

Can We Institute Medical Trust? *An exploratory  
case study of patient-staff relations at a community health  
center in the Mississippi Delta*

by  
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## **Dedications**

To my parents, who gave me all the tools needed for life's projects.

To Terrel, who instilled my love for writing.

To Dr. Green, who never told me to stop thinking.

To Dr. Centellas, who taught me that medicine is more than just the medicine.

To Chancellor Jones, whose sincerity inspires my dedication to social change.

To Dr. Young, who said anything was possible.

Lastly, this thesis is dedicated to all those working in collaborative efforts to alleviating healthcare disparities in Mississippi: your dedication and resiliency inspires me each day – to fight the worthy fight, no matter how difficult it may be.

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## **ABSTRACT**

The purpose of this study was to use the concept of the patient-centered medical home (PCMH) model and the case of the community health center (CHC) to explore social interaction and trust between patients and medical providers. While the PCMH model is being championed as revolutionizing and improving healthcare delivery, little evidence has yet to support the formation of basic social and health mechanisms, such as trust, that would result in positive health outcomes. The model's guidelines focus more on healthcare organization and information technology than developing interpersonal relationships and adapting services to meet the specific needs of diverse populations. Utilizing participant observation and informal interviews, qualitative evidence suggests that context-specific details may have more impact on healthcare delivery than methods currently addressed in the PCMH guidelines themselves.

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## INTRODUCTION

Healthcare is a resource of unequal access, whether by racial, geographic, or class divisions. For those in poverty in the Mississippi Delta region, access to healthcare is limited, even though rates of heart disease, adult-onset diabetes, obesity, and infant mortality remain high. One cannot ignore the racial health disparities of the state, with black Mississippians at higher risks for obesity, asthma, and hypertension- and diabetes-related deaths (MS State Department of Health 2011). Exploring the history of healthcare discrimination in the state may present some explanations and also offer some insight into how such disparities may be overcome.

During the mid-20<sup>th</sup> century, blacks in Mississippi were denied access to medical facilities as patients, and denied admission to the University of Mississippi Medical Center as training physicians. Many county hospitals would not admit black patients; others would, but only if patients had a fair amount of cash up front. The University Hospital in Jackson accepted black patients, but wards were segregated, over-crowded, and in deplorable condition. Making matters worse, the state encouraged aspiring black physicians to leave Mississippi by subsidizing any medical training outside the state. In 1960, the ratio between black physicians and black citizens in Mississippi was one to seventeen thousand. During the height of Jim Crow, black patients had to visit white physicians, some providing insufficient treatment or requiring exorbitant amounts of cash before service (Dittmer 2009).

A few black physicians, including Bob Smith, James Anderson, and Aaron Shirley, were determined to provide better healthcare for blacks and later formed the Medical Committee for Human Rights (MCHR), which sought to improve access to

healthcare for blacks and other disenfranchised segments of the population in Mississippi. Established by Jack Geiger, professional colleagues, and community organizers in Mound Bayou, MS, the Delta Health Center became the first widely-recognized community health center in the country, and a triumph of the civil rights movement in healthcare (Dittmer 2009).

Similar to the community health center in Mound Bayou, the CHC featured in the present study serves primarily African American patients; additionally, most of the providers and medical staff are African American. In the larger context of Mississippi and the doctors in the 1960s, this CHC becomes a place for health, community, and unity amidst a once devastatingly oppressive institutional body.

Since their conception, community health centers have aimed to serve the unique needs of their local populations, many of which are considered historically underserved and disadvantaged (Anderson and Olayiwola 2012:950). A component of President Lyndon B. Johnson's War on Poverty policy initiative, CHCs were developed to provide comprehensive care, in some cases including dental, vision, and mental health services, to all individuals regardless of ability to pay (Ku et al. 2011:vii). CHCs have been championed as facilities working to alleviate health disparities by providing patient-centered, contextually-specific care.

Renewed interest in primary care has spurred the development of the patient-centered medical home (PCMH) model, which focuses on increasing access to healthcare facilities and improving efficiency, while at the same time restoring patient autonomy in decision-making and developing a more holistic, team-based treatment approach (National Committee for Quality Assurance 2011). Because the core guidelines of CHCs



emphasize “access, quality, and cultural competency,” CHCs are in an advantageous position to incorporate the PCMH model; in fact, many health centers had already been engaging in PCMH-specific practices before the formal development of the model (Anderson and Olayiwola 2012:954; Ku et al. 2011).

Exploring what CHCs are doing in terms of attempting to provide holistic care for their patients may offer valuable insight that can be used to inform the development of patient-centered care in facilities that may not primarily function to serve historically underserved populations, or populations that are not as tightly knit. This is particularly important if rates of chronic illnesses continue to rise among individuals from multiple socioeconomic, racial, and age categories. The focus of this study was to examine the social factors involved in community-based primary care, especially trust formation between patients and staff at a CHC practicing the PCMH, and to explore the idea of developing and incorporating trust-fostering methods into standardized models of healthcare.

Upon examination, the guidelines of the PCMH model seem to place more emphasis on information technology and electronic medical records (EMR) than on methods and strategies that would lead practices to understanding and accommodating the specific needs of the populations they serve, which could lead to the formation of trust relations with patients. Others have expressed criticism that the guidelines put forth by the National Committee for Quality Assurance (NCQA) are too broad and create a superficial certification process (Dohan et al. 2013).<sup>1</sup> Based on this study conducted at a Delta-region CHC, informal kinship ties in a local context seem to fill this gap in the

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<sup>1</sup> It is important to note that the 2011 version of NCQA’s PCMH model guidelines were analyzed in this study. The NCQA is set to release new guidelines in March of 2014, which may prove to be more specific in regards to meeting the patient population’s needs.

medical model, but also raise questions about methods to institutionalize and standardize the formation of trusting relationships between patients and providers. While many social factors may influence healthcare delivery on the interpersonal level (including individual and regional perceptions of race and ethnicity, socioeconomic class, gender, and age) and thereby complicate standardizing a method of care, the repercussions of personal interpretations have the potential to impact healthcare utilization, adherence, patient satisfaction, and health outcomes. Therefore, healthcare methods that not only acknowledge the complexities of social interactions but also prepare clinical staff for such interactions are essential if we wish to see an improved healthcare system and better patient outcomes in the United States.

## **LITERATURE REVIEW**

### **Trust in Healthcare**

A review of the literature shows that while public trust in healthcare institutions, systems, and professionalism in general has been steadily declining, individuals' trust in personal physicians may be unaffected (Calnan and Rowe 2008; Betz and O'Connell 1983). In other words, trust in a personal physician or healthcare experience does not necessarily reflect trust in the medical system as a whole. Patients may view the larger healthcare system as bureaucratic and inefficient. This is important to note in the midst of healthcare reform in the United States—that macro social and economic changes, including increasing access to health insurance and facilities, may not substantially affect patient experience and health outcomes without addressing the social dimensions of healthcare delivery. American society witnessed a radical shift over the course of the 20<sup>th</sup>

century, from most physicians embodying a traditional role of providing continuous primary care to becoming a modernized specialist, widening the physical and social distance between patient and provider, despite that this relationship requires interdependence (Betz and O'Connell 1983). With these changing dynamics in the patient-provider relationship, institutional attempts are being made to reconcile this ever-widening gap. Trust is a complexly influential component of this patient-provider dyad that must be considered as broader policy changes are being made.

One way to contextualize trust in healthcare settings is through the concept of social capital. Like other forms of capital, social capital can be exchanged for access to other goods and services. Referring to intangible resources, social capital is often conceived as including trust, norms, sanctions and reciprocity within social groups that lead to social cohesion, social support, and civic engagement (Kawachi, Submaranian, and Kim 2008:3). A great deal of research has linked increases in some forms of social capital to better health outcomes, but it is still unclear exactly how social capital influences health.

Social capital is not always beneficial for members within the social group (Kawachi et al. 2008:3). Among homogenous social groups, whose members share particular identities, social resources can be designated as bonding social capital. Ichiro Kawachi, S.V. Submaranian, and Daniel Kim (2008:5) note that bonding capital may be excessively demanding on members (especially members of close-knit communities), that it may encourage conformity and thereby reject diversity and individual freedom, and that it may strengthen in-group solidarity and intensify out-group relations. In contrast, bridging social capital describes resources which are accessed through connections that

cross class, race, ethnicity, and other social boundaries (Kawachi et al. 2008:5). Regardless, an environment with high levels of social capital (whether bonding or bridging) has been shown to correspond with an environment with high levels of trust. The concept of social capital as a resource that connects people to one another and influences other social processes can be used to explore the types of relationships and obligations individuals may have to one another.

Trust is a complex concept in research, but broadly defined in healthcare it refers to the expectation that another person, group, organization, or institution will not harm and may even benefit one's wellbeing (Thom et al. 2011:148). Most importantly, this trust hinges upon the notion that the physician or provider will have the patient's best interests in mind and not "take advantage of the patient's vulnerability" (Stepanikova et al. 2006:392). Furthermore, values of trust are embedded within guiding principles of the medical professions (beneficence and non-maleficence) and play an important role in shaping patient perception of physicians, medical staff, and the healthcare system in general. Understanding the difficulty of operationalizing and identifying trust in healthcare relations, researchers have used measures of competence, compassion, privacy, reliability, and communication as indicators of medical trust (Pearson and Raeke 2000).

Empirical studies indicate that trust relations between patients and their physicians are linked to patient satisfaction (Calnan and Rowe 2008), compliance and adherence (Nguyen et al. 2009), and health outcomes (Stepanikova et al. 2006:390). As Irena Stepanikova and others (2006:391) write, "[t]rust is therefore a key component in making physician-patient relationships conducive to the healing process." Trust and its

manifestation in microlevel interpersonal relationships therefore needs to be further analyzed in healthcare systems in order to better understand its nuanced effects on patients and their utilization of healthcare services.

### **Racial/Ethnic Disparities in Healthcare Delivery**

Extensive research has also been done examining quality of care and health outcomes of ethnic minority patients in the United States, which by and large are poorer than white patients (Miranda et al. 2003). What has yet to be fully understood is the relationship of causal mechanisms for such disparities. Some analysts have proposed an imbalance of physical access to healthcare services, prejudicial bias and stereotyping among providers, or racial and ethnic differences in preference for types of healthcare interventions as different variables influencing the gap (Armstrong, Hughes-Halbert, and Asch 2006:950). Factors that may be affecting the interpersonal level of healthcare delivery need to be considered in greater detail.

Some health disparities may correlate with differences in institutional trust among minority groups, due to institutionalized medicine's history of racial discrimination and subsequent perceived likelihood of experiencing discrimination in a healthcare setting. Stepanikova and others (2006:391, 401) initially found that trust in a physician based on personal experience is lower among ethnic minority patients than white patients; but after conducting a quantitative assessment of trust among both minority and white patients, they found that this difference in trust emerged depending on the type of trust measured, either direct or indirect.

Direct trust was measured through agreement with statements regarding the provider's character—his or her perceived trustworthiness. Indirect trust was conceptualized as physician behaviors that may foster or influence trust itself, such as “providing patients with a referral, performing unnecessary tests, or [the perception of] being influenced by insurance rules in medical decisions” (Stepanikova et al. 2006:400). Patients from ethnic and racial minority backgrounds reported lower indirect trust in their physicians, while direct trust did not significantly differ between ethnic and racial categories (2006:398, 399). These findings mirror similar inconsistencies in perceptions of healthcare (Hall et al. 2001:624; Malat and van Ryn 2005:746), possibly indicating that the personal provider relationship mediates the disparity in general institutional trust among racial and ethnic minority patients. Thus, the microlevel interpretations of larger social categories including race and ethnicity, class, age, and gender must be taken into account when evaluating the dynamic interpersonal relationship between patient and provider.

Even though some researchers have proposed that African American patients may prefer healthcare providers of the same race due to historical grievances, empirical evidence indicates that preferences are more varied and complex. In an assessment of national survey data, Jennifer Malat and Mary Ann Hamilton (2006:183) found that patients who perceived between-race discrimination preferred providers of the same race. However, they also found that perception of same-race discrimination reduced the same-race preference, highlighting the need to reconceptualize discrimination as strictly a matter of race; racial concordance may not provide “a sure protection from interpersonal discrimination” (Malat and Hamilton 2006:184). They advise that more research needs to

look at the interaction of social class and race in experiences of interpersonal healthcare discrimination.

### **Theorizing the Patient-Provider Relationship**

When conceptualizing the interpersonal relationship between the patient and the provider,<sup>2</sup> sociologist Talcott Parsons provides a basic framework that can be used to explore the status hierarchy intrinsic to professional relationships, in which one party has a higher degree of knowledge and prestige than the other. In analyzing medical organizations, Parsons (1951) describes the social roles and expectations of both the physician and the patient. He notably sketches the “sick role,” a form of sanctioned “deviance” in which the ill individual has the societal obligation to seek out medical treatment in exchange for the other obligations that he or she is presently not able to fulfill. Furthermore, the patient has an obligation to cooperate with the healthcare professional, and by extension trust this professional so that the illness may be cured (as cited in Thorne and Robinson 1988:787). Counterpart to the obedient patient is the guiding physician, who brings with him an arsenal of knowledge, technical competency, and an objective authoritative standpoint (Parsons 1951:459).

Parsons (1963:27) also traces the development of the “‘early modern’ medical practitioner,” who, during mass technological advancements of the 20<sup>th</sup> century, struggled to balance two roles: as a traditional, intuitive artisanal physician and a more objective, technical-based role. During industrialization, social refuge from larger, tenuous social

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<sup>2</sup> In this study, “provider” is collectively used as reference to a multitude of healthcare providers, including physicians, nurse practitioners, and a wide range of certified nursing staff. The basic division between the healthcare professional and patient is examined, not the various degrees of status and hierarchy between professions.

organizations manifested in a public focus on developing the nuclear family, the small town, and idealizing the independent physician. As a result, values of privacy, intimacy, and the “personal touch” became priority expectations of physicians (Parsons 1963:21). For Parsons, the personal patient-physician relationship was “removed by only one step from the most central [relationship] of all, the family” (1963:27). These strong one-on-one, personal connections were essential amidst bureaucratic expansion and rapid industrialization; they were “symbol[s] of the little security left in a welter of change and anomie” (Parsons 1963:27). Security in healthcare was strengthened further by the physician’s seeming independence in a complex social system. But as we will come to see, maintaining this two-party relationship becomes more difficult as technical efficiencies become prioritized over the patient satisfaction and outcomes.

Nonetheless, Parsons’ (1951) description of the physician and patient roles is very much an “ideal type” framework. In the context of Max Weber’s writing, Parsons himself writes that the ideal type is “an ideal construction of a typical course of action...which is applicable to the analysis of an indefinable plurality of concrete cases” (as cited in Bloor and Horobin 1975:274). The ideal type must have “abstract generality and...exaggeration of empirical evidence” in order to highlight particular aspects that are under sociological investigation (as cited in Bloor and Horobin 1975:274). In other words, Parsons focuses specifically on the fundamental characteristics of patient and physician in order to investigate their primary functions in society. Although Parsons’ illustration of patient and provider roles is helpful in outlining the hierarchical structure of this dyad more basically, the influence of the larger, increasingly complex medical institution and other social factors must also be incorporated into an analysis of



interpersonal medical trust formation. And, as we have seen over the past several decades, the healthcare system has become increasingly complex—challenging Parsons’ (1951) notion of a cooperative, ideal patient-provider relationship.

In the early part of the 20<sup>th</sup> century, most physicians in the United States were general practitioners who provided services to a predominantly rural society, which meant they were tied to tight-knit communities that had their own particular norms and sanctions (Betz and O’Connell 1983:86). During “the golden age of medicine,” doctors enjoyed respect as they assumed powerful roles in society (1983:85). However, Michael Betz and Lenahan O’Connell (1983:85) report that a push for accountability of the medical field corresponded with a decline in public respect that surfaced after 1950, stemming from systemic changes that radically altered individual patient-provider relationships—a general trend in specialized medicine inevitably distanced physicians from patients. Visits were shorter, physicians were harder to come by as they became concentrated in urban centers, and patients struggled to maintain continuous care relationships (1983:86). Furthermore, specialists began focusing on the patient from one particular angle, analyzing symptoms of disease rather than the patient as a whole person (1983:90). Together with the development of urban concentration of specialty care and a rise in average physician income, specialization “further separates the professionals from the lay public because geographical and occupational communities rarely overlap” (1983:90). Physicians and patients now rely upon different elements of social control, whereas in the traditional model, both were integral members of shared communities.

Accountability in small communities is informal, extends over long periods of time, and develops within relationships, but accountability in the complex modern

healthcare system of today is based upon systems of restricted social exchange. In restricted exchange, parties involved operate with a *quid pro quo* mindset, and as a result become distressed when ends of bargains are not upheld (Betz and O’Connell 1983:87). In generalized exchange, characteristic of small communities, acts are not performed with the expectation that they will necessarily be returned; rather, local norms and group solidarity maintain community strength (1983:86). The restricted, market system of exchange that has dominated the healthcare delivery systems of the late 20<sup>th</sup> century either requires that patients trust the system of healthcare as a standardized entity, or fully trust their provider (after receiving a favorable impression) for however short or long the relationship may be, because of this overarching uncertainty of social interactions. Considering the general rising trend of bureaucratization, developing the interpersonal relationships between patients and staff may be the best way to improve healthcare delivery and outcomes.

Urbanization and industrialization of the healthcare system distanced patients from their physicians more than before, when differences in technical knowledge and income already had socially separated physicians from patients (as noted by Parsons). In addition, the expansion of professionalization created even more social estrangement. As Betz and O’Connell (1983:88) put it, “as the importance of community in the geographical sense declined, the importance of occupational community increased.” Professional attitudes, values, and technical skills cultivated in medical school became the primary focus, more so than the patient’s unique character (1983:88). Guidelines and procedures superseded the intuitive “art of medicine” that Parsons (1963) alludes to (Korsch, Gozzi, and Francis 1968:855). Barbara Korsch and Vida Francis Negrete

(1972:22) note that because of the development of mass specialization, empathy and communication have been deemed less important matters. The technical jargon, knowledge, and skills that parallel Parsons' (1951) functionalist model of prestigious medical professionals, along with the financial discrepancy between physician and patient, have combined to create a large gap in what should be a collaborative relationship based on reciprocal trust. This distance in a system of healthcare—intrinsically a deeply personal matter—requires that patients have a degree of institutional trust, a faith in the system and a faith in the science because they can no longer rely upon knowing their physicians in other social contexts. They have to trust that physicians (as a profession) have good intentions, that they have been well-trained, and that they will heal them in order for the “system” to function.

Yet, Hall and others (2001) also emphasize the entangled nature of physician trust and patient vulnerability. Other literature explores this intersection (Stepanikova et al. 2006; Thom et al. 2011; Calnan and Rowe 2008; Parsons 1951): due to the high-risk situations in healthcare, oftentimes concerning changes in quality of life or the chance of death, there is a great “potential for either trust or distrust” (Hall et al. 2001:615). Because of this vulnerability, heightened further by gaps in medical knowledge and experience, a strong need for security and guidance may help explain why physicians remain highly revered in society, despite declining institutional trust (Hall et al. 2001; Brody 1980:719). In a qualitative study examining perceptions of provider trust among chronically-ill patients, researchers found that patients entered provider-relationships “with an almost absolute trust in the professionals who would provide the healthcare” (Thorne and Robinson 1988:783), believing that the provider held the answers to their

problems. This is not surprising, considering the medical profession's government-legitimized authority resulting from occupational professionalization (Calnan 1984:75; Hall et al. 2001:627).

Conceptually, medical trust can be divided into two separate degrees, interpersonal trust and institutional trust. As previously stated, there is a large body of literature indicating that trust of biomedical systems is declining due to expansive globalization (Calnan and Rowe 2008; Kuhlmann 2006:610). Additionally, medical scandals of the past 20<sup>th</sup> century, restructuring of the medical delivery system, media highlights of medical incompetence, convenient dissemination of medical information via the internet, and a pervasive skepticism in figures of authority all have undermined patient trust in the medical institution (Calnan and Rowe 2008). Nonetheless, relations of interpersonal trust may in fact counteract these negative attitudes held towards larger entities. Empirical findings indicate that patients, by and large, have high levels of trust in their personal physicians, regardless of perceptions of the medical institution in general (Hall et al. 2001:624). Trust in personal physician or healthcare experience does not necessarily beget trust in the medical system more generally. These findings indicate that the interpersonal relationship between the patient and physician may counteract the effects of institutional *anomie*, or the disintegration of social bonds, and may influence health outcomes more than systematic changes characteristic of current healthcare reform.

Although Parsons' (1951) work lays a foundation for exploring the patient-provider relationship, and helps explain institutional legitimacy of the medical profession, it does not provide an adequate framework for analyzing the complexities of person-to-

person interactions in healthcare settings, particularly as healthcare institutions become increasingly bureaucratized. A better perspective to utilize in this analysis is that of symbolic interactionism, which is premised on several core principles, notably: humans are social actors whose actions are informed by the interpretation of others' actions, and this is the foundation of society (Charon 2007:29). Furthermore, a society of social actors hinges upon the existence of cooperation and culture which both necessarily rely upon communication and trust. In cooperation, Joel Charon explains that actors respond to each other's roles, viewing them as important and integral in the shared environment or course of action (2007:160). Using this theoretical lens to approach healthcare interactions, both patient and provider recognize each other's roles and participate interactively in the healing process.

Symbolic interactionism largely diverges from Parsons' (1951) functionalism in that it recognizes the agency of social actors and the importance of social interaction in maintaining or altering broader social structures. People may have roles to fulfill that possess certain degrees of authority, or they may be embedded within a particular class structure, but symbolic interactionists argue that these roles and macrosocial factors "are also defined, altered, legitimated, used, and shaped by each individual" in unique ways (Charon 2007:167). This provides an interpretive analytic framework for understanding patient-provider relationships and the many social factors that may come into play. It allows for patients (and providers) to have differing and potentially conflicting perspectives, and it allows for there to be dynamic, negotiable collaboration (Calnan 1984:76). Additionally, it recognizes the provider's agency. In Parsons' model, physicians must withhold judgment regarding patient desires, wishes, and behavior

(1951:458). The symbolic interactionism framework acknowledges that physicians possess biases, values, and perspectives that inevitably may impact patient care, regardless of institutional models or professional guidelines.

The patient-provider relationship can be conceived then as one that is dependent upon communication and negotiation. Recognizing that providers and patients bring their own perspectives to an interaction, scholars of medical sociology note the importance of “integrating the world of the patient and that of the physician” by finding common ground in the medical encounter (Ishikawa, Hashimoto, and Kiuchi 2013:150). This may be achieved by encouraging patients to vocalize personal perceptions of their illnesses, general feelings, and expectations of the medical encounter—in other words, through patient-centered care (Ishikawa et al. 2013:150). While this movement of re-conceptualizing social structures and interactions (e.g. the patient-provider relationship) was part of a larger transformation within the field of sociology that paralleled the political scene of the 1960s— “a search for a more humane sociology”—the transformation of increasing autonomy to patients also accompanies the development of managed healthcare systems, which frames patients as payers (Bradby 2012:32). Thus, patients are “customers” who may be expected to dictate their personal medical agendas (and take full responsibility) after receiving only technical knowledge from their providers (Ishikawa et al. 2013:148). Some current research examines mirroring transformations in evaluation methods of healthcare quality, and suggests that for-profit facilities tend to prioritize patient satisfaction over health outcomes. The consumerist movement challenges functionalist expectations of individuals’ behaviors but at the same time raises questions about medical ethical obligations. Nonetheless, for this study it is

important to conceptualize the patient-provider relationship as one that is dependent upon the many social, political, and economic dimensions of both parties involved.

### **Reciprocal Trust between Patients and Staff**

As more recent models of healthcare delivery attempt to restore autonomy to patients, some work has been done examining healthcare relations of reciprocal trust. Researchers have found that collaborative, participatory care may positively contribute to patient adherence, satisfaction, and better health outcomes (Brody 1980:721; Thorne and Robinson 1988:784). In fact, Sally Thorne and Carole Robinson (1988:784) found that one of the most influential factors affecting patients' respect of personal physicians was physician-expressed trust in their patients' competency to make healthcare decisions. For patients, being trusted by one's health provider was "affirming and validating," "promoted self-esteem, and fortified the health care relationship" (Thorne and Robinson 1988:784). When patients felt their physician believed in their competency, or ability, to manage their chronic illnesses, they remained actively engaged in their medical treatment and in turn trusted their healthcare provider's recommendations (Thorne and Robinson 1988:786). When providers failed to acknowledge their competence, "dissatisfaction...escalated" (Thorne and Robinson 1988:785). Thorne and Robinson's (1988) research suggests that developing interpersonal trust is more intricate than Parsons' (1951) role-fulfillment model. Physicians may not trust patients in their capacity and ability to be willing, obedient, and honest, particularly given the tradition of assumed unilateral trust in healthcare. Low trust in patients could alter physician and medical staff

behavior, negatively impacting patient satisfaction and self-confidence, adherence, and therefore health outcomes (Thom et al. 2011:153).

Collaborative dialogue in healthcare settings keeps patients engaged in their treatment and allows them to discuss their needs with their providers. Given the vulnerability of health and illness, maintaining a sense of self-control is important for the healing process. The factors that contribute to non-adherence are many, including costs of medication, complicated regimens, health illiteracy, and patient-provider relations lacking trust (NIH 2014). According to the Office of Behavioral and Social Sciences Research at the National Institutes of Health (NIH), “50% of people with chronic health conditions discontinue their medication within six months” (NIH 2014). If not understanding or agreeing with the course of treatment, non-adherent patients may be acting in defiance as a way to regain control over their treatment and their bodies (Brody 1980:721). When considering the symbolic interactionist framework of social behavior, fostering reciprocal trust and maintaining adherence become complicated matters that involve perceptions of both the patient and provider—perceptions related to race and ethnicity, age and gender, social class and historical context inextricably linked to the local setting of the healthcare facility.

### **Reframing the Patient-Provider Dyad**

The movements of professionalization and specialization characteristic of mid-20<sup>th</sup> century healthcare were supported by Parsons’ outline of the patient-provider relationship. Trust was expected from patients, blindly, whose inherent duty was to obediently abide “doctor’s orders.” But this shift in the American healthcare system to



one that is bureaucratized, defines efficiency in financial terms (rather than patient outcomes), and depends upon short-term relationships has contributed to the rise in medical institutional distrust. Because of the lack of stability in the institution as a whole, developing the interpersonal relationship between patients and providers may be a way to foster trust in healthcare. Researchers have shown that this one-on-one relationship can greatly impact patient adherence, satisfaction, utilization, and health outcomes. Because of these tenuous relationships and bureaucratic alienation, medical institutions can no longer require patients to blindly trust them. At the same time, bureaucratization is not likely to decline; therefore, healthcare leaders need to develop methods to ameliorate these attitudes within the already existing medical institution.

This is the problem policymakers and healthcare administrators are attempting to resolve through the patient-centered medical home (PCMH) model. The idea behind the PCMH is that increasing patient involvement in care will help foster and strengthen relations of trust between patients and providers and improve communication, which have been shown to improve health outcomes. This attempt to close the medical gap offers valuable insight into the complexity of medical trust and its systematization.

### **The Patient-Centered Medical Home Model**

As part of the movement not only to restore patient autonomy and reinvigorate trust in the healthcare system but also curb healthcare costs, the patient-centered medical home (PCMH) model is rapidly being implemented in both public and private healthcare facilities. A medical home is a centralized primary care health facility which patients can use as a focal point or “home base” for other types of care. For instance, a medical home

can provide specialist referrals or may offer mental healthcare services. Especially when working to improve care and care management for high-needs patients, such as the economically disadvantaged, the elderly, and the chronically ill, the PCMH model is in theory a more stream-lined, person-centered approach to healthcare. Developed by the American Academy of Family Physicians (AAFP), American Academy of Pediatrics (AAP), American College of Physicians (ACP), and the American Osteopathic Association (AOA), the medical home model hinges upon the following joint principles (NCQA 2011):

- Continuity, with an ongoing personal physician
- Team-based, physician-directed medical practice
- Whole person orientation
- Coordinated or Integrated care
- Quality and safety
- Enhanced access to care
- Payment to support the PCMH

By utilizing personalized, continuous medical teams, the model plans to accommodate each patient's specific needs. General practitioners, nurses, specialists, pharmacists, behaviorists, nutritionists, translators, and social workers may all be involved in a team. Facilities may have these individuals on staff or they may have fostered close relationships with those in the community, and through information technology and health information exchange they are able to easily find and share patients' health records. Furthermore, patients would no longer have to struggle with navigating through the complicated, sometimes redundant healthcare networks alone. The PCMH model is anticipated to cut costs by eliminating erroneous fees that result from repeated or unnecessary tests, overuse of the emergency rooms, and hospital readmissions. This systematic patient-centeredness, whole person orientation would ideally ensure that each patient's needs are met and that health outcomes are improved,

even if the practice could not meet all needs itself (National Conference for State Legislatures 2010; Kaye, Buxbaum, and Takach 2011).

Additionally, patients actively participate in decisions made about the degree and type of care they may receive. The PCMH model moves away from the traditional, Parsonian “gatekeeper” model of healthcare towards more patient self-management and patient-staff collaboration. Yet, because the model has undergone refinement and widespread implementation in only recent years, few published evaluations have found conclusive evidence supporting the model’s effectiveness in practice. Furthermore, other evaluations are still underway. One assessment of a network of private primary care facilities in New Jersey found little evidence of a reduction in visits and admissions (utilization), as well as minimal change in quality of services (Werner et al. 2013:491). However, researchers who surveyed patients from a collection of ten multi-payer primary care facilities in New York saw significant improvements in patient experience due to increased accessibility of care (Kern et al. 2013:406). Patients appreciated decreased waiting times and “open access” scheduling, which allows for same-day appointments, but researchers saw no significant improvements in patient-staff communication, disease management, or perceptions of staff performance (Kern et al. 2013:408). The lack of change may be attributable to the short, 15 month timeframe of the study, or possibly a ceiling effect, in that the primary care centers may not be able to improve their already high-performing services (Kern et al. 2013:408). However, it may also be an indication that the model itself has no impact on healthcare delivery practices.

The PCMH’s mixed effects on healthcare experience and delivery raise concern about the model’s particular emphasis on the procedural aspects of healthcare

organization and information technology. While the model may provide specifics on the electronic medical records (EMR) system, it neglects to address methods to see team-based care effectively actualized (Van Berckelaer et al. 2012:197; Braddock III et al. 2012:143). As other researchers warn, developing a practice solely upon the NCQA's guidelines may prove to be ineffective in providing truly patient-centered care (Van Berckelaer et al. 2012:197). The social relations needed for the underlying medical home structure and processes to achieve improved patient health outcomes warrant greater attention.

## **RESEARCH QUESTIONS**

Given that increasing bureaucracy has made the patient-provider relationship more tenuous and dependent upon social factors external from the one-on-one interaction, how can we come to negotiate trust? A community health center, which is sensitive to the needs of its patients in given contexts, practicing the patient-centered medical home model may provide valuable insight into how trust-developing methods may be standardized for other centers of care.

- How does organizational context influence relations of trust between staff and patients at a community health center?
- When considering the implementation of the patient-centered medical home (PCMH) model, can these relations of trust be instituted or created from this model?

## METHODS

For this study, participant observation was conducted at a Federally-qualified community health center (CHC) in the Delta region of Mississippi. With three primary care providers and a nursing staff ranging between 10 and 15 members, this health center provides services for a local population of approximately 18,000, nearly 80% of which identify as black or African American. Staff members I spoke with estimate that the health center sees 75 patients a day on average, when all the primary care providers are present. With 16 general exam rooms and 5 exam rooms in the pediatric wing (commonly known as “peds”), the health center offers medical services for patients with private insurance, Medicare, Medicaid, CHIP,<sup>3</sup> and uninsured individuals. In addition, the center has on-site licensed social workers, access to services such as the Women, Infants, and Children (WIC) nutrition program, physical therapy, a pediatric unit, and nutritional counseling.

Surrounded by fields of corn but located nearby the area hospital and neighborhoods, the health center prided itself on providing comprehensive healthcare for its patients and local people. Despite the large size of the health center and its 1990s décor, the people who frequented the health center made it a space of their own by greeting each other, discussing local area news and gossip, asking about the status of family members, and like typical patients, commenting on the amount of time they had to wait to see a healthcare provider. Signs decorated the walls promoting a summer health fair, the center’s walking club, diabetes testing, and a brief biography in memoriam of the center’s founder. The health center was very much divided into designated spaces, with a large waiting room in the front, and two large doors leading to the nursing station and a

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<sup>3</sup> Children’s Health Insurance Program, or Children’s Medicaid.

hallway of exam rooms and a lab tech station in the back. On the busiest days, patients waited both in the front waiting room and in the back hallways; on these days there was plenty of interaction to be witnessed, between both patients and staff members.

I made nine visits between May 27, 2013 and June 28, 2013, each approximating six hours in length. With the intent of gaining a better understanding of patient experience, I spent the majority of my time between the front waiting room of the clinic and the nurses' station, where patients waited to be led to an exam room. I had no identifying markers as a researcher besides my notebook; despite that I wore a clinic badge to better affiliate myself with the CHC, at times several staff members and patients confused me as a waiting patient.

In addition to using symbolic interactionism as a theoretical framework for this study, its principles for social investigation also informed this research method. The primary purpose of this research was exploratory, with the goal of identifying concepts that may be other areas for study using different methods in different locations. Through participant observation and informal interviews, the aim was to understand the organizational context and social dynamics of this CHC by paying close attention to details of interactions, physical spaces, and symbols. Rather than seeking out causal mechanisms, this type of research required examining broader relations of processes as they played out in the social environment itself. From here, surveys, evaluations, and more formal qualitative studies may be conducted in the future to deepen understanding of more specific concepts.

Because of the nature of trust formation and maintenance as dynamic social processes, looking at these social interactions through qualitative methods provides a

richer understanding that cannot be captured in quantitative survey methods.

Furthermore, while informal interviews limited the amount of dialogue I was able to record, using the formal interview setting alone would have prevented me from gaining a better sense of these interactions as they play out in social settings organically (Bruyn 1966).

Twenty-three informal interviews were conducted with both patients and staff, 10 with patients and 13 with staff members ranging in certification, from licensed nurse practitioner, registered nurse, to certified nurse assistant. Many of the patients I spoke with seemed to be middle-aged or older, though no demographic information was collected. It is worth noting that I interviewed only a few younger patients. Among patients, I sought to interview a mix of both men and women in order to have a more diverse breadth of perspectives. All of the staff members I spoke with are women, as I was not able to gain report with the head provider of the clinic, a male physician, until the end of the study. Interviewees were selected non-randomly; because of the informal setting and interview method, I instigated conversations with patients who seemed particularly engaging, who were talking amongst each other about the health center or healthcare in general, and those who I happened to greet. One of the great benefits of this study site was the friendliness that seemed to permeate the clinic. Every morning I was there, patients entering the clinic would greet the entire waiting room, and those waiting would return the greeting. An atmosphere such as this lends itself useful when conducting qualitative research through participant observation.

Questions related to patient-staff relationships, medical trust, and individual assessment of the CHC were composed in advance and modified before each visit,

depending upon emerging concepts. Interviews with patients were conducted in the public waiting room and nurses' station. Designed as casual conversations, interviews occasionally drifted to topics not directly related to the study, but gaining a degree of trust with interviewees was important because of my presence as a researcher and the sensitivity of issues discussed. Interviews consisted of open-ended questions that allowed patients to discuss healthcare trust in their own terms.

The identities of those observed and interviewed were kept confidential and pseudonyms were used for this document. Jottings and key quotations were handwritten during interviews, kept in a secure location, and expanded upon the following day. Interviewees' consent was obtained before participation, and developed relations with the clinic's administration ensured that I had on-going permission to continue my research. This study was approved by the Institutional Review Board at the University of Mississippi.

Participant observation is a useful method for gaining understanding of "the social life in motion" (Diamond 2006:45) from the perspectives of the social actors involved. Rather than attempting to study humans "objectively," participant observation acknowledges that the researcher will not only become a part of the social settings being studied, but also actively shapes them (Bruyn 1966). Defining a role within the field context is a critical element of participant observation, so that the researcher is in a better position to gain rapport with study participants and also gain insight into how participants organize and come to understand their social world.

As a participant-observer taking on the role of a "waiting patient," a priority was to minimally interfere with the social flow of the CHC; therefore, certain social cues



needed to be taken into account. Each morning I entered the clinic from the front door as a patient would; I dressed in casual attire and made sure to limit my conversations with staff in the presence of patients. To garner trust with staff and gain insight into their perceptions of patients, I regularly ate lunch in the staff break room. This unique relationship as both participant and researcher required constant reflection upon action, interaction, and image, but inevitably allowed me to gain an understanding of the interpersonal dynamics, relationships, and the local context that could not have been captured in formal qualitative or quantitative methods.

## **FINDINGS**

### **Patient-Provider Relationships: “They make a sacrifice for you.”**

The trust at this community health center is deeply rooted because of the CHC’s close ties to the local city. A center for health and wellness, the CHC has long been a center for community and social cohesion. The rural geographic context and relatively small size of the city contributes to the small-town atmosphere that permeated the clinic. The first woman I spoke with confidently explained: “Being in [this town], you pretty much know everyone.” The clinic itself is very much a family unit, with patients and staff describing one another in terms of kinship, both literally and figuratively. In conversation, an older man pointed at one of the nurses, saying to me, “She’s my niece. Well, actually, she’s my cousin’s daughter.” In describing the social atmosphere of the clinic, one staff member said to me, “We all family around here.”<sup>4</sup>

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<sup>4</sup> Grammar not changed in dialogue in order to maintain the integrity of participants’ voices.

I once approached two friendly women chatting about the health center between themselves; I introduced myself to Gloria<sup>5</sup> and Joanne. I asked them to explain why they like this health center in particular. Gloria, glancing upward and quickly thinking her response, answered with firm eye contact: “They make a sacrifice for you.” She explained to me that the staff here can take her aside and ask how she’s doing on a deeper level, as a person: “they don’t mean my inside.” At this health center there exist deeper connections of kin, of friendship, of community that may have profound effects on healthcare delivery, regardless of a medical model that may be in place.

One morning, as I sat alone in the waiting room, a woman entered who I could tell the staff was familiar with, since the women at the front window casually greeted her. She wore a tattered white t-shirt, and soiled blue shorts. Restless, she asked me for a cigarette. Unable to wait much longer to see a nurse, she walked to the open “WIC” door to see Ms. May, a registered nurse and licensed social worker. I could hear Ms. May’s motherly tone, gently scolding the woman. Cigarette in hand, head bowed, the woman exited the front door. May came out of her office, asking about the small golden purse lying on the floor nearby me. “Is that hers?” she asked. I nodded, and she laughed, saying, “Ain’t nothing in it.” She laughed with the women at the front desk, about the “fashion purse” and nothing in it. May then started to talk with the other women about the patient, and how she expects the staff at the clinic to feel sorry for her. At lunch, I asked Ms. May more about the patient, Julie. “She family. At least here.” May mentioned that she has a “mental condition,” and her children struggle to take care of her, as they both have full-time jobs. The nurses surrounding us were all upset by Julie’s current state,

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<sup>5</sup> Pseudonyms used to maintain participants’ confidentiality.

shaking their heads as they continued to eat their lunch. May turned to me, saying in that same concerned tone, “She know better.”

The example of Julie in particular illustrates the family dynamics that permeated the health center. The staff cared deeply for Julie, but they were still prone to critiquing her behavior, similar to a parent’s concern for a child or a family member’s concern for a relative. Before Julie left the clinic, I heard one staff member, Britney, say to her, “You look cute every day. Don’t let anybody tell you different.” The staff were committed to understanding their patients’ individual needs, providing encouragement and support that does inevitably built bonds of trust between patient and provider, but it does not appear that these bonds stem from the PCMH model.

This parental attitude, or familial social pressures, carried through to the physicians as well. Sheila, a staff nurse with a dynamic attitude and unforgivingly opinionated, told me about one of the center’s providers, the female physician Dr. Fisher. When talking about Dr. Fisher’s patients, she says “they know she’s going to fuss...if their numbers are off. She’s like their momma.” Counterpoint to these strong matriarchal figures was the head physician of the clinic, a male physician with a long-standing reputation in town. With salt and peppered hair and a large smile, he is the most popular primary care provider at the clinic, as the front desk staff informed me. Patients beamed when he walked in the room. As Gloria put it, “the Lord brought us [Dr. Thompson].”

In many ways, Dr. Thompson resembles the archetypal, patriarchal physician figure illustrated by Parsons (1951). A friendly patient even described to me what seemed to be modernized house calls, in that she is able to call Dr. Thompson at the clinic to verify the specific medication she is prescribed. The rural physician’s on-call duty and

dedication to patients' individual needs relates to his presence as an all-knowing, central figure of stability—a key and crucial figure of the rural community, especially one in which poverty and joblessness rates are high, education levels and health literacy rates are low, and dependence upon social relationships is strong. Reflecting the literature, patients here expressed their expectations of a physician as a medical expert, as someone to inform them if they are sick and explain what is happening to them as a stable, reliable source of knowledge who communicates in an open manner.

Other patients also voiced the importance of listening during physician and staff consultations. In praising Dr. Thompson, one woman pointed out that he “knows [her] history” and listens to her when she describes her symptoms. Another patient echoed her, reporting that the staff at this health center listen to the patient in a collaborative dialogue of a trusting relationship: “[They] listen at their patient because they [the patients] truly know what’s going on in their body.” The complex nature between the local community and the health center, and patients and Dr. Thompson takes time to develop. Some patients expressed to me that Dr. Thompson is their family physician, serving grandparents and grandchildren alike. While a medical model such as the PCMH attempts to foster the development of such relationships witnessed at this health center, these attempts may be futile. The informal, and sometimes formal, kinship ties that keep this health center together are dependent upon the local context—one in which patients and staff have developed strong individual relationships that cannot be simply replicated in an operational model. As patients informed me, these family-like experiences were starkly contrasted against experiences at other medical facilities.

## **Racial/Ethnic Disparities in Healthcare Delivery**

Sitting at the nurse's station, I turned to the younger woman sitting next to me and asked her about her tattoo. She introduced herself, Sanaa, and said that she was at the health center for knee pain. She told me that the last doctor she visited at a clinic in another Delta-area town told her it was only a sprain, but it turns out it is a fracture. On physicians elsewhere, Sanaa said, "They tell you what you have before you can tell them. They cut you off." She added, "[the previous doctor] didn't know how to be the expert," by misdiagnosing the patient, he failed to do his job properly.

Another patient described feeling voiceless at other medical settings as well. A frail-looking man with a cane in one hand, insulated lunchbox in the other (for his insulin), approached me one morning and asked what I was working on; his name was Stephen. We talked about my project, and he began to tell me about his healthcare experiences. At this health center, the physicians "do the best they can for you" and "make sure you take care of yourself." Physicians elsewhere "...don't care what you do," they are just there to check you in and check you out.

Stephen outlined two types of healing for me: medical treatment and medical attention. In medical treatment, "the doctor is there for you, telling you what to do." "The doctor providing only medical attention will check your pulse," he waved his hands in frustration, "and write you a prescription for a couple pills." I asked about his previous experience with receiving only medical attention, and avoiding eye contact with me, he said that it would be too upsetting to talk about.

As reflected in the literature, the interpersonal patient-provider relationship has the capacity to alter health perceptions, utilizations, and potentially outcomes, as in the

case of Sanaa. Both Sanaa and Stephen described the failures of the current healthcare delivery system—insurance rules constrain the length of appointments, and professionalism overemphasizes the patient’s set of symptoms, not whole person orientation. These patients described a need for guidance, support, and information, a need clearly not fulfilled at other care facilities.<sup>6</sup>

Furthermore, I did not ask questions directly related to race of the other providers Sanaa and Stephen (both patients I would racially categorize as black) had visited, but considering the history of racial dynamics in healthcare and my own sense of how I may have been perceived by them as a white individual, I was given the impression that these other physicians were at least not black or African American, and possibly white. It should be noted that I lack sufficient evidence to say one way or the other, but future research should explore the impacts of racial concordance and discordance between patients and providers in Mississippi.

In the United States approximately 4% of physicians identify as black (Boukus, Cassil, and O’Malley 2009) while about 27% of the United States population identifies as black or African American, 55% of whom live in the South (CDC 2014). When we break down the data even further, one can see even more striking disparities. Nearly 38% of Mississippi’s population identifies as black or African American (US Census 2012), but only 1.3% of the state’s physicians are black,<sup>7</sup> meaning the ratio of black physicians to black patients is 37:100,000 (Street et al. 2009:7). Therefore, most black Mississippians are most likely having to seek care from physicians with different racial and ethnic

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<sup>6</sup> It was not determined if these included hospitals, but definitely primary care clinics.

<sup>7</sup> This equates to 400 individuals.

backgrounds.<sup>8</sup> In addition, researchers report that the “typical” African American physician in Mississippi is a young female practicing in an urban setting, while the “typical” white physician is an older male practicing in a rural setting (Street et al. 2009:iii). For instance, African American patients living in the rural Delta, many of whom are managing multiple chronic illnesses, are most likely not seeing an African American physician. With these data in mind, it seems that historical patterns of racial stratification in healthcare persist today. So while I only gained general impressions from Sanaa and Stephen, regional and national data may provide enough grounds for inference that their physicians from previous experiences did not share their own racial or ethnic background.

Because of healthcare’s racialized history in Mississippi, it is important to note the significance of a majority African American staff serving a majority African American patient population at the health center featured in this study. Denied access to adequate healthcare services for the large part of the 20<sup>th</sup> century and earlier, black Americans in the context of this health center in Mississippi specifically are able to create an autonomous space that can be tailored to meet the needs of patient communities without threat of between-race discrimination and echoing impacts of the past.

### **The Challenge of Reciprocal Trust**

At this health center, the staff were committed to understanding their patients’ individual needs by providing encouragement and support that does help to build bonds of trust between patient and provider. Furthermore, there are strong familial relations

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<sup>8</sup> It is also important to note that these numbers do not distinguish between primary care physicians and specialists.

between staff at the health center and the patients they serve, and as a result trust. Patients expressed confidence in their provider's abilities to communicate well and to act in their best interests. Nonetheless, is the trust reciprocal? And, does it work in the patient's favor?

Despite a seemingly devoted staff, the effects of bonding social capital shift the relationships between patients and staff. With close familial ties come familial stresses, which may hinder the development of equally reciprocal trust relations. These parental, in-group relations reflect the potential negative effects of bonding social capital noted by Kawachi and others (2008). Several staff members voiced to me the issue of noncompliant<sup>9</sup> patients, so I asked them to explain why they think patients do not comply with courses of treatment. Having frequently heard about the resident pharmacist at the clinic, Dr. Bryant,<sup>10</sup> I decided to speak with her privately to understand her roles and duties. Personally managing the pharmaceutical regimen of 70 patients, mainly coping with diabetes, whose glucose, cholesterol rates, or high blood pressure fall in the "extreme" ranges, Dr. Bryant has a demanding job. I asked her about the difficulties of managing many people's care, and she told me that it requires a lot of patience. She continued to say that her patients can be hardheaded: "You hope they come 'round. Sometimes we have to have a come to Jesus." She explained that some of her patients think that their fate is to be sick—that because they have seen family members fall ill or lose limbs (to diabetes), they feel they have no alternative but to follow that same path.

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<sup>9</sup> Staff members used "non-compliance" in interviews but medical community uses "non-adherence," as I do in this paper. "Compliance" and "adherence" are seemingly interchangeable words, referring to maintaining one's healthcare regimen, but in the current literature "adherence" is the preferred term as it recognizes the patient's capacity and agency.

<sup>10</sup> Even though a majority of the staff I interviewed are African American, Dr. Bryant is a white provider.



Similar themes were brought up while in conversation with Ms. Redmond, a licensed nurse practitioner and one of the primary providers at the clinic. Friendly and talkative, Ms. Redmond was someone with whom I frequently interacted. In her office she informed me that “finances, lack of knowledge, and [that people] just don’t care” are the top reasons for non-compliance. Despite her acknowledgement of factors possibly beyond one’s own control (e.g. financial struggle), she also pointed to the individual actions of patients as contributors to non-adherence, with perhaps the underlying assumption that the patient alone is responsible for changing his or her situation. She discussed A1C blood glucose testing: “[Patients] can cheat. They eat what they want to eat.” Attempting to quickly alter their blood sugar before having the test taken in the morning, patients fast: “They think they’ve fooled you.”

In Parsons’ (1951) ideal model, there may exist a balanced relationship of trust between patient and staff, in the sense that the patient trusts the physician to fulfill his or her duties as a physician, and the physician trusts the patient to fulfill that role as an obedient, adherent patient. At this clinic, despite the patients’ expressions of trust in their providers and the apparent devotedness of staff to their patients’ particular needs, the paternal and maternal approaches to healthcare may often undermine the potential for relations of reciprocal trust. As shown in the literature, if providers are unable to trust their patients as autonomous, capable individuals, adherence may not be possible. However, contextual details must be further considered when examining the dynamic of trust in the patient-provider relationship at this particular clinic.

One of the cornerstones of bioethics today is the strengthening of patient autonomy in illness management and medical decision-making. As discussed, research

shows that more patient involvement in the course of treatment is associated with adherence and better health outcomes (Brody 1980:721; Thorne and Robinson 1988:784). However, what is required of patients in order to exercise their autonomy? While the specifics are frequently debated in medical ethics, autonomy “encompasses self-rule that is free from both controlling interference by others and limitations that prevent meaningful choice, such as inadequate understanding” (Beauchamp and Childress 2009:101). An autonomous individual follows his or her own “self-chosen plan;” those with diminished autonomy, as Tom Beauchamp and James Childress write, have limited “*liberty* (independence from controlling influences) and *agency* (capacity for intentional action)” (2009:101, 102).

Patients deemed mentally “incapable” or “unfit” to exercise legal consent may be found a party to act on their behalf (Beauchamp and Childress 2009:114). The typical biomedical case is the patient who has recently been placed on a life-supporting ventilator and is unable to verbally communicate. However, restrictions of patient autonomy can be conceptualized in cases less extreme. For instance, if a patient has low health literacy, can he or she make a “truly” informed, autonomous decision? Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Glassman 2013). It not only requires that individuals are able to comprehend information, but are also able to analyze and evaluate various medical decisions. Furthermore, varying cultural constructions around healthcare may shape one’s health literacy as defined in the Western biomedical sense. Health literacy

requires of the patient not only a great deal of analytical skill, but also at least basic biomedical knowledge.

Beauchamp and Childress emphasize that respecting patient autonomy “involves acknowledging the value and decision-making rights of autonomous persons and enabling them to act autonomously” (2009:107). Healthcare providers should therefore foster an environment that provides patients with adequate information and tailors explanations to the patients’ own capacities for understanding. Disrespecting such autonomy may “ignore, insult, [and] demean” patients’ autonomous abilities (2009:107). However, medical decision-making is often more nuanced than this polarization attempts to illustrate.

When a health center is located in a region in which general literacy rates and educational attainment levels are low, such as with this study, there is a difficult struggle to balance patient-centered autonomy with professional guidance. John Hardwig (2006) writes that current conceptions of bioethics revolve exclusively around the dynamics of the urban setting, not the rural, despite that this idea often goes unspoken. He discusses the difficulties of protecting patient privacy and information disclosure in small, tight-knit communities or towns. When healthcare staff share social spheres with their patients or see their patients in multiple contexts, they may be in a better position to know patients holistically as a personal physician, but they may also be friends, family members, or fellow church-goers. These dual loyalties complicate the patient-provider relationship that in modern bioethics is typically conceived as an impersonal relationship between two (initially) stranger parties.

From my observations featured in this case study, the degree of patient autonomy that bioethics principles wish to see attained may not quite exist at this health center. One morning at the clinic I was talking with an older man, Harold, about his diabetes type: “I don’t know what kind, I just take the pills.” Even though Harold may not be fully informed about his illness, is he still receiving sufficient care? Staff members informed me that many patients take upwards of thirteen different types of medication each day, treating multiple chronic illnesses. During routine visits, a nurse will go through the patients’ medications to ask about side effects and ensure that medications are properly labeled. I was never able to observe interactions in private exam rooms, but such qualitative research would possibly shed light on the varying degrees of patient autonomy and self-management that could not be encapsulated in a survey.

Certainly more research needs to look at how patient autonomy is conceptualized in not only various healthcare settings, but also within different geographic regions and how these conceptualizations intersect with historical context, cultural norms, and community social bonds. At the health center featured in this study, the degree of reciprocal trust is debatable, and possibly problematic in regards to adherence or notions of informed consent. Patients may be more or less blindly trusting their providers without an “adequate” understanding of their conditions and medical regimens. At the same time, when larger social forces are influencing patient’s circumstances, such as systemic poverty and poor education, we may not be able to expect healthcare staff to provide patients with the detail-oriented comprehensive and analytical skills that are expected in the bioethical literature. Rather, patient autonomy still should be respected, but it must be acknowledged that degrees of autonomy shift and change in different contexts; therefore,

the ethical debate should also change. More research needs to explore the ethical and social complexities of the patient-provider relationship, patient autonomy, and conceptions of reciprocal trust in rural, small-scale settings.

### **Summary of Findings**

The health center in this case study is an example facility that fosters trust between patients and providers. The clinical staff care deeply for the individual needs of their patients, but like a family, they are prone to critique their patients' actions. This may undermine a "truly" reciprocal relationship of trust between patients and staff but in the context of Mississippi, these strong social bonds between African Americans in a healthcare setting are profound. Racial concordance may contribute further to this environment of trust. Despite these benefits, patient autonomy may not be fully recognized; however, contextual factors including poverty and education attainment may alter the ethics of the situation. From these observations and informal interviews, it can be said that the patient-provider relationship is very complex and dependent upon contextual factors of the surrounding social, political, historical, and economic landscape. Because these complexities can have lasting impacts on patient satisfaction, utilization, and health outcomes, they should not be ignored in a medical model, even though they may seem impossible to address.

## **DISCUSSION**

### **Nuanced Patient-Provider Relations**

Although Parsons (1951) provides a basic conceptual framework for the patient-provider relationship, his work fails to encapsulate the complex social nature of such interactions, which is dependent upon both parties' own perceptions, values, and beliefs. Trust is a negotiated process between both the provider and patient, as the symbolic interaction framework outlines. This social interaction becomes a decisive factor in shaping healthcare outcomes as the medical system and medical professions continue to undergo standardization and bureaucratization and patients no longer "blindly" trust the institution. Patients interviewed in this study support this claim, seeking another care setting after previous instances in which the medical provider could not be trusted.

This qualitative research conducted at a Delta-region CHC also explores how close patient-staff relationships and forms of bonding social capital may operate to influence healthcare delivery, patient autonomy, and subsequently adherence and health outcomes. While patients may find providers trustworthy, other factors may shape providers' trust in their patients. These are open questions about patient autonomy, and should be further studied in future research efforts. Furthermore, this study considers how race and ethnicity, region, and intersectionalities of various social factors may shape patient-staff trust in context-specific ways.

### **Considering the PCMH Model in Practice**

The patient-centered medical home (PCMH) model attempts to foster the development of more holistic, person-oriented medical treatment. It is designed for staff

to coordinate patients' multiple needs (e.g. referrals to specialists, social services, mental health services) with the idea of reducing medical expenditures and creating more streamlined healthcare experiences for patients. Furthermore, the model's team-based coordinated care and patient self-management is anticipated to strengthen relations of trust between patients and medical staff.

The PCMH model acknowledges that a healthcare provider must understand the served population's unique needs, but provides no recommendations on how to complete such a task (NCQA 2011). Rather, it simply states that a PCMH practice "uses data to assess the cultural and linguistic needs of its population in order to address those needs adequately" (NCQA 2011:37). The guidelines also consider a data record of patient race, ethnicity, age, and language as an essential contribution to the practice's ability "to understand the patient population" (NCQA 2011:40). Yet, physicians and staff must have a *richer* grasp of their clientele—something the CHC featured in this study already has the advantage of, with its close connections and longstanding history with the local area and people. The nature of these relationships cannot be reduced into an institutional model of healthcare delivery. Rather, these are foundational social processes that require time and constant social engagement between the patient population and healthcare staff.

The PCMH model has been framed as a means to bridge the growing gap between patient and provider. While institutional changes play a significant role in affecting this gap, factors of the dynamic relationship between patient and provider also may affect such a gap. Factors including the perception of race or ethnicity, age, gender, social status, and the consequent perception of personality and values shape this relationship between patient and provider, supportive healthcare staff included. As a result, the

relationship not only becomes extremely complex, but also potentially very important in shaping patient satisfaction, adherence, healthcare utilization, and health outcomes, as demonstrated in this study's literature review and findings. When considering this, it is clear that changing the patient-provider relationship through a policy is not without difficulties, but it should also not be ignored, as it seemingly is in the PCMH model.

The vagueness of the PCMH's guidelines may be improved through exploration and lessons learned from community health centers (CHCs). Indeed, the PCMH's vagueness may be intentional, so that CHCs can truly customize their methods (Gurewich et al. 2012:456). A community health center, catering specifically to the local context it serves, is such a facility where patient perception of staff is in harmony with community norms and sanctions, demographics, and history, and therefore makes the community health center a favorable, trusted place for care.

However, the PCMH model was designed intentionally for implementation at many different types of centers for primary care, including facilities that may not serve as tightly-knit a population. Therefore, recognizing the importance of the many psychosocial interactional variables that impact healthcare delivery on an individual level, the lack of guidance in this policy is potentially problematic. Without further training or guidance for those facilities that are perhaps unable to meet the needs of their local populations, the model's guidelines bear similar resemblance to the medical system currently in place: one that focuses on the payer, to ensure his or her funds are spent as efficiently as possible, rather than focusing on the *patient*.



## **Cultural Competency as a Solution**

While the PCMH model does not provide enough specific direction regarding how a healthcare facility may come to tailor its delivery methods to the patient populations it serves, cultural competency training is one method considered to accommodate for social and cultural diversity in healthcare delivery, with the goal of alleviating healthcare disparities among patients from racial, ethnic, and linguistic minority backgrounds. However, there have been numerous criticisms of cultural competency training, including arguments that cultural competency fosters physician bias and stereotyping (Rowland et al. 2013). These methods tend to present characteristics of various patient populations categorically without acknowledging “intra-group variability” that stems from geographic region, historical context, income and socioeconomic status, age, gender, and even individual experience (Betancourt et al. 2003). The ultimate question then becomes, can the necessary relations of trust be formed between patient and healthcare staff through an institutional model of care? Or, do they stem purely from a local context?

In all, as exploration of the CHC studied here demonstrated, trust is embedded in social interaction. This research illuminates the social complexities of patient-staff relationships. The family-like atmosphere of this CHC is beneficial in creating a strong social network, but may yield inadvertent effects on patient self-management and adherence. Not only acknowledging that social factors influence patient-staff interpersonal relationships and interactions but also exploring *how* is crucial if we wish to provide better healthcare services.

## **Implications for Health Disparities**

Because rates of chronic illness are much higher among racial and ethnic minority groups in the United States than among whites (CDC 2014) and minority groups are projected to make up nearly 40% of the U.S. population by the year 2025 (Thompson and Denson 2002:9), it is crucial that we critically analyze these healthcare disparities from a more nuanced perspective in order to develop strategies to help alleviate such inequalities. For the sake of public health, economic development, and social justice, we can no longer ignore these communities of the national population; the stakes are simply too high. Researchers have found that even when accounting for insurance coverage and income, differences in access and utilization between non-whites and whites would still exist (Thompson and Denson 2002:6). In light of current healthcare reform, these findings indicate that alleviating healthcare disparities is a more complex endeavor than may be anticipated in popular thought.

As stated previously in the literature review, researchers have found that race-concordant patient-provider interactions are associated with higher patient satisfaction; additionally, patients will go out of their way to select a provider who shares their ethnic or racial identity when given the option (Cooper et al. 2003:912; Saha et al. 2000). Research also has shown that patients from ethnic minority backgrounds “perceive less respect and poorer communication in race-discordant” patient-provider relationships (Cooper et al. 2003:912). At the same time, when patients perceive in-group discrimination—that falls along socioeconomic status for instance—they may not prefer to have a provider of the same race (Malat and Hamilton 2006:184). Thus, further understanding how providers’ race and ethnicity is interpreted by patients, and how this

intersects with geographic region and local historical context, is an area of research that must be explored if we wish to better address racial and ethnic health disparities not only in Mississippi, but in the United States as a whole.

### **Instituting Trust-Fostering Methods**

Considering the many facets of social interactions between patients and healthcare providers, reducing these relations of trust in an institutional model cannot be done.

While the PCMH model arguably neglects addressing how to meet the needs of patient populations so that centers of primary care can tailor their own methods, ignoring these social complexities may inadvertently deem them non-essential elements of healthcare delivery when indeed they are quite the contrary. Rather, as demonstrated in this case study, trust is influenced by staff relations to and with the patient population, and these relations are shaped by the context's history; they take time to develop. In other words, these are social processes. For centers of care serving populations that are not socially cohesive or not rooted in a place of historical legacy (e.g. suburbia), developing truly patient-centered care becomes more reliant upon medical education practices and less upon relationships with the local context. Thus, expanding and diversifying medical education practices to prepare students for the myriad of social factors that influence health outcomes and patient wellbeing is absolutely vital if we wish to alleviate health disparities and curb increasing rates of chronic illness.

## **Further Areas of Study and Limitations**

This case study fills a gap in the literature by qualitatively researching a healthcare setting in which a community health center is practicing the patient-centered medical home model. Further studies similar to this one should feature CHCs in other regions of the United States, both rural and urban, in order to highlight the diversity in healthcare delivery practices. Illuminating these unique cases would help inform formation of policy that better addresses the needs of various populations.

Further qualitative studies could research in-depth the concepts brought to light in this research, including patient adherence, reciprocal trust, and racial concordance. Exploring how these concepts differ in various healthcare settings would be useful in gaining a more comprehensive understanding of the social factors that come into play and developing delivery practices that help overcome particular barriers to improving patient satisfaction and health outcomes.

There are several limitations to this study. Because interviews with patients were conducted in the public waiting room and at the nurses' station, interviewees may have felt inclined to provide answers that paint the health center in a positive light. Conducting semi-structured formal interviews with patients in private settings may reveal additional concepts or richer data; then again, it may be more difficult to garner patients' trust.

This study was exploratory in scope and did not focus on specific operations of the PCMH model in practice, although much of the literature used in this analysis evaluates the model's particular aims from financial and policy-informed standpoints. As the PCMH model continues to be implemented in various healthcare settings, qualitative

research should be a primary method in order to understand the intersectionalities of the various social factors at work.

## **CONCLUSION**

As the healthcare system continues to undergo bureaucratization, rekindling cooperative interpersonal relationships between patients and staff may prove to be a way to overcome some persistent health disparities and reducing rates of preventable chronic illness. Even though patients may not trust the healthcare system as a whole, they still prioritize and value the relationship with their primary providers, as indicated in the literature and findings. Fostering collaborative relationships of reciprocal trust is the ideal for future healthcare reform and the PCMH model; but understanding how interpretations of multiple social factors, including race and ethnicity, social class, educational attainment, age, and gender, are dependent upon different regional contexts and impact health outcomes is crucial as the United States continues to become an increasingly culturally and socially diverse nation.

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