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Perceptions of Quality of Healthcare Using a Trauma-Informed Care Perspective Among Trauma Survivors

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by

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Perceptions of quality of healthcare using a trauma-informed care perspective among trauma survivors

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Abstract

TITLE: Perceptions of quality of healthcare using a trauma-informed care perspective among trauma survivors

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Trauma is an all-too-common occurrence with the potential for several far-reaching, deleterious effects both mentally and physically. Several studies have found an association between exposure to trauma and cardiovascular, immune, and musculoskeletal system complications. It has also been linked to chronic pain, cancer, and obesity, in addition to several functional and structural neurological effects. Trauma survivors have also been found to utilize healthcare services at a higher rate than those who have not reported experiencing trauma. Trauma-informed care is a relatively novel concept that has been introduced to increase the sensitivity with which these individuals are treated when attending healthcare appointments, due to the potentially triggering effect often associated with them. However, research examining patients' perspectives using a specific trauma-informed care context is severely lacking. Therefore, this study aimed to expand the literature by examining the perceived quality of healthcare, from a trauma-informed care perspective, among survivors of trauma.

A total of 57 trauma survivors were included in the study. The results from this study found that most trauma survivors in the sample perceived the quality of their health care as adequate. Perceptions of care did not differ across demographic and trauma-related factors. However, trauma survivors with less symptoms of posttraumatic stress had better perceptions of their care compared to trauma survivors with more symptoms of posttraumatic stress. There were also significant differences between groups on different aspects of trauma-informed care. Additionally, individuals who reported a higher number of barriers to healthcare and had lower perceptions of quality of care had higher rates of healthcare utilization compared to individuals with a higher number of barriers to healthcare and higher perceptions of quality of care. This study uniquely provided an understanding of how a sample of trauma survivors perceives the quality of their healthcare interactions, using a specific trauma-informed care context based on the principles proposed by SAMHSA.

Table of Contents

List of Tables

Tables

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Chapter 1: Review of the Literature

Perceptions of quality of healthcare using a trauma-informed care perspective among trauma survivors

The American Psychiatric Association (APA) defines a traumatic event as indirect or direct "exposure to actual or threatened death, serious injury, or sexual violence (2013, p. 271)." These events can include, but are not limited to, accidents, natural disasters, fires, combat exposure, death of a family member or friend due to violence, and interpersonal violence, including physical or sexual assault.

Following a traumatic event, an individual might begin to engage in behaviors in an effort to manage the negative cognitions and emotions associated with the event, both during and after its occurrence. These coping mechanisms, such as avoidance or substance use, can be effective in the short-term but have the potential to become maladaptive in the long-term. Posttraumatic stress disorder (PTSD) occurs when an individual who has experienced a traumatic event begins experiencing intrusive symptoms, negative mood or cognitive alterations, increases in arousal or reactivity, and engages in persistent avoidance of trauma-related stimuli to the extent that it significantly impacts daily functioning (APA, 2013).

Prevalence of Trauma

The National Center for PTSD within the Department of Veterans' Affairs reports that approximately six of every ten men and five of every ten women experience at least one traumatic event in their lives (2022). Studies have estimated the prevalence of an exposure to a traumatic event in the United States adult population to be as high as 89.7% (Kilpatrick et al., 2013) and 89.6% (Milanak et al., 2019). The type of trauma exposure also varied, with women being more likely to report experiencing interpersonal trauma, or trauma that involves at least one or more perpetrators (Yehuda et al., 2015).

The way in which trauma can impact an individual varies significantly from person to person. Despite these high numbers of trauma exposure, not everyone who experiences such an event develops PTSD. Schein et al. systematically reviewed 38 observational studies of the prevalence of PTSD in the US (2021). They found that the lifetime prevalence of developing PTSD ranged greatly between 3.4% and 26.8%. Another study found that in a sample of 36, 309 adults, 68.6% of them had been exposed to one or more potentially traumatic events (PTE) and the lifetime prevalence of PTSD was 6.1% (Goldstein et al., 2016). Research indicates that there are several factors which can account for the discrepancy of trauma exposure and the development a PTSD diagnosis including resilience, personality factors, such as self-esteem or assertiveness, intelligence, information processing styles, coping styles, and interpersonal support (Agaibi & Wilson, 2005).

Risk Factors of Trauma

Although considerable variability in the number of individuals who were exposed to a traumatic event has been demonstrated across studies, there are also some similarities between studies that are quite salient. One of the most prominent is female sex as a risk factor for the development of PTSD (Goldstein et al., 2016; Lehavot et al., 2018; Schein et al., 2021; Yehuda et al., 2015). Additional risk factors include low income, younger age, other behavioral health conditions, and indigenous populations (Goldstein et al., 2016; Schein et al., 2021).

A nationally representative survey found that African Americans have higher rates of probable lifetime PTSD when compared to non-Latino Caucasian individuals (Alegria et al., 2013). Meanwhile, the same study found that Asians and Latinos have lower rates of lifetime PTSD, and these differences remained even after the researchers controlled for sociodemographic, clinical, and social factors (Alegria et al., 2013). Other studies that have also found that minority children experience disproportionately higher instances of adverse childhood experiences (ACEs) as a result of structural racism (Barnett et al., 2020; Felitti et al., 1998) and racial stigmatization (Roberts et al., 2011). In addition to this higher likelihood of exposure, there exists a possibility of factors that predispose African Americans to the development of PTSD, such as neuroendocrine alterations, including cortisol dysregulation (Alegria et al., 2013).

Several studies have also examined additional risk factors for exposure to child sexual abuse (CSA). One study systematically reviewed 72 of these that were published between 1980 and 2017 (Assink et al., 2019). The researchers identified some similar risk factors (i.e., being female), as well as several others specific to CSA. Prior victimization in general was found to have the largest effect size, including previous CSA of the original victim, other siblings or family members, as well as other types of abuse which took place in the home, and the victim's parents having a reported history of CSA (Assink et al., 2019). The researchers also identified other risk factors, including witnessing intimate partner violence within the home, parenting problems, and non-nuclear family dynamics, such as having a step-father (Assink et al., 2019).

Interpersonal Versus Non-Interpersonal Trauma

While the APA considers several different events to be considered traumatic (2013), different categories of traumatic events might elicit different reactions. The World Health Organization (WHO) differentiates non-interpersonal trauma, such as natural disasters and severe accidents, from interpersonal trauma, described as violence committed by at least one or more persons against another, such as assault or intimate partner violence (Krug et al., 2002). It is necessary to distinguish these subtypes, as several studies have found that interpersonal trauma is significantly associated with greater or more severe symptoms of PTSD among clinical samples (Breslau et al., 1998; Forbes et al., 2012; Forbes et al., 2014; Huang et al., 2017; Kilpatrick et al., 2013, Thomas et al., 2021), as well as non-clinical student samples (Cromer & Smyth, 2010).

Research has highlighted several factors that contribute to more severe trauma-related symptoms in survivors of interpersonal trauma. While all types of trauma have been found to elicit feelings of fear, studies have identified several other negative emotions unique to experiencing an interpersonal trauma, including shame and guilt (Badour et al., 2017; La Bash & Papa, 2013; Tipsword et al., 2022). One study identified shame as the primary emotion trauma survivors experienced, even greater than fear, and found a significant relationship between high levels of trauma-related shame and trauma-related symptom severity (Tipsword et al., 2022), as well as greater overall levels of negative affect associated with their trauma (Badour et al., 2017). Furthermore, in relation to interpersonal trauma alone, research has found that genetic factors affect exposure to these kinds of events, while non-interpersonal traumas are determined more by environmental factors (Lyons et al., 1993; Stein et al., 2002). Finally, individuals who experience an interpersonally traumatic event are at a higher risk of retraumatization, or being exposed to another traumatic event at a later time (Arata, 1999; Cougle et al., 2009; Lilly & Valdez, 2012). Researchers have posited that this is due to an impeded ability to correctly distinguish safe situations from dangerous ones due to alterations in the way environmental information is interpreted (Chu et al., 2019; Cougle et al., 2009).

Adverse Childhood Experiences (ACEs)

It is difficult to discuss trauma without including the landmark Adverse Childhood Experiences (ACEs) study in the discussion. The ACEs that were of focus in this study included physical, psychological, and sexual abuse, and household dysfunction, including mental illness, domestic violence, substance abuse, and the incarceration of a relative (Felitti et al., 1998). This study found that exposure to adverse events was very common, with 52.1% of the participants endorsing at least one or more of the categories and 6.2% of participants endorsing four or more (Felitti et al., 1998). Exposure to these events was found to typically be chronic, ranging from months to years, and those who reported being exposed to one ACE had an 87% chance of being exposed to another category. Furthermore, a dose-response relationship was found, meaning the greater the number of ACEs endorsed, the more likely the individual was to experience long-term negative effects (Felitti et al., 1998; Kendall-Tackett, 2009). ACE exposure was found to be linked with chronic health problems, including cardiovascular disease, cancer, chronic lung disease, skeletal fractures, headaches, autoimmune disease, obesity, and liver disease. Additionally, as a result of systemic racism, including inequality and discrimination, ACEs were found to be disproportionately higher in minority children (Barnett et al., 2020; Felitti et al., 1998).

The Effects of Trauma on the Brain

Trauma has been shown to have several structural and functional impacts on the brain, even after a single exposure (D'Andrea et al., 2011). In PTSD, the adaptive way in which fear learning and memories are processed is significantly disrupted (Harnett et al., 2020), in that individuals tend to associate fear reactions with non-threatening stimuli (Bremner et al., 2005; Fani et al., 2019; Harnett et al., 2018; Inslicht et al., 2013; Rabinak et al., 2017). The prefrontal cortex (PFC), hippocampus, and amygdala all work as a network that is responsible for fear learning and memory, and all are affected when PTSD is present (Harnett et al., 2020). The individual's ability to regulate emotions is also negatively impacted due to overactivation of the amygdala (Elzinga & Bremner, 2002; Etkin & Wager, 2007; Pitman et al., 2012; Rauch et al., 2006).

Studies have found structural differences related to trauma as well. Pitman et al. (2012) reviewed several studies that used structural magnetic resonance imaging (sMRI) and found smaller hippocampi in participants with PTSD compared to those who had never been exposed to trauma (Bremner et al., 1995; Gurvits et al., 1996; Stein et al., 1997). This likely leads to some attentional bias, as the hippocampus assists individuals in identifying stimuli within the environment to determine whether one is safe (Pitman et al., 2012). Volume differences within the PFC have also been detected (Pitman et al., 2012), as well as functional changes in traumatized individuals, as the ventromedial PFC (vmPFC) has been found to be underactive, thus failing to regulate the activity of an already overactive amygdala (Elzinga & Bremner, 2002; Rauch et al., 2006). Furthermore, the insular cortex, responsible for sensory processing, has been shown to have increased levels of activation, which might explain the hypervigilance often associated with PTSD (Aupperle et al., 2012; Simmons et al., 2008; Strigo et al., 2010). Studies have further demonstrated that patients who experience functional neurological symptoms and disorders, rather than organic, are significantly more likely to have a history of trauma (Kaplan et al., 2013; Karatzias et al., 2016; Reilly et al., 1999). Furthermore, the timing of trauma exposure might impact brain development, specifically when children are undergoing a sensitive period (Pechtel & Pizzagali, 2011; Teicher et al., 2006). This can include negative effects on the hypothalamic-pituitary-adrenal (HPA) axis and reduced hippocampal volume (Pechtel & Pizzagali, 2011; Teicher et al., 2006).

Attentional Bias in PTSD

Considering the primary objective of this study seeks to focus on the perceptions of trauma survivors, it is important to understand the mechanisms that may influence the processing of information in their environment. Previous research has demonstrated that individuals diagnosed with PTSD exhibit attentional biases that can exacerbate and maintain their symptoms (Armstrong et al., 2013; Pineles et al., 2009; Schoorl et al., 2014). Attentional bias can be defined as the early and automatic processing of stimuli, often negative, in the environment, and it is typically specific, meaning those with PTSD often focus on information specific to their trauma (Schoorl et al., 2014).

Previous research has focused on two types of attentional bias: attentional facilitation and attentional interference. Facilitation occurs when individuals experience an increased level of attention towards threat-related stimuli, while interference refers to a disrupted ability to engage in tasks because of the additional challenge of disengaging from threat-related stimuli (Pineles et al., 2009). Several studies have concluded that attentional interference is the primary type of attentional bias occurring in individuals with PTSD (Armstrong et al., 2013; Bardeen & Orcutt, 2011; Pineles et al., 2009). Relatedly, hypervigilance is one of the more pronounced symptoms of PTSD (APA, 2013). However, an increase in threat detection does not mean the individual is accurately scanning the environment. In fact, this hypervigilant state may inhibit (i.e., interfere with) the individual's ability to attend to critical information, such as evidence that they are likely not in danger (Bardeen & Orcutt, 2011). This bias is important to consider when discussing perceptions of trauma survivors, because they may inaccurately interpret environmental cues in the healthcare setting as threatening, thereby contributing to negative experiences related to their healthcare.

The Impact of Trauma on Physical Health

There is a plethora of research highlighting the short- and long-term physical effects associated with exposure to trauma. Multiple studies have found a link between trauma and ACE exposure and cardiovascular diseases (Boullier & Blair, 2018; D’Andrea et al., 2011; Felitti et al., 1998; Kalmakis & Chandler, 2015; Kartha et al., 2008; Kendall-Tackett, 2009), cancer (Boullier & Blair, 2018; Felitti et al., 1998; Schnurr, 2015), chronic lung disease (Boullier & Blair, 2018; Felitti et al., 1998; Kalmakis & Chandler, 2015), impaired immune functioning (Kalmakis & Chandler, 2015; Kendall-Tackett, 2009), obesity (Kalmakis & Chandler, 2015; van den Berk-Clark et al., 2018), and chronic pain (Kendall-Tackett, 2009; Shcnurr, 2015). Additionally, trauma exposure has been found to be related to disruption in the musculoskeletal and gastrointestinal systems (D’Andrea et al., 2011; Kartha et al., 2008). Impacted sleep has also been found to be associated with trauma exposure (Kalmakis & Chandler, 2015; Kendall-Tackett, 2009; Milanak et al., 2019). A bidirectional relationship between sleep and inflammation has also been reported, in that inflammation can lead to poor quality of sleep, while poor sleep can result in an increase in inflammation (Kendall-Tackett, 2009).

There are a number of direct and indirect factors that have been examined to explain the relationship between trauma and physical health. One study posited that individuals might turn to maladaptive coping mechanisms such as substance use and overeating to manage the immediate negative effects of trauma exposure, acting as an indirect path due to physical health consequences of these behaviors (Raja et al., 2015; van den Berk-Clark et al., 2018). Dich (2015) found that stressful events and circumstances experienced in childhood had a negative effect on men's neural development, such that areas responsible for coping and emotion regulation were negatively impacted, acting as a direct path to physical health consequences.

One study worth noting took a psychoneuroimmunological approach to understanding the association between trauma and physical health, thus looking at a more direct pathway physical health effects (Kendall-Tackett, 2009). This study examined the system of the body that is responsible for keeping the individual safe when they are thrown into a survival situation. The system includes catecholamines, the HPA axis, and the immune response. Allostatic load occurs when the body experiences trauma, in that the body is overwhelmed with stress, which then leads to chronic activation of the HPA axis, and subsequently problematic levels of the stress hormones, cortisol and norepinephrine (Kendall-Tackett, 2009). Furthermore, cytokines are released by the immune system to help the body fight disease and infection. While this response is meant to serve an adaptive purpose by protecting the body when faced with danger, trauma, and potentially severe and overwhelming stressors, can lead to a dysregulated response from this system (Kendall-Tackett, 2009). When there are too many proinflammatory reactions occurring in the body, an individual's likelihood of developing disease increases (McEwen, 2003), and their risk of developing other health problems increases, including cardiovascular issues, chronic pain, and Alzheimer's disease (Kendall-Tackett, 2009). This study also confirmed a finding from the ACEs study of a dose-response relationship between trauma exposure and health concerns, in that the more exposure to events, the more likely an individual experienced negative long-term effects (Felitti et al., 1998), and the more severe the level of inflammation (Kendall-Tackett, 2009).

The Impact of Trauma on Healthcare Perceptions and Utilization

Research has concluded that trauma exposure is significantly related to an increase in healthcare utilization (Farley & Patsalides, 2001; Guha, et al., 2020; Hager & Runtz, 2012; Kalmakis & Chandler, 2015; Raja et al., 2015; Rivara et al., 2007). Increased healthcare utilization has also been found to be associated with ACE exposure (Alcalá et al., 2017; Koball et al., 2019). However, the type of healthcare being accessed by trauma survivors varies. Studies have shown that trauma survivors are more likely to utilize emergency-based or urgent care-type services (Arnow, 2004; Bellis et al., 2017; Farley & Patsalides, 2001; Hager & Runtz, 2012), but are also more likely to avoid primary care or preventive services (Alcalá et al., 2017; Farley et al., 2002; Farley et al., 2001; Farley & Patsalides, 2001; Leeners et al., 2007). Alcalá et al. (2017) found that individuals who endorsed experiencing ACEs were less likely to report having a primary care provider and attend preventive, regular health care appointments.

In addition to these higher rates of utilization, trauma exposure has also been linked to higher rates of prescription medication needs (Farley & Patsalides, 2001;

Kalmakis & Chandler, 2015), but lower rates of medication compliance, possibly due to avoidance of physiological sensations (Kronish et al., 2012). One study found that survivors of childhood sexual abuse were less likely to utilize gynecological services, which might be especially triggering due to the sensitive nature of these visits (Guha et al., 2020). Additionally, another study which examined the association between ACEs and healthcare utilization found that individuals who reported exposure to four or more ACEs made more healthcare appointments, but were more likely to be absent without calling or canceling ahead of time (Koball et al., 2019). Overall, trauma survivors are more likely to utilize health care at higher rates, depending on the type of care being received. It is possible these individuals avoid receiving regular, primary care due to the potentially distressing nature of attending these appointments, prolonging physical health concerns that arise, and leading to the utilization of more emergency-based, acute services instead.

How Healthcare Settings Might Trigger Trauma Reactions

Despite the volume of research on the trauma survivors' perspectives of their experiences with healthcare, most research has examined general perceptions, including barriers, triggers, and utilization of services. Research using specific trauma-informed care outcomes, based on principles of trauma-informed care, however, has been lacking, and the majority of studies have emphasized provider or staff perspectives. While patients who have not experienced trauma have generally reported feelings of discomfort and fear associated with seeking healthcare services (Raja et al., 2015), this process might be all the more daunting to someone who has been exposed to trauma and may be a barrier to attending healthcare visits (Reeves & Humphreys, 2017). Those who have experienced interpersonal trauma might have an increased risk of perceiving accessing healthcare as distressing due to the required interaction with other individuals. One study found that women who reported experiencing interpersonal violence recalled their trauma after being triggered by a healthcare experience (Reeves & Humphreys, 2017). Specifically, the participant felt triggered by the provider ordering her to sit down, leading to a flashback to her relationship with an abuser. Another common theme found in this study was the impact of the interaction with the provider on the healthcare experiences of participants. Participants reported a lack of communication from providers, poor bedside manner, and less time spent with the patient (Reeves & Humphreys, 2017). Some participants acknowledged this was one of the shortcomings of health insurance, which limits the amount of time providers can spend with patients (Reeves & Humphreys, 2017).

This study also considered the impact trauma had on healthcare experiences immediately after the exposure. One participant recalled that she received healthcare services immediately in the aftermath of a traumatic event, during which she was mistreated by a provider, thus further exacerbating the difficulty of her traumatic event (Reeves & Humphreys, 2017). Another discussed her abuser taking her to receive emergency care following a physical altercation with him and the distressing impact his presence had on her throughout her time at the emergency department. She described the fear and isolation she felt throughout the process because she was unable to discuss the abuse with her providers (Reeves & Humphreys, 2017).

One systematic review examined several qualitative research studies that investigated how survivors perceived their healthcare experiences (Schippert et al., 2021). Overall, survivors reported a lack of trust in their providers and the healthcare system, which led to avoidance, not just of appointments but of disclosing their trauma as well (Schippert et al., 2021). Several survivors perceived that their providers held a negative attitude towards them, including discriminatory, racist and hostile attitudes, and that they were receiving a low quality of care (Berman et al., 2006; Shannon, 2014). Similarly, survivors felt their healthcare providers were not culturally aware or sensitive, including regarding their status as trauma survivors (Berman et al., 2006; Tobin et al., 2014) and other survivors reported providers conveying attitudes that led to them feeling as though they were undeserving of the healthcare they were receiving (Perron & Hudelson, 2006). Trauma survivors also reported significant discomfort, fear and even feelings of insult with providers' utilization of medical instruments (Fang et al., 2015; Raja et al., 2015; Shannon et al., 2012; Shannon, 2014; Tobin et al., 2014).

Quantitative research on this topic has resulted in similar conclusions as these qualitative studies. One pervasive theme identified across several studies is that trauma survivors feel powerless and report lack of control (Katon et al., 2001; Schippert et al., 2021; Tobin et al., 2014), which can be further intensified within marginalized patients, such as those of a lower socioeconomic status or minorities, where the patient perceives an even greater power differential (Elliot et al., 2005). Several negative emotions associated with healthcare visits have also been reported by trauma survivors including anxiety, fear, and generally feeling overwhelmed (Dallam, 2010; Raja et al., Schippert et al., 2021; Tobin et al., 2014). Procedures that healthcare providers often complete during an appointment can also lead to feelings of fear and retraumatization (Dallam, 2010). Female interpersonal trauma survivors have reported experiences of retraumatization when their providers utilize words or phrases that remind them of their abusers (Schippert et al., 2021), during procedures in which objects need to be used on or in a patient's body (Schachter et al., 2004; Tobin et al., 2014), such as during Papanicolaou tests (Purkey et al., 2018), and whenever touching or the provider being physically close is required (Raja, 2015), especially by male providers (Purkey et al., 2018). Beyond these triggers, trauma survivors have also reported experiencing negative emotions when they felt their provider was stereotyping them based on things like their trauma history, substance use, and sex work history (Panda et al., 2021; Thorvaldsdottir et al., 2021). Overall, there are several reasons why trauma survivors report having negative, retraumatizing experiences associated with receiving healthcare and these factors should be considered so as not to increase the discomfort already associated with health care.

Trauma-Informed Care

Considering the alarming prevalence of exposure to traumatic events, it is imperative that the needs of trauma survivors be considered during program development, specifically within human services or health care facilities. Exposure to trauma is considered a public health concern that places a significant burden on the individual, their families, and the community, both emotionally and financially. The Substance Abuse and Mental Health Service Administration (SAMHSA) developed a framework that can be implemented in behavioral health and is adaptable to other fields as well, including primary health care. A combination of trauma-specific research, interventions, and lessons from trauma survivors were integrated into this development, along with feedback from both experts and the public. The result of this is a conceptualization of trauma that includes the event, how an individual perceives the event, and the consequential effects following trauma exposure, as well as the assumption and principles outlined in a set of guidelines.

SAMHSA has identified four key assumptions that are critical to recognize in a trauma informed approach (2014). The first is realizing that trauma is a widespread problem that has a negative impact beyond the individual alone. The second assumption is that every provider within an organization or facility that is interacting with consumers of their services should have the ability to recognize the signs of trauma, including having measures in place to assist in doing so, such as trauma screeners (SAMHSA, 2014). The next key assumption is responding by implementing trauma-informed policies and procedures within the organization that remain sensitive to the knowledge that the prevalence and impact of trauma is widespread and significant. The fourth and final key assumption is resisting re-traumatization of consumers by ensuring the trauma-informed policies being implemented are effective in promoting an environment that is perceived to be safe and understanding of their experiences (SAMHSA, 2014).

SAMHSA has also identified six key principles that are critical in effectively providing a trauma-informed environment. The first principle is to ensure that every individual within the organization, staff and patients included, feel both physically and psychologically safe (SAMHSA, 2014). The next principle is trustworthiness and transparency, which is important in establishing and sustaining trust within an organization. The third principle is peer support, which would provide further support to trauma survivors who might have had similar experiences of trauma exposure (SAMHSA, 2014). The fourth principle is collaboration and mutuality, which acknowledges power differentials between staff and patients, and outlines the importance of recognizing every staff member within an organization as being an important contributor to the implementation of the trauma-informed approach. The fifth principle is empowerment, voice and choice, which acknowledges the potential discomfort that might be associated with consumers interacting with providers, who tend to be perceived as holding a position of authority (SAMHSA, 2014). This principle seeks to remove the power differential and allows the patient to collaborate with providers when making decisions, thus strengthening the relationship. The sixth and final principle outlined is cultural, historical and gender issues. This principle discusses the importance of recognizing and overcoming cultural stereotypes placed on individuals within healthcare settings and being sensitive to one's cultural identity (SAMHSA, 2014).

What Makes Trauma-Informed Care Different

One of the criticisms of trauma-informed care is that it does not distinguish itself from patient-centered care such that specific trauma-informed training would be unnecessary. However, one can argue that while SAMHSA's trauma-informed care approach is a subset of patient-centered care, not all patient-centered care is trauma-informed. Patient-centered care focuses on encouraging providers to take a collaborative approach to healthcare by considering the needs of individual patients when making health care decisions (Epstein & Street, 2011). Indeed, there are multiple principles included in the trauma-informed care approach that foster this sense of collaboration. However, trauma-informed care extends beyond regular patient-centered care, in that providers better understand the widespread impact of trauma (SAMHSA, 2014). This approach can be conceptualized as a philosophy that was proposed with the intention of addressing the extensive effects of trauma, due to the idea that trauma should be addressed using a multidisciplinary approach at a public health level (SAMHSA 2014). Research has consistently shown that the majority of patients who present to primary care have been exposed to a traumatic event (Gillespite et al., Kartha et al., 2008; SAMHSA, 2014), further highlighting the importance of adopting a more trauma-specific approach, especially in higher risk populations.

How Implementing Trauma-Informed Care Might Positively Impact Healthcare

Research has shown that when trauma survivors perceive their health care provider as conveying empathy and sensitivity, they are more likely to attend follow up medical appointments and continue to seek preventive care (Campbell, 1998). Furthermore, when providers collaborated with trauma survivors, the patients reported feeling more control and trust (Elliot et al., 2005). Elliot et al. (2005) emphasized the importance of providers transitioning from an expert model to a model that focuses on collaboration, as this perspective allows providers to empower trauma survivors, specifically women who have experienced violence.

One particular study adapted a continuing education course, originally aimed towards mental health professionals, and integrated it into an evidence-based, trauma-informed continuing medical education course for primary care providers (PCPs) called Trauma-Informed Medical Care (TI-Med) (Green et al., 2016). This course included information about adverse experiences and the potential impact they have on health, as a whole. It also encouraged collaboration between PCPs and patients, as it promoted the importance of interactions between them and trauma survivors, and the potentially therapeutic effects of this relationship for the patient (Green et al., 2016). One of the goals of this study was to examine whether patients would be able to identify any differences between providers who did and did not complete this course and evaluate whether it was effective, specifically on collaborative approaches (e.g., working with patients on decision making) (Green et al., 2016). Patients completed a survey measuring partnership before and after their providers completed the course. Results were consistent with previous research, such that those with a history of trauma and symptoms of PTSD rated their PCPs lower on this scale compared to patients without trauma, even after the course was completed (Bassuk et al., 2001; Green et al., 2012; Green et al., 2016). The researchers offered a number of hypotheses about this finding, including past research indicating that providers perceive themselves to have limited abilities working with trauma survivors (Green et al., 2011), subsequently reducing their feelings of comfortability and competency relating to these patients (Green et al., 2016). While the results did not indicate a statistically significant improvement in trauma survivors' perceptions of the partnership, there was some slight improvement which might have been significant with a larger sample size (Green et al., 2016).

The same researchers previously conducted a study in which primary care providers were either randomly assigned to complete a TI-Med course or placed on a waitlist (Green et al., 2015). After providers received this training, each one saw three standardized patients, each with a complete detailed background, for a 15-minute appointment during which they were instructed to treat and counsel the patient. The audio from each of these encounters was recorded and blinded raters were utilized to use standardized codes to rate the providers on their interactions with the patients (Green et al., 2015). The results showed that providers who received the TI-Med training scored higher on the quality of patient-centered interactions (Green et al., 2015) compared to providers who did not receive trauma-informed training.

Implementing a trauma-informed approach has had a positive impact on providing patients with skills and resources that may not have otherwise been provided. One study compared a trauma and violence-informed cognitive behavioral therapy (TVICBT) intervention to standard perinatal care among pregnant women who endorsed a history of domestic violence (Mantler et al., 2021). Despite the group assigned to the TVICBT condition initially having more severe PTSD symptoms, this intervention was more effective in providing participants with adaptive coping mechanisms than the group that received standard perinatal care (Mantler et al., 2021). Another study that took place in a pediatric primary care setting had wellness navigators in place who were responsible for addressing families who endorsed at least one ACE (Barnett et al. 2020). The wellness navigators were then able to provide them with community resources they determined were appropriate, following individual meetings with each family with the most common being insurance, childcare, and housing (Barnett et al., 2020).

Employing a trauma-informed care context may also positively impact a trauma survivor's disclosure. Multiple researchers have posited, and found, that disclosure of trauma can be healing (Jeffreys et al., 2010; Machtinger et al., 2015). However, studies have found that negative reactions to disclosure of sexual assault among women were related to negative outcomes, such as the development of maladaptive coping skills (Brooks et al., 2019; Littleton, 2010; Ullman & Peter-Hagene, 2014), and an increase in symptoms of depression, anxiety, and posttraumatic stress (Hakimi et al., 2018; Orchowski et al., 2013). Conversely, positive reactions were related to more positive outcomes, such as the trauma survivor's sense of self-worth and self-appraisal (Littleton, 2010). Jeffreys et al. (2010) found that when veterans perceived their providers as caring and communicative, they were more likely to disclose their trauma than when providers were perceived as uninterested or lacking concern. This finding, combined with the results of the beneficial outcomes experienced when a trauma disclosure is met positively, provides further evidence of the importance of implementing trauma-informed care.

National Initiatives for Trauma-Informed Care

SAMHSA is just one of the federal agencies that has been supporting the effort to increase awareness for trauma-informed care. The Interagency Task Force on Trauma-Informed Care (TIC Task Force) was established after the Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment (SUPPORT) for Patients and Communities Act of 2018 was passed, which is responsible for identifying, evaluating and making recommendations for providing trauma-informed care, and how other federal agencies can respond to families affected by trauma (SAMHSA, 2022). This task force includes various federal departments of the United States, including the Department of Health and Human Services, Department of Defense, Department of Justice, Department of Education, Department of the Interior, Department of Veterans Affairs, the Department of Housing and Urban Department, and several agencies established within these departments (SAMHSA, 2022).

The United States Preventive Services Task Force (USPSTF, 2018) has provided recommendations based on several groups that advise routine screening for interpersonal violence for women of reproductive age. These groups include the American Academy of

Family Physicians (Dicola & Spaar, 2016), American College of Obstetricians and Gynecologists (ACOG, 2012) American Academy of Neurology (Schulman & Hohler, 2012), American Academy of Pediatrics (Thackeray et al., 2010), Institute of Medicine Committee on Preventive Services for Women (Institute of Medicine, 2011), and the Women's Preventive Services Guidelines supported by the Health Resources and Services Administration (HRSA, 2017). The USPSTF reported that this kind of screening is moderately beneficial and providers should assist with prevention and delivery of services to women experiencing interpersonal violence (2018). This moderately beneficial rating indicates that while there is some evidence that screeners can accurately identify interpersonal violence in women, there is a lack of evidence regarding the effectiveness of brief interventions or providing referral information without ongoing supportive interventions (USPSTF, 2018).

Purtle and Lewis (2017) completed a study that identified every bill that had been introduced in Congress that mentioned the term "trauma-informed" between 1973 and 2015, and found that from 2010 to 2015, the number of bills introduced had increased from 0 to 28, although only two of them became laws. Additionally, the National Conference of State Legislatures (NCSL, 2021) has identified at least 37 states, along with the District of Columbia, that currently have laws in place to address either childhood trauma, toxic stress, or ACEs. Several states have implemented practices such as trainings on trauma-informed practices, created task forces to address trauma, or improved the quality of mental health services provided to those who were exposed to trauma (NCSL, 2021).

Barriers to Healthcare

There are a plethora of factors that make it difficult for individuals to obtain healthcare services, from systematic-level barriers to individual challenges. From a systems standpoint, there are financial considerations and challenges that hinder millions of people from accessing services (Iezzoni, 2020). Keisler-Starkey and Bunch (2020, p.3) reported that in 2019, 26.1 million Americans, or eight percent of the population, did not have any form of health insurance, and even those with either private or public health insurance must contend with the stringent, unforgiving polices limiting this spending. The cost of healthcare is a tremendous barrier for several people and many report avoiding care because of it (Iezzoni, 2020; Keisler-Starkey & Bunch, 2020; Stepanikova & Oates, 2017). Other factors that have been found to act as barriers to healthcare access include a lack of education and health literacy as well as difficulty communicating, including challenges related to language barriers, (Tait & Chibnall, 2014).

Additionally, there are several psychosocial factors that may act as barriers in the healthcare arena. An individual’s gender identity may act as such for several reasons, including the stigma associated with identifying as non-cisgender (Lund & Burgess, 2021; Roberts & Fantz, 2014). Several trans persons have reported experiencing discriminatory behavior directed at them, with 25-30% of participants in one survey reporting that they had experienced some form of harassment or violence within a healthcare setting (Goldstein et al., 2017). One study found that 19% of the participants had been refused care as a result of their gender identity (Grant et al., 2010).

Another psychosocial factor that is important to consider is race and ethnicity. Stepanikova and Oates (2017) found that African Americans were most likely to lack health insurance, followed by Native Americans, with many reporting that they avoided receiving any form of care because of the cost associated with healthcare. However, the cost of healthcare is simply one reason African Americans tend to have lower levels of healthcare services (Collins & Rocco, 2014; Feagin & Bennefield, 2014; Smedley et al., 2009). The medical history of detrimental, unethical practices associated with African Americans is extensive, which has continued to contribute to a deep sense of mistrust in medical providers by those in this community (Bhopal, 1998). African Americans were often used as medical subjects, including during surgical experiments without the use of anesthesia, during the Tuskegee syphilis study, when doctors claimed the progression of the disease differed between races and continued to withhold treatment despite its discovery during the time of the study, and the eugenics movement, when several Black women were sterilized without their knowledge or consent (Feagin & Bennefield, 2014). On a similar note, minorities typically have less access to healthcare services, including those of a high quality (Smedley et al., 2009), and are less likely to seek out these services in the first place (Mueller et al., 1998). When African Americans do receive healthcare services, perceived racial discrimination is likely, which can exacerbate the negative feelings already associated with the healthcare system (Stepanikova & Oates, 2017).

Several factors at an individual level may also act as barriers to the utilization of healthcare services. Past experiences can influence an individual’s likelihood of accessing healthcare in the future, including time constraints, such as feeling rushed during an appointment, unclear instructions from providers (Hesselink et al., 2012) and a general fear of receiving health care (Raja et al., 2015; Schippert et al., 2021; Schumann

& Lang, 2020). Interestingly, body-related shame is also associated with avoidance of health care, particularly among patients with a higher BMI (Mensinger et al., 2018).

One research study surveyed 1,500 rural healthcare providers to examine what kinds of barriers to care they believe their patients experience (Brems et al., 2006). These providers reported experiencing barriers that providers in urban locations might not experience, including limited resources, such as not having enough specialists available, or colleagues for consultation on certain cases (Brems et al., 2006). They also reported having more complications with confidentiality and lack of privacy issues due to the smaller, closer nature often present in smaller, rural locations (Brems et al., 2006). This study also identified other barriers that have been identified in several aforementioned studies, including challenges with language barriers, patients avoiding care due to stigma (Brown & Herrick, 2002; Fife & Wright, 2000), and difficulty accessing services because of transportation challenges and costs (Brems et al., 2006).

Interaction of Trauma and Barriers to Healthcare

While there are several potential barriers to accessing healthcare services, trauma exposure itself can contribute some unique, additional challenges of its own. Although stigma is a barrier that has often been reported, the stigma of mental illness that trauma survivors might experience also makes it difficult to receive health care (Clement et al., 2015; Dockery et al., 2015). There is also stigma associated with being the victim of certain kinds of trauma, namely abuse (Calton et al., 2016; Overstreet & Quinn, 2013; Phillips et al., 2021), including internalized stigma, that is, the extent an individual believes the stereotypes placed on abuse victims to be true of themselves (Overstreet & Quinn, 2013; Phillips et al., 2021). Negative consequences of disclosing trauma can act as a barrier to treatment as well (Robinson et al., 2020), including providers lacking empathy, being insensitive, or lacking education on trauma (Panda et al., 2021; Phillips et al., 2021).

Logistical barriers that affect healthcare utilization include difficulty accessing services, long wait times for appointments, and a lack of awareness on how to obtain services (David et al., 2008; Panda et al., 2021; Phillips et al., 2021; Randhawa et al., 2018). Another unique barrier identified in a qualitative study completed with 40 postpartum women with opioid use disorder was fear towards an abusive partner who might retaliate with violence, or who had control of money or resources (Phillips et al., 2021). This population also reported fear of consequences regarding involvement with child welfare services and law enforcement (Phillips et al., 2021). Research that has focused on participants with a trauma history who also engaged in substance use reported that these individuals often worry about how they will be perceived by healthcare providers (Phillips et al., 2021; Randhawa et al., 2018). Importantly, one study that surveyed 62 adult survivors of child trafficking found that 64% of the participants reported they would access trauma-informed care services if they were available within their communities (Panda et al., 2021).

Provider and Staff Perspectives on Trauma-Informed Care

Research on provider and staff perspectives on trauma-informed care has found the majority of participants hold positive views towards trauma-informed approaches (Bruce et al., 2018; Kassam-Adams et al., 2015). However, there is some variability in perceptions of trauma-informed care according to the type of healthcare provider assessed. Nurses typically hold more favorable views of trauma-informed care (Bruce et al., 2018; Kassam-Adams et al., 2015) compared to medical doctors who showed favorable opinions at a much lower rate (Bruce et al., 2018). These studies also found that self-rated levels of competence in delivering trauma-informed care is relatively high, with the majority of participants rating themselves greater than at least somewhat competent.

Despite these generally positive views, providers have identified several barriers to implementing trauma-informed care including limited time with patients, lack of knowledge on how to respond, lack of knowledge on trauma-informed care practices, discomfort associated with asking patients about trauma history, and concerns about retraumatization of patients (Bruce et al., 2018; Reeves, 2015). One study examined the extent to which trauma-informed care was implemented in a multidisciplinary agency that served homeless individuals and included physical health services as well as behavioral and community services (Crawford, 2022). Of all the disciplines surveyed, the medical clinic within this agency scored significantly lower than the others in terms of delivering trauma-informed care (Crawford, 2022). Another study consisting of 345 providers found that only 36% of the 67 agencies included completed a trauma-informed care self-assessment to measure adherence to these principles (Unick et al., 2019). Of these, only 32% implemented any changes following the results of the assessment, and only 19% considered patients' or consumers' opinions (Unick et al., 2019).

Studies have also compared the difference in trauma-informed care service delivery following trauma-specific trainings for providers and staff. Purtle (2020) systematically reviewed 23 studies that included such components. Although there was some variability in terms of research designs that limited the strength of this review, several studies demonstrated an overall improvement in knowledge, attitudes, and behaviors of trauma-informed practices following training completion (Purtle, 2020). Overall, providers and staff are often used in research that examines opinions of, or adherence to trauma-informed care principles within a variety of settings, perhaps due to the ease of access to this population in comparison to patients or consumers.

One study, conducted in Canada, examined both patient and provider perspectives using a trauma-specific outcome measure, unlike past research which has utilized general outcomes (Kokokyi et al., 2021). The researchers developed a trauma-informed care survey, based on the guidelines proposed by SAMHSA (2014), to measure the extent patients reported their PCPs were providing care that adhered to these guidelines, and how often PCPs reported they were delivering trauma-informed care (Kokokyi et al, 2021). Following the development of the survey, a pilot study was conducted utilizing university students and physicians and was modified after further consultation from patients and physician advisors. Questions regarding the perceived importance of trauma-informed care were also included in the survey. Overall, 296 patients completed the survey and reported receiving trauma-informed care at a slightly above average rate (Kokokyi et al., 2021). The 60 physicians that completed the survey reported they were providing their patients with higher levels of trauma-informed care than the patients reported receiving it (Kokokyi et al., 2021). Furthermore, while both patients and PCPs rated trauma-informed care as being generally important, providers perceived it to have a higher level of importance than patients.

Chapter 2: Study Rationale and Justification

The literature on the widespread prevalence of trauma exposure and the far-reaching negative effects it has on both physical and mental health is well-established. Considering the significant number of patients who present to primary care who have a history of trauma, it is of utmost importance that providers receive training on how to adequately interact with these patients. Several studies have examined the perspectives of trauma survivors and their experiences within the healthcare system, in general. There have also been a number of studies completed with the purpose of examining whether trauma-informed approaches were in place, the extent to which they were being adhered, using a trauma-specific quality of care measure, and opinions on trauma-informed care, that reflected staff perspectives (Bruce et al., 2018; Crawford, 2022; Kassam-Adams et al., 2015; Purtle, 2020; Reeves, 2015; Unick et al., 2019). However, to our knowledge, only one study has examined patient perspectives using a trauma-specific quality of care outcome, addressing components of trauma-informed care, formally defined by SAMHSA (2014). (Kokokyi et al., 2021). Clearly, the patient perspective has not been adequately examined based on recommended current standards of trauma-informed care.

The present study examined how trauma survivors perceive the quality of healthcare they have received, from a trauma-informed care perspective, based on the principles proposed by SAMHSA. This study distinguishes itself from previous research in several ways. First, the study by Kokokyi et al. (2021) was completed in Canada using a general population, while this study examined participants living in the United States who have reported experiencing a traumatic event. As previous research has noted, trauma survivors tend to report more negative perceptions of their healthcare providers and the healthcare system as a whole compared to those who have not been exposed to trauma (Green et al., 2016). Therefore, it is important to obtain these perspectives to provide a better understanding of how their experiences can be improved. More notably, results from Kokokyi et al. (2021) found an important discrepancy between the providers' and patients' perspectives; that is, providers reported they were delivering trauma-informed care at higher rates than patients reported they were receiving it. Considering the number of completed studies that assessed provider perspectives, this finding makes assessing the patient perspective all the more salient. While one previous study examined patient perspectives following providers' completion of a trauma-informed training program, the researchers did not utilize a specific trauma-informed outcome measure (Green et al., 2016). Furthermore, similar to the aforementioned study, the researchers did not examine this within a trauma-specific population. Additionally, the present study included other variables that might be affected by trauma survivors' healthcare experiences, including barriers and utilization, that have not been addressed in previous research.

The findings from this study sought to do the following: provide further evidence of the importance of implementing trauma-informed approaches on a larger scale, encourage researchers to consider the perspectives of the patient to be just as critical, if not more so, than providers when looking to examine the implementation of or adherence to trauma-informed care, and, ultimately drive the development of a standardized, empirically validated measure to assess for trauma-informed quality of care from a patient perspective.

Chapter 3: Objectives and Hypotheses

- Objective 1: To examine the perceived quality of healthcare, from a trauma-informed care perspective, among survivors of trauma.

    Hypothesis 1.1: The perceived quality of healthcare, from a trauma-informed care perspective, will overall be rated poorly by trauma survivors.

- Objective 2: To examine the differences between demographic groups on perceived quality of trauma-informed care in trauma survivors.

    Hypothesis 2.1: Trauma survivors of minority status (e.g., indigenous, African-American, Hispanic) will report lower perceived quality of care, from a trauma-informed perspective, compared to survivors of non-minority status (e.g., non-Hispanic Caucasian).

    Hypothesis 2.2: Trauma survivors who identify as female will report lower perceived quality of care, from a trauma-informed perspective, compared to survivors of other gender identities.

    Hypothesis 2.3: Trauma survivors of a lower socioeconomic status will report lower perceived quality of care, from a trauma-informed perspective, compared to survivors of higher socioeconomic status.

- Objective 3: To examine the differences between groups, based on trauma-related factors, on perceived quality of trauma-informed care in trauma survivors.

    Hypothesis 3.1: Trauma survivors with multiple traumas will report lower perceived quality of care, from a trauma-informed perspective, compared to survivors who have less trauma exposure.

Hypothesis 3.2: Survivors of interpersonal trauma will report lower perceived quality of care, from a trauma-informed perspective, compared to survivors exposed to other types of trauma.

Hypothesis 3.3: Trauma survivors with more severe posttraumatic stress symptoms will report lower perceived quality of care, from a trauma-informed perspective, compared to survivors with less severe posttraumatic stress symptoms.

- Objective 4: To examine the relationship between perceived quality of care, from a trauma-informed perspective, healthcare utilization, and barriers to healthcare.

    Hypothesis 4.1: Trauma survivors with lower perceived quality of care, from a trauma-informed perspective, will report lower rates of healthcare utilization compared to survivors with greater perceived quality of care.

    Hypothesis 4.2: Healthcare utilization will be influenced by the interaction of perceptions of quality of care and barriers to treatment. Individuals with higher perceptions of quality of care and fewer barriers to treatment will report greater scores on a healthcare utilization measure.

Chapter 4: Methods

Eligible participants were required to be: (1) at least 18 years of age or older, (2) able to read and write English fluently, and (3) have experienced at least one traumatic event in their lifetime. Additionally, (4) participants were required to have attended at least one outpatient healthcare appointment (virtual or in-person) within the past six months. Approval from the Florida Institute of Technology Institutional Review Board was obtained prior to the initiation of recruitment. All participants were asked to provide informed consent prior to their participation in this study. Participants were recruited through online survey requests.

Data Collection Procedures

Participants were directed to the survey through a link provided on the consent form. Participants completed the survey on a personal electronic device (e.g., computer, phone, or tablet). Information about this survey was distributed on the internet by websites such as Facebook, as well as email containing information about the study and a link to access the study. The online survey consisted of 87 items and took approximately 15-20 minutes to complete. To begin the survey, participants were required to consent after reading the provided information describing the study. Participants first verified their eligibility by completing an initial set of questions provided in Appendix B and were informed they may withdraw from completing the survey at any time. Participants were able to return to a previous question by using the “back” button within the survey, if needed. Data collected from the survey was entered into a HIPAA-compliant database which de-identified personal information of all participants.

Outcome Measures

Participants were directed to access the survey located on the Qualtrics website. All data collected was saved and stored onto a secure server location at the Department of Psychology at the Florida Institute of Technology. The primary components of the survey included the following: (see Appendix B for full survey):

Study Eligibility

Eligible participants were 18 years or older, were able to read and write English fluently, endorsed experiencing one or more traumatic events during their lifetime, and had attended an outpatient healthcare appointment within the past six months, excluding dental and eye appointments. Traumatic events were assessed by items included on the Brief Trauma Questionnaire (BTQ) developed by Schnurr et al. (1999) to obtain information on the number and types of traumatic events endorsed by individuals (e.g., military trauma, life-threatening illness, childhood physical and sexual abuse). Participants were considered eligible if they indicated they experienced at least one item on the BTQ.

Demographics

Demographic characteristics that were collected include age, gender identity, sexual orientation, race, ethnicity, region of residency, relationship status, socioeconomic status (individual and household income), and education level.

Trauma Information and History

Participants were asked about their past traumatic experiences using the Brief Trauma Questionnaire (BTQ) a 10-item questionnaire developed by Schnurr et al. (1999). This questionnaire includes the types of trauma experienced by participants. The types of trauma assessed by the survey include military combat, serious car/work accidents, major natural or technological disasters, life-threatening illnesses, physical abuse, physical attacks, sexual abuse, other situations involving serious injury or the threat of serious injury, violent death of a family member or friend, and witnessing a situation in which someone was seriously injured or killed, or being fearful of witnessing someone being seriously injured or killed. The number and types of trauma experienced by participants were reported. For the purpose of this study, interpersonal traumas include war zone events, physical abuse or assault, and sexual abuse or assault. Non-interpersonal traumas include serious accidents, natural or technological disasters, illnesses, sudden loss, and witnessing an event. These categories are based on previous research that has conceptualized interpersonal trauma in this manner (Huang et al., 2017; Thomas et al., 2021).

Posttraumatic Stress. The Posttraumatic Stress Disorder Checklist – Fifth Edition (PCL-5) was developed by Blevins et al., (2015) to measure individuals' experiences of trauma and symptoms of posttraumatic stress disorder (PTSD) based on criteria from the DSM-5. There are twenty items included in this measure, to which respondents answer on a 0-4 Likert-type scale (with 0 being "not at all"; 1 being "a little bit"; 2 being "moderately"; 3 being "quite a bit"; and 4 being "extremely") how much they have been bothered by the symptom presented in each question within the past month. A total severity score (range of 0-80) was obtained after calculating a total score for the twenty items. According to initial research, a cutoff score between 31-33 is indicative of a probable diagnosis of PTSD. Additionally, a diagnosis of PTSD can be made by considering each DSM-5 criteria to be met when an item is rated as a 2 or higher, with one criterion from cluster B being met (which corresponds to items 1-5), one from cluster C (items 6 and 7), two items from cluster D (items 8-14), and two items from cluster E (items 15-20).

It is important to note that the purpose of this study was not to determine the presence of or diagnose participants with PTSD, but rather to examine the effects of past traumatic experiences on an individual's current level of functioning. For the purpose of this study, a higher score on this measure indicated a higher degree of negative impact on an individual's functioning and greater likelihood of meeting criteria for a diagnosis of PTSD based on the DSM-5 criteria.

Perceptions of Quality of Care

Participants were asked about their perception of the quality of care, from a trauma-informed care perspective, they received at an outpatient healthcare appointment attended within the past six months. There have been a number of measures developed for a variety of settings, including relational, organizational, and community, to examine the extent that settings adhere to trauma-informed care guidelines. Despite this, challenges remain in measuring the quality of care from the patients' perspective due to varying definitions of trauma-informed care and a lack of research on the development of measures in this area (Champine et al., 2019). For the purpose of this study, we attempted to identify a measure within a healthcare context that includes components of trauma-focused services and organizational environment and practices. However, the organizational measures included in a meta-analysis conducted by Champine et al. (2019) that met the above criteria were created to be completed by the staff from their perspective (Baker et al., 2016; Bassuk et al., 2017; Coordinated Care Services, Inc., 2019; Fallot & Harris, 2011; Hargreaves et al., 2016; Hummer & Dollard, 2010; Knoche et al., 2018; Yatchmenoff, 2016).

Therefore, the survey that was developed by Kokokyi et al. (2021) was used in this study to measure quality of care from the patient perspective. This survey utilizes the trauma-informed care framework proposed by SAMHSA and focuses on the six core principles of trauma-informed care previously summarized (Kokokyi et al., 2021). The Patient TIC survey includes 29 items that assess the extent to which patients report receipt of trauma-informed care, and their opinion on whether each item related to their care was important (Kokokyi et al., 2021). This survey was adapted for the current study. Questions that assess the patients' perceived importance of the elements of trauma-informed care, in general, were not included. Furthermore, some of the items included in the survey were adapted to ensure patients understood each item (e.g., "respond in a patient-focused manner if you were to disclose past trauma;" patient-focused was described as being respectful and responsive). Another item that asks about awareness of cultural identity, including sexuality, was adapted to include gender identity.

Participants were asked to consider their overall healthcare experience within the last six months, and to report how often they received services from their outpatient providers that were trauma-informed using a 5-point Likert scale. Total scores on this measure range from to 0 to 116, with higher scores indicating a higher quality of care, from a trauma-informed care perspective. Kokokyi et al. (2021) also created subscales within this measure to measure the extent that each of the six principles proposed by SAMHSA (2014) were being followed. Subscales included safety; trustworthiness and transparency; peer support; collaboration and mutuality; empowerment, voice and choice;

and cultural, historical and gender issues. The authors also included an additional trauma subscale to determine whether providers are inquiring about specific traumatic events and responding to disclosures in a sensitive manner. A total score for each subscale was also calculated.

The items included under the trauma subscale include the following: “asked about adverse (stressful) childhood experiences and past emotional trauma” and “responded in a patient-focused (respectful, responsive) manner.” The items included within the safety subscale include the following: “provided a physical space that was not perceived as threatening,” “made you feel welcome by being warm and friendly, and using a welcoming tone of voice,” “allowed and encouraged expression of feelings (even negative emotions) without judgment (e.g., not asserting their judgment on you),” “made you feel emotionally safe by providing reassurance and validating your experiences,” and “responded appropriately to your nonverbal communication.” Items included within the trust subscale were “communicated openly (e.g., provided all relevant information, was transparent) and initiated communication,” “listened to you (e.g., paid attention to what you were saying, not interrupting you) and made eye contact with you when interacting with you,” “used professional tone to convey genuine concern,” “provided informed consent prior to performing any medical activities (e.g., touching you or any medical examinations),” “explained rationale before performing something,” and “acknowledged and took responsibility for their miscommunications.” The following items were included within the collaboration subscale: “found out what was most pressing for you,” “clarified your understanding of your reasons for seeking services,” “explained things in a way you could understand (e.g., use plain language without jargon),” “checked your understanding of information provided," "recognized and equalized power imbalances (e.g., understanding you are an expert in your own life, speaking to you at your level)," "used statements (e.g., "It's your decision," "It's not me to decide") that made collaboration and choice explicit," "outlined consent and format of treatment," "provided you with choices that fit your life circumstances for treatment preferences," and "involved you in decisions surrounding your care." The items included on the empowerment subscale were as follows: "empowered you by providing encouragement, using positive language, and avoiding criticism," "helped you identify your strengths and skills that facilitate management of your own care," and "helped you identify your challenges and difficulties that may get in the way of treatment." The item regarding including others who may be helpful in patient care was the only item included on the peer support subscale ("inquired about others who may be helpful to include in your care (e.g., family member"). The following items were included within the cultural sensitivity subscale: "had awareness of your cultural identity, including sexuality and gender identity," "asked you about your cultural beliefs of your health and illness and how you preferred to treat yourself," and "respected your cultural preference for treatment."

A question asking participants to rate the overall quality of care they received in a way that was sensitive to their trauma was added to provide additional data, should the variability of responses be minimal. Finally, a qualitative item was added that asked participants to provide a brief description of their healthcare experience.

Healthcare Utilization

Participants were asked about their healthcare utilization within the past six months, that includes how often they attended various outpatient appointments, and the types of providers seen (e.g., primary care, ER, specialist). A total score for healthcare utilization, ranging from 0 to 23, was developed based on the visits they attended within the last six months, and the number of health providers they endorsed seeing, with higher scores interpreted as higher rates of healthcare utilization. Specific questions regarding the COVID-19 pandemic were added to this measure, including whether this pandemic has impacted their ability to access healthcare. This measure was adapted from a previous doctoral research project to measure healthcare utilization in patients with chronic pain (Teufert, 2022).

Nature of Outpatient Healthcare Visit

Participants were asked to select which item(s) applied most accurately to the nature of their healthcare visit. This item was included because there may potentially be some instances during which adhering to trauma-informed care principles may not necessarily play as critical of a role than others, in comparison. For example, these principles might be considered or perceived to be more important during a women's annual healthcare visit than during an illness or injury-related visit.

Barriers to Treatment

The Barriers to Healthcare Checklist – Short form, a 17-item self-report questionnaire, was utilized to determine the types of barriers participants have experienced in accessing healthcare (Raymaker et al., 2017a). This measure was developed along with a Long-Form of the measure using participants, both with and without disabilities, to assess barriers to healthcare. The Short-Form used in this study was found to have better content and construct validity compared to the Long-Form, (Raymaker et al., 2017b). Participants responded to these barriers in the form of a checklist by selecting all barriers that have made it difficult or inhibited them from accessing healthcare services.

Chapter 5: Research Design and Data Analysis

This study utilized a cross-sectional design. Descriptive statistics (e.g., means, standard deviations, and frequencies) were calculated for participant demographics and the primary outcomes (perceptions of quality of care, trauma-related factors, healthcare utilization). Differences in perceptions of quality of care between participants on demographic and trauma-related factors were evaluated using independent samples t-tests. A two-way between groups ANOVA was used to assess the interaction effect between perceived quality of care and barriers to treatment on healthcare utilization. Data was analyzed through the Statistical Package for the Social Sciences (SPSS), version 27.0. Analyses were considered significant at the $p < .05$ level.

Chapter 6: Results

Participants

Demographic Variables

A total of 104 individuals consented to and began the online survey for this study. Of these, five were excluded because they had not attended a healthcare appointment within the past six months. Another individual was excluded for not being age 18 or older, leading to a total of 98 eligible participants. Of these, 36 participants were excluded because they did not complete more than 80 percent of the survey, including key aspects of the survey, such as trauma-related or quality of care items. Another five people were excluded because they indicated the healthcare appointment they attended was with a mental health professional (e.g., psychiatrist or psychologist). The final sample consisted of 57 participants (M_{age} = 32.55, SD = 13.69, age range: 18 – 68 years), including 15 men (M_{age} = 41.33, SD = 17.72, age range: 22 – 68 years), 32 women (M_{age} = 30.00, SD = 11.25, age range: 18 – 61 years), two individuals who identified as transgender (M_{age} = 25.00, SD = 8.49, age range: 19 – 31 years), two individuals who identified as gender-fluid (M_{age} = 33.50, SD = 0.707 , age range: 33 – 34 years), one individual who identified as gender queer, and five individuals who described themselves as non-binary (M_{age} = 27.00, SD = 6.08, age range: 19 – 34 years). The majority of individuals identified as White/Caucasian (*n* = 48; 84.2%) and non-Hispanic/Latino (*n* = 48; 84.2%). Two individuals did not report their race or ethnicity. Most participants were employed (*n* = 35; 61.4%) and lived in the Southern United States (*n* = 22; 38.6%). See Table 1 for additional demographic information.

Trauma Variables

Trauma outcomes reported by the participants showed total scores on the BTQ were generally high, with a majority of participants endorsing that they were exposed to more than one traumatic event (*n* = 48; 84.2%). The most frequently endorsed traumas were sexual abuse/assault (*n* = 34; 59.6%), childhood physical abuse (*n* = 30; 52.6%), and witnessing an event (*n* = 28; 49.1%). See Table 2 for additional information regarding frequencies of traumatic exposure.

The Posttraumatic Stress Disorder Checklist – Fifth Edition (PCL-5) is a trauma measure that assess individuals' experiences of trauma and symptoms of PTSD based on DSM-5 criteria. Scores of between 31 to 33 are indicative of a probable diagnosis of PTSD and indicate some impact on the individual's functioning. Participants were grouped into categories based on their PCL-5 scores; those with a score of $\leq$ 30 were assigned to the low PTSS (posttraumatic stress symptoms) group (n = 28; 49.1%), and individuals with a total score of $\geq$ 31 were assigned to the high PTSS group (n = 29; 50.9%).

Instances of trauma disclosure and reactions to these disclosures were also obtained in this sample. The majority of participants reported that they disclosed their trauma to someone after it happened (*n* = 48; 84.2%), and when they did, the individuals they disclosed to were described as supportive (*n* = 34; 59.6%), blaming/rejecting, (*n* = 5; 8.8%), or neutral (*n* = 9; 15.8%). Participants were also asked whether they disclosed their trauma to their healthcare providers. Approximately half indicated that they disclosed their trauma to their provider (*n* = 29; 50.9%%), and when they did, described their provider as supportive (*n* = 17; 29.8%), blaming/rejecting (*n* = 1; 1.8%), or neutral (*n* = 11; 19.3%). Twenty-eight participants (49.1%) reported they did not disclose.

Healthcare Variables

Regarding participants' healthcare utilization outcomes, several reported they attended a healthcare appointment two to three times within the past six months (*n* = 26; 45.6%), with a majority of participants reporting they attended more than one healthcare appointment within the last six months (*n* = 44; 77.2%). The types of providers most frequently seen within the past six months were primary care providers (*n* = 41%; 71.9%), specialists (*n* = 32; 56.1%), and/or ER/Clinic/Urgent care providers (*n* = 15; 26.3%). A majority of participants (*n* = 36; 63.2%) also reported seeing more than one type of provider within the last six months.

The most common reasons participants attended healthcare visits were for routine physical exam/preventive healthcare visit (*n* = 28, 49.1%), lab work (*n* = 20; 35.1%), and illness (*n* = 20; 35.1%). Twelve people also indicated "other" to describe the nature of their visit, and reported reasons such as gender issues, birth control related appointments, and medication follow-ups. A majority of participants reported their efforts to seek healthcare had not been affected by the COVID-19 pandemic (*n* = 36; 63.2%). Similarly, most participants also reported that healthcare visits were not more difficult to access due to the pandemic (*n* = 34; 59.6%). See Table 3 for additional information on healthcare-related variables, including number of visits, types of providers, and nature of visit.

Several participants responded to the qualitative item included towards the end of the survey (i.e., provide a brief description of your healthcare experience). Overall, several participants reported positive experiences with their primary care providers.

However, there were also some participants who reported feeling their primary care provider did not take the time to listen and was dismissive, specifically regarding mental health concerns. Several participants reported negative experiences with specialist providers, including feeling rushed, not feeling as though providers were getting to the root of their problems, and/or feeling dismissed. Other participants reported they felt as though their providers did not believe them regarding certain concerns or pain levels. There were also some responses indicating positive experiences, including participants who reported they felt their providers made them feel safe, were respectful, and took the time to listen and understand their concerns. See Appendix C for samples of participant responses.

Objective 1 To examine the perceived quality of healthcare, from a trauma-informed care perspective, among survivors of trauma.

Hypothesis 1.1 The perceived quality of healthcare, from a trauma-informed care perspective, will overall be rated poorly by trauma survivors

To investigate the hypothesis that trauma survivors would rate their perceived quality of care using a trauma informed care perspective, a total score on the trauma-informed care (TIC) survey was calculated for each participant. Total scores on the 29-item survey ranged from 0-116. In the absence of a standardized cutoff on this measure to describe levels of quality care, a score of 2, on average, (each item scored on a 5-point scale ranging from 0 to 4) across the domains of the survey, equating to a total score of 58, was used to define perceptions of adequate provider-delivered trauma-informed care; using this scoring approach, providers, on average, were described as delivering aspects of trauma-informed care at least “sometimes.” A score of < 58 indicated providers, on average, delivered aspects of trauma-informed care “never” or “rarely,” defined for purposes of this study objective as “poor” quality care.

Based on these metrics, the majority of participants (*n* = 34; 59.6%) reported receipt of adequate quality trauma-informed care, while 23 participants (40.4%) reported receipt of poor quality care. As a result, Hypothesis 1.1 was not firmly supported. For exploratory purposes, a more stringent criteria for quality of care was also created. A cutoff score of 87 was used to identify participants who perceived their providers, on average, to be delivering trauma-informed care at least “frequently” or “almost always,” defined for purposes of this study objective as “good” quality of care. Using this criterion, 18 participants (31.6%) perceived their quality of care to be good.

The overall mean score on the TIC survey was 70.25 (*SD* = 37.69). Total scores were also calculated for each subscale of the TIC survey. Subscale scores were determined based on the scoring procedures described by Kokokyi et al. (2021). Subscale score comparisons were not performed, due to differing numbers of items that load onto each subscale, resulting in variable score ranges across subscales. On the Trauma and Cultural Sensitivity subscales, survivors tended to score at the lower end, potentially indicating a perceived area of weakness with respect to their healthcare. See Table 4 for descriptive information related to subscale scores.

Objective 2 To examine the differences between demographic groups on perceived quality of trauma-informed care in trauma survivors.

Hypothesis 2.1 **Trauma survivors of minority status (e.g., indigenous, African-American, Hispanic) will report lower perceived quality of care, from a**

trauma-informed perspective, compared to survivors of non-minority status (e.g., non-Hispanic Caucasian).

To investigate the hypothesis that trauma survivors of a minority status would report a lower perceived quality of care from a trauma-informed care perspective than trauma survivors of non-minority status, participants were coded based on their reported ethnic/racial status. Participants were categorized as a minority when they identified as any race other than White/Caucasian, and when they reported they were Hispanic/Latino. Therefore, the minority group consisted of participants who identified as Hispanic/Latino, Black/African American, Asian, American Indian/Alaska Native, Hawaiian Native/Other Pacific Islander, Biracial/Multiracial, or other (n = 13; 22.8%), while the non-minority group consisted of participants who reported they were non-Hispanic White/Caucasian (n = 42; 73.7%). Two participants did not report their race or ethnicity.

An independent samples *t*-test was performed to compare total scores on the trauma-informed care (TIC) survey between these groups. Although the dependent variable, perceived quality of care, violated the assumptions of normality (skewness = .37), an independent samples t-test was maintained as the analysis of choice after due consideration and research. According to Pallant (2020), a *t*-test is robust, and therefore relatively tolerant if this assumption is violated with large enough sample sizes, such as a sample of $\geq$ 30. Levene's test suggested that variances in scores were statistically equivalent, F = 0.280., p = .059. Results showed no significant differences in the total scores on the TIC survey for minority (M = 60.54, SD = 26.07) and non-minority participants (M = 73.52, SD = 26.54), $t(53)$ = 1.55, p = .06. The hypothesis that minority participants would have lower perceptions of quality of care was not supported.

Given that the difference in total scores between these groups approached statistical significance, exploratory analyses were conducted to compare group differences on subscale scores. Independent samples *t*-tests were conducted to compare total scores on the seven subscales within the survey. Although scores on the Collaboration subscale were not normally distributed (skewness = .37), an independent samples t-test was maintained as the analysis of choice due to the robustness of this analysis (Pallant, 2020). Levene's test suggested that variances in scores were statistically equivalent, *F* = 1.78, *p* = .19. Results showed that there was a statistically significant difference in total scores on the Collaboration subscale on the TIC survey between minority (*M* = 19.54, *SD* = 10.24) and non-Hispanic Caucasian participants (*M* = 25.07, *SD* = 7.70), *t*(53) = 2.09, *p* = .02.

Assumption tests suggested that scores on the Empowerment subscale were normally distributed. Levene's test suggested that variances in scores were statistically equivalent, *F* = 0.07, *p* = .79. Results indicated a statistically significant difference in total scores on the Empowerment subscale of the TIC between minority (*M* = 5.15, *SD* = 3.44) and non-Hispanic Caucasian participants (*M* = 7.14, *SD* = 3.24), *t*(53) = 1.91, *p* = .03. Total scores between the minority/non-minority groups on all other TIC subscales were statistically equivalent.

***Hypothesis 2.2* Trauma survivors who identify as female will report lower perceived quality of care, from a trauma-informed perspective, compared to survivors of other gender identities.**

To investigate the hypothesis that trauma survivors who identified as female would have lower perceptions of quality of care compared to survivors of other gender identities, participants who identified as female were coded as female (*n* = 32; 56.1%), while those who identified as male or any other gender were coded as male/other (*n* = 25; 43.9%). An independent samples *t*-test was performed to compare total scores on the TIC survey between these groups. Although the dependent variable, perceived quality of care, violated the assumptions of normality (skewness = .41), an independent samples t-test was maintained as the analysis of choice due to the robustness of this analysis (Pallant, 2020). Levene's test suggested that variances in scores were statistically equivalent, *F* = 1.12, *p* = .30. Results showed that total scores on the TIC survey were statistically equivalent for female participants (*M* = 73.19, *SD* =28.63) compared to male/other participants (*M* = 66.48, *SD* = 26.52), *t*(55) = 0.91, *p* = .18. The hypothesis that female participants would have lower perceptions of quality of care was not supported.

Hypothesis 2.3 **Trauma survivors of a lower socioeconomic status will report lower perceived quality of care, from a trauma-informed perspective, compared to survivors of higher socioeconomic status**

To investigate the hypothesis that trauma survivors of a lower socioeconomic status will report lower perceived quality of care compared to survivors of higher socioeconomic status, participants were split into corresponding groups based on SES levels. Household income was utilized to create two groups, considering the small sample size. This variable was also more normally distributed than individual income. Participants who indicated their household income varied between $0-59,999 per year were coded as low SES (*n* = 27; 47.4%), while participants who indicated their household income was ≥$60,000 were coded as high SES (*n* = 30; 52.6%).

An independent samples *t*-test was performed to compare total scores on the TIC survey between these groups. Although the dependent variable, perceived quality of care, violated the assumptions of normality (skewness = .45), an independent samples t-test was maintained as the analysis of choice due to the robustness of this analysis (Pallant, 2020). Levene's test suggested that variances in scores were statistically equivalent, *F* = 1.68, *p* = .20. Results showed that total scores on the TIC survey were not statistically different for low SES (*M* = 70.26, *SD* =30.09) and high SES participants (*M* = 70.23, *SD* = 25.86), *t*(55) = .003, *p* = .50. The hypothesis that trauma survivors of a lower socioeconomic status would have lower perceptions was not supported.

Objective 3 To examine the differences between groups, based on trauma-related factors, on perceived quality of trauma-informed care in trauma survivors.

Hypothesis 3.1 **Trauma survivors with multiple traumas will report lower perceived quality of care, from a trauma-informed perspective, compared to survivors who have less trauma exposure.**

To investigate the hypothesis that trauma survivors with multiple traumas would have lower perceptions of quality of care compared to survivors with less trauma exposure, participants were split into corresponding groups based on the number of items endorsed on the BTQ measure. Considering the median of total items endorsed on the BTQ (*Mdn* = 3), participants who endorsed exposure to three items or less were coded as Low trauma exposure (*n* = 29; 50.9%), while those who endorsed exposure to more than three items were coded as High trauma exposure (*n* = 28; 49.1%).

An independent samples *t*-test was performed to compare mean scores on the TIC survey between these groups. Although the dependent variable, perceived quality of care, violated the assumptions of normality (skewness = .43), an independent samples t-test was maintained as the analysis of choice due to the robustness of this analysis (Pallant, 2020). Levene's test suggested that variances in scores were statistically equivalent, $F = 1.39$, $p = .25$. Results showed that total scores on the TIC survey were not statistically different for Low trauma exposure ($M = 74.07$, $SD = 24.19$) and High trauma exposure participants ($M = 66.29$, $SD = 30.84$), $t(55) = 1.06$, $p = .15$. The hypothesis that trauma survivors with higher trauma exposure would have lower perceived quality of care was not supported.

Hypothesis 3.2 **Survivors of interpersonal trauma will report lower perceived quality of care, from a trauma-informed perspective, compared to survivors exposed to other types of trauma.**

To investigate the hypothesis that survivors of interpersonal trauma perceived quality of care to be lower compared to survivors exposed to non-interpersonal trauma, participants were split into corresponding groups based on the type of trauma experienced. Participants who endorsed any interpersonal trauma exposure (war zone events, physical abuse or assault, and sexual abuse or assault) were coded as interpersonal trauma exposed ($n = 45$; 78.9%), regardless of whether they had also been exposed to non-interpersonal trauma. Participants who endorsed only non-interpersonal exposures (serious accidents, natural or technological disasters, illnesses, sudden loss, or witnessing an event) were placed in the non-interpersonal exposed group ($n = 12$; 21.1%). These categories are based on previous research that has conceptualized interpersonal trauma in this way (Huang et al., 2017; Thomas et al., 2021).

An independent samples *t*-test was then performed to compare total scores on the TIC survey between these groups. Assumption tests suggested that scores were normally distributed. Levene's test suggested that variances in scores were statistically equivalent, *F* = 0.20, *p* = .66. Results showed that total scores on the TIC survey were not statistically different between the interpersonal trauma exposed (*M* = 69.00, *SD* = 28.30) and non-interpersonal trauma exposed participants (*M* = 74.92, *SD* = 25.86), *t*(55) = -0.65, *p* = .26. The hypothesis that survivors of interpersonal trauma would have lower perceptions was not supported.

Hypothesis 3.3 **Trauma survivors with more severe posttraumatic stress symptoms will report lower perceived quality of care, from a trauma-informed perspective, compared to survivors with less severe posttraumatic stress symptoms.**

To investigate the hypothesis that trauma survivors with more severe posttraumatic stress symptoms (PTSS) would have lower perceptions of quality of care compared to survivors with less severe PTSS, participants were split into corresponding groups based on their PCL-5 scores. A cutoff score of 31 was utilized to categorize participants based on manualized scoring procedures of the PCL-5. Participants with a total PCL-5 score of < 31 were coded Low PTSS (*n* = 28; 49.1%) while participants with a total PCL-5 score of ≥ 31 were coded High PTSS (*n* = 29; 50.9%).

An independent samples *t*-test was conducted to compare total scores on the TIC survey between these groups. Although the dependent variable, perceptions of quality of care, violated the assumptions of normality (skewness = .43), the *t*-test was maintained as the analysis of choice due to its robustness (Pallant, 2020). Levene's test suggested that variances in scores were statistically equivalent, *F* = 2.36, *p* = .13. Results showed that there was a statistically significant difference in total scores on the TIC survey between Low PTSS (*M* = 77.25, *SD* = 24.34) and High PTSS participants (*M* = 63.48, *SD* = 29.42), *t*(55) = 1.92, *p* = .03. The hypothesis that survivors with more severe PTSS would have lower (i.e., poorer) perceptions of quality of care was supported.

Exploratory analyses were conducted to compare group differences on TIC subscale scores. Independent samples *t*-tests were conducted to compare total TIC scores on the seven subscales within the survey. Although scores on the Safety subscale were not normally distributed (skewness = .43), an independent samples t-test was maintained as the analysis of choice due to the robustness of this analysis (Pallant, 2020). Levene's test suggested that variances in scores were statistically equivalent, *F* = 1.10, *p* = .30. Results showed that participants with Low PTSS had statistically significant higher total scores on the Safety subscale of the TIC survey (*M* = 14.57, *SD* = 4.57) than the scores obtained for the High PTSS participants (*M* =11.79, *SD* = 5.21), *t*(55) = 2.14, *p* = .02.

Scores on the Trust subscale were not normally distributed (skewness = .43). However, an independent samples t-test was maintained as the analysis of choice due to its robustness (Pallant, 2020). Levene's test suggested that variances in scores were statistically equivalent, *F* = 1.79, *p* = .19. Results showed that there were statistically significant differences between the Low PTSS (*M* =17.75, *SD* = 5.51) and High PTSS participants (*M* = 14.97, *SD* = 6.22), *t*(55) = 1.79, *p* = .04 on the total scores of the TIC Trust subscale.

Assumption tests suggested that scores on the Collaboration subscale were normally distributed. Levene's test suggested that variances in scores were statistically equivalent, *F* = 2.45, *p* = .12. Results showed that there was a statistically significant difference in total scores on the Collaboration subscale on the TIC survey for Low PTSS (M = 26.11, SD = 7.49) and High PTSS participants (M = 21.10, SD = 9.60), $t(55) = 2.19$, $p = .02$.

Assumption tests suggested that scores on the Empowerment subscale were normally distributed. Levene's test suggested that variances in scores were statistically equivalent, $F = 0.25$, $p = .62$. Results showed that the total scores on the Empowerment subscale of the TIC survey were significantly different between the Low PTSS (M = 7.71, SD = 3.20) and High PTSS participants (M = 5.66, SD = 3.46), $t(55) = 2.33$, $p = .01$. Total scores between these groups on all other subscales were statistically equivalent.

Objective 4. To examine the relationship between perceived quality of care, from a trauma-informed perspective, healthcare utilization, and barriers to healthcare.

Hypothesis 4.1 **Trauma survivors with lower perceived quality of care, from a trauma-informed perspective, will report lower scores on a healthcare utilization measure compared to survivors with greater perceived quality of care.**

To investigate the hypothesis that trauma survivors with lower perceived quality of care scores would report lower scores on a healthcare utilization measure than survivors with a greater perceived quality of care, participants were split into corresponding groups based on scores on the TIC survey. Considering the median total score for perceptions of quality of care, (Mdn = 71), participants with a total score on perceptions of quality of care < 71 were coded as Lower TIC (n = 28; 49.12%), while participants with a total score ≥ 71 were coded as Higher TIC (n = 29; 50.88%).

An independent samples t-test was performed to compare mean scores between these groups. Although the dependent variable, healthcare utilization, violated the assumptions of normality (skewness = .44), the *t*-test was maintained as the analysis of choice due to its robustness (Pallant, 2020). Levene's test suggested that variances in scores were statistically equivalent, $F = 2.70$, $p = .11$. Results showed that scores on a healthcare utilization measure were statistically equivalent for Low TIC ($M = 3.64$, $SD = 1.73$) and High TIC participants ($M = 3.34$, $SD = 1.23$), $t(55) = 0.75$, $p = .23$. Therefore, this hypothesis was not supported.

Hypothesis 4.2 **Healthcare utilization will be influenced by the interaction of perceptions of quality of care and barriers to treatment. Individuals with higher perceptions of quality of care and fewer barriers to treatment will report greater scores on a healthcare utilization measure.**

To investigate the hypothesis that healthcare utilization will be influenced by the interaction of perceptions of quality of care and barriers to treatment, a two-way between-groups ANOVA was conducted. Although the dependent variable, healthcare utilization, violated the assumptions of normality (skewness = .32), a two-way between groups ANOVA was maintained as the analysis of choice due to the robustness of this analysis (Pallant, 2020).

Considering the median total score for perceived quality of care, (*Mdn* = 71), participants with a total score on the TIC survey < 71 were coded as Low TIC ($n = 28$; 49.12%), while participants with a total score ≥ 71 were coded as High TIC ($n = 29$; 50.88%). Barriers to treatment was coded as low or high for the analyses using the median of the sample on this variable (*Mdn* = 3). Participants who reported < 3 barriers to treatment ($n = 28$; 49.1%) were coded as Low barriers, and participants who endorsed ≥ 3 barriers to treatment ($n = 29$; 50.9%) were coded as High barriers. The most commonly reported barriers to treatment included: concerns about cost or insurance (*n* = 19; 33.3%), trouble following up on care (*n* = 19; 33.3%), fear, anxiety, embarrassment, or frustration (*n* = 17; 29.8%), providers or staff not taking patient communications seriously (*n* = 16; 28.0%), and difficulty making appointments (*n* = 14; 24.6%). See Table 5 for additional information regarding frequencies of barriers to treatment within this sample.

For the two-way between groups ANOVA, the independent variables were perceived quality of care (low, high) and barriers to treatment (low, high), and the dependent variable was healthcare utilization. Levene's test suggested that variances in scores were statistically equivalent, $F = 2.13$, $p = .11$. The main effect for perceived quality of care was not statistically significant $F(1, 53) = 0.19$, $p = .67$. The main effect for barriers to treatment was also not statistically significant $F(1, 53) = 0.54$, $p = .47$. There was a significant interaction between perceived quality of care and barriers to treatment on healthcare utilization $F(1, 53) = 5.81$, $p = .02$. There was a statistically significant difference in healthcare utilization between the high and low perceived quality of care groups when they reported a higher number of barriers to treatment $F(1, 53) = 4.19$, $p = .046$, partial $\eta^2 = 0.73$. Participants with high barriers and lower TIC scores ($M = 4.05$, $SD = 1.87$) had significantly greater healthcare utilization scores than those with high barriers and higher TIC scores ($M = 2.90$, $SD = 1.20$). See Table 6 for details.

Chapter 7: Discussion

The findings on the deleterious effects of trauma on physical health, via direct and indirect means, have been well-established. Research has also indicated that attending a healthcare appointment has the potential to be a triggering or otherwise unpleasant experience for individuals who have experienced a past trauma. Providers who utilize trauma-informed care principles can potentially help to mitigate this discomfort by treating individuals in a manner that is sensitive to trauma exposure, whether or not they choose to inquire about the patient's history, or regardless of whether patients decide to disclose. Given that as high as 89.7% of people within the United States have experienced one or more traumatic events, the importance of understanding whether a trauma-informed framework is beneficial is critical.

While research has examined the extent to which healthcare providers are adhering to principles of trauma-informed care based on the provider and staff perspectives, research on the patient perspective is lacking. Only one previous study conducted in Canada has examined patient perspectives using a trauma-informed specific quality of care outcome with the components of trauma-informed care, formally defined by SAMHSA (Kokokyi et al., 2021). The current study is the first, to our knowledge, to examine the patient perspective on adherence to trauma-informed care principles within the United States.

Results of the current study indicated that the majority of the sample reported being exposed to more than one traumatic event. Over half of the sample reported experiencing sexual abuse/assault and/or childhood physical abuse, while just under half reported they witnessed a traumatic event. Furthermore, approximately half of the sample obtained scores on an objective measure of PTSD that indicates a probable diagnosis of PTSD. Most of the participants within the sample also reported attending more than one healthcare appointment and seeing more than one type of provider within the last six months. A majority also reported that the COVID-19 pandemic did not impact their efforts to seek healthcare or healthcare accessibility. More importantly, approximately half of participants reported they did not disclose their trauma to their healthcare providers. Future qualitative research might focus on why and when individuals decide to disclose trauma to their providers to determine whether the implementation of trauma-informed care principles may play a role.

Our findings also indicated that overall, approximately 40% of trauma survivors in the study sample rated their perceived quality of healthcare as less than adequate, defined as provider-delivered trauma-informed care occurring rarely or never. This suggests that although providers have made strides in delivery of trauma-informed care with their patients, there is still a need for continued improvement in many domains. Results also indicated that there were no differences on overall perceptions of quality of care, using a trauma-informed care context, based on various demographic variables including race, ethnicity, identified gender, and socioeconomic status. Likewise, participants did not have differing perceptions of their care based on the number of traumatic events to which they were exposed or the type of trauma experienced (interpersonal vs. non-interpersonal).

There was, however, a difference in perceptions of care based on severity of posttraumatic stress symptoms (PTSS). Participants who scored higher on an objective measure of PTSS, i.e., had more symptoms of posttraumatic stress, were more likely to rate their care as lower (i.e., poorer) quality than participants who reported lower levels of stress on this measure. For this study, this measure was not utilized to determine a diagnosis of PTSD. However, these results suggest that trauma survivors with posttraumatic stress symptoms that reach a clinical threshold may perceive the quality of their care to be lower than trauma survivors without clinically elevated symptoms. More specifically, survivors with high PTSS perceived their providers to be delivering aspects of trauma-informed care less consistently in the areas of safety, trust, collaboration, and empowerment. The clinical implication of these results is that training for providers would benefit from focusing on areas that trauma survivors have identified as potential deficits in health care delivery.

This finding is consistent with previous studies that have found that survivors generally perceive their healthcare to be of low quality overall and report a lack of trust in their providers (Schippert et al., 2021). Trauma survivors have also reported experiencing feelings of discomfort and fear during healthcare interactions (Fang et al., 2015; Raja et al., 2015; Shannon et al., 2012; Shannon, 2014; Tobin et al., 2014). This is evidenced in findings from this study, which found that survivors with greater posttraumatic stress symptoms did not perceive their providers to be consistently delivering aspects of trauma-informed care as it relates to the principle of safety. Furthermore, survivors with more posttraumatic stress symptoms perceived a lack of adherence to the principles of collaboration and empowerment by their providers, similar to research in which trauma survivors have reported feeling powerless and a lack of control during interactions with providers (Katon et al., 2001; Schippert et al., 2021; Tobin et al., 2014).

The principle of safety was outlined by SAMHSA (2014) to promote the belief that all staff, not just providers, who have interactions with patients have a responsibility to ensure patients feel physically and psychologically safe. SAMHSA (2014) described this principle as one of high priority. Considering trauma can be conceptualized, ultimately, as the removal of safety, the finding that participants with higher levels of posttraumatic stress had lower scores on the Safety subscale of TIC compared to participants with lower levels of posttraumatic stress is particularly troubling. Despite many healthcare providers likely not being trained in the assessment or identification of post-traumatic stress, it is of utmost importance that they engage in behaviors which allow their patients to feel safe. In working with patients with post-traumatic stress symptoms, providers can increase their level of communication when performing certain tasks, such as asking patients for informed consent prior to touching, ensuring patients are comfortable being alone in a room with the provider, or simply asking the patient what they can do to increase their comfort level and sense of safety. To improve perceptions of trustworthiness and transparency in patients with high PTSS, providers can engage in similar behaviors as they would to improve patients' sense of safety, including informed consent and open communication. Providers can also ensure they are taking the time to listen to patients without interrupting, using a professional tone, and explaining their rationale prior to performing any exam or procedure. Additionally, it is important to acknowledge the time constraints of the health care system that impact provision of service. Therefore, engaging in behaviors, such as making eye contact when the patient is speaking, or even acknowledging time constraints can be beneficial.

The principles of collaboration and empowerment emphasize the importance of providers sharing the decision-making with patients and reducing the power differential. The findings that trauma survivors with higher posttraumatic stress in this sample perceived their providers to be less consistent in delivering care embraced by these principles supports previous research that survivors feel powerless (Katon et al., 2001; Schippert et al., 2021; Tobin et al., 2014). Providers can ensure they ask patients what their concerns are and why they are seeking services. One of the common themes throughout this sample's qualitative responses was whether or not participants felt heard. Those who did not feel heard elaborated on the negative impact it had on their overall healthcare experience, while participants who reported they were heard by their providers felt like they were important and their concerns mattered. Ensuring patients that they have a voice in their treatment can also help to reduce any potential feelings of discomfort with a providers' role. Finally, providers can work to empower their patients by providing subtle encouragements, avoiding criticism, and helping them to identify potential factors that might help or hinder their care. Facilities might also benefit from allowing patients to provide feedback on their healthcare experiences, with the option of submitting them anonymously, and ensuring they are taking steps to take any suggestions into account.

While results showed there were no differences in overall perceived quality of trauma-informed care between minority and non-minority participants, there were differences in perceptions on certain subscales representing the principles of collaboration and empowerment. Specifically, minority participants had lower scores on the Collaboration and Empowerment subscales of the TIC survey. Given the history of racially harmful practices within the medical field, this warrants further examination. Minorities are already more likely to perceive a greater power differential between themselves and providers, especially if their provider is from the majority culture (e.g., an African American patient with a Caucasian doctor) (Elliot et al., 2005). Therefore, providers can work to reduce this power differential, in a similar manner to what was recommended for high PTSS patients; asking patients what their concerns are, why they are seeking services, taking the time to listen to and understand their patients' concerns, and ensuring patients have a say in their treatment, while also providing encouragement and avoiding criticism. It is also worth noting that there was a small number of minority participants who completed the survey, such that future research would benefit from attempting to study a larger, more diverse sample.

Finally, results indicated that perceived quality of care had an impact on healthcare utilization when participants reported a greater number of barriers to healthcare. Participants who reported a greater number of barriers to healthcare and had lower perceptions of care had higher healthcare utilization than participants who reported a greater number of barriers to healthcare and had higher perceptions of care. Initially, this finding was surprising, given that it might be assumed that the combination of more barriers and lower perceptions of care would lead to fewer outpatient visits. However, individuals with higher healthcare utilization may have had more experiences to report regarding their interactions with healthcare providers, and potentially more negative experiences. These individuals may also be attending more outpatient appointments, with the intention of finding a provider with whom they are comfortable and/or who provides better quality of care. Given the cross-sectional nature of the study, it is difficult to determine the direction of the association between perceptions of care and health care utilization, i.e., the extent to which each drives the other, as well as the impact of barriers on this relationship. Additionally, it is possible that the type of barriers individuals encounter have a greater impact than the total number of barriers experienced on healthcare utilization outcomes. For example, there may be fewer obstacles involved in overcoming a transportation barrier than overcoming a lack of insurance, or financial-related barriers when seeking care. How these collective factors influence perceptions of healthcare and the use of services is an area of future study.

Chapter 8: Limitations of Study and Directions for Future Research

There are several methodological limitations within this study that restrict the definitive conclusions that can be drawn. First, the small sample size and small group sizes likely affected our ability to detect statistically significant group differences. Recruitment was another significant limitation, which in turn negatively impacted the sample size. Despite 98 eligible individuals beginning the survey, only 57 of those completed the survey in its entirely. Thirty-six participants did not complete a vast majority of the survey. It is possible several individuals discontinued prematurely due to the potentially triggering nature of the survey items. Therefore, there exists a possibility that, participants who completed the survey in its entirety differ from those who discontinued prematurely, affecting the overall generalizability to the is population of trauma survivors. In order to address this limitation, future research should be conducted with larger samples. Recruitment efforts might be more successful targeting patients in specific clinics, hospitals or other healthcare facilities, with the intention of improving overall practices. This may prove more successful and incentivizing than recruitment via social media, where the benefits are more limited.

Although the primary outcome measure used to assess trauma-informed quality of care in our sample of survivors was adequate to address the objectives of the current study, it is not without its limitations. The survey measure was developed by researchers for a previous study, based on the trauma-informed care framework created by SAMHSA (Kokokyi et al., 2021). Although the researchers collaborated with patient and physician advisors and piloted the measure on students (Kokokyi et al., 2021), this measure has not been empirically validated and was slightly adapted for use in this study. There are several surveys that have been developed to assess the extent to which providers and staff believe they adhere to TIC practices which have been subject to empirical validation and reliability. However, surveys assessing the patient perspective are not as widely available. There are also differences in the number of items that loaded onto each subscale of the parent survey, which limited the analyses that could be performed to examine significant differences in total scores across the subscales. Additional item analyses may be warranted to determine whether there were any specific behaviors or skills that providers lacked and must be improved to enhance patient interactions during healthcare visits.

Another limitation that must be considered is the cross-sectional design of the study which limits the ability to determine directionality of the relationship between participants' trauma histories, perceptions of healthcare experiences, and their healthcare utilization. Future studies might utilize a longitudinal design and further assess whether there are other factors that affect healthcare perceptions, outside of exposure to traumatic events.

Despite these limitations, the study is one of few to assess trauma informed care principles from the patient perspective. To our knowledge, it is the first study that was completed within the United States assessing this perspective. Considering the difficulties encountered with recruitment, it is possible that the reason for this gap in the literature is due to the accessibility of the population of interest. It is likely that are fewer obstacles in recruiting a sample of healthcare employees than patients, especially when considering issues such as confidentially. Furthermore, healthcare providers may be more likely than the general population to recognize the significance of research than the general public, and therefore be more inclined to participate. Efforts to make survivors aware of the clinical utility of ongoing research and the importance of their contributions and participation in such studies should be emphasized.

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Table 1

Demographic Variables

	(*N* = 57) *M (SD)*
Age	32.55 (13.69)
	n (%)
Gender	
Female	32 (56.1%)
Male	15 (26.3%)
Other	10 (17.6%)
Race	
White/Caucasian	48 (84.2%)
Black/African American	1 (1.8%)
Biracial/Multiracial	4 (7.0%)
Other	3 (5.3%)
Ethnicity	
Hispanic/Latino	7 (12.3%)
Non-Hispanic	48 (84.2%)
Region of Residency	
Northeast	12 (21.1%)
West	9 (15.8%)
Midwest	9 (15.8%)
South	22 (38.6)
Employment	
Employed	35 (61.4)
On Disability	1 (1.8%)
Retired	1 (1.8%)
Unemployed	7 (12.3%)
Student	13 (22.8%)
Education Level	
Some High School	2 (3.5%)
High School Diploma/GED	13 (22.8%)
Technical	4 (7.0%)
Degree/Certificate	
Associate’s Degree	9 (15.8%)
Bachelor’s Degree	18 (31.6%)
Graduate Degree	11 (19.3%)
Household Income	
$0 - $19,999	8 (14.0%)
$20,000 - $39,999	11 (19.3%)
$40,000 - $59,999	8 (14.0%)
$60,000 - $79,999	10 (17.5%)
$80,000 - $99,999	5 (8.8%)
$100,000 - $119,999	6 (10.5%)
More than $120,000	9 (15.8%)

Table 2

Frequencies for Traumatic Events

Event	Total Sample (*N = 57)* *n* (%)
War zone/Combat	7 (12.3%)
Serious accident	18 (31.6%)
Natural/Technological Disaster	16 (28.1%)
Life-threatening Illness	8 (14.0%)
Childhood physical abuse	30 (52.6%)
Physical Assault	13 (22.8%)
Sexual abuse/assault	34 (59.6%)
Other situation	23 (40.4%)
Sudden/violent loss	22 (38.6%)
Witnessed an event	28 (49.1%)

Note. Percentages may not add up to 100.0 due to participants endorsing more than one item.

Table 3

Frequencies for Healthcare Utilization Variables

Event	Total Sample (*N = 57)* *n* (%)
Total # of Visits	
One	13 (22.8%)
2-3	26 (45.6%)
4-5	7 (12.3%)
6-8	4 (7.0%)
9-15	4 (7.0%)
16-20	1 (1.8%)
21-30	2 (3.5%)
Type of Provider	
Primary Care Provider	41 (71.9%)
Osteopathic Doctor	1 (1.8%)
Orthopedic Surgeon or Specialist	7 (12.3%)
Pain Specialist	3 (5.3%)
Rheumatologist	1 (1.8%)
Physical or Occupational Therapist	10 (17.5%)
Specialist	32 (56.1%)
ER/Clinic/Urgent Care	15 (26.3%)
Holistic Medicine (e.g., chiropractor)	2 (3.5%)
Nature of Visit	
Routine Physical Exam/Preventive Visit	28 (49.1%)
Injury and/or Accident	14 (24.6%)
Illness	20 (35.1%)
Lab Work	20 (35.1%)
Vaccination(s)	11 (19.3%)
Pap Smear/Pelvic Examination	11 (19.3%)
Procedural (e.g., colonoscopy)	6 (10.5%)
Prenatal Visit	1 (1.8%)
Holistic wellness visit	4 (7.0%)
Other	12 (21.1%)
Disclosed Trauma to Provider	29 (50.9%)
Healthcare Provider Reaction to Disclosure	
Supportive	17 (29.8%)
Blaming/Rejecting	1 (1.8%)
Neutral	11 (19.8%)
N/A Did Not Disclose	28 (49.1%)
COVID-19	
Efforts to Seek Healthcare Affected	21 (36.8%)
Healthcare Visits Harder to Access	23 (40.4%)

Note. Percentages may not add up to 100.0 due to participants endorsing more than one item.

Table 4

Mean Total Scores on TIC Subscales

Subscale	Score *M (SD)*	# of Items on Survey	Minimum	Maximum
Trauma	2.75 (2.54)	2	0	8
Safety	13.16 (5.06)	5	0	20
Trust	16.33 (6.00)	6	0	24
Collaboration	23.56 (8.92)	9	0	36
Empowerment	6.67 (3.46)	3	0	12
Peer Support	2.11 (1.35)	1	0	4
Cultural Sensitivity	5.67 (3.70)	3	0	12
Total	70.25 (27.69)	29	0	116

Table 5

Frequencies for Barriers to Healthcare Treatment

Barrier	Total Sample (*N* = *57)* *n* (%)
Fear, anxiety, embarrassment, or frustration keeps me from getting primary care.	17 (29.8%)
I have trouble following up on care (e.g. going to pharmacy, taking prescribed drugs at the right time, or making a follow-up appointment).	19 (33.3%)
I have difficulty understanding how to translate medical information into concrete steps that I can take to improve my health.	4 (7.0%)
I don't understand the healthcare system.	4 (7.0%)
It is too difficult to make appointments.	14 (24.6%)
I have problems filling out paperwork.	3 (5.3%)
My behaviors are misinterpreted by my provider or the staff.	6 (10.5%)
My providers or the staff do not take my communications seriously.	16 (28.1%)
I cannot find a healthcare provider who will accommodate my needs.	7 (12.3%)
My providers or the staff do not include me in discussions about my health.	5 (8.8%)
Communication with my healthcare provider or the staff is too difficult.	8 (14.0%)
When I experience pain and/or other physical symptoms, I have difficulties identifying them and reporting them to my healthcare provider.	12 (21.1%)
Sensory discomforts (e.g. the lights, smells, or sounds) get in the way of my healthcare.	5 (8.8%)
Concerns about cost or insurance coverage keep me from getting primary care.	19 (33.3%)
I do not have a way to get to my doctor's office.	1 (1.8%)
I have inadequate social, family, or caregiver support.	7 (12.3%)
I find it hard to handle the waiting room.	4 (7.0%)

Note. Percentages may not add up to 100.0 due to participants endorsing more than one item.

Table 6

Factorial ANOVA Results of Perceptions of Quality of Healthcare and Barriers to Treatment on Healthcare Utilization

Source	*SS*	*df*	*MS*	*F*
Between	14.21	3	4.74	2.28
Perceptions of Care	0.39	1	0.39	0.19
Barriers	1.12	1	1.12	0.54
Perceptions of Care * Barriers	12.07	1	12.07	5.81*
Within	110.04	53	2.08	
Total	819.00	57		

Note. *p < .05

Appendix A: Letter of Information and Informed Consent

Primary Investigator:

Jane A. Komen, M.S.
Department of Psychology, Florida Institute of Technology
(Email): jkomen2019@my.fit.edu

Co-Investigator:

Vida L. Tyc, Ph.D.
Department of Psychology, Florida Institute of Technology
(Email): vtyc@fit.edu

Please read this consent document carefully before you decide to participate in this study.

Purpose of the Study

This study is being conducted to learn more about how adults who are 18 years or older and have experienced trauma perceive the quality of the healthcare they receive. Furthermore, this study will examine several factors associated with the differences in these perceptions of quality of healthcare. Finally, this study will also examine the relationship between perceptions of quality of care, barriers to accessing healthcare, and healthcare utilization. This information will be used to provide healthcare providers with information about their patients' perceptions of the care they are receiving, and continue to emphasize the importance of treating patients in a way that is sensitive to their trauma.

Eligibility

In order to participate, you must be 18 years of age or older, have experienced at least one traumatic event in your lifetime, and be able to read and write in English fluently. In addition, you must have attended at least one outpatient healthcare appointment within the past six months.

Procedures of the Study

If you are eligible to participate in the study, you will be asked to complete an online survey. The survey will consist of questions regarding your past experiences of trauma, any barriers you have experienced when seeking healthcare, and your experiences with the quality of care you receive. You will be able to change any of your responses by selecting the "Back" button to return to the previous page. We estimate that the questionnaire will take approximately 20 minutes to complete.

Potential Risks and Benefits

The risks of participating in this study are minimal. However, you will be asked about your past experiences of trauma and healthcare, which you may find stressful. You may choose not to respond to any question that makes you uncomfortable and are free to discontinue your participation at any point during the study. While unlikely, there is a risk of loss of privacy. We will keep your study information private and confidential and all data will be de-identified and kept in a database that only researchers have access to.

There will be no direct benefits to you by taking part in this study. However, the information obtained from this study may be used to help other people who have experienced trauma.

Compensation

There will be no compensation for participating in this study.

Discontinuation of the Study

Participation in this study is **voluntary**. You are under no obligation to participate in this study, and you are free to withdraw from the study at any time without consequences to you. There is no penalty for not participating. You may refuse to answer any questions that we ask you. If you decide to withdraw from the study, the information provided by you will not be retained.

Confidentiality

All responses obtained from you will be kept confidential. No identifying information will be collected during this survey. All data collected will be entered into a HIPAA-compliant database and stored on a password-protected server located in the Department of Psychology at Florida Institute of Technology. Only authorized researchers will have access to this information.

Information about Participating as a Study Project

Any questions about study participation may be directed to Jane A. Komen (Principle Investigator) via email (jkomen2019@my.fit.edu).

This study has been reviewed and approved by the Institutional Review Board. If you have any ethical questions or concerns about the study, these may be directed to:

Dr. Jignya Patel, Chair for the Institutional Review Board
Institutional Review Board Office, School of Psychology
150 W University Blvd
Melbourne, Florida, 32901
(P): 321-674-7347
(E): FIT_IRB@fit.edu

Consent

In order to keep your information confidential, your name or signature is not required. Please indicate your choice below. Should you choose to participate, you will be directed automatically to the survey.

○ I have read the information presented above about a study being conducted by Jane Komen (Principal Investigator) of the School of Psychology at Florida Institute of Technology. I am 18 years or older, and I understand that I may withdraw from the study at any time. I agree to participate in this study.

○ I have read the information presented about this study and I do not wish to participate.

Appendix B: Survey

You are invited to participate in this study that asks about your experiences within the healthcare system and traumatic events you have experienced. Thank you very much for your time and support.

Qualifying Information:

In order to determine your eligibility to participate, please answer the following questions:

1. **Are you 18 years of age or older?**

○ Yes
○ No *(will be routed to end of survey)*

2. **Are you able to read and write English fluently?**

○ Yes
○ No *(will be routed to end of survey)*

3. **Have you attended an outpatient healthcare visit (virtual or in-person) within the past six months?**

○ Yes
○ No *(will be routed to end of survey)*

The following questions ask about events that may be extraordinarily stressful or disturbing for almost everyone. Please select "yes" or "no" to report what has happened to you.

If you answer "Yes" for an event, please answer any additional questions that follow it to report: (1) whether you thought your life was in danger or you might be seriously injured; and (2) whether you were seriously injured.

4. **Have you ever served in a war zone, or have you ever served in a noncombat job that exposed you to war-related casualties (for example, as a medic or on graves registration duty)?**

○ Yes
○ No

4a. If the event happened, did you think your life was in danger or you might be seriously injured?

○ Yes
○ No

4b. If the event happened, were you seriously injured?

○ Yes
○ No

5. Have you ever been in a serious car accident, or a serious accident at work or somewhere else?

○ Yes
○ No

5a. If the event happened, did you think your life was in danger or you might be seriously injured?

○ Yes
○ No

5b. If the event happened, were you seriously injured?

○ Yes
○ No

6. Have you ever been in a major natural or technological disaster, such as a fire, tornado, hurricane, flood, earthquake, or chemical spill?

○ Yes
○ No

6a. If the event happened, did you think your life was in danger or you might be seriously injured?

○ Yes
○ No

6b. If the event happened, were you seriously injured?

○ Yes
○ No

7. Have you ever had a life-threatening illness such as cancer, a heart attack, leukemia, AIDS, multiple sclerosis, etc.?

○ Yes
○ No

7a. If the event happened, did you think your life was in danger or you might be seriously injured?

○ Yes
○ No

8. Before age 18, were you ever physically punished or beaten by a parent, caretaker, or teacher so that: you were very frightened; or you thought that you would be injured; or you received bruises, cuts, welts, lumps, or other injuries?

○ Yes
○ No

8a. If the event happened, did you think your life was in danger or you might be seriously injured?

- Yes
- No

8b. If the event happened, were you seriously injured?

- Yes
- No

9. Not including any punishments or beatings you already reported in Question 5, have you ever been attacked, beaten, or mugged by anyone, including friends, family members or strangers?

- Yes
- No

9a. If the event happened, did you think your life was in danger or you might be seriously injured?

- Yes
- No

9b. If the event happened, were you seriously injured?

- Yes
- No

10. Has anyone ever made or pressured you into having some type of unwanted sexual contact? <u>Note</u>: By sexual contact we mean any contact between some else and your private parts or between you and someone else's private parts.

- Yes
- No

10a. If the event happened, did you think your life was in danger or you might be seriously injured?

- Yes
- No

10b. If the event happened, were you seriously injured?

- Yes
- No

11. Have you ever been in any other situation in which you were seriously injured, or have you ever been in any other situation in which you feared you might be seriously injured or killed?

- Yes
- No

11a. If the event happened, were you seriously injured?

- ○ Yes
- ○ No

12. Has a close family member or friend died violently, for example, in a serious car crash, mugging, or attack?

- ○ Yes
- ○ No

12a. If the event happened, were you seriously injured?

- ○ Yes
- ○ No

13. Have you ever witnessed a situation in which someone was seriously injured or killed, or have you ever witnessed a situation in which you feared someone would be seriously injured or killed? Note: Do not answer "yes" for any event you already reported in the above questions.

- ○ Yes
- ○ No

14. Select 'Yes' if:

(1) You answered 'yes' to any of the traumatic experiences asked about previously,

(2) and if applicable, felt your life was in danger or you might be seriously injured.

- ○ Yes
- ○ No

Demographics

15. What is your current age?

- ○ ______

16. What sexual orientation do you identify with?

- ○ Heterosexual (i.e., attracted to other sex)
- ○ Homosexual (i.e., attracted to same sex)
- ○ Bisexual
- ○ Asexual
- ○ Pansexual
- ○ Other: ____________________

17. What gender do you identify with?

- ○ Female
- ○ Male
- ○ Transwoman (MTF)
- ○ Transman (FTM)
- ○ Gender Fluid

- ○ Two-spirit
- ○ Other: ___________________

18. What is your race?

- ○ White/Caucasian
- ○ Black/African American
- ○ Asian
- ○ American Indian/Alaskan Native
- ○ Hawaiian Native/Other Pacific Islander
- ○ Biracial/Multiracial
- ○ Other: __________________

19. What is your ethnicity?

- ○ Hispanic/Latino
- ○ Non-Hispanic/Latino

20. How would you describe the region you currently live in?

- ○ Urban/City
- ○ Rural/Country
- ○ Suburban

21. What geographic region do you currently reside in?

- ○ **Northeast**: Maine, New Hampshire, Vermont, Massachusetts, Rhode Island, Connecticut, New York, New Jersey, and Pennsylvania.
- ○ **Midwest**: Ohio, Indiana, Illinois, Michigan, Wisconsin, Minnesota, Iowa, Missouri, North Dakota, South Dakota, Nebraska, and Kansas.
- ○ **South**: Delaware, Maryland, District of Columbia, Virginia, West Virginia, North Carolina, South Carolina, Georgia, Florida, Kentucky, Tennessee, Alabama, Mississippi, Arkansas, Louisiana, Oklahoma, and Texas.
- ○ **West**: Montana, Idaho, Wyoming, Colorado, New Mexico, Arizona, Utah, Nevada, Washington, Oregon, California, Alaska, and Hawaii.

22. What is your current relationship status?

- ○ Single
- ○ In a relationship
- ○ Married
- ○ Divorced
- ○ Widowed

23. Are you currently living with your partner?

- ○ Yes
- ○ No
- ○ N/A (No spouse / partner)

24. What is your highest level of education completed?

- ○ I did not graduate high school

- High school diploma/GED
- Technical Degree/Certificate
- Associate’s Degree
- Bachelor’s Degree
- Master’s Degree
- Doctoral Degree

25. What is your occupational status?

- Employed full-time
- Employed part-time
- On disability
- Retired
- Unemployed
- Student

26. Socioeconomic Status

a) Individual:	$0-$19,999	$20,000- $39,999	$40,000-$59,999
	$40,000-$59,999	$60,000- $79,999	$80,000-$99,999
	$100,000-$119,999	More than $120,000	
b) Household:	$0-$19,999	$20,000- $39,999	$40,000-$59,999
	$40,000-$59,999	$60,000- $79,999	$80,000-$99,999
	$100,000-$119,999	More than $120,000	

Trauma Specifics and History

Below is a list of problems that people sometimes have in response to a very stressful experience. Please read each problem carefully and then select one of the responses to indicate how much you have been bothered by that problem ***<u>in the past month</u>****.*

In the past month, how much were you bothered by:

27. Repeated, disturbing, and unwanted memories of the stressful experience?

- Not at all (0)
- A little bit (1)
- Moderately (2)
- Quite a bit (3)
- Extremely (4)

28. Repeated, disturbing dreams of the stressful experience?

- Not at all (0)
- A little bit (1)
- Moderately (2)
- Quite a bit (3)
- Extremely (4)

29. Suddenly feeling or acting as if the stressful experience were actually happening again (as if you were actually back there reliving it)?

○ Not at all (0)
○ A little bit (1)
○ Moderately (2)
○ Quite a bit (3)
○ Extremely (4)

30. Feeling very upset when something reminded you of the stressful experience?

○ Not at all (0)
○ A little bit (1)
○ Moderately (2)
○ Quite a bit (3)
○ Extremely (4)

31. Having strong physical reactions when something reminded you of the stressful experience (for example, heart pounding, trouble breathing, sweating)?

○ Not at all (0)
○ A little bit (1)
○ Moderately (2)
○ Quite a bit (3)
○ Extremely (4)

32. Avoiding memories, thoughts, or feelings related to the stressful experience?

○ Not at all (0)
○ A little bit (1)
○ Moderately (2)
○ Quite a bit (3)
○ Extremely (4)

33. Avoiding external reminders of the stressful experience (for example, people, places, conversations, activities, objects, or situations)?

○ Not at all (0)
○ A little bit (1)
○ Moderately (2)
○ Quite a bit (3)
○ Extremely (4)

34. Trouble remembering important parts of the stressful experience?

○ Not at all (0)
○ A little bit (1)
○ Moderately (2)
○ Quite a bit (3)
○ Extremely (4)

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

- Not at all (0)
- A little bit (1)
- Moderately (2)
- Quite a bit (3)
- Extremely (4)

36. Blaming yourself or someone else for the stressful experience or what happened after it?

- Not at all (0)
- A little bit (1)
- Moderately (2)
- Quite a bit (3)
- Extremely (4)

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

- Not at all (0)
- A little bit (1)
- Moderately (2)
- Quite a bit (3)
- Extremely (4)

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

- Not at all (0)
- A little bit (1)
- Moderately (2)
- Quite a bit (3)
- Extremely (4)

39. Feeling distant or cut off from other people?

- Not at all (0)
- A little bit (1)
- Moderately (2)
- Quite a bit (3)
- Extremely (4)

40. Trouble experiencing positive feelings (for example, being unable to feel happiness or have loving feelings for people close to you)?

- Not at all (0)
- A little bit (1)
- Moderately (2)
- Quite a bit (3)
- Extremely (4)

41. Irritable behavior, angry outbursts, or acting aggressively?
○ Not at all (0)
○ A little bit (1)
○ Moderately (2)
○ Quite a bit (3)
○ Extremely (4)

42. Taking too many risks or doing things that could cause you harm?
○ Not at all (0)
○ A little bit (1)
○ Moderately (2)
○ Quite a bit (3)
○ Extremely (4)

43. Being “super alert” or watchful or on guard?
○ Not at all (0)
○ A little bit (1)
○ Moderately (2)
○ Quite a bit (3)
○ Extremely (4)

44. Feeling jumpy or easily startled?
○ Not at all (0)
○ A little bit (1)
○ Moderately (2)
○ Quite a bit (3)
○ Extremely (4)

45. Having difficulty concentrating?
○ Not at all (0)
○ A little bit (1)
○ Moderately (2)
○ Quite a bit (3)
○ Extremely (4)

46. Trouble falling or staying asleep?
○ Not at all (0)
○ A little bit (1)
○ Moderately (2)
○ Quite a bit (3)
○ Extremely (4)

Note: continue with the rest of this survey.

47. Did you disclose your trauma to anyone after it happened?

- ○ Yes
- ○ No

48. How did the person/people you disclosed to react?

- ○ They were supportive
- ○ They were blaming/rejecting
- ○ They were neutral
- ○ N/A; I did not disclose

49. Did you disclose your trauma to your healthcare provider?

- ○ Yes
- ○ No

50. How did your healthcare provider react?

- ○ They were supportive
- ○ They were blaming/rejecting
- ○ They were neutral
- ○ N/A; I did not disclose

Healthcare Utilization

51. How many <u>outpatient</u> healthcare visits have you attended in the last six months (virtual or in-person)?

- ○ None (0)
- ○ One visit (1)
- ○ 2-3 visits (2)
- ○ 4-5 visits (3)
- ○ 6-8 visits (4)
- ○ 9-15 visits (5)
- ○ 16-20 visits (6)
- ○ 21-30 visits (7)
- ○ 31-40 visits (8)
- ○ 41-50 visits (9)
- ○ More than 50 visits (10)

52. In the past six months, what types of <u>outpatient</u> health providers have you visited? Please check all that apply. *(Possible 13 points)*

- ○ Primary Care Provider (1)
- ○ Osteopathic Doctor (1)
- ○ Orthopedic surgeon or specialist (1)
- ○ Pain specialist (1)
- ○ Rheumatologist (1)
- ○ Rehabilitation Physician or Physiatrist (1)
- ○ Physical therapist or Occupational therapist (1)
- ○ Specialist (neurologist, endocrinologist, gynecologist, pulmonologist, cardiologist, etc.) (1)

- ○ ER/Clinic/Urgent Care (1)
- ○ Chiropractor, acupuncturist, massage therapist (1) (and/or other holistic medicine)
- ○ Other: please specify _____ (1)

53. What was the nature of your outpatient healthcare visit? Please check all that apply.

- ○ Illness
- ○ Injury and/or accident
- ○ Routine physical exam/Preventive healthcare visit
- ○ Pap smear/Pelvic examination
- ○ Vaccinations(s)
- ○ Lab work (e.g., blood work)
- ○ Procedural (e.g., colonoscopy)
- ○ Prenatal visit
- ○ Holistic wellness visit (e.g., chiropractor)
- ○ Other: please specify _______

54. Have your efforts to seek healthcare been affected by COVID-19?

- ○ No
- ○ Yes

55. Are healthcare services harder to access post-COVID-19?

- ○ No
- ○ Yes

Barriers to Healthcare

56. Please indicate which of the following have interfered with your ability to seek or receive healthcare services in the past <u>six</u> months, if any. *Please check all that apply.*

- ○ Fear, anxiety, embarrassment, or frustration keeps me from getting primary care.
- ○ I have trouble following up on care (e.g. going to pharmacy, taking prescribed drugs at the right time, or making a follow-up appointment).
- ○ I have difficulty understanding how to translate medical information into concrete steps that I can take to improve my health.
- ○ I don't understand the healthcare system.
- ○ It is too difficult to make appointments.
- ○ I have problems filling out paperwork.
- ○ My behaviors are misinterpreted by my provider or the staff.
- ○ My providers or the staff do not take my communications seriously.
- ○ I cannot find a healthcare provider who will accommodate my needs.
- ○ My providers or the staff do not include me in discussions about my health.
- ○ Communication with my healthcare provider or the staff is too difficult.
- ○ When I experience pain and/or other physical symptoms, I have difficulties identifying them and reporting them to my healthcare provider.

- Sensory discomforts (e.g. the lights, smells, or sounds) get in the way of my healthcare.
- Concerns about cost or insurance coverage keep me from getting primary care.
- I do not have a way to get to my doctor's office.
- I have inadequate social, family, or caregiver support.
- I find it hard to handle the waiting room.

Quality of Healthcare

For each of the following questions, please consider your experience, in general, in reference to your overall healthcare experience within the last six months. Please answer how often you have received the following services from an outpatient provider(s)/facility.

57. Provided a physical space that was not perceived as threatening (e.g., adequate lighting, private area for you to complete screening questionnaires, adequate and safe distance between you and your healthcare provider).

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

58. Made you feel welcome by being warm and friendly, and using a welcoming tone of voice.

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

59. Found out what was most pressing for you.

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

60. Clarified your understanding of your reasons for seeking services.

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

61. Communicated openly (e.g., provided all relevant information, was transparent) and initiated communication.

- ○ Never (0)
- ○ Rarely (1)
- ○ Sometimes (2)
- ○ Frequently (3)
- ○ Almost always (4)

62. Listened to you (e.g., paid attention to what you were saying, not interrupting you) and made eye contact with you when interacting with you.
- ○ Never (0)
- ○ Rarely (1)
- ○ Sometimes (2)
- ○ Frequently (3)
- ○ Almost always (4)

63. Allowed and encouraged expression of feelings (even negative emotions) without judgment (e.g., not asserting their judgment on you).
- ○ Never (0)
- ○ Rarely (1)
- ○ Sometimes (2)
- ○ Frequently (3)
- ○ Almost always (4)

64. Made you feel emotionally safe by providing reassurance and validating your experiences.
- ○ Never (0)
- ○ Rarely (1)
- ○ Sometimes (2)
- ○ Frequently (3)
- ○ Almost always (4)

65. Used professional tone to convey genuine concern.
- ○ Never (0)
- ○ Rarely (1)
- ○ Sometimes (2)
- ○ Frequently (3)
- ○ Almost always (4)

66. Responded appropriately to your nonverbal communication.
- ○ Never (0)
- ○ Rarely (1)
- ○ Sometimes (2)
- ○ Frequently (3)
- ○ Almost always (4)

67. Asked about adverse (stressful) childhood experiences and past emotional trauma.

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

68. Responded in a patient-focused (respectful, responsive) manner.

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

69. Explained things in a way you could understand (e.g., use plain language without jargon).

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

70. Provided informed consent prior to performing any medical activities (e.g., touching you or any medical examinations).

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

71. Explained rationale before performing something.

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

72. Checked your understanding of information provided.

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

73. Acknowledged and took responsibility for their miscommunications.

- Never (0)
- Rarely (1)

○ Sometimes (2)
○ Frequently (3)
○ Almost always (4)

74. Recognized and equalized power imbalances (e.g., understanding you are an expert in your own life, speaking to you at your level).
○ Never (0)
○ Rarely (1)
○ Sometimes (2)
○ Frequently (3)
○ Almost always (4)

75. Empowered you by providing encouragement, using positive language, and avoiding criticism.
○ Never (0)
○ Rarely (1)
○ Sometimes (2)
○ Frequently (3)
○ Almost always (4)

76. Used statements (e.g., “It’s your decision,” “It’s not me to decide”) that made collaboration and choice explicit.
○ Never (0)
○ Rarely (1)
○ Sometimes (2)
○ Frequently (3)
○ Almost always (4)

77. Outlined consent and format of treatment.
○ Never (0)
○ Rarely (1)
○ Sometimes (2)
○ Frequently (3)
○ Almost always (4)

78. Helped you identify your strengths and skills that facilitate management of your own care.
○ Never (0)
○ Rarely (1)
○ Sometimes (2)
○ Frequently (3)
○ Almost always (4)

79. Helped you identify your challenges and difficulties that may get in the way of treatment.
○ Never (0)

- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

80. Provided you with choices that fit your life circumstances for treatment preferences.

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

81. Involved you in decisions surrounding your care.

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

82. Inquired about others who may be helpful to include in your care (e.g., family member).

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

83. Had awareness of your cultural identity, including sexuality and gender identity.

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

84. Asked you about your cultural beliefs of your health and illness and how you preferred to treat yourself.

- Never (0)
- Rarely (1)
- Sometimes (2)
- Frequently (3)
- Almost always (4)

85. Respected your cultural preference for treatment.

- Never (0)

○ Rarely (1)
○ Sometimes (2)
○ Frequently (3)
○ Almost always (4)

86. Overall, on a scale of 1-10, how would you rate the quality of care you received, in a way that was sensitive to your trauma (1 being the lowest quality, 10 being the highest quality)?

87. Please provide a brief description of your healthcare experience.

Appendix C: Qualitative Responses

The following are some of the participants' responses to item 87 on the survey ("Please provide a brief description of your healthcare experience): *Note. Some responses have been edited to protect participant confidentiality.*

1. "My symptoms were dismissed and as a result I got the wrong diagnosis."

2. "I was restrained during my birth and operated on when I begged them to stop. I have injuries and have to beg for pain meds – they just keep referring me to other doctors. Sometimes they just tell me what's wrong without trying to understand."

3. "I had an ER visit and the doctor rushed even though it wasn't very busy. He made me feel like he just wanted to get me in and out and overall did a poor job with what I needed."

4. "While the treatment was not harmful to my trauma, it did not recognize its impact. Additionally, my provider did not seem to understand my symptoms and has not demonstrated clear concern or dedication to making sure that my symptoms are understood and addressed."

5. It has generally been effective, but I often find myself missing bits of information I feel should have been proactively disclosed by the doctor."

6. "I often ask to be warned if there will be a loud or sudden noise, and to have things explained as they are happening. Most everyone is aware and does their best to accommodate me after that."

7. "Person centered, informative, and respectful of lifestyle."

8. "With my primary care doctor, it's fine. Anything with the XX Clinic is a disaster."

9. "Overall, good. There were moments when I felt a little bit judged and the people that worked with me were not always empathetic. Professional but it wasn't a great experience. I forgot about having herpes on my lip and the nurse condescendingly pointed out that I did, indeed, have herpes before…it made me feel dirty. Other than that, the other nurses/assistants were just fine."

10. "Throughout the numerous traumas I had, most of the time I chose not to report them. During my annual visit, I tried to talk to my PCP about issues concerning mental health and she brushed it off as all related to environmental stressors without helping me find ways to manage."

11. "Healthcare is tiring and expensive."

12. "I went to see a doctor but she doesn't seem to understand me. Could be a cultural difference."

13. “My PCP is so calm, comforting, and has the most empathetic personality. She took the time to get to know me and the things that are hard for me. She makes sure I am comfortable with everything she does and has given me all the resources I need to help better myself.”

14. “I am very happy with my healthcare providers, they make me feel safe and always do their best for me.”

15. “I have been seeing the same healthcare professional since I was born so it was routine and normal with him.”

16. “Family doctor always shows he cares and sees me when necessary.”

17. “I recently found a new primary care provider who has been amazing about taking my preferences into consideration and listening to all of my issues (physical AND mental). She’s also been great about actually doing something about the things I say are issues and finding solutions to problems. However I’ve had bad experiences in the past with doctors, especially when I was under 18. If I had an issue they’d suggest waiting for the issue to resolve itself or refer me to another specialist who couldn’t see me for weeks or months. Mental healthcare with doctors was practically nonexistent as well. I’m really glad I found my current primary care provider.”

18. “I had an emergency cesarean section with my daughter after 31 hours of labor and three hours of pushing. My anesthesiologist called me a liar repeatedly when I told him my epidurals were not working. He had to give me three different ones and stated that he'd never given anyone as much anesthesia as he was giving me and it was much more than someone my size should be getting. Apparently, I metabolize it very quickly. Since he refused to believe me and couldn't get me numb they had to put me under general anesthesia to deliver my daughter. On the one hand, I was lucky that my doctor believed me because she checked to see if I could feel anything before cutting me open - she pinched me with some instrument, and I screamed...twice. Had she not believe me, as the anesthesiologist didn't, she may have cut me open while I was awake. However, after missing my daughter’s birth, and not even meeting her on her birthday, I honestly think I may have preferred to be awake, regardless. This happened 3.5 years ago and I still think about it almost every day. I cried at least twice a day for the first year. Missing the birth of my daughter, and not holding her for hours, and being unable to hold her or even reach her as she cried all night, because of all the drugs, they gave me, was devastating to me. I was given fentanyl without any explanation of what kind of medication it was, just that it would ‘take the edge off my pain’ and the nurse was very insistent that I take it. I was bullied into an epidural hours and hours earlier than I wanted one because my nurse didn't enjoy having to reposition the fetal monitor every time I had to use the restroom, which was often at that point in my pregnancy. I was threatened with having my arms strapped down if I didn't stop moving in the OR before the surgery.”

19. “I didn’t disclose any trauma to this healthcare professional and he did not touch me. He was pretty good at explaining the way the medications worked and all of the different options that were available.”

20. “Depends on the specialist. I have poor experiences with some. My primary care doctor is very understanding and I enjoy talking to her. I hesitate to go sometimes because I have social anxiety and it’s hard for me to brave the waiting room sometimes.”