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Associations Between Patient-provider Trust and HIV Care Continuum Outcomes

James Caldwell
University of Central Florida

ASSOCIATIONS BETWEEN PATIENT-PROVIDER TRUST
AND HIV CARE CONTINUUM OUTCOMES

by

JAMES DILLON CALDWELL
M.A., University of Central Florida, 2016
B.A., University of Central Florida, 2015

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Major Professor: Amanda Koontz

ABSTRACT

The current research examines trust as a component of the Healthcare Relationship Scale (HCR) using data from the Medical Monitoring Project (MMP), a program designed by the Centers for Disease Control and Prevention (CDC). This dataset focuses on the experiences and needs of people living with HIV (PLWH). We examined how relationships between people living with HIV and their HIV providers may be associated with two distinct variable groups: (1) socio-demographic characteristics, such as age, gender, race, education and poverty status; and (2) patient health as it relates to the continuum of care, such as patient-rated general health, adherence to a care plan, and trust of information from healthcare providers. To analyze these groups, we used confidence intervals to examine statistical significance between mean trust scores. We present the use of emotional tuning as a possible mediator which could be used to strengthen patient trust and improve the patient-provider relationship. The research finds differences in trust by the aforementioned variable groups. These findings add to the growing body of literature on patient-provider trust, focusing specifically on people living with HIV by examining the role of trust in patient health, and broaden the application of emotional tuning.

ACKNOWLEDGEMENTS

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LIST OF ABBREVIATIONS/NOMENCLATURE/ACRONYMS

AIDS - Acquired Immunodeficiency Syndrome

ART - Adherence to Antiretroviral Therapy

CDC - Centers for Disease Control and Prevention

HCR - Healthcare Relationship (Scale)

HIV - Human Immunodeficiency Virus

HIV-CT - HIV Counseling & Testing

MMP - Medical Monitoring Project

PLWH - Persons living with HIV

SES - Socioeconomic Status

CHAPTER 1: INTRODUCTION

Although research in the field of sociology of emotions has grown over the years, no such research has looked to examine the unique effect one's emotional output has on patient care. Understanding the work of HIV healthcare providers is even more important today, with 37.7 million people globally living with HIV and with advancements in science and an overwhelming improvement in mortality, 28.2 million currently receiving antiretroviral therapies (UNAIDS, 2021). Broadening the application of the concept of emotional labor into the field of HIV healthcare and applying the new concept of emotional tuning (Caldwell, 2016) affords researchers, policymakers, and health professionals a new understanding of the work that is being performed by HIV Care Providers and a possible route to improving patient trust.

Previous research has shown how providers perceive their own emotional output as a tool, which can be used to improve patient cognizance when delivering pertinent information related to the patient's HIV status and treatment plan (Carey et. al., 2018; Preau et. al., 2004). I put forth the conceptualization of *emotional tuning*, an extension of *emotion work*, which can be understood as the process of one individual scanning or reviewing the emotional state of another, and then acting accordingly based on their interpretation of the other's emotional state, in order to develop trust. This subset of emotion work can be applied in various ways, as the individual may "match" the emotions of another by lowering the tone of their voice and slowing their cadence, or by placing themselves in a situation similar to the client being assisted, by drawing on empathy. Inversely, healthcare workers may contrast the emotions of clientele in an attempt to

change their own emotional state or that of another, often in an attempt to improve patient health outcomes (Caldwell, 2016). In either case, the establishment of trust is an integral component to the patient-provider relationship and is often mediated by a patient's interpretation of the emotional output of their respective healthcare provider.

When discussing the role of trust in healthcare research, Bova et al. (2012) put forth a widely used scale known as the healthcare relationship scale (HCR) for measuring components of patient trust. Past research, which utilizes the healthcare relationship (HCR) trust scale, positions trust as an essential component to successful patient-provider interactions (Bova et al. 2012). Patients must place their trust in the hands of a provider in the establishment of a patient's plan of care, and a provider trusts their patient will disclose all relevant information and adhere to their plan of care as recommended. This reciprocation is paramount to successful prevention and timely intervention of HIV (Murray and McCrone 2015). The patient-provider relationship has been widely researched in a variety of settings. Most frequently, patient-provider relationships are mediated through a providers' bedside manner, a concept which, over time, has changed due to its evolving characteristics (Atchley 1963; Cormier 2015; Jourard 1960; Stebbins 2020).

A literature review on the operationalization of the concept of bedside manner reveals no concrete, critical attributes; instead, positive bedside manner is often described as an interpretive interaction, dependent solely on how a provider's care is interpreted by the patient, based on a patient's unique expectation of care. A large portion of this interpretation exists in the patient's perception of various emotions. Most often, traits used to describe positive bedside manner include a provider who is empathetic, possesses a friendly disposition, is a good listener, an

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effective communicator, courteous, as well as being caring and respectful. Adversely, negative bedside manners are often characterized by interactions which are perceived as rude, arrogant, dismissive, uncaring or indifferent (Bendapudi et al. 2006; Ucko 2006); (Finch 2005; Luthy et al. 2005; Roter 2000). All of the attributes listed above are reliant on perceptual emotional transactions between provider and patient, perceptions that are often made as early as the first visit (Flickinger et al. 2016). This is a component of emotion perception, a process that is routine, efficient, and, to some degree, automatic (Barrett, Mesquita, and Gendron 2011). Positioning the patient-provider relationship in this way is both multifaceted and subjective; however, correlations between improved patient health (Roter 2000; Blasi et al. 2001), medication adherence (Pellowski et al. 2017), retention (Dang et al. 2016), more effective visits (Blasi et al. 2001), open communication (Flickinger et al. 2016) and reductions in readmittance (Parent et al. 2018) have all been shown to be positively correlated with improved patient-provider relationships. This is especially important when considering patients currently in managed care. HIV healthcare providers often refer to this type of managed care, as part of the "continuum" by engaging with a team of providers, long term, with the goal of viral suppression and general health (Gov 2021). Patient-provider communication, as well as displays of empathy, trust and respect for patients is shown to have a significant improvement in care engagement (Carey et al. 2018) and long-term quality of life (Préau et al. 2004).

Previous studies have demonstrated the importance of patient-provider relationships in medical care engagement among people with HIV(Wood et al. 2018); patient demographics play a huge role in patient-provider trust. Establishing trust among marginalized communities involves taking into account the experiences of patients and, understanding the impact

discrimination has on the establishment of a trusting patient-provider relationship (Sohler et al. 2007). Studies have shown that interacial anxiety, a lack of racial concordance, discrimination and cultural dissimilarity in healthcare settings is a contributor to weakened trust and increased levels of social mistrust (Budhwani et al. 2021; Earl et al. 2013; Ransome et al. 2017).

The current study addresses gaps in the extant research by analyzing the role patient-provider trust has on patient health outcomes, how trust differs by socio-economic variables, and how emotional tuning may be presented as a possible mediator. Data for this work was provided by the Medical Monitoring Project (MMP), a program created by the Centers for Disease and Prevention (CDC) which focuses specifically on patient-provider trust, care continuum outcomes, and socio-economic variables among people living with HIV (PLWH). Understanding how these variable groups interact provides valuable insight in the future of HIV treatment, and a potential for future studies which may utilize improvements in patient trust as a catalyst for improved patient health, and more focused emotion work performed by providers. For the purpose of the current study, patient trust is viewed as an interpretive, paradigmatic relationship between patient and provider. The process of which involves a patient analyzing the emotional output of a provider, and based upon the provider's behavior, deciding whether trust is warranted or not. Trust in this way is an integral component of the patient-provider relationship. We can also analyze trust as a modality of action that is relational, emotional, asymmetrical, and anticipatory. From this approach, trust does not necessarily hinge on the uptake of knowledge but through emotional involvement and sense-making (Engdahl and Lidskog 2014).

The following will review literature on the concept of emotion, including emotion work, emotion labor and emotional tuning, as well as the connection each of these has to trust, and the

importance of each in the healthcare setting. We will then focus on the use of trust in the establishment of the patient-provider relationship, and the application of the Healthcare Relationship Scale (HCR). This will lead into a reflexive statement and methodology prior to analyzing the findings and further delving into the application of emotional tuning as a potential component of improved trust among patient and provider

CHAPTER 2: LITERATURE REVIEW

I.   Emotion Work and Emotion Labor

Understanding the human emotive experience through a sociological lens offers context to the current study. Much of the current literature, focusing on the sociology of emotions utilizes either a macro-level approach - which focuses heavily on the structural and cultural exchange of emotion, or the micro level approach - which looks more deeply into the connections that exist between the social and psychological experience of the individual. This is best explained by Thoits's (1989) work providing historical context for the creation of the subfield of emotion work. Various research has addressed the complexities encompassed by the sociology of emotions by studying emotional labor performed in the workplace (Hochschild 1979, 1983; Thoits 1989, 1991), and even more specifically, the effects emotionally laborious work has on the individual (Shoptaw, Stein, and Rawson 2000; Sutton and Rafaeli 1987)

Sociology of emotions can be understood as the study of emotions as related to individual and cultural social environments. Thoit's (1989) work describes emotions as "culturally delineated types of feelings or affects" in that they exist somewhere in between the individual and their social world. This process is heavily influenced by one's positionality within their social world, an understanding that uncovers the broad social influence that lies beneath one's emotional experience. By understanding emotion as inherently social, researchers are able to study the environment and stimuli associated with these emotions and their salient situational factors. Viewing emotions as various, graduated, individual experiences has shaped the research

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methodologies associated with emotional labor. Emotions are highly social and as such, are often the product of socialization, humans are taught emotion (Thoits 1989).

Expanding upon this, when an individual approaches a social situation, they do so with an understanding of which emotions should or should not be present, based on ongoing socialization. These norms dictate what is appropriate to a specific situation. If an individual's felt emotions do not align to these prescribed norms, they may act in essentially one of two ways. The first involves attempting to elicit an emotion that is not organically present, and the second is to prevent an emotion that is present from being physically noticeable. This back-and-forth management of emotions is known as emotion work (Hochschild 1983). When one is faced with these norms in their workplace, they may feel as though this emotion work is tied to the expectations of the work they do. Thus, the norm shifts from being simply social to one that is ingrained within the responsibilities of the work they do; this is defined as emotion labor.

To provide an understanding of the origins of the term "emotion labor" and the subsequent expansion of its application throughout various working environments, the following section is organized historically. The literature review will first examine Hochschild's introduction of the concepts of "emotion labor" and "emotion work," which set the foundation for the core research area that will be applied in the present study. Following this, works will then be reviewed that helped expand these concepts in relation to healthcare, before then delving into research specific to HIV Healthcare Providers. The current study looks to contribute to the field of sociology of emotion by examining these concepts within the work done by HIV Healthcare Providers and the impact this has on patient trust and subsequently, patient health outcomes.

In 1979, Arlie Hochschild first applied the term emotional management to the workplace. In its simplest form, emotional management can be understood as an individual's attempt to intentionally shape the way in which their feelings are expressed in a particular environment. Hochschild's (1979) work applied this ideology to day-to-day emotion work as an implicit expectation of how one is to behave while at work. Hochschild (1979) put forth the terms emotion work and feeling rules, as based in social structure, through her piece that focused on the dynamics one is faced with when employed in an emotionally laborious position. Through this work, Hochschild identified gaps in the work of Goffman, Mead, Blumer, and Freud; based in, and expanding on these gaps, she constructed a framework for her own understanding of how and when emotions are managed (Hochschild 1979).

Hochschild (1979: 562) describes three techniques that she believes are utilized in the process of emotion work. The first of which is *cognitive*: "the attempt to change images, ideas, or thoughts in the service of changing the feelings associated with them." Second, she defines *bodily* emotion work as "the attempt to change somatic or other physical symptoms of emotion," offering the example of "trying not to shake." Last, she introduced *expressive* emotion work, like "trying to smile," defining this process as the attempt to "change expressive gestures in the service of changing inner feeling." She further clarifies that *expressive* emotion work involves the attempt to deeply change a feeling; rather than *bodily* emotion work, in simply trying to change the physical display, *expressive* emotion work attempts to internally change the feeling to result in a more appropriate manner externally (Hochschild 1979).

Accordingly, Hochschild (1979) goes on to explain the strain that one may face when either the environment does not elicit a response, or adversely when a response is not appropriate

for a specific environment. In addition, Hochschild (1979) defines "feeling rules" as directives that affect the extent, direction, and duration of a feeling. She gives examples of extent as feeling "too" angry, direction as feeling happy when one "should" feel sad, and durations as how long one "should" feel a certain way. Based on these feeling rules, she argues individuals may feel strain when they do not feel an environment is eliciting a response or if they perceive their response is not appropriate for a specific environment (Hochschild 1979). She presents each feeling rule as a form of social exchange.

When applied to specific labored tasks, Hochschild (1979) put forth the understanding of emotions as a commodity in the workplace. Using the analysis of several working-class jobs, she defined emotional labor in the workplace by outlining the lack of genuine feeling and meaning that one is able to experience or create during their workday. Hochschild's (1979: 570) example of an airline stewardess demonstrates how workers are often required to display overwhelmingly positive outward emotion with "relatively low financial rewards and little authority." In such positions, the management of feelings aims at creating a sense of a meaningful—even if brief—relationship between the employee and customer. Blue collar labor, such as that completed by a highway construction worker, typically requires the machine-like repetition of tasks with no need or time for outward displays of emotion towards customers or as an explicit component of their job duties. Inversely, highly emotive work requirements in other positions oftentimes require workers to engage with clientele with strict control over outward displays of emotion which are outlined as an expectation of the job.

II.   Emotion Labor in the Healthcare Setting

More specifically relevant to the current study, Hochschild (1983) explains the dynamic between patient (customer) and doctor (employee), one that is most interesting as it relies so heavily on trust in situations where one's health is the topic of discussion. Hochschild (1983) describes the ebb and flow of emotion within and between a doctor and their patient, positing how doctors and patients enter into treatment with emotional expectations regarding their care. Doctors are trained professionally to treat physical ailments but are also knowingly expected to understand and uphold appropriate bedside manner. The way doctors present the information to patients and the subsequent management of feelings afterward is often mediated by the treating physician as part of appropriate patient care (Hochschild 1983).

Building from Hochschild's work, Rafaeli and Sutton (1987) helped to situate her work in relation to job-specific expectations by focusing specifically on what they term "role expectations." These expectations influenced what they deemed emotional transactions, and the subsequent outcomes of these transactions. In the organizational context, the authors state that three leading forces work to shape these emotional transactions. First, organizations use recruitment and selection as ways to ensure that they are hiring individuals who are capable of displaying particular emotions. This first tenant is followed by socialization, whereas the organization trains individuals on the management of displayed emotion by first engraining what emotions have been deemed appropriate or inappropriate for the workplace. Lastly, individuals are policed by a system of rewards and punishments, a system of feedback that praises employees for acceptable behavior by incentivizing appropriate displays, and reprimanding inappropriate displays of emotion (Rafaeli & Sutton, 1987).

As previous research has shown, those who work in highly emotive positions are often faced with increased stress as a consequence of display roles and deep acting. Thoits (1991) publication uncovered an interesting link between one's role identity, which she defines as "self-conceptions based on enduring, normative, reciprocal relationships with other people" , and individual stress (Thoits, 1991). Thoits focused on the effects stress had on one's role identity, as this particular identity is an ongoing social process that depends heavily on the upkeep of role expectations. Similarly, ones' attachment to their role identity, and subsequent success or failure has a large effect on ones' psychological well-being and self-conception. Thoits posits as individuals spend more time within a specific role it becomes more salient to their identity, and thus role expectations become, by relation, more crucial to one's mental health. Accordingly, prior research suggests that such emotionally laborious positions may both become even more salient to a role identity and yet cause burnout through the need for deep acting and expressing normative emotions that may run counter to one's own defined feelings.

In a similar way, PLWH are expected to take on what Parsons (1951) deemed the "sick role." This involves taking on a new role that differs from the typical societal expectations one may experience when they are well (Parsons 1951). New expectations are established as a result of one's illness, including cooperation with one's caregivers. In this way, trust hinges on a degree of dependency whereas the patient becomes reliant on the provider for medical care. In the event one rejects the sick role, by questioning medical authority, or asserting their own experiential authority, they may experience obstacles in the development of a successful, productive patient-provider relationship and be categorized as rebellious, angry or irresponsible (Crossley 1998). This creates an emotionally laborious situation for the patient as well, where

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they experience both stigma, as a result of their diagnosis and popular social stereotypes related to infection, and reliance. Reliance exists in this dynamic without regard to socioeconomic status or other social factors. Though a person with insurance, or a person with greater wealth may have the privilege of choice, in that they can choose the provider they wish, from a larger network, they are still reliant on an HIV healthcare provider, this in and of itself can be disempowering. Contemporary work focusing on the sick role among PLWH shows an immense change as compared to earlier expectations of those with chronic illness. The new narrative employs a somewhat subversive tone, shifting the narrative from the patient as a "compliant , passive medical object of care" towards "the sick person as the subject, the active agent of care" (Kleinman 2020). This is a marked shift in the way in which the sick role is applied to PLWH. Negotiating the power dynamic present in interactions between patient and provider requires emotion work, patients must be willing to share their expectations, be vulnerable about disclosing their sexual behavior and risks, and simultaneously, HIV healthcare providers must be sensitive, knowledgeable, and aware of the unique expectations each patient has.

The aforementioned literature provides an understanding of the emotion work that HIV care providers utilize in negotiating the highly emotive experiences of the work they do. If the providers define themselves as having agency, how do they regulate, express, and handle the negative emotions that may appear during their interactions with clientele? Zapf et al.'s (1999) study focused on emotion-work as a source of stress and looked to uncover the ways in which health workers in various roles experienced and expressed emotion in their day-to-day tasks. The research consisted of data collection utilizing three samples of individuals who were employed in areas which require high levels of emotional labor. For the purpose of this study, I will be

focusing only on the first sample which examined employees working in a home for handicapped children, as it more specifically addresses the effects of emotional labor as related to positions in the healthcare field. Zapf et al.'s research aimed to measure five variables that operate concurrently as a measure of emotional labor: (1) Job Satisfaction, the positive or negative sentiments one has towards the work they perform; (2) Psychosomatic Complaints, the bodily and psychological effects that work has on the individual (i.e.-stress, exhaustion, anxiety); (3) Irritation or anger, impatience and annoyance experienced during work; (4) Self-esteem, the value one places on themselves as a member of their workplace; and lastly (5) Burnout, the combination of various negative experiences either physical or mental that push an employee to eventually become disinterested, or detached from the work they do. The research showed, through an exploratory factor analysis that broke down the emotional displays of the employees, found those employed in the aforementioned field ranked higher than the others in all categories. The second test performed in the study looked at the variety of patient emotions that the employees face, finding that those employed in human services were often exposed to a wider array of emotions then those employed in other sectors. Lastly, the researchers aimed to measure "sensitivity requirements" which sought to understand how much of the worker's position was reliant on the information that they knew about their clientele (i.e. knowing the clients background or history as a salient job requirement) (Zapf et al. 1999). This research uncovered the existence of numerous facets of emotional labor performed in healthcare settings, positing an existence of multiple contributing factors that have both positive and negative effects with respect to the psychological wellbeing of the healthcare worker. We now understand providers are expected to engage in emotion labor in their day-to-day interactions with patients, we will now consider how providers perceive the impact of this work.

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III.   Provider Perceptions of Emotion Labor

Working in HIV care is understandably difficult. Historically, the pandemic has been strongly gendered, sexualized, and stigmatized as a disease that effects predominantly homosexual men. Many highly funded organizations work to assist those who are seen as existing within a high-risk group with programming and preventative education campaigns that address the needs of the at-risk group. A recent study using data from the Medical Monitoring Project Provider Survey (n=1234) focuses on the demographics, qualifications, and satisfaction of the HIV Care Provider workforce, this highlights those who bear the burden of emotional labor. The study found, HIV Care Providers are predominantly heterosexual (85%), white (63%), and male (57%). Characteristics of work, in the aforementioned study shows that a majority of HIV care providers work more than 40 hours per week on patient care (63%) and have worked in the field for 10 or more years (71%) providing continuous, direct care to between 51-200 patients (39%) (Weiser, et al., 2016).

When we focus on the demographics of the group most impacted by new HIV infections, as of May 2022, young, gay, and bisexual men who have sex with men (MSM) still outnumber all other subpopulations as the largest at-risk group, accounting for 69% of new HIV infections (UNAIDS, 2021). Given this context, and more specific to the work HIV Healthcare Providers are tasked with, Wienhardt, Carey, Johnson and Bickham (1999) conducted a meta-analysis of the research on the effects that HIV Counseling and Testing (HIV-CT) has on sexual risk behaviors. This research concluded that HIV-CT work to provide an effective means of prevention for those who are infected as well as those who are currently negative. The work HIV healthcare providers do, in this respect, can be seen as an efficient means for HIV prevention in

both negative and positive clientele (Weinhardt et al. 1999). Their research which looked at 27 studies in total presents an interesting fact about the overall effectiveness of HIV-CT, influencing HIV counselors to renegotiate the impact that they have on the possible prevention of the virus. This notion for some may be a realization of the counselors' own agency, or lack thereof.

Shoptaw, Stein and Rawson's research (2000) examined the negative effects Providers face when working with clients who are HIV positive. The study examined 134 Counselors from 34 substance abuse clinics in the United States in an effort to explain factors that contribute to employee burnout. The study looked at predictors of burnout factors among drug counselors who treat HIV + clientele and found that 42% of burnout factors could be explained by the percentage of clientele the counselor treats who are HIV+ (Shoptaw, Stein and Rawson, 2000). In a closer examination, Westburg and Guindon's work (2004) offers a broader understanding of emotions experienced by healthcare providers who serve HIV positive patients. Their study which examined responses from 94 participants illustrates the varied types of emotions, both defined as positive and negative in relation to mental health, that are reported during interactions with HIV+ clients. The most common emotions reported in the study in order were "(1) empathy, (2) sympathy, (3) sadness, (4) frustration, and (5) fulfillment" (Westburg and Guindon 2004). It is safe to say that sympathy and empathy have a likelihood to increase patient-physician trust and, overall allow for a more positive experience.

This undoubtedly effects the connection counselors have to the clients they serve, as such research suggests, perceived agency can help to counter such negative outcomes. Therefore, when studying the work performed by HIV Healthcare Providers, it is important to understand the position the provider holds, and the believed agency or power that they have over the

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prevention and treatment of the individuals they serve. More specifically, if healthcare workers

see the impact their work has on a person, or group of people, they may become more involved

in their work as they view it as vital to the prevention or management of the pandemic. Seeing

one's work as the possible solution to a worldwide pandemic, while rewarding, also, as outlined,

puts a great deal of pressure on HIV healthcare providers. The work providers do, in supplying

antiretroviral therapies, connecting PLWH to their care continuum, and educating patients on

risk reduction techniques has led to improvements in disease mortality. AIDS-related mortality

has declined by 53% among women and girls and by 41% among men and boys since 2010

(CDC 2020). In this way, trust is paramount, as those who have been diagnosed with HIV are

entrusting their providers with their treatment and by extension, their life.

IV. Defining Trust and its Role in Patient-Provider Relationships

The current study defines trust as a multifaceted concept reliant most often on the

establishment of principled behavior, predicated by social interaction, whether direct or indirect

(Glaeser et al. 2000). In the medical setting, trust hinges on (1) personal, direct interactions, such

as competence, confidence, physician control, compassion, reliability, dependability and open

communication, as well as (2) impersonal, professional qualifications such as skill, knowledge

and education (Anderson and Dedrick 1990; Mechanic 1998; Pearson and Raeke 2000). We trust

our physicians and other providers will utilize their training and education to our best interests.

Empirical research on patient-provider trust shows some variability with respect to which factors

have the greatest impact on trust in the relationship between patient and provider. Qualities such

as interpersonal and technical competence, moral comportment, and vigilance have proven to be important factors associated with patient-provider trust (Murray and McCrone 2015).

With respect to care provided to PLWH, trust is integral to successful care. Success in this way is defined as connecting PLWH to the HIV care continuum. This involves following a timeline from diagnosis, to achieving and maintaining viral suppression (Hogg 2018). The HIV/AIDS epidemic has been met, historically, with stigma, shame, and hatred, fueled by a cultural response to the virus and its relationship to the LGBTQ community (Grossman and Stangl 2013). Mounting research shows the impact stigma has on patient-provider trust, and its implications related to treatment for historically stigmatized groups (Cipollina and Sanchez 2019). In this way, stigma acts as a barrier to patient-provider trust, hindering HIV testing (Turan et al. 2011), dose adherence (Rao et al. 2007; Rintamaki et al. 2006), disclosure (Tsai et al. 2013), trust (Kay et al. 2018) and retention in care (Naar-King et al. 2007). The process of gaining trust among PLWH requires a period of give and take between patient and provider, allowing trust to grow over time (Carr 2001).

The process by which trust is earned differs also by dimensions of patient health. Patients with chronic illness often experience trust levels which wax and wane, differing from early periods of diagnosis, where trust may be absolute and often unrealistic, to eventual long-term treatment, where trust often tapers off and is based in reality and experience. These differing levels of trust have been related to frustration and confusion surrounding one's health, and the role the provider plays with respect to long term care (Thorne and Robinson 1988). Trust in this way can act as a mediator between patient and provider, and have an immense impact on a

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patient's health (Gopichandran 2019; Graham et al. 2015; Pellowski et al. 2017). Healthcare is not a one size fits all transactional interaction, instead, patients bring unique expectations about their health, expectations that are shaped by previous interactions with the healthcare system, knowledge of their own health, and societal assumptions related to how they believe the relationship between patient and provider should look (Dansereau et al. 2015; Meredith et al. 1997; Wachira et al. 2018; Williams et al. 1995). Emotional interpretations undoubtedly play a huge role in the way patients perceive patient-provider relationships, as mentioned below, in the creation of the Healthcare Relationship Scale (HCR), emotional connection is a key component of collaborative trust. Previous work shows how HIV care providers work to influence the emotional state of the patients they treat via *expressive*, *bodily,* and *cognitive* emotion work. One way in which this is done is through the employment of *emotional tuning* (Caldwell, 2016).

   V. Emotional Tuning

      Emotional tuning, a concept put forth by Caldwell (2016), can be understood as the process of one individual scanning or reviewing the emotional state of another, and then acting accordingly based on their interpretation of the other's emotional state. This subset of emotion labor works in various ways, as the individual may "match" the emotions of another by lowering the tone of their voice and slowing their cadence, or by placing themselves in a situation similar to the client being assisted. Inversely, providers may contrast the emotions of clientele in an attempt to change their own emotional state or that of another. In contrasted emotional tuning, testers mentioned the process of "reading" the state of their client, and then working to either improve their mood or emotional state, for example, cheering up the client or focusing on the positives of the situation in an effort to bring the client to a place of understanding, or in cases

when the client seemed unaware or infrangible by the risks they were taking, counselors would work to instill fear, or a more realistic understanding of the dangers of risky sexual behavior by speaking lower, moving closer to the client, or by changes in facial expressions to project the seriousness of these risks. Most often, HIV care workers engaged in emotional tuning as an attempt to elicit emotions from their patients - often tied to the belief that it was the providers responsibility to ensure they expressed themselves in a way that encouraged an understanding of the patients diagnosis, education surrounding sexual risk, and adherence to care.

The process of engaging in *emotional tuning* is presented in *expressive*, *bodily,* or *cognitive* emotion work. *expressive* emotion work, as mentioned, involves suppressing one's emotions, this is exemplified in an excerpt of Caldwell's (2016) research:

" I was nervous because (the client) put all of her trust into my hands and I was extremely nervous, and I just felt terrible because I didn't know if I was the best person to help and I definitely couldn't show that because I didn't want to show her how scared I was for her."

Establishing patient-provider trust in this way, via expressive emotion work, is seen as the process of controlling a patient's perception of a provider's emotional state, by being perceived as confident, caring, and qualified to handle a patient's diagnosis, even when a provider may feel inadequately prepared to do so.

Bodily Emotion work on the other hand is the attempt to control one's somatic expressions in an effort to change the perception of one's emotional state. Hiding or masking one's visceral or emotional reactions for the believed benefit of the patient. This typically involves being aware of your outward, physical associations of emotion, watching one's face or

holding back one's emotions until they are in space where they believe it is appropriate to express themselves, as they *truly* feel. This is best exemplified by a quote in Caldwell's (2016) research focusing on a young female HIV healthcare worker who discussed the need to hide or conceal outward, physical emotions deemed inappropriate during interactions with patients:

> " I try not to be too emotional with my clients, after they leave it is a completely different story, I remember especially the first one (reactive result) I ever had was just kind of scary for the both of us I think, I was trying to make sure my voice wasn't too shaky or anything like that."

This shows how emotion work plays a key role in how Healthcare Providers understand the way in which their patients perceive them, and the assumed importance of hiding or changing physical and emotional manifestations.

Cognitive emotion work involves attempting to change one's thoughts or images in an effort to change the feelings associated with a particular emotional situation. HIV Healthcare providers were noted to focus more heavily on the positive aspects of the work they do, by shielding or discounting the more emotional aspects inherent in their interactions with patients. In the aforementioned study, this was often exhibited through changing their perception of the work being performed, to renegotiate the meaning they associate with a positive test. By reframing reactive or positive tests as a good thing, they may renegotiate their emotional response to a reactive test, viewing a reactive test as one more individual who now knows their status and can move into treatment. Providers are engaging in cognitive emotion work, unlike bodily and expressive, even when not in the presence of the patient, this work is often done alone, as a way to improve their future interactions with patients.

Emotional tuning is a concept which focuses on the perception of providers, based on the overwhelming assumption that particular interpretations of one's emotional state may have an impact on patient care. No research to date has examined how patients perceive the emotion work providers engage in, and by extension, no research to date has shown whether or not this emotion work, as it relates to improved patient-provider relationships, has any impact on patient health. The current work looks to connect these three concepts based on the premises: (1) Providers engage in emotion work, (2) Emotion work is an integral component of the patient-provider relationship, (3) Trust is integral to the patient-provider relationship, (4) Patient trust has implications for patient health. In an effort to understand how these assumptions are related, the current research focuses on the use of the Health-Care Relationship Trust Scale (HCR).

Trust, in this way, is constructed via interactions between patient and provider and is dependent on the unique needs of each patient. Providers are tasked with meeting patients where they are, in terms of their experience with HIV, their reaction to their diagnosis, and their understanding of treatment. This involves ensuring providers are aligned with the emotional state of the patients they treat, so as to ensure patients understand information being relayed to them. If a patient is visibly upset, crying or angry, a provider must make changes to their own emotional output to attempt to bring a patient to an emotional state that is conducive to a productive exchange of information. If a patient is cathartic, unphased or apathetic, a provider is expected to interact with a patient in such a way to ensure the seriousness of the situation is understood. If a patient's emotional interpretation of a provider's output is misaligned, a patient may misconstrue the intentions of the provider, becoming unreceptive to care. Inversely, when the emotions of the provider and patient are appropriately aligned, the opportunity for receptiveness to care exists. Providers must present themselves in a manner that fosters trust.

Understanding this unique, multifaceted interaction between patient and provider lays the groundwork for the current study. If we understand the importance of trust in the patient-provider relationship, and we understand emotion work as foundation for the interpretation of trustworthy interactions, it is feasible to argue a provider, in this, could engage in emotion work which improves patient trust and by extension, patient health. The following sections will outline the process of data collection and analyzation and explore differing trust scores by sociodemographic variables, and patient health/risk reduction techniques to better understand the interaction between patient trust scores and these two variable groups of interest.

CHAPTER 3: METHODOLOGY

I.   Sample

The current study is exploratory in nature and as such, the first of its kind to analyze trust within the parameters outlined. The current research uses data from the Medical Monitoring Project (MMP), a national program, which is designed to understand the experiences, and needs of people living with HIV. The MMP is supported by state and local health departments along with the Centers for Disease Control and Prevention (CDC). The largest of its kind, this nationally representative sample provides behavioral and medical record data on adults diagnosed with HIV in the United States, using data from the latest collection cycle available, 2018 (N=4050).

In 2015, MMP introduced an updated sampling technique which includes all adults diagnosed with HIV in the United States. This differs from their previous strategy which only sampled PLWH currently receiving HIV medical care. While some information about the sampling technique is provided, much of the specifics are proprietary. This updated sampling technique selects an appropriate number of persons both locally and nationally to ensure representative data is collected. The first of which focuses on geographic areas, the second focuses on HIV status. Since 2009, twenty-three jurisdictions have conducted MMP research, allowing researchers to include over 70% of the total cases of HIV infection and AIDS in the United States (CDC 2020). The current research uses secondary data, provided by the CDC in the form of output to analyze the variables of interest.

I.   Reflexivity Statement

The current work was inspired by the author's own interactions with the field of HIV testing and counseling. As a young gay boy, raised in the conservative South I had very limited interactions with individuals within the LGBTQ+ community. Most of the information I received was negative and religious in nature, likening those within the community to sinners who would eventually, as a result of their sin be burdened with HIV. The inspiration for this research came after a college professor in a small community college history class made an erroneous statement, that, by the end of the semester, "two students would be infected with HIV and two more would be pregnant" (I believe this was his attempt to dissuade us from sexual activity). This statement startled me. I immediately left the room, got into my car and drove an hour south to the nearest metro area where I could access a rapid HIV test. I remember sitting in a clinic in south Orlando that catered specifically to the homeless with my partner, Alex, who had come along and agreed to get tested as well to calm my anxiety. We waited and eventually received our results, and though we both were non-reactive, I couldn't shake the experience. For a few days thereafter I pondered the emotions I felt, the information I had been exposed to and the immense stress experienced while waiting for our test results. I then reflected on this experience, and had a difficult time wrapping my head around the immense stress I assumed the HIV healthcare provider might have experienced. The healthcare provider whose job it was to deliver both non-reactive and reactive results every single day. I imagined my experience as a tiny fraction of their day-to-day life. I continued to imagine this experience throughout my early twenties and eventually, decided to embark on research on the topic, with the goal to assist healthcare providers who may also work in emotionally laborious positions. This experience has

shaped my passion for supporting HIV healthcare providers and informed much of my work in the field.

Though my previous research on emotion work via emotional tuning, and my own personal experiences have primed my understanding of the relationship between patient and provider, its application is especially suited for an analysis of patient trust. As mentioned before, patient trust is an interpretive concept, based predominantly on the way in which a patient perceives the emotional output of their provider. As outlined below, the dependent variable (HCR-revised) is a combination of thirteen questions all which measure a patient's interpretations, based on a provider's behavior. It is important that we delineate, the scale is a measure of meaning making or the meaning one attaches to a stimulus. Following this premise, providers have the ability to actively engage with their patients' emotional state via emotional tuning.

There are two conceptual groups of interest which have been analyzed with respect to patient trust in the current study: sociodemographic characteristics, and patient health outcomes as they relate to HIV care. The following sections outline how these variables were operationalized by the CDC, and how they will be analyzed with respect to trust.

III. Measures

Dependent Variable

The dependent variable is the HCR- revised trust scale, calculated by combining a participant's total trust score (based on their response to 13 Likert scale questions) into a single score (TRUS_COMB). The HCR-revised trust scale variables, which are devised of thirteen questions

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(Table I.), with five responses via a 5-item Likert scale (0= none of the time, 1= some or a little of the time, 2=occasionally, 3=most of the time, 4=all of the time). To provide a general analysis of patient trust, a previously validated, revised trust score was created by combining all 13 trust variables (Chronbach's $\alpha = .96$) (Bova et al. 2012).

Table 1: Trust Variables and Descriptions

Variable Name	Description
TRUS1N8	How often does your healthcare provider discuss options and choices with you before healthcare decisions are made?
TRUS2N8	My healthcare provider is committed to providing the best care possible.
TRUS3N8	My healthcare provider is sincerely interested in me as a person.
TRUS4N8	My healthcare provider is an excellent listener.
TRUS5N8	My healthcare provider accepts me for who I am.
TRUS6N8	My healthcare provider tells me the complete truth about my health-related problems.
TRUS7N8	My healthcare provider treats me as an individual.
TRUS8N8	My healthcare provider makes me feel that I am worthy of his/her time and effort.
TRUS9N8	My healthcare provider takes the time to listen to me during each appointment.
TRUS10N8	I feel comfortable talking to my healthcare provider about my personal issues.
TRUS11N8	I feel better after seeing my healthcare provider.
TRUS12N8	How often do you think about changing to a new healthcare provider?
TRUS13N8	How often does your healthcare provider consider your need for privacy?

The dependent variables listed above are based heavily in the perception of emotion. Asking about the patient's experiences with providers by asking them to measure sincerity, listening, acceptance, worth and comfort all involve emotional evaluation and require the provider (whose trust is being measured) to perform emotion work. If a patient reports feeling "worthy of a providers time" or feeling as though a provider is "accepting" or an "excellent listener", for example, this requires emotion work on behalf of the provider – these perceptions or feelings are interpretive.

Independent Variables

Sociodemographic Variables:

The comparison of patient-provider trust scores and patient demographic variables relies on the use of eleven variables of interest:

- **Age (_AGEGRP3)** in the study is split into four groups (1) 0-29 years, (2) 30-39 years, (3) 40-49 years, (4) >= 50 years.

- **Education (_EDUC)** is split into three groups (1) less than High School diploma (2) High School diploma or equivalent (3) greater than High School diploma.

- **Race (_NEWRACE2_13)** is split into four groups (1) White, non-Hispanic, (2) Black, non-Hispanic, (3) Hispanic or Latino, (4) Other.

- **Gender (_GENDER)** follows a four-category system (1) Male, (2) Female, (3) Transgender, (4) Intersex.

- **Sexual Orientation (SEXOR_N5)** is split into four groups (1)Lesbian or Gay, (2) Straight, that is, not gay, (3) Bisexual, (4) Something else.

- **English Language Ability (LANWL1N3)** is split into four groups (1) Very well, (2) Well, (3) Not well, (4) Not at all.

- **Birthplace (_BORN2)** is split into two groups (1) Not U.S. Born, (2) U.S. Born.

- **Homeless Status (_HOMELESS2)** is split into two groups (1) Not homeless, (2) Homeless.

- **Poverty Level (_POVERTY2_15)** is split into two groups (1) Above poverty level, (2) At or below poverty level.

- **Incarceration (JAIL_N5)** is split into two groups (1)Never incarcerated, (2) Incarcerated, at least once.

- **Health Insurance (_HTHINS_TYPE_15)** is split into five groups (1) Any private insurance, (2) Public insurance only, (3) Ryan White (RW)/ADAP only, (4) Unspecified insurance, (5) No insurance or coverage.

Patient Health and Risk Reduction Variables:

- **General Health (GENHLTN8)** is split into five groups (1) Poor, (2) Fair, (3) Good, (4) Very Good, (5) Excellent.

- **Seeking Information about HIV (INFTX1N8)** is a binary (0) No, (1) yes.

INFT3N Variables measure trust in information related to HIV care or treatment from:

- **Nurse, doctor, or other healthcare worker (INFT3N8A)** split into 3 groups (0) Not at all, (1) Somewhat, (2) A great deal.

- **Family or friend (INFT3N8B)** split into 3 groups (0) Not at all, (1) Somewhat, (2) A great deal.

- **Centers for Disease Control and Prevention (INFT3N8C)** split into 3 groups (0) Not at all, (1) Somewhat, (2) A great deal.

- **State or local health departments (INFT3N8D)** split into 3 groups (0) Not at all, (1) Somewhat, (2) A great deal.

- **Community-based organization (INFT3N8E)** split into 3 groups (0) Not at all, (1) Somewhat, (2) A great deal.

- **Religious organization (INFT3N8F)** split into 3 groups (0) Not at all, (1) Somewhat, (2) A great deal.

- **Conversed with outreach worker or prevention program worker (TALK_5A)** binary (0) No, (1) Yes.

- **Conversed with doctor, nurse or other healthcare worker (TALK_5B)** binary (0) No, (1) Yes.

- **Frequency of missed dose of HIV Medication (MISEVRN8)** split into four groups (1) Often, (2) Sometimes, (3) Rarely, (4) Never, not even once.

- **Perception of adherence to dosage in past 30 days (_ADH1_N5)** split into six groups (1) Very poor, (2) Poor, (3) Fair, (4) Good, (5) Very good, (6) Excellent.

- **General satisfaction with HIV care (GESAT_8)** split into four groups (1) Very satisfied, (2) Somewhat satisfied, (3) Somewhat dissatisfied, (4) Very dissatisfied.

- **Patient viral load detectable/undetectable(_RCNTVLSTATUS_LT200_MRA)** binary (0) Undetectable, (1) Detectable.

- **Sustained viral suppression (_ALLVLSTATUS_LT200_MRA)** binary (0) Undetectable, (1) Detectable.

- **Patient needs are being met (_UNMETNEED_18)** split into three groups (0) Yes, >=1 unmet needs, (1) No, received all needed services, (2) Didn't need any services.

- **Patient missed appointment in past 12 months (MSAPPT_8)** binary (0) No, (1) Yes.

- **Patient retained in care (_CAREHRSA12_MRA_18)** binary (0) No, not retained in care (1) Yes, retained in care.

IV.   Analytic Strategy

To understand the relationship our two variable groups of interest have with patient trust, based on our research questions, an output table was procured from the CDC following their protocols, and the provided output was analyzed. Median scores were produced for each independent variable, as well as 95% confidence intervals. These intervals, or ranges tell us whether or not median differences are statistically significant. If the ranges provided for each variable overlap, it is assumed there is no statistically significant difference between the variables, if they do not overlap, it is assumed there is a statistically significantly difference. While statistical significance is important, we will be considering the use of practical significance (Kirk 1996) in later sections as this allows for an interpretation of the usefulness of the statistic in the real world. The following section will highlight the findings of the research, organized by sociodemographic characteristics and then patient health outcomes and risk reduction characteristics.
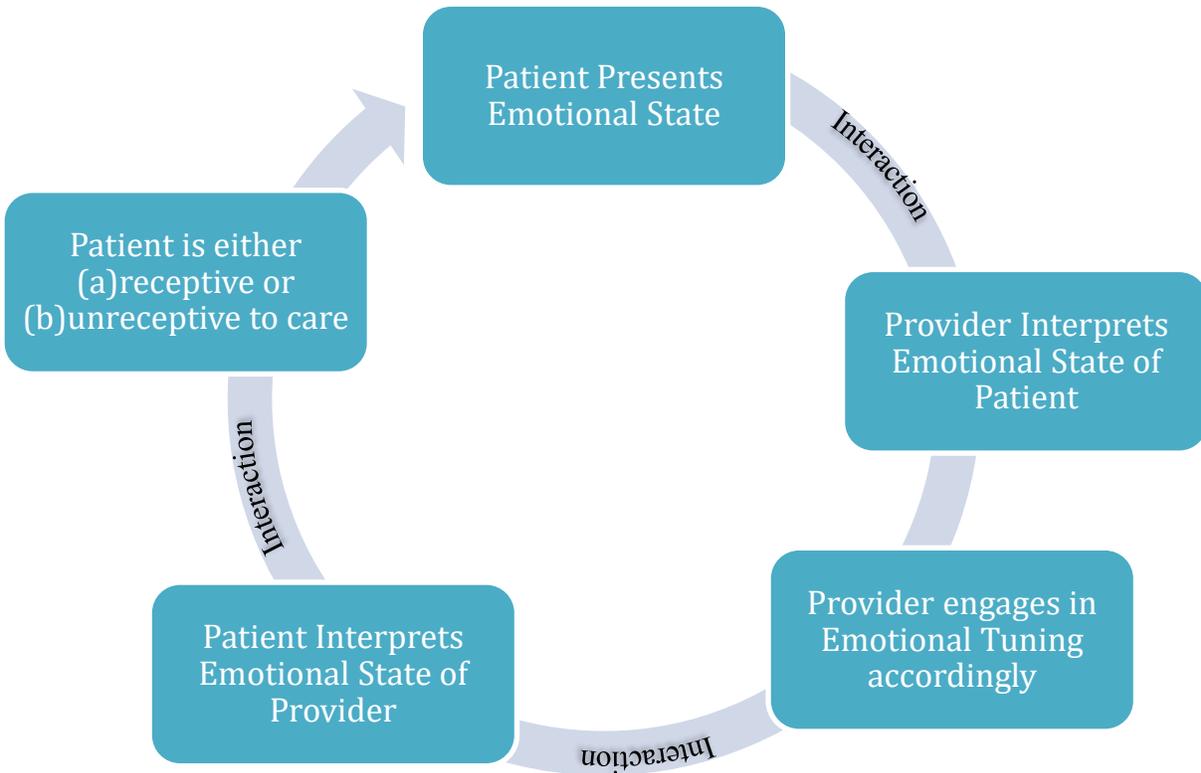
Figure 1: The Construction of Trust as a Process of Emotional Tuning

IV. The Development of the Healthcare Relationship Trust Scale

Data for the current study uses the Healthcare Relationship (HCR) trust scale as used in the Medical Monitoring Project (MMP) provided by the Centers for Disease Control and Prevention (CDC). In an effort to understand patient-provider trust, and to develop a scale to measure this concept, Bova et al (2006) developed the Health Care Relationship (HCR) Trust Scale. This 15-item scale has been popularized for its internal consistency, test-retest reliability, and construct validity. The HCR trust scale is widely used in health research and is especially appropriate for studying samples of PLWH as its development included, specifically, a diverse, vulnerable sample of patients currently using HIV primary care sites. Bova and colleagues utilized mixed

methodology to test the validity and reliability of the current scale. The scale is based on the

development of six key components of "collaborative trust"

1. **Knowledge sharing** - the ability of the provider to explain things in a complete and
    understandable nature.

2. **Emotional connection** - showing compassion, caring and empathy towards the patient,
    described as being "down to earth"

3. **Professional connection** - being open-minded, vigilant, watchful, and committed.

4. **Respect** - treating the patient as an individual, making them feel worthy of the provider's
    time and effort. Patient privacy is also mentioned here as a facet of respect.

5. **Honesty** - telling the patient the truth, being sincere and avoiding artificial niceness.

6. **Partnership** - appreciating when the patients "know something" about their own needs
    (reciprocity) and providing options for care based on this knowledge. (Bova et al.
    2006)".

Trust is measured through six components which fall into three broader categories -
Interpersonal connection, respectful communication, and professional partnering. Utilizing these

findings, a series of fifteen questions were developed to measure some aspect of the

aforementioned components of collaborative trust. Table I in Chapter 3 outlines how these

questions are worded.

CHAPTER 4: RESULTS

As an exploratory study, the aim of this research is to identify possible areas of interest as they relate to patient/provider trust, and possible differences as they relate to patient sociodemographic variables, patient health outcomes and risk reduction. Tables II and III show the results of the weighted percentages with associated 95% confidence intervals (CI), describing prevalence ratios with predicted marginals used to assess differences between groups. Median scores for each group varied, as shown in Table II which focuses on sociodemographic variables. The sociodemographic characteristics focus on patient age, education, race, gender, sexual orientation, English language proficiency, citizenship status, living arrangement, poverty level, incarceration history and health insurance coverage, in that order. The patient health and risk reduction variables focus on patient rated general health, information seeking behavior and from which sources a patient is likely to trust said information, communication with a provider or their support staff, adherence to care, general patient satisfaction with care, and whether a patient feels their needs are being met.

Table 2. Trust Scores by Sociodemographic Variables

	HCR TRUST- REVISED	
	Median	95% CI
Patient age group		
(1)0-29 yrs	49.97	48.82-51.12
(2)30-39 yrs	50.5	49.99-51.01
(3)40-49 yrs	50.7	50.30-51.10
(4)>=50 yrs	50.91	50.57-51.24
Education		
<High School	50.77	50.40-51.14
HS Diploma or equivalent	51.02	50.76-51.28
>High School	50.59	50.27-50.92
Race		
White, non-Hispanic	50.58	50.12-51.04
Black, Non-Hispanic,	51.05*	50.75-51.34
Hispanic or Latino	50.38*	50.02-50.74
Other	50.35	49.83-50.87
Gender		
Male	50.59	50.28-50.89
Female	51.05	50.85-51.25
Transgender	51.03	50.11-51.94
Intersex	.	.
Sexual Orientation		
Lesbian or Gay	50.58	50.18-50.99
Straight, that is, not gay	51.01*	50.81-51.20
Bisexual	50.22*	49.75-50.69
Something Else	50.19	49.35-51.04
English Language Ability		
Very Well	50.81	50.50-51.12
Well	50.36	49.81-50.92
Not well	50.34	48.79-51.88
Not at all	50.87	50.31-51.44
Birthplace		
Not U.S. Born (0)	50.76	50.42-51.10
U.S. Born (1)	50.56	49.88-51.24
Homeless status		
not homeless (0)	50.78	50.45-51.12
homeless (1)	49.86	49.03-50.69
Poverty level		
Above poverty level (0)	50.72	50.40-51.04
at or below poverty level (1)	50.69	50.31-51.07

Incarceration history		
Never incarcerated (0)	50.77	50.44-51.09
Incarcerated, at least once (1)	49.51	47.99-51.04
Health insurance		
Any private insurance	50.77	50.38-51.17
Public insurance only	50.69	50.43-50.95
RW/ADAP only	50.96	49.83-52.09
Unspecified insurance	49.4	44.78-54.01
No insurance or coverage	48.91	43.80-54.03

*p<.05

I.   Analysis of Sociodemographic Variables and Trust Scores

Differences Amongst Racial Demographics

Patient sociodemographic variables, with respect to race, show only two groups with statistically significant differences - those who identify as Hispanic/Latino have significantly lower patient trust scores (50.38) compared to those who identify as Black/non-Hispanic (51.05). Overwhelmingly, health research as it relates to trust focuses on differences between non-Hispanic whites and non-Hispanic blacks. Research on the effect of trust in adherence to treatment among Latino immigrants has shown a lack of trust as a possible barrier to adherence to treatment in other healthcare settings, such as behavioral health, as well as diabetes care among others (Amirehsani et al. 2017; Falgas-Bague et al. 2019). This finding follows the research done by Ransome et. al (2017) showing how trust may facilitate earlier diagnosis, and improved continuum outcomes among racial/ethnic minority groups (Ransome et al. 2017).

Differences Amongst Sexual Orientation

Sexual orientation also showed significant differences between two groups of interest. Bisexual

respondents reported lower trust scores (50.22) than their straight (51.01) counterparts. Prior research has shown, those in the LGBT community as a whole have warranted fears about the U.S. Healthcare system (Priest 2021), however, none to date show specific differences among subgroups within the LGBT community (comparing lesbian identifying individuals with those who identify as gay or bisexual, or transgender). Many health initiatives related to HIV testing, education, and care focus specifically on gay men, understandably so as this group has historically experienced the highest rate of new infections. An unintended consequence of this may be the exclusion of programs which focus on all sexual orientations, and thus an exclusion of programming catered at those who identify as straight, lesbian, transgender, or bisexual.

Table 3. Median Patient/Provider Trust scores among persons diagnosed

	HCR TRUST- REVISED	
	Median	**95% CI**
Patient-Rated General Health		
Poor	49.72	48.17-51.27
Fair	50.31	49.99-50.64
Good	50.74	50.30-51.18
Very Good	50.82	50.32-51.31
Excellent	51.12	50.90-51.33
Sought Information about HIV		
No	50.93	50.44-51.42
Yes	50.67	50.34-51.00
Trust of Information From:		
Doctor or other healthcare worker		
Not at all	50.08	.
Somewhat	48.83*	47.66-49.99
A great deal	50.81*	50.45-51.17
Family or friend		
Not at all	50.78	50.29-51.27
Somewhat	50.53	50.23-50.82
A great deal	50.99	50.37-51.60
Centers for Disease Control		
Not at all	49.66	48.62-50.71
Somewhat	50.12	49.65-50.60
A great deal	50.79	50.39-51.18
State or local health department		
Not at all	49.87	48.50-51.25
Somewhat	50.17	49.77-50.57
A great deal	50.86	50.48-51.24
Community-based organization		
Not at all	50.55	50.04-51.07
Somewhat	50.51	50.03-50.99
A great deal	50.88	50.48-51.28
Religious organization		
Not at all	50.56	50.07-51.05
Somewhat	50.74	50.28-51.21
A great deal	51.00	50.64-51.37
Conversed with outreach worker or prevention program worker		
No	50.75	50.37-51.13

| | HCR TRUST- REVISED | |
	Median	**95% CI**
Yes	50.68	50.40-50.97
Conversed with Doctor, Nurse, or other healthcare worker		
No	50.54	50.14-50.93
Yes	50.86	50.56-51.17
Frequency of missed dose of HIV medication		
Often	49.68	48.73-50.63
Sometimes	50.23	49.70-50.76
Rarely	50.8	50.48-51.12
Never	51.05	50.84-51.27
Perception of adherence to dosage in past 30 days		
No, < 100% dose adherence	50.35	49.96-50.73
Yes, 100% dose adherence	51.01	50.84-51.18
Patient viral load detectable/undetectable		
Undetectable (0)	50.77	50.42-51.12
Detectable (1)	50.7	50.03-51.38
Sustained viral supression		
Undetectable (0)	50.73	50.40-51.07
Detectable (1)	50.95	50.40-51.49
Patient needs are being met		
Yes, >=1 unmet needs	50.44	50.09-50.78
No, rcvd. all needed services	50.98	50.64-51.32
Didn't need any services	50.75	49.45-52.04
Patient missed appointment in last 12 months		
No	50.88*	50.52-51.24
Yes	50.14*	49.79-50.50
Patient retained in care		
No, not retained in care	50.62	50.18-51.05
Yes, retained in care	50.76	50.42-51.10
General satisfaction with HIV care		
Very satisfied	51.05*	50.90-51.20
Somewhat satisfied	44.52*	43.50-45.53
Somewhat dissatisfied	39.12*	34.70-43.54
Very dissatisfied	33.21*	

*P<.05

II.   Analysis of Patient Health / Risk Reduction Techniques and Trust Scores

Differences Amongst Patient Trust of Information

Information received from a nurse, doctor, or other healthcare professional showed an increase in median trust levels, with those reporting trusting information somewhat (48.83) scoring slightly lower than those reporting trusting information a great deal (50.81). While this seems obvious, trusting an individual also typically involves trusting the information they provide. Trust, as mentioned, is integral to the patient-provider relationship, the findings of this study mirror that of others, exemplifying how trust can mediate medical seeking behavior, self-rated health, and improved lifestyle behaviors (participating in far less risky behavior)(Hardin et al. 2018).

Differences Among Patients who have Missed Appointments

Those patients who had missed at least one appointment in the last twelve months (50.14) had lower patient trust scores than those who did not (50.88), pointing to trust as a possible mediator of adherence to care. This aligns with previous studies which show how lack of trust is associated with poorer health outcomes, including patient linkage, retention and adherence to HIV care (Graham et al. 2015).

Differences Among General Satisfaction with Care

Significant differences were noted between multiple levels of satisfaction. Overall, higher levels of satisfaction correlated with higher median trust scores. Significant differences were noted between those who report being very satisfied (51.05) and those who are somewhat satisfied (44.52), somewhat dissatisfied (39.12) and very dissatisfied (33.21). Trust and satisfaction with care are interrelated, in that trust in one's provider is a component of one's satisfaction with their care. Benkert et al (2006) found race (perceptions of racism and mistrust of white providers) to be a mediating variable, accounting for 27% of the variance in satisfaction with care (Benkert et al. 2006).

CHAPTER 5: DISCUSSION, LIMITATIONS AND
DIRECTIONS FOR FUTURE RESEARCH

I.   Discussion & Limitations

The aim of this research is to identify possible areas of interest as they relate to patient/provider

trust, and further the application of emotional tuning. While a handful of the variables of interest

show statistical significance, I highlight the importance of considering the practical significance

(Kirk 1996) of those variables that did not meet the threshold of statistical significance. As

shown in Table I, many variables of interest are approaching statistical significance, yet did not

qualify under the current .05 threshold. This idea of statistical vs. practical significance also

feeds into the limitations of the current research, leaning towards a less conservative analytic

strategy may produce more statistically significant results. Practical significance in this way

allows us to consider differences that traditional statistical significance may miss, especially

when analyzing human experience. Using an example from the data, two confidence intervals

that overlap by a mere .02, but have 10–20-point differences on either side that are not shared are

not statistically significant. By ignoring the overwhelming data outside of this overlap, we fail to

consider individual experiences that make up these data points. In this research especially, all

nuances should be considered as possible areas of future research.

        Approaching the data in this way allows us to consider the real-world application of our

findings and examine the experiences of people living with HIV, whereas small changes in trust

scores could be catalysts for improved patient outcomes. Future research should focus on each of

the thirteen components of our HCR trust scale independently to examine how each aspect of

patient trust impacts patient health outcomes, for example, does the perception of acceptance, of

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listening to a patient, or empowerment have the largest mediating effect on overall trust scores?

This insight will allow for a greater understanding of exactly which aspects of trust are related to

improved patient health outcomes and allow future initiatives to be more focused.

In relation to emotional labor, much research has been focused on employee burnout as a

potential effect of employment in emotionally laborious environments, specifically those

employed in the area of human services who face sizable role expectations. For instance,

Brotheridge and Grandey's (2002) study looked to examine emotionally intensive labor and its

possible effect on employee burnout. Their research surveyed 238 participants on emotions in the

workplace. Participants, who were all employed in various fields, were examined based on their

experience of emotional exhaustion as a result of the felt need to hide negative emotions by

following perceived display rules. Additionally, the category of workers in the study who

worked in the field of human service, similar to the present study, reported more time spent with

customers performing these display rules, and a greater variety of emotional demands than other

sectors of the workforce. Burnout can therefore derive from the greater stress of hiding negative

feelings, and thus may be associated with career dissatisfaction. Beyond this, deep acting can

additionally affect such career dissatisfaction and potential burnout. The study also drew from

Hochschild's understanding of deep acting, which is defined as the process of controlling

internal thoughts and feelings to meet mandated display rules and found that those employed in

human services reported the highest level of deep acting and higher levels of emotional

exhaustion as compared to other types of workers in the study relating this to the frequency and

duration of their interactions with customers (Brotheridge and Grandey 2002). This is immensely

important in the current study as it inspires future research which may aim to prevent employee

burnout by applying the findings presented in the current work, and the consequential relationship between emotional labor and rates of burnout, a potential barrier to successful patient-provider relationships. Using the current research, providers make focus on the emotion work that has the most significant impact on patient trust and patient health and focus less on those aspects of patient trust that have little to no impact. In doing this, providers may reduce the amount of emotion work they are engaging in, and by extension, prevent burnout.

In addition to analytic and conceptual limitations, the current research is limited by the collection cycle, though data exists for cycles as early as 2007, the HCR variables were not included until 2018 making longitudinal studies difficult. As future cycles become available, it would be interesting to understand how each year differs and how significance changes when multiple cycles are combined. Trust is a subjective experience, and a difficult concept to quantify. While the HCR trust scale and the revised HCR do an excellent job at measuring patient trust, it is difficult to identify, in detail, specific events which lead to a patient's median score. Further research should analyze the concepts by disaggregating the combined trust score (HCR), as this will give more specific, measurable outcomes which can be used for more focused improvement strategies. Additionally, the process by which data is acquired is quite lengthy and arguably inaccessible for the lay person. Much of the analyses requested were not approved as the CDC did not find the research question to be of importance. This is a significant barrier to access for data that is touted as being publicly available.

CHAPTER 6: CONCLUSION AND FUTURE RESEARCH

Overall, increasing patient trust is imperative to improving the patient provider relationship. As shown in the current study, there are several groups which report significantly higher levels of trust, and multiple health outcomes related to increased trust scores among patient and provider. Understanding trust, as outlined in the HCR as a process based in emotional interpretation, it is understood that these interpretations are impacted by emotional labor on behalf of the provider. Emotional labor is the mediating force between patient-provider trust, as shown in the current study through the use of the HCR trust scale. Though this scale does not explicitly name emotional interpretation as a key component of patient/provider interactions, it is apparent in the wording of the survey instrument that emotional interpretation is being measured. Using words like acceptance, interest, worthiness, comfort, feeling, and the evaluation of active listening, it is clear that the trust scale itself is measuring the patient's interpretation of the provider's emotional output. With this in mind, the current study shows how improving patient trust (as an emotionally interpretive process) can and does have an impact on patient health outcomes.

Related to patient sociodemographic features, efforts to improve median trust scores among Hispanic patients and bisexual patients should be considered. With respect to patient health, and risk reduction techniques, higher trust scores are associated with greater levels of general satisfaction, fewer missed appointments, and greater trust of information related to HIV received from doctors, nurses, and other healthcare providers. Ensuring future initiatives focus on the unique needs of each demographic may improve HIV prevention and increased literacy

around the subject. This may involve more inclusive prevention education, focusing on those not currently labeled as a high-risk group, or finding ways to ensure other social identities do not feel excluded from the narrative.

Understanding provider trust as an interpretive process uncovers the importance of emotion work in the healthcare field. Highlighting the importance of emotional perception and interpretation, and the possible influence emotional tuning has on these perceptions, one may argue providers, through emotional tuning, have the ability to improve patient-trust. Empowering providers by uncovering the process of emotional tuning, and its potential impact on patient trust should inform future studies. These findings support previous studies related to patient health outcomes with the addition of emotional labor and its impact on patient trust as a legitimate factor to be considered.

By understanding which facets of provider behavior impact improved patient scores, we should also focus on those behaviors that are detrimental to undermining patient trust. For instance, does asking a patient to reschedule an appointment have a lasting impact on their trust of the provider, if so, how can this and similar situations be avoided? With respect to emotion work and emotional tuning, what steps can be taken to ensure providers are aware of the impact their emotional state has on patient trust and subsequent patient-provider relationships? What bodily, expressive, and cognitive emotion work has the greatest impact on patient perceptions, and which should the provider focus on if improving patient trust is a goal? If we view trust as something that is constructed through interaction, what steps can providers take to ensure alignment with patient needs? Research which could examine the perspective of the patient and provider, post treatment session would provide timely insight into the expectations and interpretation of their interactions. Too often, research on patient and provider are done

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separately - either focusing on the patient, or the provider. If a pre-treatment session existed, where patient and provider were given the opportunity to share their unique perspectives, expectations, and concerns before conversations specific to the patient's diagnosis took place, how might this impact the patient-provider relationship?

HIV care is unique in that those impacted by this disease often face harsh social criticism. The movement surrounding other chronic illnesses, such as cancer, position those impacted as "survivors", however, the same is not said for PLWH. HIV diagnosis is often followed by an accusatory tone, seen as the result of a completely preventable choice, a byproduct of risky behavior. With this in mind, healthcare providers would benefit from understanding how these social assumptions impact healthcare engagement and expectations of care, and the impact this has on a patient's willingness to trust the healthcare system. Undoubtedly, the work HIV healthcare providers do is invaluable in preventing and managing HIV, this research positions emotional tuning, a form of emotion work, as a tool providers can utilize to foster trust within the patient provider relationship.

APPENDIX

IRB LETTER

UCF

UNIVERSITY OF CENTRAL FLORIDA

<u>NOT HUMAN RESEARCH DETERMINATION</u>

February 4, 2021

Dear James Caldwell:

On 2/4/2021, the IRB reviewed the following protocol:

Type of Review:	Initial Study
Title of Study:	HIV Counseling Work
Investigator:	James Caldwell
IRB ID:	STUDY00002657
Funding:	None
Grant ID:	None
Documents Reviewed:	• HRP-251- FORM - Faculty Advisor Scientific-Scholarly Review -CALDWELL SIGNED.pdf, Category: Faculty Research Approval; • HRP-250-FORM- Request for NHSR - CALDWELL - 01-14-2021.docx, Category: IRB Protocol; • Variables of Interest, Category: Other

The IRB determined that the proposed activity is not research involving human subjects as defined by DHHS and FDA regulations.

IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities are research involving human in which the organization is engaged, please submit a new request to the IRB for a determination. You can create a modification by clicking **Create Modification / CR** within the study.

If you have any questions, please contact the UCF IRB at 407-823-2901 or irb@ucf.edu. Please include your project title and IRB number in all correspondence with this office.

Sincerely,

Katie Kilgore
Designated Reviewer

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