatic experiences in an adult community sample: gender differences and test-retest stabilities of the items in a brief betrayal-trauma survey. *Journal of Trauma & Dissociation*, 7(3), 39–63. doi:10.1300/J229v07n03\_04
- Green, B. L., Kaltman, S. I., Chung, J. Y., Holt, M. P., Jackson, S., & Dozier, M. (2012). Attachment and health care relationships in low-income women with trauma histories: A qualitative study. *Journal of Trauma & Dissociation*, *13*, 190–208. http://doi.org/10.1080/15299732.2012.642761
- Grissom, N., Iyer, V., Vining, C., & Bhatnagar, S. (2007). The physical context of previous stress exposure modifies hypothalamic–pituitary–adrenal responses to a subsequent homotypic stress. *Hormones and Behavior*, *51*, 95–103. doi:10.1016/j.yhbeh.2006.08.011
- Hall, M. A., Dugan, E., Zheng, B., & Mishra, A. K. (2001). Trust in physicians and medical institutions: What is it, can it be measured, and does it matter? *The Milbank Quarterly*, *79*, 613–639. doi:10.1111/1468-0009.00223

- Hall, M. A., Zheng, B., Dugan, E., Camacho, F., Kidd, K. E., Mishra, A., & Balkrishnan,
  R. (2002). Measuring patients' trust in their primary care providers. *Medical Care Research and Review*, *59*, 293–318. doi:10.1177/1077558702059003004
- Hayes, A. F. (2013). Introduction to Mediation, Moderation, and Conditional Process Analysis: A Regression-Based Approach. New York: Guilford Press.
- Haywood Jr., C., Lanzkron, S., Ratanawongsa, N., Bediako, S. M., Lattimer, L., Powe, N.
  R., & Beach, M. C. (2010). The association of provider communication with trust among adults with sickle cell disease. *Journal of General Internal Medicine*, 25, 543–548. http://doi.org/10.1007/s11606-009-1247-7
- Heimer, C. A. (2001). Solving the problem of trust. In K.S. Cook (Ed.), *Trust and Society*, (pp. 40-88). New York: Russell Sage.
- Horowitz, R. (2013). *In the Public Interest: Medical licensing and the disciplinary process.* New Jersey: Rutgers University Press.

Ho, B., & Liu, E. (2010). Does sorry work? The impact of apology laws on medical malpractice (SSRN Scholarly Paper No. ID 1744225). Rochester, NY: Social Science Research Network. Retrieved from http://papers.ssrn.com/abstract=1744225

- Institute of Medicine. (1999). *To Err is Human: Building a Safe Health System*. Retrieved from http://www.nap.edu/books/0309068371/html/
- Kahn, W. A. (2005). *Holding Fast: The Struggle to Create Resilient Caregiving Organizations*. New York: Brunner Routledge Psychology Press.

Kaler, M. E. (2009). The world assumptions questionnaire: Development of a measure of the assumptive world. Retrieved from http://conservancy.umn.edu/handle/11299/55049

Kantz, M. E., Harris, W. J., Levitsky, K., Ware, J. E., & Davies, A. R. (1992). Methods for assessing condition-specific and generic functional status outcomes after total knee replacement. *Medical Care*, *30*, 240-252. doi: 10.1097/00005650-199205001-00024.

- Kao, A. C., Green, D. C., Davis, N. A., Koplan, J. P., & Cleary, P. D. (1998). Patients' trust in their physicians. *Journal of General Internal Medicine*, 13, 681–686. http://doi.org/10.1046/j.1525-1497.1998.00204.x
- Kennedy, F., Clarke, S., Stopa, L., Bell, L., Rouse, H., Ainsworth, C., ... Waller, G. (2004). Towards a cognitive model and measure of dissociation. *Journal of Behavior Therapy and Experimental Psychiatry*, 35, 25–48. doi:10.1016/j.jbtep.2004.01.002

King, A., Daniels, J., Lim, J., Cochrane, D. D., Taylor, A., & Ansermino, J. M. (2010).
Time to listen: A review of methods to solicit patient reports of adverse events. *Quality and Safety in Health Care*, *19*(2), 148–157.
doi:10.1136/qshc.2008.030114

Klest, B., & Freyd, J. J. (2007). Global ratings of essays about trauma: development of the great code, and correlations with physical and mental health outcomes. *Journal of Psychological Trauma*, 6, 1–20. http://doi.org/10.1300/J513v06n01\_01

- Knapp, P. (2009). My lawyer told me to say I'm sorry: Lawyers, doctors, and medical apologies. *Faculty Scholarship*. Retrieved from http://open.wmitchell.edu/facsch/237
- Kroenke, D. K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9. Journal of General Internal Medicine, 16, 606–613. doi:10.1046/j.1525-1497.2001.016009606.x
- Lansky, D., Butler, J. B. V., & Waller, F. T. (1992) Using health status measures in the hospital setting: From acute care to 'outcomes management'. *Medical Care*, 30(5), 57-73.
- LaVeist, T. A., Isaac, L. A., & Williams, K. P. (2009). Mistrust of health care organizations is associated with underutilization of health services. *Health Services Research*, 44, 2093–2105. doi:10.1111/j.1475-6773.2009.01017.x
- Leape, L., Lawthers, A. G., Brennan, T. A., & Johnson, W. G. (1993). Preventing medical injury. *Quality Review Bulletin*, 19, 144–149.
- Lease, M., Hullman, J., Bigham, J. P., Bernstein, M. S., Kim, J., Lasecki, W., ... Miller, R. C. (2013). *Mechanical Turk is not anonymous* (SSRN Scholarly Paper No. ID 2228728). Rochester, NY: Social Science Research Network. Retrieved from <u>http://papers.ssrn.com/abstract=2228728</u>

Lee, Y. Y., & Lin, J. L. (2010). Do patient autonomy preferences matter? Linking patient-centered care to patient–physician relationships and health outcomes. *Social Science & Medicine*, 71, 1811–1818. http://doi.org/10.1016/j.socscimed.2010.08.008

- Mason, W., & Suri, S. (2011). Conducting behavioral research on Amazon's Mechanical Turk. *Behavior Research Methods*, *44*, 1–23. doi:10.3758/s13428-011-0124-6
- Mattox, E. A. (2010). Identifying vulnerable patients at heightened risk for medical error. *Critical Care Nurse*, *30*(2), 61–70. http://doi.org/10.4037/ccn2010102
- McEwen, B. S. (2012). Brain on stress: How the social environment gets under the skin.
   *Proceedings of the National Academy of Sciences*, 109, 17180–17185.
   doi:10.1073/pnas.1121254109
- Mead, N., Bower, P., & Hann, M. (2002). The impact of general practitioners' patientcentredness on patients' post-consultation satisfaction and enablement. *Social Science & Medicine*, 55, 283–299.
- Monteith, L. L., Bahraini, N. H., Matarazzo, B. B., Soberay, K. A., & Smith, C. P. (under review). A preliminary investigation of institutional betrayal related to military sexual trauma. *Journal of Traumatic Stress*.
- Mechanic, D. (1996). Changing medical organization and the erosion of trust. *The Milbank Quarterly*, 74(2), 171–189. http://doi.org/10.2307/3350245
- Mechanic, D., & Schlesinger, M. (1996). The impact of managed care on patients' trust in medical care and their physicians. *The Journal of the American Medical Association*, 275, 1693–1697. doi:10.1001/jama.1996.03530450083048.
- Mechanic, D. (1998). The functions and limitations of trust in the provision of medical care. *Journal of Health Politics, Policy and Law, 23*, 661–686.
  doi: 10.1215/03616878-23-4-661
- Mollborn, S., Stepanikova, I., & Cook, K. S. (2005). Delayed care and unmet needs among health care system users: When does fiduciary trust in a physician matter?

*Health Services Research*, *40*, 1898–1917. http://doi.org/10.1111/j.1475-6773.2005.00457.x

- Morken, I. M., Bru, E., Norekval, T. M., Larsen, A. I., Idsoe, T., & Karlsen, B. (2014). Perceived support from healthcare professionals, shock anxiety and posttraumatic stress in implantable cardioverter defibrillator recipients. *Journal of Clinical Nursing*, 23, 450–460. http://doi.org/10.1111/jocn.12200
- Murray, S. L., & Holmes, J. G. (1997). A leap of faith? Positive illusions in romantic relationships. *Personality and Social Psychology Bulletin*, 23, 586–604. http://doi.org/10.1177/0146167297236003
- Noyes, R., Kukoyi, O. A., Longley, S. L., Langbehn, D. R., & Stuart, S. P. (2011). Effects of continuity of care and patient dispositional factors on the physicianpatient relationship. *Annals of Clinical Psychiatry*, 23, 180–185.
- Oppenheimer, D. M., Meyvis, T., & Davidenko, N. (2009). Instructional manipulation checks: Detecting satisficing to increase statistical power. *Journal of Experimental Social Psychology*, 45, 867–872. doi:10.1016/j.jesp.2009.03.009.
- Paolacci, G., Chandler, J., & Ipeirotis, P. G. (2010). Running experiments on Amazon Mechanical Turk. *Judgment and Decision Making*, 5, 411–419.
- Peabody, F. W. (1927). The care of the patient. *Journal of the American Medical* Association, 88, 877 – 882. doi:10.1001/jama.1927.02680380001001
- Pennebaker, J. W. (1982). *The Psychology of Physical Symptoms*. New York, NY: Springer Verlag Publishing.
- Quealy, K., & Sanger-Katz, M. (2014, October 29). Obama's Health Law: Who Was Helped Most. *The New York Times*. Retrieved from

http://www.nytimes.com/interactive/2014/10/29/upshot/obamacare-who-washelped-most.html

- Rempel, J. K., Ross, M., & Holmes, J. G. (2001). Trust and communicated attributions in close relationships. *Journal of Personality and Social Psychology*, *81*, 57–64. http://doi.org/10.1037/0022-3514.81.1.57
- Rheingold, A. A., Acierno, R., & Resick, H. S. (2004). Trauma, posttraumatic stress disorder, and health risk behaviors. In P. P. Schnurr & B. L. Green (Eds.), *Trauma and health consequence of exposure to extreme stress* (pp.. 217-243). Washington, DC: American Psychological Association.
- Rickert, A. L. (2012). Patient-centered care: What it means and how to get there. Retrieved from http://healthaffairs.org/blog/2012/01/24/patient-centered-carewhat-it-means-and-how-to-get-there/
- Russell, S. (1999). An exploratory study of patients' perceptions, memories and experiences of an intensive care unit. *Journal of Advanced Nursing*, *29*, 783-791. doi: 10.1046/j.1365-2648.1999.00953.x
- Safran, D. M., Kosinski, A. R., Tarlov, W. H., Rogers, D. A., Taira, N., Lieberman, J. E., & Schwappach, D. L. (2008). Against the silence: Development and first results of a patient survey to assess experiences of safety-related events in hospital. *BMC Health Services Research*, *8*, 59. http://doi.org/10.1186/1472-6963-8-59
- Schenker, Y., Arnold, R. M., & London, A. J. (2014). The Ethics of Advertising for Health Care Services. *The American Journal of Bioethics*, 14(3), 34–43. http://doi.org/10.1080/15265161.2013.879943

- Schwarz, N., & Sudman, S. (2012). Autobiographical Memory and the Validity of Retrospective Reports. Springer Science & Business Media.
- Sexton, K., & Linder, S. H. (2011). Cumulative risk assessment for combined health effects from chemical and nonchemical stressors. *American Journal of Public Health*, 101, 81–88. doi: 10.2105/AJPH.2011.300118.
- Simes, R. J. (1986). An improved Bonferroni procedure for multiple tests of significance. *Biometrika*, 73, 751-754.
- Smith, C. P. (2014, April). Unawareness and expression of interpersonal and institutional betrayal. Paper presented at The Western Psychological Association, Portland, OR.
- Smith, C. P., & Freyd, J. J. (2013). Dangerous safe havens: Institutional betrayal exacerbates sexual trauma. *Journal of Traumatic Stress*, 26, 119–124. doi:10.1002/jts.21778
- Smith, C. P., & Freyd, J. J. (2014). Institutional betrayal. American Psychologist, 69, 575–587. http://doi.org/10.1037/a0037564
- Spitzer, R. L., Williams, J. B. W., Kroenke, K., Linzer, M., de Gruy, F. V., Hahn, S. R., ... Johnson, J. G. (1994). Utility of a new procedure for diagnosing mental disorders in primary care: The PRIME-MD 1000 study. *The Journal of the American Medical Association*, 27, 1749-1756.
- Sundby, E. L. (2013, November 3). You Also Can't Keep Your Doctor. *Wall Street Journal*. Retrieved from http://www.wsj.com/articles/SB1000142405270230452750457917171042378044 6

- Suurmond, J., Uiters, E., de Bruijne, M. C. Stronks, K., & Essink-Bot, M.-L. (2011).
   Negative health care experiences of immigrant patients: A qualitative study. *BMC Health Services Research*, *11*, 10-18. http://doi.org/10.1186/1472-6963-11-10
- Thom, D. H., Ribisl, K. M., Stewart, A. L., & Luke, D. A. (1999). Further validation and reliability testing of the Trust in Physician Scale. *Medical Care*, 37, 510–517. http://doi.org/10.1097/00005650-199905000-00010
- Thorne, S. E., & Robinson, C. A. (1988). Health care relationships: The chronic illness perspective. *Research in Nursing & Health*, 11, 293–300. http://doi.org/10.1002/nur.4770110504
- Tsai, C., Bayliss, M. S., & Ware, J. E. (1997). SF-36® Health Survey Annotated Bibliography: Second Edition (1988-1996). Boston, MA: Health Assessment Lab, New England Medical Center.
- U.S. Census Bureau (2013). Current Population Survey. http://www.census.gov/quickfacts/table/PST045214/0
- Ware, J. E., Snow, K. K., Kolinski, M., & Gandeck, B. (1993). SF-36 Health Survey manual and interpretation guide. Boston: The Health Institute, New England Medical Centre, Boston, MA.
- Ware, J. E. (1998). The Primary Care Assessment Survey: Tests of data quality and measurement performance. *Medical Care, 36*, 728-39. doi: 10.1097/00005650-199805000-00012
- Weathers, F., Litz, B., Herman, D., Huska, J., & Keane, T. (1993, October). The PTSD Checklist: Reliability, validity, and diagnostic utility. Paper presented at the
annual meeting of the International Society for Traumatic Stress Studies, San Antonio, TX.

- Whetten, K., Leserman, J., Whetten, R., Ostermann, J., Thielman, N., Swartz, M., &
  Stangl, D. (2006). Exploring lack of trust in care providers and the government as a barrier to health service use. *American Journal of Public Health*, *96*, 716–721. http://doi.org/10.2105/AJPH.2005.063255
- Ziminski-Pickering, C. E., & Rempusheski, V. F. (2014). Examining barriers to selfreporting of elder physical abuse in community-dwelling older adults. *Geriatric Nursing*, 35, 120–125. doi:10.1016/j.gerinurse.2013.11.002



Figure 1. Healthcare Ad Establishing Fiduciary Trust

Figure 2. Health Ad Establishing Safety



Race	Ν	% / 707	2013 - US Census - %
Caucasian	516	73	62.6
Black/AA	73	10.3	13.2
Hispanic	46	6.5	17.1
Asian	44	6.2	5.3
Native American	19	2.7	0.2
Multiracial	9	1.3	2.4
Gender	N	% / 707	2013 - US Census - %
Male	297	42	49.2
Female	400	56.6	50.8
GQ	5	0.7	
Trans	2	0.3	
Did not report	3	0.4	
Sexual Orientation	Ν	% / 707	-
Heterosexual	629	89	
Lesbian	14	2	
Gay	13	1.8	
Bisexual	42	5.9	
Other	7	1	
Did not report	2	0.3	

Table 1. Demographic Information: Personal Characteristics

Education	Ν	% / 707	2013 - US Census - %
Some HS	2	0.3	8.5
High School	81	11.5	28.5
Some college	201	28.4	21.4
Associate's	85	12	7.5
Bachelor's	220	31.1	17.6
Some graduate school	30	4.2	
Master's	72	10.2	7.2
Doctorate/Other advanced	16	2.3	3.1
Monthly Income	Ν	% / 707	2013 - US Census - %
Median	1750		2354
500	103	14.6	
1000	127	18	
1500	113	16	
2000	98	13.9	
2500	93	13.2	
3000	54	7.6	
>3000	117	16.5	

Table 2. Demographic Information: Education and Income

Item Content	% Endorsing
Choice in Healthcare <sup>1</sup>	
Insurance covered them	75.5
Recommended to me	36.5
Near to my home	52.5
Only doctor for my condition	3.5
Referred by another provider	17.7
Emergency, I had no choice	11.9
Only option, I had no choice	5
Average distance from care, in miles	
0-5	37.6
6-10	35.9
11-15	12.7
16-20	7.5
20+	6.2
Healthcare need/use	
Daily prescription	46.4
Condition requiring monitoring	36.2
Current serious health condition	12.6
Previous serious health condition	24.5
Lifetime hospitalizations	
0 – 3	74.4
4 – 7	18.8
8 - 11	3.8
12 +	3

Table 3. Healthcare Contact History

<sup>1</sup>Not cumulative

Table 4. Healthcare Behaviors

Item Content	% Endorsing
How often do you see a doctor?	
Less than once per year	58.7
Once per month	36.4
2-3 times per month	3.3
Once per week	1.3
2-3 times per week	0.3
In the past year I <sup>1</sup>	
Ignored a Dr.'s advice	23.9
Did not keep a follow-up appointment	26.7
Postponed/delayed needed care	40.7
Did not seek needed care at all	30.8
Did not fill a prescription	17.3
Took a prescription not as prescribed	20.1

 $^{-1}(M = 1.5, SD = 1.43)$ 

Scale	Items	alpha	М	SD
Trust in Own Physician				
Wake Forest Scale <sup>1</sup>	5	0.92	3.70	0.89
PCA Survey <sup>2</sup>	9	0.88	3.82	0.68
TIP Scale <sup>3</sup>	11	0.94	3.60	0.83
Composite Trust <sup>4</sup>	25	0.97	3.70	0.76
Trust in Insurance <sup>1</sup>	5	0.90	2.47	0.98
Trust in All Doctors <sup>1</sup>	5	0.90	3.04	0.84
Trust in Researchers <sup>1</sup>	4	0.79	3.07	0.78
Trust of Healthcare Orgs. <sup>5</sup>	17	0.90	2.79	0.64

Table 5. Trust in Healthcare Organizations and Providers

<sup>1</sup>Items from Wake Forest Scales measuring Trust described in Hall et al., 2002 <sup>2</sup>Items from Primary Care Assessment Survey (PCA) Survey described in Safran et al., 1998

<sup>3</sup>Items from Trust in Physician (TIP) Scale described in Anderson & Dedrick, 1990 <sup>4</sup>Composite score computed from mean of Wake Forest, PCA, and TIP measures <sup>5</sup>Items from scales described in LaVeist, Isaac, & Williams, 2009; reversed scored to indicate trust rather than mistrust

Scale	Items	alpha	М	SD
Wessex	40	0.95	0.73	0.62
PHQ Depression	9	0.91	6.23	5.92
PCL-C	17	0.94	14.34	13.66
World Assumptions	22	0.88	1.65	0.38

Table 6. Mental Health Descriptives

Measure	Items	alpha	М	SD
PILL	55	0.99	1.13	0.67
SF-36				
Physical Functioning	10	0.73	90.66	12.8
Role Functioning - Physical	4	0.71	78.64	29.18
Role Functioning - Emotional	3	0.65	66.57	34.44
Energy/Fatigue	4	0.87	46.74	22.62
Emotional Well-being	5	0.88	65.65	22.45
Social Functioning	2	0.85	78.69	24.52
Pain	2	0.86	76	21.71
General Health	5	0.86	62.1	22.71
Health compared to 1 year ago	1		54.56	21.31
Total Scale	36	0.91	72.33	15.98

Table 7. Physical Health Descriptives

MEACULPA item	Ν	% / 707
I was prescribed an unnecessary medication	198	28
I was given an incorrect diagnosis	191	27
I was not notified of test results	174	24.6
I had an allergic reaction to medication	173	24.5
I underwent an unnecessary procedure or test.	159	22.5
I had a procedure was more painful than I expected	155	21.9
I experienced unexpected side effects of a procedure or medication	149	21.1
I received inaccurate insurance information	136	19.2
My personal information (e.g., name, diagnosis, schedule) was incorrect	96	13.6
I needed to return to hospital after discharge for emergency care	83	11.7
I had post-surgical complications	78	11
I found the medical facilities were old, run down, or in disrepair	75	10.6
I was prescribed an incorrect medication dosage	72	10.2
I developed an infection related to a medical procedure	58	8.2
Other medical error, adverse experience, or lasting/unexpected pain associated with medical care	51	7.2
I was prescribed a medication that interacted with existing medication	50	7.1

Table 8. Negative Medical Experiences, Adverse Consequences, and Unexpected or Lasting Pain Assessment (MEACULPA)

Total MEACULPA	Frequency	% / 707
0	141	19.9
1	152	21.5
2	124	17.5
3	83	11.7
4	61	8.6
5	48	6.8
6	37	5.2
7	20	2.8
8	12	1.7
9	11	1.6
10	5	0.7
11	6	0.8
12	4	0.6
13	0	0
14	1	0.1
15	2	0.3

Table 9. MEACULPA Frequencies

## Table 10. Institutional Betrayal Questionnaire – Healthcare (IBQ-H)

IBQ-H item	N	% / 707
Not taking proactive steps to prevent unpleasant healthcare experiences?	223	31.5
Responding inadequately to your concerns or reports of a negative experience, if shared?	175	24.8
Denying your experience in some way?	175	24.8
Making it difficult to report a negative experience or share concerns?	151	21.4
Creating an environment in which a negative experience seemed more likely to occur?	149	21.1
Creating an environment in which unpleasant healthcare experiences seemed common or normal?	143	20.2
Creating an environment where you no longer felt like a valued member of the institution?	121	17.1
Creating an environment where continuing to seek care was difficult for you?	98	13.9
Mishandling your protected personal information?	73	10.3
Covering up adverse medical events?	42	5.9
Punishing you in some way for reporting a negative healthcare experience?	30	4.2
Suggesting your experience might affect the reputation of the institution?	27	3.8

Total IBQ	Frequency	% / 707
0	240	33.9
1	151	21.4
2	93	13.2
3	73	10.3
4	54	7.6
5	34	4.8
6	26	3.7
7	11	1.6
8	8	1.1
9	10	1.4
10	2	0.3
11	2	0.3
12	3	0.3

Table 11. IBQ-H Frequencies

Scale	Race	М	SD	$F^{l}$	Scale	М	SD	$F^{I}$
Trust in Physicians								
Wake Forest					All Doctors			
Scale	Caucasian	3.67	0.90	.84		3.02	0.84	1.11
	Asian	3.76	0.76			3.27	0.67	
	Native American	3.73	0.88			2.99	0.77	
	Black	3.83	0.94			3.07	0.93	
	Hispanic	3.85	0.64			3.13	0.71	
PCA Survey					Med. Research	ers		
	Caucasian	3.81	0.66	.73		3.08	0.84	.64
	Asian	3.83	0.63			3.27	0.67	
	Native American	3.80	0.67			2.99	0.77	
	Black	3.92	0.72			3.07	0.93	
	Hispanic	3.94	0.57			3.13	0.71	
TIP Scale					Healthcare Org	S.		
	Caucasian	3.61	0.83	.59		2.79	0.66	1.23
	Asian	3.75	0.72			3.00	0.50	
	Native American	3.65	0.76			2.72	0.57	
	Black	3.69	0.92			2.78	0.62	
	Hispanic	3.73	0.59			2.79	0.47	
Insurance								
	Caucasian	2.39	0.96	10.30**				
	Asian	2.75	0.79					
	Native American	2.12	0.88					
	Black	3.09	1.05					
	Hispanic	2.46	0.95					

Table 12. Racial Differences in Trust in Healthcare Individuals and Organizations

(*N*) = Caucasian (516), Asian (44), Native American (19), Black/African American (73), Hispanic (46)

<sup>1</sup>Test of between group differences, *F* (4, 463), family-wise alpha corrected to p < .007\*\*p < 0.001

Scale	Race	М	SD	$F^{I}$
MEACULPA				
	Caucasian	2.80	2.67	2.73
	Asian	1.98	2.07	
	Native American	2.95	2.30	
	Black	1.99	1.99	
	Hispanic	2.28	2.38	
IBQ-H				
	Caucasian	2.05	2.36	1.58
	Asian	1.39	1.67	
	Native American	2.32	2.29	
	Black	1.77	2.14	
	Hispanic	1.52	1.50	

Table 13. Racial Differences in Negative Medical Experiences and Institutional Betrayal

(N) = Caucasian (516), Asian (44), Native American (19),

Black/African American (73), Hispanic (46)

<sup>1</sup>Test of between group differences, F (4, 463), family-wise alpha corrected to p < .007

Scale	Monthly Income <sup>1</sup>
Trust in Own Physician Scales	
Wake Forest Scale	.08
PCA Survey	.06
TIP Scale	.09
Composite Trust	.08
Trust in Insurance	.02
Trust in Doctors (in General)	.09
Trust in Medical Researchers	.003
Trust in Healthcare Orgs.	.02
Non-Compliance	06
MEACULPA	06
IBQ-H	05

Table 14. Correlations Between Socio-Economic Differences and Trust, Negative Medical Experiences, and Institutional Betrayal

<sup>1</sup>Monthly income was treated as a continuous variable, even though respondents chose one of seven \$500 increments

Scale	MEACULPA	IBQ-H	Non-Compliance <sup>1</sup>
Trust in Own Physician Scales			
Wake Forest Scale	36**	40**	24**
PCA Survey	35**	39**	22**
TIP Scale	37**	42**	26**
Composite Trust	38**	42**	25**
Trust in Insurance	24**	24**	17**
Trust in Doctors (in General)	45**	46**	25**
Trust in Medical Researchers	32**	32**	13**
Trust in Healthcare Orgs.	43**	45**	22**
Non-Compliance	.41**	.36**	

Table 15. Correlations between Negative Medical Experiences, Institutional Betrayal,Non-Compliance, and Trust

<sup>1</sup>Non-Compliance = Total non-compliance healthcare behaviors endorsed

\**p* < .01

\*\**p* < 0.001

Scale	MEACULPA	IBQ-H	Non-Compliance
Wessex Dissociation	.26**	.31**	.24**
PHQ Depression	.23**	.26**	.26**
PCL-C	.31**	.34**	.32**
Negative World Assumptions	.28**	.29**	.25**

Table 16. Correlations between Negative Medical Experiences, Institutional Betrayal, and Mental Health

<sup>1</sup>Non-Compliance = Total non-compliance healthcare behaviors endorsed

\*\*Correlation is significant at the 0.001 level

Scale	MEACULPA	IBQ-H	Non-Compliance <sup>1</sup>
PILL Mean	.38**	.34**	.28**
SF-36 Total	36**	40**	32**
Physical Functioning	30**	32**	20**
Role Functioning - Physical	31**	31**	20**
Role Functioning - Emotional	21**	23**	33**
Energy	19**	20**	22**
Emotional Well-being	16**	21**	21**
Social Functioning	30**	33**	24**
Pain	38**	38**	23**
General Health	35**	31**	25**

Table 17. Correlations between Negative Medical Experiences, Institutional Betrayal, Non-Compliance and Physical Health

<sup>1</sup>Non-Compliance = Total non-compliance healthcare behaviors endorsed

\*\**p* < 0.001

Figure 3. Forgetting Negative Medical Experiences And Institutional Betrayal



**Any Forgetting** 

Items	MEACULPA	IBQ-H	Hospitalization	Non-
			History	Compliance <sup>1</sup>
Surgical Procedures	.34**	.25**	.35**	.14**
Injuries	.38**	.27**	.26**	.22**
Illnesses	.48**	.32**	.34**	.28**
Preventative Care	.24**	.17**	.13**	.11*
Non-Compliance <sup>1</sup>	.41**	.36**	.10*	

Table 18. Correlations between Negative Medical Experiences, Institutional Betrayal,

<sup>1</sup>Non-Compliance = Total non-compliance healthcare behaviors endorsed

\**p* < 0.01

and Healthcare History

\*\**p* < 0.001

	Items	М	SD	N (any)	% / 707
Childhood					
Low	2	0.18	0.44	115	16.27
Medium	4	0.33	0.69	165	23.34
High	4	0.61	0.98	240	33.95
Adulthood					
Low	2	0.27	0.52	161	22.77
Medium	4	0.23	0.58	120	16.97
High	4	0.51	0.88	221	31.26
Lifetime					
Low	4	0.45	0.74	230	32.53
Medium	8	0.56	1.03	225	31.82
High	8	1.11	1.56	326	46.11

Table 19. Low, Medium, and High Betrayal Trauma Histories by Age

Lifetime Betrayal Trauma Type						
Scale	Low	Medium	High			
Wessex Dissociation Mean	.19**	.34**	.36**			
PHQ Depression Total	.08	.27**	.35**			
PCL-C Total	.16**	.38**	.44**			
Negative World Assumptions	.03	.23**	.28**			
PILL	.18**	.23**	.35**			
SF-36 Total	17**	30**	36**			

Table 20. Correlations between Betrayal Trauma and Mental and Physical Health

\*\**p* < 0.001

Predictor		S	tep 1			S	tep 2			S	tep 3		
	В	SE	β	$\Delta R^2$	В	SE	β	$\Delta R^2$	В	SE	β	$\Delta R^2$	R <sup>2</sup>
Dissociation <sup>1</sup>													
High BT <sup>2</sup>	.14	.01	.36**	.13**	.12	.02	.30**	.02**	.11	.02	.28**	.02**	.17**
MEACULPA					.04	.01	.15**		.03	.02	.01		
IBQ-H									.05	.01	.20**		
Depression													
High BT	1.33	.14	.35**	.12**	1.16	.14	.30**	.01*	1.10	.15	.29**	.01*	.14**
MEACULPA					.27	.09	.12*		.04	.12	.02		
IBQ-H									.37	.14	.15*		
PCL-C <sup>3</sup>													
High BT	3.89	.30	.44**	.20**	3.33	.32	.38**	.03**	3.19	.32	.36**	.01**	.24**
MEACULPA					.92	.19	.17**		.30	.26	.06		
IBQ-H									.99	.29	.17*		
Negative World Assumptions													
High BT	.07	.02	.28**	.08**	.05	.01	.20**	.04**	.04	.01	.19**	.01*	.13**
MEACULPA					.03	.01	.20**		.02	.01	.10		
IBQ-H									.02	.01	.14*		

Table 21. Four Hierarchical Multiple Regression Models Predicting Mental Health From High Betrayal Trauma, Negative Medical Experiences, and Institutional Betrayal in Healthcare

<sup>1</sup>Wessex Dissociation Scale; <sup>2</sup>Total High Betrayal Trauma events endorsed on Brief Betrayal Trauma Scale; <sup>3</sup>PCL-C = Post-traumatic Checklist-Civilian Scale; <sup>\*\*</sup>p < 0.001; <sup>\*</sup>p < 0.01

Predictor		S	tep 1			S	Step 2			S	tep 3		
	В	SE	β	$\Delta R^2$	В	SE	β	$\Delta R^2$	В	SE	β	$\Delta R^2$	R <sup>2</sup>
SF-36													
High BT	-3.65	.36	36**	.13**	-2.70	.37	27**	.06**	-2.43	.37	24**	.03**	.22**
MEACULPA					-1.62	.22	27**		67	.30	11		
IBQ-H									-1.60	.34	23**		
PILL													
High BT	.15	.02	.35**	.13**	.10	.02	.25**	.08*	.10	.02	.24**	.004	.22**
MEACULPA					.08	.01	.29**		.06	.01	.23**		
IBQ-H									.03	.02	.09		
$p^{**} > 0.001; p^{*} < 0.01$													

Table 22. Two Hierarchical Multiple Regression Models Predicting Physical Health From High Betrayal Trauma, Negative MedicalExperiences, and Institutional Betrayal in Healthcare

Predictor		S	tep 1			S	step 2			S	step 3		
	В	SE	β	$\Delta R^2$	В	SE	β	$\Delta R^2$	В	SE	β	$\Delta R^2$	R <sup>2</sup>
Trust in Physician <sup>1</sup>													
High BT	09	.02	<b>-</b> .18 <sup>**</sup>	.03**	03	.02	05	.11**	01	.02	02	.04**	.18**
MEACULPA					10	.01	36**		04	.01	15*		
IBQ-H									10	.02	31**		
Trust in Healthcare Orgs. <sup>2</sup>													
High BT	08	.02	<b>-</b> .19 <sup>**</sup>	.04**	02	.02	04	.15**	004	.02	01	.04**	.23**
MEACULPA					10	.02	42**		05	.01	22**		
IBQ-H									08	.01	29**		
Trust in All Doctors <sup>3</sup>													
High BT	12	.02	22**	.05**	04	.02	07	.16**	02	.02	04	.03**	.24**
MEACULPA					14	.01	43**		08	.02	25**		
IBQ-H									10	.02	26**		

Table 23. Three Hierarchical Multiple Regression Models Predicting Trust From High Betrayal Trauma, Negative Medical

Experiences, and Institutional Betrayal in Healthcare

<sup>1</sup>Composite Trust Scales – Wake Forest Scale, PCA Survey, and TIP Scale; <sup>2</sup>LaVeist et al., 2009 scale; <sup>3</sup>Wake Forest Survey subscale; \*\*p < 0.001; \*p < 0.01



Figure 4. Effect of Negative Medical Experiences on Trust in Physician Partially Mediated by Institutional Betrayal and Moderated by Trust in Institution

Note: Bolded coefficients indicate non-zero indirect effects of Negative Medical Experiences on Trust in Physician Composite Covarying with the mediator and outcome in this model is hospitalization history

Outcome: $M$ (IBQ-H)											
Predictor		Coeff.	SE	р	LLCI	ULCI					
Constant		0.69	0.17	0.0001	0.35	1.02					
MEACULPA	$a_1$	0.64	0.03	<.0001	0.58	0.70					
Hospitalization		-0.23	0.10	0.02	-0.42	-0.04					
	Outcome: Y (Trust in Phys. Composite)										
Predictor		Coeff.	SE	р	LLCI	ULCI					
Constant		3.19	0.14	<.0001	2.91	3.48					
MEACULPA	с'	-0.06	0.02	0.0004	-0.09	-0.03					
IBQ-H	$b_1$	0.02	0.04	0.59	-0.06	0.10					
I-Trust	$b_2$	0.32	0.06	<.0001	0.20	0.45					
IBQ-H x I-Trust	b3	-0.06	0.02	0.0012	-0.10	-0.03					
Hospitalization		0.18	0.04	<.0001	0.09	0.26					
		Outcome	: Y (Trust in P	hys. Composite) a	t Moderator						
IBQ-H		Coeff.	Boot SE	Boot LLCI	Boot ULCI						
Low I-Trust (-1 SD	))	-0.04	0.02	-0.07	-0.01						
High I-Trust (+1 S	D)	-0.09	0.02	-0.13	-0.06						

Table 24. Regression Coefficients for the Effect of Negative Medical Experiences onTrust in Physician by Institutional Betrayal and Moderated by Trust in Institution



Figure 5. Effect of Negative Medical Experiences on Trust in Doctors in General Partially Mediated by Institutional Betrayal and Moderated by Trust in Institution

Note: Bolded coefficients indicate non-zero indirect effects of Negative Medical Experiences on Trust in Doctors in General Covariates of the mediator and outcome in this model are hospitalization history

Table 25. Regression Coefficients for the Effect of Negative Medical Experiences on Trust in Doctors in General by Institutional Betrayal and Moderated by Trust in Institution

Outcome: M (IBQ-H)									
Predictor		Coeff.	SE	р	LLCI	ULCI			
Constant		0.69	0.17	0.0001	0.35	1.02			
MEACULPA	$a_1$	0.64	0.03	<.0001	0.58	0.70			
Hospitalization		-0.23	0.10	0.02	-0.42	-0.04			
Outcome: <i>Y</i> (Trust in Doctors in General)									
Predictor		Coeff.	SE	р	LLCI	ULCI			
Constant		3.19	0.15	<.0001	2.59	3.18			
MEACULPA	с'	-0.09	0.02	<.0001	-0.12	-0.06			
IBQ-H	$b_1$	0.01	0.04	0.7318	-0.10	0.07			
I-Trust	$b_2$	0.22	0.07	0.0007	0.09	0.36			
IBQ-H x I-Trust	$b_3$	-0.04	0.02	0.0332	-0.08	-0.004			
Hospitalization		0.11	0.04	0.0090	0.02	0.19			
Outcome: Y (Trust in Doctors in General) at Moderator									
IBQ-H		Coeff.	Boot SE	Boot LLCI	Boot ULCI				
Low I-Trust (-1 SD)		-0.05	0.01	-0.07	-0.02				
High I-Trust (+1 SD)		-0.08	0.02	-0.12	-0.05				



Figure 6. Effect of Negative Medical Experiences on Trust in Healthcare Organizations Partially Mediated by Institutional Betrayal and Moderated by Trust in Institution

Note: Bolded coefficients indicate non-zero indirect effects of Negative Medical Experiences on Trust in Healthcare Organizations Covarying with the mediator and outcome in this model is hospitalization history Table 26. Regression Coefficients for the Effect of Negative Medical Experiences on Trust in Healthcare Organizations by Institutional Betrayal and Moderated by Trust in Institution

	Outcome: M (IBQ-H)					
Predictor		Coeff.	SE	р	LLCI	ULCI
Constant		0.69	0.17	0.0001	0.35	1.02
MEACULPA	$a_1$	0.64	0.03	<.0001	0.58	0.70
Hospitalization		-0.23	0.10	0.02	-0.42	-0.04
		Outcome	: Y (Trust in H	lealthcare Organization	ations)	
Predictor		Coeff.	SE	р	LLCI	ULCI
Constant		2.56	0.11	<.0001	2.35	2.78
MEACULPA	c'	-0.06	0.01	<.0001	-0.08	-0.04
IBQ-H	$b_1$	0.01	0.03	0.6142	-0.08	0.04
I-Trust	$b_2$	0.23	0.05	<.0001	0.13	0.32
IBQ-H x I-Trust	$b_3$	-0.03	0.01	0.0266	-0.06	-0.004
Hospitalization		0.08	0.03	0.0046	0.03	0.15
		Outcome	: Y (Trust in H	lealthcare Organiz	ations) at Modera	ıtor
IBQ-H		Coeff.	Boot SE	Boot LLCI	Boot ULCI	
Low I-Trust (-1 SD)		-0.04	0.01	-0.06	-0.02	
High I-Trust (+1 SD)		-0.07	0.01	-0.09	-0.04	



Figure 7. Effect of Negative Medical Experiences on Trust in Healthcare Organizations Moderated by Trust in Physician and Mediated by Institutional Betrayal

Note: Bolded coefficients indicate non-zero indirect effects of Negative Medical Experiences on Trust Healthcare Organizations Covariates of the mediator and outcome in this model are hospitalization history Table 27. Regression Coefficients for the Effect of Negative Medical Experiences on Trust in Healthcare Organizations Moderated by Trust in Physician and Mediated by Institutional Betrayal

	Outcome: M (IBQ-H)						
Predictor		Coeff.	SE	р	LLCI	ULCI	
Constant		2.55	0.47	.0001	1.62	3.48	
MEACULPA	$a_1$	0.54	0.08	<.0001	0.38	0.69	
Trust in Phys.	$a_2$	-0.57	0.12	<.0001	-0.81	-0.33	
MEACULPA x Trust in Phys.	<i>a</i> <sub>3</sub>	0.01	0.02	.6716	-0.03	0.05	
Hospitalization		-0.12	0.09	.1933	-0.29	0.06	
		Outcome: Y	(Trust in He	ealthcare Orgs.	)		
Predictor		Coeff.	SE	р	LLCI	ULC	
Constant		1.52	0.16	<.0001	1.21	1.87	
MEACULPA	c'	0.02	0.03	0.4000	-0.03	0.08	
IBQ-H	$b_1$	-0.05	0.01	.0001	-0.07	-0.02	
Trust in Phys.	$b_2$	0.39	0.04	<.0001	0.31	0.47	
MEACULPA x Trust in Phys.	b3	-0.02	0.01	.006	-0.03	-0.01	
Hospitalization		0.06	0.03	.0426	0.002	0.12	
		Outcome: Y	(Trust in He	ealthcare Orgs.	) at Moderato	r	
MEACULPA		Coeff.	SE	р	LLCI	ULC	
Low Trust in Phys. (-1 SD)		-0.03	0.01	.0012	-0.05	-0.01	
High Trust in Phys. (+1 SD)		-0.06	0.01	<.0001	-0.09	-0.04	



Figure 8. Effect of Negative Medical Experiences on Trust in Physician Mediated by Institutional Betrayal but Not Negative World Assumptions

Note: Bolded coefficients indicate non-zero indirect effects of Negative Medical Experiences on Trust in Healthcare Organization Covarying with the mediator and outcome in this model is hospitalization history
Table 28. Regression Coefficients for the Effect of Negative Medical Experiences on Trust in Physician Mediated by Institutional Betrayal but Not Negative World Assumptions

		Oute	come: M (IB	Q-H)		
Predictor		Coeff.	SE	р	LLCI	ULCI
Constant		-0.12	0.37	0.7461	-0.85	0.61
MEACULPA	$a_1$	0.59	0.1	<.0001	0.39	0.78
World Assumptions	$a_2$	0.36	0.22	0.1034	-0.07	0.79
MEACULPA x WA	<i>a</i> <sub>3</sub>	0.02	0.05	0.6777	-0.08	0.13
Life HBT		0.13	0.04	0.0021	0.05	0.21
Hospitalization		-0.21	0.09	0.0138	-0.38	-0.04
		Outcome: Y	(Trust in Ph	ys. Composite)	1	
Predictor		Coeff.	SE	р	LLCI	ULCI
Constant		4.11	0.16	<.0001	3.79	4.43
MEACULPA	с'	0.04	0.06	0.536	-0.08	0.16
World Assumptions	<i>c</i> <sub>2</sub> ′	20	0.1	0.039	-0.39	-0.01
IBQ-H	$b_{I}$	-0.14	0.07	0.0403	-0.28	-0.01
IBQ-H x WA	$b_2$	0.03	0.04	0.4949	-0.05	0.10
MEACULPA x WA	<i>C</i> 3′	-0.05	0.03	0.1835	-0.11	0.02
Life HBT		0.002	0.02	0.9215	-0.03	0.04
Hospitalization		0.17	0.04	<.0001	0.10	0.25



Figure 9. Effect of Negative Medical Experiences on Physical Health Multiply Mediated by Institutional Betrayal and Non-Compliance

Note: Bolded coefficients indicate non-zero indirect effects of Negative Medical Experiences on Physical Health Covarying with the mediators and outcome in this model is hospitalization history and high betrayal trauma history

	Outcome: $M_1$ (IBQ-H)					
Predictor		Coeff.	SE	р	LLCI	ULCI
Constant		0.55	0.14	.0001	0.28	0.81
MEACULPA	$a_1$	0.65	0.02	<.0001	.60	0.69
Hospitalization		-0.22	0.09	0.015	-0.39	-0.04
		Outcome: N	I2 (Non-Con	mpliance)		
Predictor		Coeff.	SE	р	LLCI	ULCI
Constant		0.98	0.11	<.0001	0.76	1.19
MEACULPA	$a_2$	0.17	0.03	<.0001	0.11	0.22
IBQ-H	$d_{21}$	0.09	0.03	.0037	0.03	0.14
Hospitalization		-0.002	0.07	.9745	-0.15	0.14
		Outcome:	Y (Health -	SF-36)		
Predictor		Coeff.	SE	р	LLCI	ULCI
Constant		85.51	1.27	<.0001	83.01	88.01
MEACULPA	<i>c'</i>	-0.23	0.31	.4553	-2.89	-1.29
IBQ-H	$b_1$	-1.91	0.34	<.0001	-2.57	-1.15
Non-Comp.	$b_2$	-2.08	0.41	<.0001	-2.89	-1.29
Hospitalization		-4.00	0.79	<.0001	-5.56	-2.44
		Outcome	: Indirect ef	fects on Y (Health	n - SF-36)	
			Boot			
Path		Coeff.	SE	Boot LLCI	Boot ULCI	
MEACULPA->IBQ-I	Η	-1.24	0.24	-1.72	-0.77	_
MEACULPA->IBQ-I	H->Non-Comp	-0.12	0.06	-0.26	-0.02	
MEACULPA->Non.	Comp	-0.35	0.1	-0.57	-0.18	

Table 29. Regression Coefficients for the Effect of Negative Medical Experiences onPhysical Health Multiply Mediated by Institutional Betrayal and Non-Compliance



Figure 10. Effect of Negative Medical Experiences on Depression (PHQ-9) Multiply Mediated by Institutional Betrayal and Non-Compliance

Note: Bolded coefficients indicate non-zero indirect effects of Negative Medical Experiences on Depression Covarying with the mediators and outcome in this model is hospitalization history and high betrayal trauma history

	Outcome: $M_l$ (IBQ-H)						
Predictor		Coeff.		SE	р	LLCI	ULCI
Constant		0.42		0.13	0.0014	0.16	0.68
MEACULPA	$a_1$	0.64		0.02	<.0001	0.59	0.69
Life HBT		0.15		0.04	0.0002	0.07	0.23
Hospitalization		-0.22		0.09	0.0109	-0.39	-0.05
		Outc	some: $M_2$	(Non-Compli	ance)		
Predictor		Coeff.		SE	р	LLCI	ULCI
Constant		0.95		0.11	<.0001	0.73	1.17
MEACULPA	$a_2$	0.17		0.03	<.0001	0.11	0.22
IBQ-H	$d_{21}$	0.07		0.03	0.0251	0.01	0.13
Life HBT		0.04		0.03	0.1965	-0.02	0.11
Hospitalization		-0.01		0.07	0.8684	-0.16	0.13
		Outco	ome: Y (D	epression - P	HQ-9)		
Predictor		Coeff.		SE	р	LLCI	ULCI
Constant		3.05		0.49	<.0001	2.09	4.02
MEACULPA	с'	-0.12		0.13	0.3459	-0.36	0.13
IBQ-H	$b_1$	0.34		0.13	0.0125	0.07	0.60
Non.Comp	$b_2$	0.73		0.16	<.0001	0.42	1.04
Life HBT		1.07		0.14	<.0001	0.79	1.35
Hospitalization		0.36		0.31	0.2441	-0.24	0.95
		Outcom	e: Indirec	et effects on Y	(Depression -	PHQ-9)	
Path			Coeff.	Boot SE	Boot LLCI	Boo	t ULCI
MEACULPA->IBC	2-Н		0.21	0.1	0.03	C	0.41
MEACULPA->IBC	Q-H->Non	. Comp	0.03	0.02	0.001	C	0.08
MEACULPA->Not	n. Comp		0.13	0.04	0.06	0	0.22

Table 30. Regression Coefficients for the Effect of Negative Medical Experiences onDepression (PHQ-9) Multiply Mediated by Institutional Betrayal and Non-Compliance



Figure 11. Effect of Negative Medical Experiences on Dissociation (Wessex) Multiply Mediated by Institutional Betrayal and Non-Compliance

Note: Bolded coefficients indicate non-zero indirect effects of Negative Medical Experiences on Dissociation Covarying with the mediators and outcome in this model is hospitalization history and high betrayal trauma history

Outcome: $M_l$ (IBQ-H)							
Predictor		Coeff.		SE	р	LLCI	ULCI
Constant		0.42		0.13	0.0014	0.16	0.68
MEACULPA	$a_1$	0.64		0.02	<.0001	0.59	0.69
Life HBT		0.15		0.04	0.0002	0.07	0.23
Hospitalization		-0.22		0.09	0.0109	-0.39	-0.05
		Outo	come: M <sub>2</sub>	(Non-Compl	iance)		
Predictor		Coeff.		SE	р	LLCI	ULCI
Constant		0.95		0.11	<.0001	0.73	1.17
MEACULPA	$a_2$	0.17		0.03	<.0001	0.11	0.22
IBQ-H	$d_{21}$	0.07		0.03	0.0251	0.01	0.13
Life HBT		0.04		0.03	0.1965	-0.02	0.11
Hospitalization		-0.01		0.07	0.8684	-0.16	0.13
		Outco	me: Y (D	issociation - V	Wessex)		
Predictor		Coeff.		SE	р	LLCI	ULCI
Constant		.38		0.05	<.0001	0.28	0.48
MEACULPA	с'	-0.01		0.01	0.3520	-0.04	0.01
IBQ-H	$b_1$	0.05		0.01	0.0002	0.02	0.08
Non.Comp	$b_2$	0.05		0.02	0.0009	0.02	1.09
Life HBT		0.11		0.01	<.0001	0.08	0.14
Hospitalization		0.06		0.03	0.0547	-0.001	0.12
		Outcon	ne: Indire	ct effects on	Y (Dissociation	- Wessex)	
Path			Coeff.	Boot SE	Boot LLCI	Boot	ULCI
MEACULPA->IBO	Q-Н		0.03	0.01	0.03	0	.06
MEACULPA->IBO	Q-H->Non	. Comp	0.003	0.001	0.0002	0	.01
MEACULPA->No	n. Comp		0.01	0.004	0.004	0	.02

Table 31. Regression Coefficients for the Effect of Negative Medical Experiences on Dissociation (Wessex) Multiply Mediated by Institutional Betrayal and Non-Compliance



Figure 12. Effect of Negative Medical Experiences on Posttraumatic Distress (PCL-C) Multiply Mediated by Institutional Betrayal and Non-Compliance

Note: Bolded coefficients indicate non-zero indirect effects of Negative Medical Experiences on Posttraumatic Distress Covarying with the mediators and outcome in this model is hospitalization history and high betrayal trauma history

Table 32. Regression Coefficients for the Effect of Negative Medical Experiences on
Posttraumatic Distress (PCL-C) Multiply Mediated by Institutional Betrayal and Non-
Compliance

			Outcom	e: $M_l$ (IBQ-H	I)		
Predictor		Coeff		SE	р	LLCI	ULCI
Constant		0.42		0.13	0.0014	0.16	0.68
MEACULPA	$a_1$	0.64		0.02	<.0001	0.59	0.69
Life HBT		0.15		0.04	0.0002	0.07	0.23
Hospitalization		-0.22		0.09	0.0109	-0.39	-0.05
		Out	come: M <sub>2</sub>	(Non-Comp	liance)		
Predictor		Coeff		SE	р	LLCI	ULCI
Constant		0.95		0.11	<.0001	0.73	1.17
MEACULPA	$a_2$	0.17		0.03	<.0001	0.11	0.22
IBQ-H	$d_{21}$	0.07		0.03	0.0251	0.01	0.13
Life HBT		0.04		0.03	0.1965	-0.02	0.11
Hospitalization		-0.01		0.07	0.8684	-0.16	0.13
		Outcome:	Y (Posttra	aumatic Distr	ess - PCL-C)		
Predictor		Coeff		SE	р	LLCI	ULCI
Constant		4.78		1.06	<.0001	2.69	6.87
MEACULPA	с'	-0.15		0.27	0.5850	-0.68	0.38
IBQ-H	$b_I$	0.91		0.29	0.0018	0.34	1.48
Non.Comp	$b_2$	1.86		0.34	<.0001	1.19	2.53
Life HBT		3.08		0.31	<.0001	2.48	3.69
Hospitalization		1.29		0.66	0.0511	-0.006	2.59
		Outcome:	Indirect e	ffects on Y (I	Posttraumatic D	istress PCL	-C)
Path			Coeff.	Boot SE	Boot LLCI	Boo	t ULCI
MEACULPA->II	BQ-H		0.58	0.23	0.13	1	.04
MEACULPA->II	BQ-H->No	n. Comp	0.09	0.05	0.004	C	0.20
MEACULPA->N	lon. Comp		0.32	0.10	0.17	C	0.56



Figure 13. Effect of High Betrayal Trauma on Institutional Betrayal Multiply Mediated by Physical Illness Symptoms, Physicians Visits and Negative Medical Experiences

Table 33. Regression Coefficients for the Effect of High Betrayal Trauma on Institutional Betrayal Multiply Mediated by Physical Illness Symptoms, Physicians Visits and Negative Medical Experiences

	Outcome: $M_l$ (PILL)						
Predictor		Coeff.	SE	р	LLCI	ULCI	
Constant		0.96	0.03	<.0001	0.9	1.01	
Life HBT	$a_1$	0.15	0.02	<.0001	0.12	0.18	
		Outcome: <i>I</i>	$M_2$ (Physician V	isits)			
Predictor		Coeff.	SE	р	LLCI	ULCI	
Constant		1.22	0.05	<.0001	1.13	1.31	
Life HBT	$a_2$	0.05	0.02	0.0064	0.01	0.08	
PILL	$d_{21}$	0.18	0.04	<.0001	0.11	0.26	
		Outcome:	M <sub>3</sub> (MEACUL	PA)			
Predictor		Coeff.	SE	р	LLCI	ULCI	
Constant		0.14	0.24	0.5612	-0.33	0.61	
Life HBT	<i>a</i> <sub>3</sub>	0.4	0.06	<.0001	0.28	0.52	
PILL	$d_{31}$	1.01	0.14	<.0001	0.73	1.29	
Physician Visits	$d_{32}$	0.64	0.14	<.0001	0.37	0.91	
		Outco	ome: Y (IBQ-H)				
Predictor		Coeff.	SE	р	LLCI	ULCI	
Constant		0.1	0.16	0.5423	-0.22	0.41	
Life HBT	с'	0.11	0.04	0.0063	0.03	0.2	
PILL	$b_1$	0.18	0.1	0.0645	-0.01	0.37	
Physician Visits	$b_2$	-0.04	0.09	0.6315	-0.23	0.14	
MEACULPA	b3	0.61	0.03	<.0001	0.56	0.66	
	Outcome: Ind	lirect effects on	Y (IBQ-H)				
Path		Coeff.	Boot SE	Boot LLC	I Boo	ot ULCI	
HBT->PILL		0.03	0.02	-0.007		0.06	
HBT->PILL->PV		-0.0013	0.003	-0.008	(	0.004	
HBT->PILL->MEA	CUPLA	0.09	0.02	0.06		0.13	
HBT->PILL->PV->	MEACUPLA	0.01	0.004	0.005		0.02	
HBT->PV		-0.002	0.005	-0.01	(	0.007	
HBT->PV->MEACU	JLPA	0.02	0.009	0.005		0.04	
HBT->MEACUPLA		0.25	0.05	0.15		0.35	

#### APPENDIX A: CONSENT

Thank you for your interest in our research project. The following is a summary of the project:

**Purpose**: We are interested in understanding how experiences with healthcare institutions (e.g., hospitals, insurance companies, doctor's offices) may affect the well-being of individuals accessing healthcare through these institutions. This information will be used to better understand the different experiences individuals have within healthcare systems.

**Participation**: Any MTurk worker over the age 18 who has used healthcare in the United States is eligible to participate. If you choose to participate, you will be asked to answer questions about yourself (e.g., age, medical conditions), your experiences within healthcare systems, and psychological and physical well-being. Participation is expected to take about 45 minutes.

You can choose to stop participating at any time and/or leave any question unanswered. Only completed surveys will result in payment, however, this is determined by a valid pattern of responses (i.e., enough time is spent on each page to suggest items are being read carefully, instructions are followed) rather than every item being answered. Risk of participation is expected to be minimal but some questions ask about past events that may be upsetting to recall.

Only your MTurk workerID will be visible to researchers and any identifying information associated with this ID will not be linked in any way to your responses on this survey. We will not include workerIDs in any publicly available dataset. Information about participants will only be described in aggregate form (e.g., "Women who have had multiple surgeries"). Participation or lack thereof will in no way affect your relationship with the researchers or the University of Oregon.

For contributing to this project, you will be paid \$5 through your Amazon Mechanical Turk account. Given the anonymous nature of the responses, we will be unable to provide any type of individualized feedback. You may print a copy of this consent information using your browser's print option to retain for your records.

**Who we are**: Carly Smith, M.A., M.S., a doctoral candidate in clinical psychology at the University of Oregon and Jennifer Freyd, Ph.D., professor of psychology at the University of Oregon. We welcome any questions or concerns.

#### **Our contact information**:

Carly Smith: carlys@uoregon.edu Jennifer Freyd: jjf@uoregon.edu

If you have questions about your rights as a participant in this research project, please contact the University of Oregon Research Compliance Services at (541) 346-2510 or ResearchCompliance@uoregon.edu.

Please click "I Agree to participate" to continue.

### APPENDIX B: HEALTHCARE USE

Over the course of this survey, you will be asked to think about your experiences in the United States healthcare system. Some questions ask you to think about "your doctor", which may not always call to mind a specific individual. In these cases, you will be instructed to respond based on the doctor you have seen most often or most recently. If you have had many different experiences in healthcare systems, you may wonder which doctor or healthcare system you should be referring to in order to answer some questions. Please try to refer to experiences that you feel you can describe the best.

How often do you need to see a doctor?

- **O** Less than once per year
- **O** Once a month
- **O** 2-3 Times a month
- **O** Once a week
- 2-3 Times a week
- O Daily

Check all that apply to you:

- □ I take prescribed medications every day
- □ I have a medical condition that requires monitoring by a healthcare provider
- □ I currently have a serious health condition
- □ I have previously had a serious health condition, but no longer have one

How many times have you been hospitalized in your life?

- **O** 0-3
- **O** 4-7
- **O** 8-11
- 12 or more times

Have you ever accessed healthcare in a country other than the United States?

- O Yes
- O No

In general, how did that healthcare compare to that you have access in the United States (U.S.)?

- **O** Much worse than U.S. healthcare
- **O** Somewhat worse than U.S. healthcare
- **O** About the same as U.S. healthcare
- **O** Better than U.S. healthcare
- **O** Much better than U.S. healthcare

#### APPENDIX B, CONT.

How did you choose your doctor/health care system? (check all that apply)

- □ My insurance covered it
- $\hfill\square$  They were recommended to me
- □ They were nearby where I live
- $\hfill\square$  This was the only doctor who could treat my condition
- □ I was referred by another healthcare provider
- □ I went there in an emergency and could not choose
- **D** They were the only option, I did not choose among others

How far, on average, do you have to travel to reach your typical healthcare provider?  $\bigcirc$  0-5 miles

- 6-10 miles
- 11-15 miles
- 16-20 miles
- **O** 20 or more miles

### APPENDIX C: DEMOGRAPHICS

What is your age?

- **O** 18-25
- **O** 26-35
- **O** 36-45
- **O** 46-55
- **O** 56-65
- **O** 66-75
- $\bigcirc$  76 or older

What is your approximate individual monthly income?

- **O** \$0-500
- **O** \$501-1000
- **O** \$1001-1500
- **O** \$1501-2000
- **O** \$2001-2500
- **O** \$2501-3000
- **O** >\$3000

What is your primary sexual orientation?

- **O** Heterosexual
- **O** Lesbian
- O Gay
- **O** Bisexual
- Other:

What is your race? (You may check more than one)

- Asian
- □ American Indian or Alaska Native
- Black or African American
- □ Native Hawaiian or other Pacific Islander
- □ White
- □ Hispanic/Latino/a
- □ Mixed race
- Other: \_\_\_\_\_

### APPENDIX C, CONT.

Which best describes your gender?

- O Man
- O Woman
- **O** Genderqueer/non-conforming
- **O** Transgender

What is the highest level of education you have completed?

- Primary/elementary school
- Some middle school
- Middle school
- $\bigcirc$  Junior high
- **O** Some high school
- **O** High school
- Some college
- O Associate's degree
- **O** Bachelor's degree
- **O** Some graduate school
- O Master's degree
- **O** Doctorate
- **O** Other advanced degree

#### APPENDIX D: MEDICAL HISTORY

This section will ask about a variety of reasons you may have sought medical care including surgeries, injuries or emergencies, illnesses or physical conditions, and preventative procedures. These are lists of the most common medical experiences, but they are not exhaustive. Each section will have a field for you to provide other information if you choose.

Which of the following surgical procedures have you had (please check all that apply):

- □ Bone or joint transplant/replacement
- □ Organ or gland transplant/removal (e.g., tonsilectomy)
- □ Tissue removals (e.g., masses, cysts, etc.)
- □ Amputation
- □ Cancer-related (e.g., tumorectory)
- □ Reproductive (e.g., tubal ligation, vasectomy, cyst removal)
- Cesarean delivery
- □ Cosmetic or elective surgery (e.g., Lasik)
- □ Other surgeries or procedures: \_\_\_\_\_

For which of the following injuries/emergencies have you sought medical care (please check all that apply):

- □ Stroke
- □ Heart attack
- □ Respiratory failure
- Emergency injury (e.g., sprains, broken bones, cuts, burns, bullet wound)
- □ Head trauma (e.g., concussion)
- □ Allergic reaction
- □ Other injuries or emergencies: \_\_\_\_\_

### APPENDIX D, CONT.

For which of the following illnesses/chronic conditions have you sought medical care (please check all that apply):

- □ HIV
- □ Cancer
- □ Hemophilia
- Coronary Artery Disease
- Cardiovascular disorder (e.g., atrial fibrillation, arrhythmia)
- Renal Disease
- □ Skin disorders (e.g., cysts, acne, dermatitis)
- □ Check this box to indicate you are reading each item
- □ Joint disorders (e.g., carpal tunnel, osteoarthritis)
- □ Back problems
- □ Cholesterol problems
- Upper respiratory conditions (e.g., cold, pneumonia, bronchitis, allergies)
- □ Viral infections (e.g., chicken pox, flu, shingles)
- Asthma
- □ Mental health (e.g., anxiety, bipolar disorder, depression)
- □ Pregnancy/Childbirth
- Chronic neurologic disorders (e.g., Multiple Sclerosis, ALS)
- □ High blood pressure
- □ Headaches and migraines
- Diabetes
- □ Hepatitis
- □ Sexual transmitted infection
- Gastro-intestinal distress
- Autoimmune disease (e.g., lupus, Lyme's disease, Crohn's disease)
- □ Kidney or gallstones
- □ Urinary tract infection
- □ Hereditary disorders (e.g., hemophiliac, anemia)
- Other illness or conditions: \_\_\_\_\_

For which of the following other illnesses/conditions have you sought preventative medical care (please check all that apply):

- □ Reproductive
- □ Cancer Screening
- □ Vaccination
- Other preventative care: \_\_\_\_\_\_

#### APPENDIX E: HEALTHCARE BEHAVIOR

In the past 12 months, have you done any of the following?

- □ A physician gave me advice that I did not take
- □ I did not keep a follow-up appointment with a physician
- □ I postponed or delayed seeking care I felt I needed
- □ I did not seek medical care at all even when I felt I needed it
- □ I chose not fill a prescription
- □ I took a prescribed medication differently than recommended (e.g., stopped early, changed dosage)

## APPENDIX F: WAKE FOREST TRUST IN PHYSICIAN

Please indicate your agreement with the following items about your primary physician. If you do not have a primary physician, please respond based on the physician you see most frequently or if that is not applicable, the one you have seen most recently.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Sometimes my doctor cares more about what is convenient for him/her than about my medical needs	0	0	0	0	0
My doctor is extremely thorough and careful	О	О	О	О	О
I completely trust my doctor's decisions about which medical treatments are best for me	O	О	0	O	O
My doctor is totally honest in telling me about all of the different treatment options available for my condition	0	0	0	0	0
All in all, I have complete trust in my doctor	Ο	Ο	О	O	0

## APPENDIX G: PRIMARY CARE ASSESSMENT SURVEY – TRUST

Please indicate your agreement with the following items about your primary physician. If you do not have a primary physician, please respond based on the physician you see most frequently or if that is not applicable, the one you have seen most recently.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I can tell my doctor anything	О	О	О	О	0
My doctor sometimes pretends to know things when he/she is really not sure	О	О	О	О	О
I completely trust my doctor's judgments about my medical care	О	О	О	О	0
My doctor cares more about holding costs down than about doing what is needed for my health	0	0	О	О	О
My response to this item will be agree if I am reading carefully	О	О	О	О	О
My doctor would always tell me the truth about my health, even if there was bad news	О	О	О	О	О
My doctor cares as much as I do about my health	О	О	О	О	O
If a mistake was made in my treatment, my doctor would try to hide it from me	О	О	0	0	0
All things considered, I trust my doctor	О	О	О	0	О

# APPENDIX H: TRUST IN PHYSICIAN SCALE

Please indicate your agreement with the following items about your primary physician. If you do not have a primary physician, please respond based on the physician you see most frequently or if that is not applicable, the one you have seen most recently.

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
I doubt that my doctor really cares about me as a person	О	О	О	О	О
My doctor is usually considerate of my needs and puts them first	0	О	0	О	О
I trust my doctor so much I always try to follow his/her advice	0	О	0	О	О
If my doctor tells me something is so, then it must be true	0	О	0	О	О
I sometimes distrust my doctor's opinion and would like a second one	О	О	О	О	О
I trust my doctor's judgments about my medical care	О	О	О	О	О
I feel my doctor does not do everything he/she should for my medical care	О	0	0	О	О
I trust my doctor to put my medical needs above all other considerations when treating my medical problems	0	0	0	0	0
My doctor is a real expert in taking care of medical problems like mine	О	О	0	О	О
I trust my doctor to tell me if a mistake was made about my treatment	О	О	0	О	О
I sometimes worry that my doctor may not keep the information we discuss totally private	О	О	О	О	О

# APPENDIX I: WAKE FOREST TRUST IN DOCTORS

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Sometimes doctors care more about what is convenient for them than about their patients' medical needs	0	0	0	0	0
Doctors are extremely thorough and careful	О	О	О	О	Ο
I completely trust doctors' decisions about which medical treatments are best	0	О	O	0	0
A doctor would never mislead me about anything	O	О	0	О	0
All in all, I trust doctors completely	Ο	Ο	Ο	О	Ο

Please indicate your agreement with the following items about doctors in general.

# APPENDIX J: WAKE FOREST TRUST IN MEDICAL RESEARCHERS

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Doctors who do medical research care only about what is best for each patient	0	О	0	0	О
Doctors tell their patients everything they need to know about being in a research study	0	O	0	O	0
Medical researchers treat people like "guinea pigs"	0	О	О	О	О
I completely trust doctors who do medical research	Ο	Ο	Ο	Ο	Ο

Please indicate your agreement with the following items about medical researchers.

# APPENDIX K: WAKE FOREST TRUST IN INSURERS

Please indicate your agreement with the following items about your insurance company. If you have more than one insurance company, please respond based on your primary insurance provider or if that is not applicable, the one you have interacted with most recently.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
My insurance company cares more about saving money than about getting me the treatment I need	0	0	0	O	O
I feel like I need to double check everything my insurance company does	0	0	О	О	0
I believe my insurance company will pay for everything it is supposed to, even really expensive treatments	0	0	0	0	0
If I have a question, I think my insurance company will give a straight answer	О	0	О	О	О
All in all, I have complete trust in my insurance company	О	Ο	О	Ο	Ο

# APPENDIX L: MEDICAL MISTRUST INVENTORY

Please indicate your agreement with the following items about healthcare systems in general.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
People need to be cautious when dealing with health care organizations	О	О	О	О	0
Patients have sometimes been deceived or misled by health care organizations	0	О	О	О	О
When health care organizations make mistakes they usually cover it up	0	О	О	О	О
Health care organizations have sometimes done harmful experiments on patients without their knowledge	0	О	О	О	O
Health care organizations don't always keep your information totally private	0	О	0	О	О
I will choose neutral for this item if I am reading each item on this list fully	О	О	0	О	О
Sometimes I wonder if health care organizations really know what they are doing	О	О	0	О	О
Mistakes are common in health care organizations	Ο	О	0	0	О
I trust that health care organizations will tell me if a mistake is made about my treatment	0	0	О	0	0
Health care organizations often want to know more about a patient's business than they need to know	0	О	О	О	0

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
The patient's medical needs come before other considerations at health care organizations	0	0	0	О	о
Health care organizations are more concerned about making money than taking care of people	0	0	0	0	•
Health care organizations put the patient's health first	0	О	0	0	Ο
Patients should always follow the advice given to them at health care organizations	О	О	0	О	O
I typically get a second opinion when I am told something about my health	О	О	0	О	O
I trust that health care organizations check their staff's credentials to make sure they are hiring the best people	0	О	О	О	о
They know what they are doing at health care organizations	О	О	0	0	O
I trust that health care organizations keep up with the latest medical information	О	О	О	О	О

## APPENDIX L: CONT.

### APPENDIX M: MEACULPA

Thinking back on your experiences accessing healthcare, you experience any of the following?

- □ I was given an incorrect diagnosis
- □ I underwent an unnecessary procedure or test.
- □ I had an allergic reaction to medication
- □ I was prescribed an unnecessary medication
- □ I was prescribed an incorrect medication dosage
- $\Box$  I was prescribed a medication that interacted with existing medication
- □ I developed an infection related to a medical procedure
- □ My personal information (e.g., name, diagnosis, schedule) was incorrect
- □ I was not notified of test results
- □ I had a procedure was more painful than I expected
- □ I had post-surgical complications
- □ I needed to return to hospital after discharge for emergency care
- □ I found the medical facilities were old, run down, or in disrepair
- □ I received inaccurate insurance information
- □ I experienced unexpected side effects of a procedure or medication
- □ Other medical error, adverse experience, or lasting/unexpected pain associated with medical care? (Please describe briefly below)

#### APPENDIX N: INSTITUTIONAL BETRAYAL QUESTIONNAIRE - HEALTHCARE

This section will ask you to think about healthcare institutions that you have interacted with in the United States where the medical experiences reported in the previous section took place. This may or may not call to mind specific individuals. This may include large systems such as the United States healthcare system as a whole, hospitals, or insurance companies. It may also call to mind smaller parts of these systems such as a hospital department, a health clinic, or a doctor's office staff. You indicated having the following medical experiences:

#### [Endorsed items from MEACULPA]

As you progress though this section, you may think about different institutions at different points. We are interested in whether you have ever had any of the following experiences at any time, related to the events listed above. The examples listed with each item are meant to help you think of ways this may have happened but may not apply directly to your experience.

In thinking about the experiences seeking healthcare you described in the previous section, did a healthcare institution play a role by (check all that apply)...

- □ Not taking proactive steps to prevent unpleasant healthcare experiences (e.g., by explaining procedures, side effects, etc.)?
- □ Creating an environment in which unpleasant healthcare experiences seemed common or normal (e.g., minimizing your concerns, delivering serious news in a casual way)?
- Creating an environment in which a negative experience seemed more likely to occur (e.g., an apparent lack of communication between providers, lack of clear or consistent policies)?
- Making it difficult to report a negative experience or share concerns (e.g., difficultly contacting provider, not being given a chance to ask questions, no clear avenue for sharing dissatisfaction)?
- Responding inadequately to your concerns or reports of a negative experience, if shared (e.g., you were given incorrect or inadequate information or advice that was not feasible for you to follow)?
- Mishandling your protected personal information (e.g., unauthorized release of medical history, losing records, not keeping track of complaints or concerns)?
- Covering up adverse medical events (e.g., not immediately informing you of a mistake in treatment, withholding information about healthcare coverage, or not disclosing prior records of know risks for a treatment)?
- Denying your experience in some way (e.g., your concerns were treated as invalid, your prior history was dismissed as unimportant)?

### APPENDIX N: CONT.

- Punishing you in some way for reporting a negative healthcare experience (e.g., you were labeled as problematic or responsible for a lack of recovery or timely healthcare delivery)?
- □ Suggesting your experience might affect the reputation of the institution (e.g., your experience was contrasted with the "typical" one, you were discouraged from seeking a second opinion or sharing your experiences with others)?
- □ Creating an environment where you no longer felt like a valued member of the institution (e.g., you had to repeatedly remind providers of your identity or treatment history, your primary identity was your medical condition rather than a person, you were discriminated against due to a personal characteristic)?
- □ Creating an environment where continuing to seek care was difficult for you (e.g., your appointments were repeatedly changed or cancelled at short notice, seeking healthcare was financially or personally difficult and not supported by the institution)?

Please briefly identify the institution involved (e.g., insurance company, doctor's office, private hospital, VA system, etc. -- you do not need to provide a specific name):

Prior to this experience, was this an institution or organization you trusted?

- Not at all
- Very little
- **O** A good deal
- **O** Very much

Have you sought healthcare from this institution since having any of these experiences? • No

O Yes

#### APPENDIX O: BETRAYAL TRAUMA INVENTORY - FORGETTING

When you reflect upon these experiences in healthcare systems (either the medical events or the institutional involvement), what has your memory been like for the event/s you experienced? We are interested in the entirety of your experience, so different items may describe your memory for different experiences. Please select all that apply.

- □ I have a good memory for the event/s now and always have.
- □ I have a good memory for the event/s now, but there was a time when I had trouble remembering it/them.
- □ I have only partial memory for the event/s, and I have always had some trouble remembering it/them.
- □ I have only partial memory for the event/s, but there was a time when I could not remember it/them at all.
- □ I have only partial memory for the event/s now, but I think I used to remember it/them much better.
- □ Someone told me that the event/s happened, but I have no memory of it/them.

# APPENDIX P: BRIEF BETRAYAL TRAUMA SURVEY

Please indicate whether each of the following events happened to you. If you have not experience the event, just leave it blank.

	Before age 18	After age 18
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.		
You were in a major automobile, boat, motorcycle, plane, train, or industrial accident that resulted in similar consequences.		
You were deliberately attacked that severely by someone with whom you were not close.		
You were emotionally or psychologically mistreated by someone with whom you were not close.		
You were neglected or had such basic essential needs or resources withheld from you by someone with whom you were not close. This neglect or withdrawal of basic needs could have been willful or not.		
You were made to have sexual contact or participate in sexual activity by someone with whom you were not close.		
You were made to have some form of sexual contact or participate in sexual activity by someone with whom you were very close.		
You were deliberately attacked so severely as to result in marks, bruises, blood, broken bones, or broken teeth by someone with whom you were very close (such as a parent or lover).		
You were emotionally or psychologically mistreated by someone with whom you were very close.		
You were neglected or had basic essential needs or resources withheld from you by someone with whom you were very close. This neglect or withdrawal of basic needs could have been willful or not.		

# APPENDIX Q: POST-TRAUMATIC STRESS DISORDERS CHECKLIST

Below is a list of problems and complaints that people sometimes have in response to stressful life experiences. Please read each one carefully, then check one of the items to the right to indicate how much you have been bothered by that problem in the past month.

	Not at all	A little bit	Moderately	Quite a bit	Extremely
Repeated, disturbing memories, thoughts, or images of a stressful experience from the past	О	О	О	О	О
Repeated, disturbing dreams of a stressful experience from the past	О	О	О	0	О
Suddenly acting or feeling as if a stressful experience were happening again (as if you were reliving it)	0	О	0	О	О
Feeling very upset when something reminded you of a stressful experience from the past	О	О	Ο	0	О
Having physical reactions (e.g., heart pounding, trouble breathing, sweating) when something reminded you of a stressful experience from the past	О	О	0	О	O
Avoiding thinking about or talking about a stressful experience from the past or avoiding having feelings related to it	0	О	О	О	0
Avoiding activities or situations because they reminded you of a stressful experience from the past	0	О	0	О	0
Trouble remembering important parts of a stressful experience from the past	О	О	О	О	О
Loss of interest in activities that you used to enjoy	О	О	О	О	О
Feeling distant or cut off from other people	О	О	Ο	О	Ο
Feeling emotionally numb or being unable to have loving feelings for those close to you	О	О	О	О	О
Feeling as if your future will somehow be cut short	О	О	Ο	О	0
Trouble falling or staying asleep	О	О	Ο	О	Ο
Feeling irritable or having angry outbursts	О	О	Ο	О	Ο
Having difficulty concentrating	0	Ο	0	Ο	0
Being "super-alert" or watchful or on guard	0	Ο	0	Ο	0
Feeling jumpy or easily startled	0	Ο	0	Ο	0

# APPENDIX R: WORLD ASSUMPTIONS QUESTIONNAIRE

Please rate the following statements on how much you agree or disagree with each.

	Strongly Disagree	Disagree	Agree	Strongly Agree
Most people can be trusted.	0	0	О	0
I don't feel in control of the events that happen to me.	О	О	О	О
You usually can know what is going to happen in your life.	О	Ο	О	О
It is difficult for me to take most of what people say at face-value.	О	О	О	О
It is very difficult to know what others are thinking.	О	0	О	О
Anyone can experience a very bad event.	О	Ο	О	О
People often behave in unpredictable ways.	Ο	Ο	О	О
People are less safe than they usually realize	О	Ο	О	О
For the most part, I believe people are good.	О	Ο	О	О
I have a great deal of control over what will happen to me in my life.	О	O	0	О
You never know what's going to happen tomorrow.	О	Ο	О	О
Other people are usually trustworthy.	О	Ο	О	О
People's lives are very fragile.	О	Ο	О	О
It is hard to know exactly what motivates another person.	О	O	О	О
Most people cannot be trusted.	О	0	О	О
People fool themselves into feeling safe.	О	0	О	О
It is hard to understand why people do what they do.	О	O	O	О
Most of what happens to me happens because I choose it.	О	O	0	О
Terrible things might happen to me.	О	Ο	О	О
It is ultimately up to me to determine how events in my life will happen.	О	O	O	О
It can be very difficult to predict other people's behavior.	0	0	0	Ο
What people say and what they do are often very different things.	Ο	0	0	Ο

# APPENDIX S: WESSEX DISSOCIATION SCALE

This questionnaire asks about experiences that you may have in your daily life. Using the scale below, please indicate how often you have experiences like these. It is important that your answers state how often you have these experiences when you are not under the influence of alcohol or drugs.

	Never	Rarely	Sometimes	Often	Very Often	All the time
Unwanted images from my past come into my head	О	О	О	О	Ο	O
I hear voices when no one has actually said anything	О	О	0	О	Ο	O
Other people describe meetings we have had but that I cannot remember	О	О	0	О	Ο	Ο
Unwanted memories come into my head	О	О	Ο	О	0	Ο
My personality is very different in different situations	О	О	О	О	Ο	Ο
My mood can change very rapidly	О	О	Ο	О	•	Ο
I have vivid and realistic nightmares	О	О	Ο	О	0	Ο
I don't always remember what people have said to me	О	О	О	О	Ο	Ο
I feel physical pain, but it does not seem to bother me as much as other people	О	О	O	О	Ο	O
I smell things that are not actually there	О	О	Ο	О	•	Ο
I remember bits of past experiences, but cannot put them together	О	О	О	О	O	Ο
I have arguments with myself	О	О	Ο	О	•	Ο
I do not seem to be as upset by things as I should be	О	О	О	О	O	O
I act without thinking	О	О	Ο	О	•	0
I do not really seem to get angry	О	О	Ο	О	0	Ο
I just feel numb and empty inside	0	О	0	О	0	Ο
I notice myself doing things that do not make sense	О	0	О	0	0	0
Sometimes I feel relaxed and sometimes I feel very tense, even though the situation is the same	О	О	O	О	О	О
Even though it makes no sense, I believe that doing certain things can prevent disaster	0	0	0	Ο	0	0

	Never	Rarely	Sometimes	Often	Very Often	All the time
I have unexplained aches and pains	0	0	Ο	0	Ο	Ο
It feels as if there is more than one of me	0	О	0	Ο	0	ο
Unwanted thoughts come into my head	0	Ο	Ο	0	Ο	Ο
My mind just goes blank	О	О	0	О	Ο	Ο
I feel touched by something or someone that is not there	0	0	О	0	0	0
I have big gaps in my memory	О	О	Ο	О	0	0
I see something that is not actually there	О	О	Ο	О	0	0
My body does not feel like my own	О	О	0	О	0	Ο
I cannot control my urges	О	О	0	О	0	Ο
I feel detached from reality	О	О	Ο	О	0	0
Chunks of time seem to disappear without my being able to account for them	О	О	О	О	0	O
I sometimes look at myself as though I were another person	О	О	О	О	0	O
Things around me do not seem real	О	О	Ο	О	0	0
I do not seem to feel anything at all	О	О	Ο	О	0	•
I taste something that I have not eaten	О	О	Ο	О	0	•
I find myself unable to think about some things, however hard I try	О	О	О	О	0	O
I talk to myself as if I were another person	О	О	0	О	0	Ο
I do not seem to feel physical pain as much as other people	О	О	О	О	0	O
I hear things that are not actually there	0	О	0	О	Ο	Ο
I find myself in situations or places with no memory of how I got there	О	О	О	О	0	O
It is absolutely essential that I do some things in a certain way	0	0	O	0	0	0

### APPENDIX S: CONT.
# APPENDIX T: PATIENT HEALTH QUESTIONNAIRE – DEPRESSION

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things	0	0	0	0
Feeling down, depressed, or hopeless	O	0	О	O
Trouble falling or staying asleep, or sleeping too much	O	0	О	O
Feeling tired or having little energy	О	0	0	О
Poor appetite or overeating	0	0	Ο	0
Feeling bad about yourself or that you are a failure or have let yourself or your family down	О	O	О	O
Trouble concentrating on things, such as reading the newspaper or watching television	О	О	О	0
Moving or speaking so slowly that other people could have noticed -or- being so fidgety or restless that you have been moving around a lot more than usual	О	О	О	0
Thoughts that you would be better off dead or of hurting yourself in some way	О	О	О	О

#### APPENDIX U: RAND SHORT-FORM HEALTH SURVEY

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

- □ Cut down the amount of time you spent on work or other activities
- □ Accomplished less than you would like
- Didn't do work or other activities as carefully as usual

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks . . .

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you feel full of pep?	О	Ο	О	Ο	Ο	Ο
Have you been a very nervous person?	О	О	О	O	0	О
Have you felt so down in the dumps that nothing could cheer you up?	О	0	0	0	0	О
Have you felt calm and peaceful?	О	O	О	0	0	О
Did you have a lot of energy?	О	Ο	Ο	Ο	Ο	О
Have you felt downhearted and blue?	О	0	О	0	O	О
Did you feel worn out?	О	Ο	О	0	0	О
Have you been a happy person?	Ο	0	О	0	0	Ο
Did you feel tired?	Ο	Ο	Ο	0	0	Ο

## APPENDIX U: CONT.

This section will ask you to describe your physical health in a variety of ways. Please note the timeframes differ between the questions. At times, you may find yourself reporting about the same or similar experiences. This is not meant to be confusing; we are often asking about different frames of time (e.g., lifetime vs. past four weeks). Please also pay attention to the response options, these will change across sections. There are no right or wrong responses and you may leave any items blank you do not wish to answer.

In general, how would you describe your health?

- Excellent
- Very Good
- O Good
- O Fair
- O Poor

Compared to one year ago, how would you rate your health in general now?

- Much better now than one year ago
- **O** Somewhat better now than one year ago
- **O** About the same
- **O** Somewhat worse now than one year ago
- **O** Much worse now than one year ago

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? (select all that apply)

- □ Cut down the amount of time you spent on work or other activities
- □ Accomplished less than you would like
- □ Were limited in the kind of work or other activities
- □ Had difficulty performing the work or other activities (for example, it took extra effort)

During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- Not at all
- Slightly
- **O** Moderately
- Quite a bit
- **O** Extremely

#### APPENDIX U: CONT.

The following items are about activities that you might do during a typical day. How much does your health now limit you in any of these activities?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	0	0	0
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	О	О	О
Lifting or carrying groceries	Ο	Ο	Ο
Climbing several flights of stairs	0	О	Ο
Climbing one flight of stairs	Ο	Ο	Ο
I will indicate I am not limited on this item	О	0	О
Bending, kneeling, or stooping	Ο	Ο	Ο
Walking more than a mile	Ο	Ο	Ο
Walking several blocks	Ο	Ο	Ο
Walking one block	0	Ο	Ο
Bathing or dressing yourself	O	Ο	0

How much bodily pain have you had during the past 4 weeks?

- O None
- **O** Very mild
- O Mild
- O Moderate
- O Severe
- **O** Very Severe

During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- **O** Not at all
- **O** A little bit
- **O** Moderately
- Quite a bit
- **O** Extremely

## APPENDIX U: CONT.

During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- **O** All of the time
- **O** Most of the time
- **O** Some of the time
- **O** A little of the time
- **O** None of the time

How true or false are the following statements to you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
I seem to get sick a little easier than other people	О	0	О	О	О
I am as healthy as anybody I know	О	О	О	O	О
I expect my health to get worse	О	0	О	0	O
My health is excellent	О	О	Ο	Ο	Ο

# APPENDIX V: PENNEBAKER ILLNESS AND LIMBIC LANGUIDNESS SCALE

Several common symptoms or bodily sensations are listed below. Most people have experienced most of them at one time or another. We are currently interested in finding out how prevalent each symptom is among various groups of people. Please indicate how frequently you experience each symptom.

	Have never or almost never experienced the symptom	Less than 3 or 4 times per year	Every month or so	Every week or so	More than once every week
Eyes water	0	0	Ο	Ο	0
Itchy eyes or skin	0	Ο	Ο	Ο	Ο
Ringing in ears	0	Ο	Ο	Ο	Ο
Temporary deafness or hard of hearing	0	0	O	О	0
Lump in throat	O	Ο	Ο	Ο	Ο
Choking sensations	0	Ο	Ο	Ο	Ο
Sneezing spells	0	Ο	Ο	Ο	Ο
Running nose	O	Ο	Ο	Ο	Ο
Congested nose	0	Ο	Ο	Ο	Ο
Bleeding nose	O	Ο	Ο	Ο	Ο
Asthma or wheezing	0	Ο	Ο	Ο	Ο
Coughing	0	Ο	Ο	Ο	Ο
Out of breath	0	Ο	Ο	Ο	Ο
Swollen ankles	0	Ο	Ο	Ο	Ο
Chest pains	0	Ο	Ο	Ο	Ο
Racing heart	0	Ο	0	0	Ο
Leave this item blank	0	Ο	Ο	Ο	Ο
Cold hands or feet even in hot weather	0	O	O	0	O
Leg cramps	0	Ο	0	0	Ο
Insomnia or difficulty sleeping	0	Ο	0	0	Ο
Toothaches	0	Ο	0	0	Ο
Upset stomach	0	0	0	0	0
Indigestion	0	0	0	0	0
Heartburn or gas	0	0	0	Ο	0

APPENDIX V: CONT.

	Have never or almost never experienced the symptom	Less than 3 or 4 times per year	Every month or so	Every week or so	More than once every week
Abdominal pain	0	Ο	Ο	Ο	О
Diarrhea	0	Ο	Ο	Ο	Ο
Constipation	0	Ο	Ο	Ο	Ο
Hemorrhoids	Ο	О	Ο	Ο	O
Swollen joints	Ο	О	Ο	Ο	O
Stiff or sore muscles	0	Ο	Ο	Ο	Ο
Back pains	0	Ο	Ο	Ο	Ο
Sensitive or tender skin	0	Ο	Ο	Ο	Ο
Face flushes	0	Ο	Ο	Ο	Ο
Tightness in chest	0	Ο	Ο	Ο	Ο
Skin breaks out in rash	0	Ο	Ο	Ο	Ο
Acne or pimples on face	0	Ο	Ο	Ο	Ο
Acne/pimples other than face	0	Ο	Ο	Ο	Ο
Boils	0	Ο	Ο	Ο	Ο
Sweat even in cold weather	Ο	Ο	Ο	Ο	O
Strong reactions to insect bites	Ο	Ο	Ο	Ο	O
Headaches	0	Ο	Ο	Ο	Ο
Feeling pressure in head	Ο	Ο	Ο	Ο	O
Hot flashes	Ο	Ο	Ο	Ο	O
Chills	Ο	О	Ο	Ο	O
Dizziness	Ο	О	Ο	Ο	O
Feel faint	0	Ο	Ο	Ο	O
Numbness or tingling in any part of body	0	О	О	О	О
Twitching of eyelid	0	Ο	Ο	Ο	0