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Agency And Resistance Strategies Among Black Primary Care Patients

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**AGENCY AND RESISTANCE STRATEGIES AMONG BLACK PRIMARY
CARE PATIENTS**

by

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DISSERTATION

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

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DEDICATION

To Dr. Susan Eggly, who has been a staunch advocate of my efforts and my growth as a scholar. Thank you so much for always believing in me, for pushing to me to produce my very best work, and providing the valuable insight that has influenced much of my thinking. I am so very fortunate to have had you as a guiding light during my development as a scholar.

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CHAPTER 1

Introduction

Humans have a natural inclination to form relationships. Within all interpersonal relationships, there is an ebb and flow, a pull and push for power. This balance of power represents a dynamic process that varies according to the nature of the relationship and the roles of the individuals (Burgoon & Hale, 1984). The patient-physician dyad represents a relationship in which power is inherently asymmetrical, yet each individual can potentially claim a greater measure of power (Ainsworth-Vaughn, 1998). While the physician's position and expert knowledge affords him or her a greater measure of power, the patient may potentially claim power by using a more participatory and partnering role within the dyad. Ultimately, the power differential within the patient-physician dyad is not necessarily fixed.

Understanding this process of power-claiming is essential. Russell (1938) notes, "The fundamental concept in social science is Power; in the same way that Energy is the fundamental concept in the physics" (p.10). Power works upon and within the patient-physician dyad. Within the dyad, the patient and physician enact communicative acts that may serve to claim power in subtle or covert ways, verbally or nonverbally. Power also works upon the dyad externally, as larger contextual factors influence the pre-existing attitudes and beliefs for both the patient and the physician – which in turn influence their perception of the other and the resulting communication (Dovidio, Hebl, Richeson, & Shelton, 2006). Acknowledging these contextual factors is especially important when attempting to understand how marginalized individuals participate during the clinical interaction. Whereas several studies have suggested that marginalized patients

do not participate actively in clinical interactions (e.g., Street, Gordon, & Haidet, 2007), critical literature suggests that the marginalized are perhaps not passive; instead, their experience navigating throughout inequitable practices and institutions often equips them with the ability to enact power in subtle, often unrecognized ways (Dutta & Basu, 2008; Trethewey, A., 1997). The health disparities that exist for marginalized individuals are well known - but are these patients powerless?

This project examines the ways in which black primary care patients utilize agency and resistance strategies during clinical interactions. The exploration of this topic is timely, as research indicates that black patients are often less active during the clinical interaction when compared to white patients. The research questions that guide this analysis attend to the inquiry of the nature of agency and resistance among black primary patients with a history of previous discrimination. Using qualitative content analysis, we examine the transcripts of video recorded interactions, as well as the video recorded interaction in order to observe the verbal and nonverbal strategies utilized by patients. The resulting analysis produced a typology of agency and resistance strategies that provide insight into the ways in which black primary care patients participate during the clinical interaction. The results of this study represent a contribution to contemporary health research and health interventions.

Before examining the role of power within patient-physician interactions involving marginalized patients, one must first understand how the larger structure of the healthcare delivery system is potentially disempowering. An ample literature demonstrates the gaping chasm of equity in healthcare delivery for marginalized individuals. Dutta (2011) defines marginalization as the “continued construction of a

group, class, sector at the bottom of a social system, with no access or limited access to the basic resources for living” (p. 2). Markers of marginalization vary widely, and can include factors such as class, caste, race, gender, and nationality of origin. Most categories of marginalization are similar in that they represent an economic impact that signals a lack of access to basic resources (Dutta, 2011). Individuals existing within these margins experience inequity across a variety of contexts. The disparities in healthcare that marginalized individuals face are particularly pronounced, especially for racial and ethnic minorities, and those with low socioeconomic standing.

Research provides a number of examples to support the existence of health care disparities for marginalized patients. The National Institute of Health defines health disparities as, “gaps in the quality of health and health care that mirror differences in socioeconomic status, racial and ethnic background, and education level” (National Institute of Health, 2014). These disparities are well documented in literature. In a study of disparities within the Veteran Affairs health system, Saha et al. (2008) found that health care providers provided less patient education and recommended less aggressive treatment methods for black and Latino patients when compared to whites, leading to poorer health outcomes (Saha et al., 2008). Black patients were also less likely to undergo cardiac catheterization when compared to whites and tended to receive less information from physicians about cardiovascular procedures. Likewise, blacks and Latinos were less likely to receive influenza vaccines, and were also less likely to be informed that influenza vaccines were available and recommended (Saha et al., 2008). In a study of cancer care, black patients were more likely to be underdosed or given substandard chemotherapy regimens when compared to white patients, an inequity that

could not be explained by other biological factors (Griggs et al., (2003). Last, Manfredi, Kaiser, Matthews, and Johnson (2010) found that black patients were less likely to receive the name or referral for a cancer expert when compared to white patients. Thus, the authors conclude “being African American...appears to be associated uniquely with disadvantages in instrumental communication dimensions and in receiving information about cancer experts and specialized cancer centers” (p. 289). These studies illustrate an alarming inequity in care for marginalized patients.

In 2003, the Institute of Medicine released a report concluding that there were no obvious or straightforward causes for these disparities (Smedley, 2003). It did, however, identify patient-physician communication as one of the potential key contributing factors in health disparities. While some minority patients prefer racial concordance with their physician (Garcia, Paterniti, Romano, & Kravitz, 2003), and racially concordant patient-physician pairings can result in improved adherence (Traylor, Schmittiel, Uratsu, Mangione, & Subramanian, 2010), the dearth of minority physicians (especially in cancer care) lessens the probability of such pairings. In an effort to address this issue, health scholars have developed and implemented numerous interventions designed to improve the quality of communication within racially discordant dyads.

Patient activation is a contemporary health intervention that has been utilized in an attempt to address the power differential that exists within the patient-physician dyad. Physicians inherently claim a greater share of power within the patient-physician dyad as a result of Aesculapian (i.e., medical) expert power (Ainsworth-Vaughn, 1998). One of the ways that the patient activation intervention attempts to treat this imbalance in power is by empowering the patient. In his ecological model of communication in health

encounters, Street (2003) identifies three specific behaviors that could potentially promote greater patient participation during the clinical encounter: information seeking and provision, assertive utterances, and emotional expressions. Health scholars have built upon this model with the shared goal of fostering greater “active” behaviors from the patient during the clinical interaction. Various patient activation interventions have been developed with the goal of encouraging these active behaviors.

Within a patient activation intervention, a patient may learn how to strategically use communication as a vehicle for achieving improved clinical communication with the physician (Gordon, Street, Sharf, & Soucek, 2006; Post, Cegala, & Marinelli, 2001). The goal of “activating” patients to exhibit these types of participatory behaviors is laudable in light of research that shows that physicians’ communication behaviors are influenced by their perceptions of the patients. Indeed, Street et al. (2007) identified a powerful relationship between the physicians’ communication behaviors and the patient’s communication and ethnicity. Physicians were more patient-centered and less contentious during clinical interactions with patients who presented as good communicators (Street et al., 2007), using behaviors such as question asking and providing information. Additionally, when patients presented a positive affect and were more involved they received more patient-centered communication. Conversely, physicians were contentious with black patients who were perceived as less effective communicators (Street et al, 2007). This study shows that physicians’ perceptions of marginalized patients influences the nature of the communication during the clinical interaction.

Patient activation endeavors to address this problem by cultivating an “activated” patient that demonstrates more participatory behaviors during the clinical interaction (Street et. al, 2007). As a result of this increased participation and interaction, marginalized patients could theoretically receive more information and more patient-centered communication. The increased degree of communication would enable patients to function more collaboratively during the decision-making process, and enable physicians to better tailor their information to the needs of the patient. Several studies have shown that patient activation interventions have been successful in fostering more participatory behavior during clinical interactions involving marginalized patients (Cortes, Mulvaney-Day, Fortuna, Reinfeld, & Alegria, 2006; Cunningham, Hibbard, & Gibbons, 2011). These findings show that patient activation may improve the reciprocal process of communication within the patient-physician dyad by influencing the communication style of the patient.

Whereas the idea of patient activation acknowledges the power differential within the patient-physician dyad and seeks to change behavior and, potentially, outcomes by changing the behavior of the individual patient, this approach does not allow for the consideration of systemic factors that influence how marginalized individuals interact with the healthcare system when attempting to obtain health services. Marginalization is not the result of individual behaviors but rather the result of overarching structures that systematically subjugate individuals (Dutta, 2001; Tretheway, 1997). The communication and health behaviors of marginalized individuals should not be largely attributed to individualized traits and characteristics. Instead, scholars should strive to gain a more comprehensive understanding of how marginalized community members’

communication behaviors and power-claiming strategies are influenced by top-down power structures in order to gain an understanding of how these structures influence the way that marginalized patients manage health related matters. Patients' experiences in marginalization, and within discriminatory structures, ultimately influence the ways in which they assert agency when attempting to gain health resources, and even when communicating with physicians about their health. Thus, any patient activation intervention utilized with marginalized patients should take into account the larger cultural and systemic factors that shape their communication behavior and subsequent interactions with physicians.

Indeed, Dutta (2008) asserts that power functions to potentially constrain agency and mediate access to resources. Dutta and Basnyat (2010) define agency as an individual's ability to locate, negotiate and enact choices within the larger structures that he or she resides within. It is reasonable, therefore, to expect that patients may exert their agency strategically during interactions with the healthcare system, such as clinical interactions. As Dutta (2008) posits, demonstrations of patient agency are not solely the result of patient characteristics, but instead are largely influenced by the individual's relationship to larger power structures. Any health intervention that endeavors to improve clinical communication with marginalized patient must recognize the larger role of power, and how it influences the nature of patient agency.

Marginalized patients may demonstrate agency in ways that reflect the strategic behaviors developed in response to subjugation. Health scholars and subsequent health interventions may not necessarily acknowledge or understand these behaviors because they are not studied within the larger contexts of the social determinants of health.

Health interventions that focus on individual behaviors and fail to address broader structural determinants of health will always fall short of achieving health equity (Thomas, Quinn, Butler, Fryer & Garza, 2011). Any intervention that endeavors to address inequity in healthcare *must* acknowledge power. Patient activation, with its current emphasis on changing the behavior of the individual (i.e., the patient) in order to achieve the desired outcome (i.e., more participation in the clinical interaction), fails to acknowledge the countless other inequitable and discriminatory factors that contribute to health disparities in the health care delivery system.

An understanding of these dynamics would provide health scholars with the insight needed to provide more effective health interventions. At present, health interventions such as patient activation endeavor to change the individual behavior of the patient and operate upon the assumption that the patient lives in a vacuum. Dutta (2008) highlights the deficiencies of this perspective in his study of poor workers in West Bengali. When questioned, workers indicated that they were very much aware of what constituted a healthy diet and provided examples for the researchers. Their reality, however, as poor workers living within a larger environment that placed a hefty premium on healthy foods, did not allow them to consistently make the healthiest choices. This example illustrates that health scholars must develop interventions that go beyond treating the individual and also address the myriad contextual factors that influence how patients are able to assert their agency when managing their health. In this case, behavior that might be negatively regarded as noncompliance takes on a greater depth of meaning when viewed within the larger framework of structure, wherein marginalized community members do not have the same access to health resources.

Another example of this deficiency in health scholars' approaches can be found when examining the ways in which some health interventions attribute positive and negative values to patient behavior without fully accounting for the myriad shaping influences. Within the patient activation perspective, passivity is perceived negatively and thought to be a contributing challenge to optimal communication in the patient-physician dyad. From this perspective, the passive patient is one who seems powerless in interactions with providers, failing to ask questions or volunteering information without prompting from the physician (Roter, 1977). Roter posits that patients may demonstrate passivity for a number of reasons, such as a reluctance to appear ignorant, but they generally dislike assuming a passive role when interacting with the physician. Certainly, this may be true for some patients but scholars must investigate the degree to which this generalization applies to other patients, especially marginalized patients. Just as marginalized patients strategically enact agency in response to overarching structures, patients may also strategically adapt their communication when speaking with health care providers. Marginalized patients are unique in that they have become accustomed to navigating through various impedances to acquiring health resources. Health scholars should more closely examine how these experiences might influence the degree to which marginalized patients interact with these physicians. Are marginalized patients perhaps already "active" or enacting agency during the interaction, or are they passive? Further, if some marginalized patients do indeed enact their agency during the interaction, are they able to enact resistance, wherein the patients challenge the physician and/or the recommended treatment plan?

The notion of agency goes beyond the concept of “activation” espoused by Street (2003) that focuses on just specific preferred behaviors (e.g., providing information without being prompted). Instead, agency represents an individual’s capacity to act, and in clinical communication, can be recognized as the “language and action that are constructed, negotiated and maintained through effective communication” (Young, Kim, Shu,, Baker, Schmidt, Camp & Barfield, 2010). When enacting agency during the clinical interaction, the patient is demonstrating his or her ability to influence events according to their preferences, needs and desires (Koenig, 2011).

Often, patients may enact agency by resisting the physician and/or his plan. Patients may passively enact resistance by withholding their approval of the physician’s plan (Keonig, 2011; Stivers, 2005), but they may also choose to enact resistance in an active way. Dutta (2001) describes this process of active resistance as “communicative actions and processes that challenge, navigate and attempt to change... these actions are often disruptive, and allow the patient to express her will” (p.38). In her discussion of interactional resistance, Stivers (2005) defines active resistance as “a sequence of action regarding the treatment such as a challenge, queries about the effectiveness of appropriateness of the medication or about alternative treatments” (p. 980). Resistance allows the patient to move beyond the agentive act of expressing his or her will to an active process of pushing, disrupting and/or challenging the clinical process in an attempt to reach the patient’s desired aim. Patients who enact resistance during the clinical process reject the passive compliant role of the “good patient” (Mulcahy, Parry, & Glover, 2010) in order to reach their desired goal.

An important distinction to make at this juncture is the difference between a patient's enactment of agency and the enactment of resistance. As previously noted, Koenig (2011) defines agency as the patient demonstrating his or her ability to influence events according to their preferences, needs and desires. Patients may enact agency by exhibiting a range of verbal and nonverbal behaviors within the clinical interaction that are not resistance, such as those taught in patient activation interventions. Resistance, while an enactment of agency, goes beyond a patient's expressed preferences, opinions and information-seeking, and serves as a tool for patients to challenge and disrupt the physician and the medical interaction processes (Dutta, 2008; Stivers, 2005). Clearly, resistance is an act of agency. Yet, agency does not always result in enacted resistance.

Existing literature shows that individuals enact resistance when attempting to influence the interaction outcome on their own behalf (Koenig, 2011) and their children's behalf (Cohn, 2009; Stivers, 2005). Koenig (2011) provides the example of a patient that strategically uses silence to withhold acceptance of a treatment plan. The patient's failure to immediately provide acceptance of the physician's treatment plan represents a form of resistance. As Koenig explains, failure to provide normative acceptance of the treatment recommendation slowed the forward progress of the interaction and prompted the physician to provide an alternative that the patient eventually accepted. In this case, silence can be understood not only as an enactment of the patient's agency, but also as enactment of resistance. Stivers (2005) reported a similar process of resistance by parents when advocating for their children to receive a prescription for antibiotics during illness. Parents enacted resistance by withholding acceptance of the proposed treatment plan and actively resisting when the physician indicated an unwillingness to recommend

antibiotics. These studies demonstrate that patients may go beyond the expression of agency and even utilize resistance strategies when attempting to reach the desired outcome during the clinical interaction. For patients, resistance strategies may be a useful means of advocating for themselves.

Tretheway (1997) also described a pattern of resistance outside of the contexts of medical interactions in her study of low-income blacks that utilized a social services agency. Tretheway explains that marginalized individuals are rarely passive and instead, seek out alternate ways of obtaining resources in larger structures. Tretheway found that participants utilized several subtle mechanisms and maneuvers to enact their resistance and obtain services, such as refusing confessional practices, fighting bureaucracies, playing games and breaking rules. Within this critical framework, it is evident that marginalized individuals enact their agency via resistance to obtain health and social services in ways that often are not acknowledged or accepted.

Tretheway's study uses a comprehensive approach to understanding not only the behavior of the participants, but also the surrounding contexts that influence that behavior. The subtle, seldom recognized mechanisms that these participants utilized when interacting with the social services organization were not merely in response to the requirements that they were ordered to meet. Rather, these behaviors were the result of their lived experiences within inequitable, discriminatory systems. While this perspective provides a great deal of insight into how marginalized individuals enact agency and resistance in a social services setting, less is known about the adaptive behaviors that marginalized patients display during medical interactions. Thus, the purpose of the

present study is to gain an understanding of how marginalized, underserved patients enact agency and resistance when interacting with physicians during the clinical encounter.

The study at hand endeavors to build upon the small body of literature that addresses the ways in which marginalized patients enact agency and resistance in several ways. First, this study seeks to challenge the assumptions of contemporary health interventions, such as patient activation, by examining if and how marginalized patients already enact agency in clinical interactions. As Thomas et al. (2011) assert, interventions targeted at racial/ethnic minorities must address larger structural factors by taking into account the many factors that produce and reproduce inequity, and how marginalized individuals are potentially constrained as a result when attempting to obtain health services, but attempt to find greater equality through resistance. Researchers must acknowledge that, for those individuals who have been exposed to discrimination within the larger structures, demonstrations of agency and resistance may manifest in both subtle and overt ways. This study, therefore, takes into account the contextual factors that patients share during clinical discussions to understand how agentic and resistance strategies are used among black primary care patients with a history of discrimination.

Second, this study utilizes Dutta's (2001) culture-centered approach as a critical lens to understand the communication behavior of marginalized patients in the clinical context. Dutta's culture-centered approach is perfectly suited to address the communication behavior of marginalized patients. Unlike many other health theories and approaches, the culture-centered approach assumes an interdependent relationship between structure, culture and agency. Within this framework, race and culture are treated with an understanding of the larger structure, which often serves as a constraining

force. This approach does not espouse a superficial “culturally sensitive” approach that endeavors to persuade without first committing fully to understanding the cultural context, but instead provides a fully contextualized understanding of the interrelated nature of structure, agency and culture. Researchers using a culture-centered approach recognize that the nature of marginalized individuals’ attempts to obtain health services is largely reflective of the surrounding context and overarching structures. The culture-centered approach, and its emphasis on the interrelated nature of culture, agency and structure, provides the foundation for the truly integrative approach scholars have recommended (e.g., Anderson, 1996) and will inform interpretation of the study’s results. As such, the proposed study seeks to understand how marginalized patients use resistance strategies by foregrounding cultural understanding and recognition of the structures that often shape patient agency and resistance.

Last, the study at hand provides a typology of marginalized patients’ observed agency and resistance strategies in the context of the clinical encounter. This feature of the study provides the foundation for theory-building and directed growth of the literature. This study seeks to obtain a more nuanced understanding of how marginalized patients use resistance strategies – despite existing literature that often describes this patient population as passive (Street et al., 2007). While the typology is developed based upon the behavior of individual behavior, the results are interpreted using a critical perspective that acknowledges the structural and contextual factors that patients describe during their interactions with the physician. Adopting this critical approach during the subsequent analysis may provide some insight into the absence or presence of marginalized patients’ resistance strategies.

This study has practical significance for communication scholars and health interventions. Specifically, this study seeks to extend contemporary health interventions, such as patient activation, that encourage patients to adopt certain idealized behaviors in order to improve clinical communication. Patient activation, for example, encourages three specific idealized behaviors (Street, Gordon, Ward, Krupat, & Kravitz, 2005). This project seeks to understand how marginalized patients might already be active, and explores the wider range of participatory behaviors. Understanding the role of patient resistance presents further opportunities for growth and exploration in health interactions. While resistance might not be an idealized behavior, it may prove to be a useful and successful strategy for marginalized patients.

Findings from this study will address the underlying assumptions of contemporary health interventions, such as patient activation, which assume that patients are passive and need to adopt idealized behaviors; instead, this study endeavors to understand how patients are perhaps *already* active. Just as this project aims to acknowledge the contextual and structural factors that patients share during the interaction, contemporary health interventions should acknowledge and treat not only the medical problems brought to the interaction, but also the larger issues that shape and the patient's health and health behavior. Lastly, findings from this study can be used to create health interventions that do not solely place the burden of change on the patient, but rather encourage physicians to identify ways in which they can partner with patients in the management of their own health.

In Chapter One, the rationale for the dissertation is provided, along with its potential contribution to patient-provider literature. Chapter Two provides a literature

review of patient-provider literature, as well as an overview of the culture-centered approach and the research goals of the study at hand. Chapter Three provides a detailed accounting of the methodology employed by the proposed study. Chapter Four presents the findings of the study, as well as the resulting typology of resistance strategies, along with a discussion of these findings. Finally, Chapter Five discusses implications and limitations of the study, as well as suggestions for future research.

CHAPTER TWO

Literature Review

The landscape of patient-provider interactions has evolved greatly, particularly in regards to the balance of power in the patient-physician dyad. The following literature review provides a general overview of the transitory nature of the roles within the patient-physician relationship, as well as the role of power within the patient-physician dyad. Additionally, the literature review will discuss the ways in which patients, specifically marginalized patients, enact agency and resistance within the clinical interaction and the resulting implications. Finally, this chapter will review the research goals and the research questions that guide the present study.

Clinical Communication

The process of communication within the patient-physician interaction exists across several dimensions. Albrecht et al. (2009) explains, “Clinical communication occurs when patients, physicians, and family/companions attend one another and begin interpreting one another’s verbal and nonverbal, explicit and implicit, obvious and subtle behavior” (p.49). This definition reflects the many influences and variables that act upon the process of communication within the interaction. Indeed, the patient and the physician can enter the interaction with attitudes and beliefs that influence their perceptions about the other, which in turn influences the nature of the communication within the dyad. According to Street (2003), both patient and physician enter the clinical encounter with preexisting predispositions, such as attitudes and stereotypes related to ethnicity and cognitive-affective influences. As Albrecht et al.’s definition of clinical communication indicates, these influences are not always expressed overtly but may be

conveyed in implicit or subtle ways, via verbal or nonverbal behavior. Thus, the production of meaning within the patient-provider dyad is the product of an exchange that has been influenced by myriad factors and influences.

One factor that must be considered is the power differential that permeates patient-provider interactions in the United States. Patients within the dyad face an asymmetrical balance of power. The expert power of the physician further reifies this imbalance. Ainsworth-Vaughn (1992) explains that unequal access to medical knowledge and technology creates conditions in which one party must depend on the other. As a result, physicians are much more likely than patients to unilaterally exercise power within the interaction. As the gatekeepers of information and treatment, physicians' choices in negotiation carry a greater weight and impact than those of the patient (Ainsworth-Vaughn, 1992).

This precarious balance leads to a dilemma that creates unique and potentially detrimental challenges for patients. In particular, patients must negotiate for power with the understanding that their health and health outcomes may be adversely or compromised as the result of the interaction. Patients may attempt to claim power or enact resistance, but they should consider that their treatment plan may be potentially influenced by the physician's assessment of their presentation. As such, the patient may receive treatment recommendations that are influenced by a confluence of factors that go beyond biomedical considerations. Ainsworth-Vaughn (1992) explains, "Participant's personal, social and professional histories are brought into the event and serve as bases for the power negotiation that takes place there" (p.279).

Despite their benevolent intentions, Pauley (2011) asserts that providers are ultimately gatekeepers, with the power to influence the course of the interaction. As such, negotiations within clinical interactions are not always easy. Physicians may have expert power, but increasingly savvy patients (who increasingly access the Internet and other sources to secure information) complicate the negotiation for power. In addition, physicians should attempt to address the power disparity by improving the patient's bargaining position with efforts such as increased display of personal vulnerability (Pauley, 2011).

Indeed, clinical communication represents the struggle for dominance between the physician and patient. Roter and McNeilis (2003) assert:

The medical dialogue is the fundamental instrument through which the battle over paradigms is being waged; the patient problems will be anchored in either a biomedical and disease context or a broader and more integrated illness context that incorporates the patient perspective. In other words, the nature of the patient's problems will be established and the visit's agenda and therapeutic course will be determined by whatever wins out (p.122).

Mishler (2003) further expands upon this idea and offers recommendations for a change in clinical communication. Referring to the discourse of medicine, which is most often characterized by a physician-dominated interview, Mishler urges practitioners to develop alternative practices that "interrupt the voice of medicine" and give priority to hearing patients' narratives and contextualized explanations of illness that use everyday language" (p.437). Such an approach centralizes the needs of the patient as opposed to

allowing the physician to dominate the encounter with a biomedical approach to identifying and treating illness.

Mishler's assertion shows the importance of attending to surrounding context. While physicians may be primarily concerned with attending to the biomedical and technical aspects of the patient's illness, they must also allow room for the patient's "knowledge." All too often, the expert knowledge of practitioners and scholars is given the designation of trusted knowledge, while patient knowledge is given little credence (Airhihenbuwa, 2000). In order to centralize patient needs, physicians must allow for the emergence of the voice of the life world during clinical interactions. This approach promotes the enactment of patient agency, which might manifest in several ways. Such an "interruption" of the voice of medicine (Mishler, 2003) allows the patient and the physician to connect through collaborative discourse. This ultimately empowers the patients to take control of their health plans, actively supporting or resisting suggested treatment plans as they attempt to identify the best contextual fit.

Mishler's recommendation represents an ideal in contemporary healthcare that has resulted from a lengthy evolution in patient-physician literature. Whereas greater patient power is promoted in contemporary patient-physician literature, previous literature features an extensive history of a physician-dominated ideal.

The Patient Role

In keeping with the ever-evolving nature of the health care system, conceptualizations of the ideal roles for patients and physicians have evolved over time. For many years, the physicians were expected to exert professional dominance during the clinical interaction and patients were expected to take a submissive role (i.e., paternalism)

(Roter & McNeilis, 2003). In twenty-first health care settings, however, patients are encouraged to assume a greater degree of participation during the clinical interaction (i.e., consumerism). The evolution of the patient and physician roles has provided a platform for a dyad shift in power, setting up a “battlefield” where wars over power and paradigms are waged (Roter & McNeilis, 2003).

Paternalism. The oldest and, for many patients, the most familiar conceptualization of the patient-provider relationship is paternalism. Paternalism, the bedrock upon which the clinical dyad is built, is characterized by low patient power and high physician power. In this model, the paternalistic physician assumes an authoritative role with the passive, accommodating patient (Parsons, 1951; Roter 2000, 2003). The physician assumes the dominant role within the dyad, and exercises his or her greater power by dominating agenda setting, goals, and decision-making in regard to both information services (Roter, 2000, p.7). As a result, the physician’s communication is heavily influenced by the voice of medicine, which consists of biomedical language and a marked absence of the patient’s voice (Roter, 2000).

Patients in this subordinated role are expected to adopt a passive role during the clinical interaction. The physician, in turn, assumes a paternalistic stance as an all-knowing authority that compels the patient to accept the recommended treatment for his or her own good (Cockerham, 2012). In his explication of the sick role, Parsons (1951) promoted the passive patient role as an ideal, explaining that it is the responsibility of the patient to seek medical care when ill. The physician, in turn, is responsible for providing the best treatment recommendation, according to his or her estimation and judgment.

The patient, therefore, assumes the role of a trusting child and the physician becomes the all-knowing parental figure that makes decisions on the patient's behalf (Parons, 1951).

Paternalism relies upon physicians to utilize their expert knowledge in order to provide the best treatment plan for the patient, but its lack of patient participation has been shown to be highly problematic and potentially compromises quality of care for patients. As Roter (2003) explains, this model effectively silences the patient's voice as the physician assumes complete responsibility for the agenda-setting and decision-making processes. The assumption that the physician's treatment plan is in the best interest of the patient is indeed a faulty one; it takes for granted that the patient's values and preferences match those of the physician (Roter, 2000). Even in cases in which the patient does not acquiesce to the paternalistic role of the physician, Roter (2003) points out that the asymmetrical nature of the patient-physician relationship never allows the patient to have equal footing within the clinical interaction. The result is an exchange that fails to properly identify and satisfy the needs of the patient.

When operating within the passive role, patients do not have the ability to fully benefit from the quality and content of information provisioning that they prefer. Pratt (1976) describes a pattern involving passive patients that results in a clear deficiency of physician-imparted information. When the patient fails to ask questions or provide cues that signal the breadth and depth of explanation or information that she wishes to receive, the physician interprets this silence as a possible lack of understanding, or alternatively, complete understanding. As a result, physicians tailor their delivery to match their perceptions of the patient's interest or cognition and the patient receives less detailed information (Pratt, 1976).

Assuming a passive role during the clinical interaction also prevents the patient from providing vital contextual information. When patients' voices are absent, they cannot assert the need to pursue a decision-making process and treatment plan that addresses all aspects of their illness nor can they fully explore the options and alternatives that exist outside of the physician's recommended treatment plan. Roter (2000) explains that medical visits that are more participatory and responsive to patients' instrumental and emotional needs result in improved health outcomes and better problem resolution. Without the patient's feedback, the physician is left to make decisions on the patient's behalf that may or may not adequately address the various dimensions of need.

Patient passivity also allows a physician to be more influenced by his or her preexisting attitudes or biases while making decisions. As physicians' judgment and ultimate decisions can be based in part on their perception of the client, and on the predisposing influences that affect their perception, there is a distinct risk of rendering a treatment plan that resonates with the physician's own attitudes or beliefs (whether explicit or implicit) about that patient (Stepanikova, 2012). The implications of this are especially alarming for marginalized patients in light of research that shows that physicians' biases can influence their treatment plans (Stepanikova, 2012; van Ryan & Saha, 2011). As a result of this bias, physicians may (knowingly or unknowingly) construct treatment recommendations that disadvantage minority patients, such as rendering a less serious diagnosis or being less likely to refer them to a specialist (Stepanikova, 2012; van Ryn & Saha, 2011). Without the partnership and feedback of the patient, the paternalistic physician is more likely to provide a treatment plan that fits his or her perceptions of the patient. Thus, unilateral decision-making and potential biases

on the part of the physician ultimately work against the best interests of the patient and potentially contribute to health disparities.

Consumerism. Roter's (1977) work signals a departure from the ideal of the passive patient. Roundly rejecting Parson's conceptualization of paternalism and his promotion of the passive patient role, Roter sought to challenge the prevailing belief that patients should rely upon the judgment of their doctors when seeking care. Consistent with the ideals of the growing self-help movement, Roter (1977) advocated a reconceptualization of the physician-centered model of clinical communication.

Understanding the need to eschew the passive patient role, Roter expressed the importance of patients adopting a consumer perspective of the patient-physician relationship in order to foster more active participation. Consumerism, which is characterized by low physician power and high patient power, represents a reversal of paternalism. The patient-physician interaction is redefined so that it resembles a marketplace transaction where buying power rests with the consumer – in this case, the patient. In this model, patients are responsible for setting the agenda, stating goals, and the decision-making process (Roter, 2000). Patients then use their power to demand information and technical services that reflect their own values. The physician, in turn, is expected to accommodate patients' requests and function as a "technical consultant with the obligation to provide information and services contingent on patient preferences (and within professional norms)" (Roter, 2000, p. 7).

In consumerism, patients are encouraged to assume a more active role during the clinical interaction. As Pratt (1976) explains, patients should approach the interaction as an opportunity to problem-solve instead of passively participating or blindly submitting.

The patient role within this framework features a patient that is actively participating in the clinical interaction in order to secure a dialogue and treatment plan that best reflects their goals, values, and decision-making. As Roter (1977) asserts, patient activation, responsibility, and the negotiation of care are the essential ingredients to the consumer perspective.

The concept of the active patient, or patient activation, clearly provides a blueprint for encouraging patients to take a more active role and assume more responsibility in their interactions with physicians. Roter (1977) proposed that patient education should play a key role in advancing the consumer perspective and in developing and implementing a pragmatic intervention that could potentially foster these skills in patients. For Roter, question-asking is integral to increasing patient participation as it increases the provision of information given to the patient, thereby providing the knowledge needed to inform decision-making processes. As such, Roter developed a health education intervention designed to increase patient participation during clinical communication by increasing the frequency of patient questions. Participants in the experimental intervention met with a health educator prior to their clinical visit and reviewed a questions-asking protocol. During this session, patients identified any questions that they wanted to ask about their illness, physician recommendations, diet, and lifestyle choices. At the conclusion of the study, Roter (1977) found that patients randomized into the experimental group asked more questions, with fewer indirect questions, when compared to the placebo group patients. This study demonstrated that health intervention could effectively increase active participation patients during the clinical interaction. In addition, Roter's supposition that increased question-asking could

positively influence health outcomes was supported. The experimental group in the study demonstrated higher appointment-keeping ratios, which has direct implications for improved adherence.

Patient Activation

Contemporary patient activation literature has built upon Roter's study and framework, with interventions designed to increase patient participation. In his ecological model of communication in health encounters, Street (2003) identifies three specific behaviors that could potentially promote greater patient participation during the clinical encounter. Within this model, patient participation is operationalized as information seeking and provision, assertive utterances and emotional expressions. Street defines asking questions as "utterances in interrogative form intended to seek information and clarification" (2003, p. 968). Assertive responses are defined as "utterances in which the patient expresses his or her rights, thoughts, beliefs, interests and desires as in offering an opinion, making recommendations, making a request, disagreeing or interrupting" (2003, p.968). Expressions of concern are defined as "utterances in which the patient expresses worry, anxiety, fear, frustration, and other forms or negative affect or emotions" (2003, p. 968). Haidet, Kroll and Sharf (2006) have asserted that this framework should be expanded to include the sharing and exploration of the patient's narrative.

A growing body of literature has demonstrated the continued effectiveness of patient activation interventions in increasing patient participation (Salyers et al. 2009, Cortes, Mulvaney-Day, Fortuna, Reinfield & Alegria, 2006; Cunningham, Hibbard, & Gibbons, 2011; Alegria, Sribney, Perez, Laderman, & Keefe, 2009). In addition, research

shows that patients who demonstrate more active verbal and nonverbal behaviors during the clinical interaction are likely to receive more “facilitative” and patient-centered physician communication (Street et al., 2005; Street et al., 2007). Cegala and Post (2009) found that physicians working with high participation patients “especially explored both patients’ disease and illness experience and they devoted more attention to understanding the whole person and establishing common ground” (p. 207). The authors conclude, “We think it is at least plausible that the extent of a patient’s participation in the interview was a significant factor in shaping how physicians interacted with him/her” (Cegala & Post, 2009, p.207).

Increased patient participation during the clinical interaction also has implications for health outcomes. Haidet et al. (2006) found that negotiated empowerment, defined as a set of illness management strategies such as disease monitoring, preventive actions, and greater engagement with the physician, was productive for patients, as it involved active patient behaviors; passivity/fatalism was least productive, as it “served to stymie efforts toward illness management by either patient or physician” (p.326). In their study of mental health patients, Salyers, Matthias, Spann, and Lydick (2009) found that patient activation was positively associated with illness management and negatively related to substance abuse. In addition, qualitative analyses of the transcribed clinical interactions showed that active patients played an active role in partnership building and directing treatment (Salyers et al., 2009).

In review, where power was once clearly held by the physicians, contemporary movements, such as patient activation, encourage a patient role that is much more dominant, with equal or greater power given to the patient. This demonstrates a clear

paradigm shift in patient-provider research. This proposed shift in power is especially important for patient populations that exhibit fewer participatory behaviors during the clinical interaction. Marginalized patients, especially racial and ethnic minorities, experience alarming inequities in healthcare. These disparities in healthcare in turn contribute to disparities in health outcomes. Therefore, understanding how marginalized patients enact agency during the clinical interaction is imperative.

This understanding also has implications for patient activation literature. Using a culture-centered approach, it becomes clear that greater examination must be given to the communication behaviors of marginalized patients. The perceived passivity that patient activation aims to address may belie a much more complex, calculated understanding of how to manage the power differential in the patient-provider interaction. Indeed, patient activation seeks to foster the demonstration of ideal patient behaviors in order to improve the quality of the clinical interaction. Yet marginalized community members may use not only active strategies, but resistance strategies such as challenging the physician, that are not readily accepted in the highly structured format of the medical consultation, and these demonstrations may not be accepted as a form of desirable patient participation. Clearly, there is much to be considered when attempting to activate the marginalized patient.

Activation and the Marginalized Patient. Improving clinical communication with minority patients has implications for addressing health disparities. In 2003, the Institute of Medicine reported that the that inequities in health care delivery that black patients experienced could not be fully attributed to issues of access or patient preferences (“Unequal Treatment,” n.d.); the report did, however, suggest that preexisting patient and physician attitudes influenced behavior during the medical interaction and

contributed to racial disparities in recommended treatment regimens. Several studies have shown that there is a lesser degree of participation during clinical interactions that include marginalized individuals (Cegala & Post, 2009; Eggly et al., 2011). For example, black patients are often considered poor communicators (Street, Gordon, & Haidet, 2007) and ask fewer questions when compared to white patients (Eggly et al., 2011).

Marginalized patients' displays of passivity could potentially lead to mistreatment from physicians. Street, Gordon, and Haider (2007) found that physicians' demonstrated more patient-centered behaviors with the patients that exhibited more participatory behaviors. The most powerful relationship, the authors found, existed between the physician's communication behaviors and the patient's communication and ethnicity. Physicians were "contentious" with black patients when compared with white and Hispanic patients, perceiving them as less effective communicators when sharing history, symptoms, understanding treatment options and answering questions. This research demonstrates how marginalized patients with less participative communication styles are more likely to receive less information during the clinical interaction and to potentially experience discriminatory treatment from physicians.

Given that research shows active patient behavior fosters more facilitative communication with physicians, patient activation has been lauded as an ideal approach for positively impacting clinical communication with minority patients (Cortes, Mulvaney-Day, Fortuna, Reinfeld, & Alegria, 2006; Cunningham, Hibbard, & Gibbons, 2011). Patient activation interventions, which often consist of question prompt lists (QPLs) and coaching, have been used to teach marginalized patients how to better negotiate and participate in the medical encounter. Question prompt lists provide patients

with a variety of topics or proposed questions that can be posed to the physician during the medical interaction. Research shows that physicians perceive marginalized patients who have been trained to using these interventions as less passive in clinical interactions than their counterparts who have not received training (Cegala, Street & Clinch, 2007). Thus, the patient activation approach, which disrupts the traditional physician-centered model by encouraging active patient participation, seems to help rectify the disparity. Physicians' preexisting attitudes and beliefs are potentially influenced by the patient's active contribution to the interaction, and patients have the opportunity to shape the interaction and the quality of information provisioning. In turn, the greater degree of information provisioning from physicians may allow patients to assume responsibility for their health by seeking health solutions that resonate with their personal values and beliefs, and identifying and selecting a treatment together with the physician which could potentially increase adherence.

While the aims of the patient activation intervention are laudable, its underlying assumptions must be critically examined. From one perspective, patient activation attempts to interrupt the physician's dominance and allow the patient to interject his/her will into the interaction. In many cases, communication serves as the bridge that unites patients physicians by improving the quality of communication in the clinical encounter. As the patient demonstrates greater participation, the physician is more likely to provide a greater degree of information. Equipped with this information, the patient is better positioned to make informed choices. This intervention addresses several dimensions of potential communication deficiencies, namely the need for increased information sharing and provisioning. Yet the intervention is still built on physician-centered principles.

This intervention seeks to teach patients how to better perform the compliant patient role. While asking questions and providing feedback do allow patients to exercise power (Wang, 2006), patients are expected to do so in accordance with the physician's agenda. The onus is on the patient to demonstrate idealized behaviors that will assist the physician. As a result, the physician is not prompted to garner a greater understanding of the patient and the external influences that shape the illness and illness experience in order to develop the most appropriate treatment plan for the patient. It is naïve to assume that the clinical interaction exists within a vacuum. The patient will leave at the close of the interaction and return to the very circumstances and structures that in part shape their attitudes, beliefs and perceptions. Failing to acknowledge these larger structures and determinants of health is failing to acknowledge the complexity of health disparities.

The marginalization of individuals occurs as the result of a complex confluence of power and structure, enacted in subtle and overt ways. Understanding and addressing the delivery and utilization needs of marginalized patients requires an approach that acknowledges the complexity of the process of marginalization. The patient activation approach endeavors to influence the individual behavior of the patient in order to improve clinical communication and health outcomes. Yet this approach fails to address the myriad factors that influence the ways that patients, especially marginalized patients, may choose to enact their agency. Failure to exhibit the desired "active" behavior may not be the result of a communication deficiency in the marginalized individual but rather an adaptive response to the environment and structures that they must function within.

These adaptive responses are not always understood within the larger contexts of culture and structure. For example, studies (Dovidio, Hebl, Richardson & Shelton, 2006;

Stepanikova, Zhang, Wieland, Eleazer, & Stewart, 2011) have shown that blacks in racially discordant dyads are more likely to exhibit less positive behavior during the clinical interaction, such as lower levels of eye contact and less direct body orientation. At a superficial level, these findings may seem to point to feelings of mistrust, but they may also be indicative of a deeper pattern of adaptation. In their explication of the oppression hypothesis, Dovidio et al. (2006) describe how the process of chronic stigmatization leads oppressed groups to exhibit “systematic nonverbal skills and behaviors that differ from those members of dominant groups and that are functional for coping with their low status” (p.483). These adaptive behaviors include a tendency to be more vigilant and guarded, “making them more inhibited in their emotional expression and nonverbal behavior” (p. 483). The authors go on to explain that blacks utilize these coping/resistance strategies, including disengagement, when interacting in interracial interactions (Dovidio, Hebl, Richeson, & Shelton, 2006). When foregrounded within this understanding, nonverbal behavior that was previously framed as negative can be reframed as a natural adaptive response. As the culture-centered approach indicates, these marginalized individuals strategically enact their resistance in a way that is reflective of their experiences in the larger social structures.

Clearly, a critical approach is needed to further interrogate what activation might look like in minority and marginalized communities. Patient activation endeavors to address the inherent power differential in the patient-physician dyad, but it focuses rather myopically on changing individual behavior. It may successfully teach marginalized patients how to adopt behaviors that are endorsed and approved by the dominant approach to health communication scholarship, but it does not seek an understanding of

how marginalized patients may already be active which would allow greater consideration of the patient's standpoint, and the thoughts, opinions and values that affect the patient's orientation to the interaction and ultimately, the proposed treatment plan.

This narrow focus demonstrates a lack of understanding of the roles of culture, agency and structure. In most cases, marginalized community members are not unaware of what constitutes healthy behaviors and the need to adopt them (Dutta, 2008). Instead, their health behaviors are shaped and influenced by the constraining forces of social structures. In order to truly address health disparities, health scholars and health interventions must first gain an accurate understanding of the complex factors that impact the choices and behaviors of marginalized individuals.

The culture-centered approach provides an ideal framework for providing a culturally contextualized understanding of how marginalized individuals enact their agency (i.e., become "active") during the clinical encounter. As Dutta (2007) asserts, marginalized community members adopt behaviors that are compatible with their cultural understandings and the surrounding structure. The culture-centered approach provides a foundation for a reframing of communication behaviors that have previously been overlooked or considered undesirable by approaches such as patient activation.

A Critical Examination of Patient Activation

The emphasis given to changing the behavior of the individual in the patient activation approach reveals a myopic view and assessment of marginalized community members and the ways in which they enact agency. Noting this presence of an increasingly interwoven discourse of empowerment and increased patient responsibility in contemporary health care initiatives, Anderson (1996) explains that an emphasis on

empowering the the individual fails to acknowledge the institutional practices that perpetuate inequity (p. 698). She further explains:

...meaningful discussion on how to empower people will begin only when there is recognition of the historical factors that have shaped our institutions, and the multiple forces of class, race, gender and other oppressions. Until we unmask the unquestioned and taken-for-granted ideologies that are at the foundation of movements like self-care, and that are interwoven into seemingly liberatory ideas like empowerment, we will continue to produce '*recipes for health and health care delivery*' that privilege those who are already privileged, and disenfranchise those who are dispossessed (p. 703).

As Anderson (1996) asserts, health scholars and practitioners cannot fully understand how to empower without understanding the broader context and the forces that potentially disempower marginalized individuals (Dutta, 2008).

While marginalized patients are subjugated, one should not assume that they are powerless. Indeed, marginalized community members do have power, which is enacted in ways that are largely reflective of the surrounding culture and structure. Just as marginalized community members learn to strategically interact with power structures in order to obtain necessary resources, marginalized patients strategically enact their agency, and if necessary, resistance in order to obtain desired health resources. This complex process inevitably influences the ways in which marginalized patients interact with the health care system. Though they are often perceived as disempowered, marginalized patients strategically enact power during clinical interactions. In some

cases, patient agency is demonstrated when patients resist the constraining power of health care practitioners.

Power, Agency, and Patients. Consistent with the critical tradition, health scholars and practitioners should be mindful of the ways that power functions to subjugate and disadvantage marginalized individuals, especially when developing “solutions” intended to address health inequities. In particular, Dutta (2008) cautions scholars to critically examine how power functions to potentially constrain agency and mediate access to resources among marginalized communities. Dutta (2008) explains, “The interconnected web of power and social structure influences the health experiences of the marginalized community member” (p.163). Dutta’s admonition reveals not only the importance of understanding the interconnected nature of power and social structure but also the ways in which the marginalized may strategically interact with them in order to gain access to health services. As such, any intervention that fails to address the overarching issues of structure and power fails to adequately address the complexities of health inequities for the marginalized.

In addition, interventions that fail to account for the history of discrimination within the healthcare system and individual patients will also likely fail to adequately address health disparities due to the lack of trust between marginalized (i.e., black) patients and physicians. For example, in the wake of the Tuskegee experiments, a continued history of systematic discrimination in the healthcare system has engendered distrust for marginalized patients. These feelings of distrust are still very much relevant and are reflected in the findings of contemporary studies. In an exploratory study involving blacks, Hispanics, and whites, Jacobs et al. (2011) found that black patients

held the expectation they would be discriminated against, as well as the likelihood that they would be “experimented on,” or treated as a “guinea pig” (p.94). Clearly, distrust shapes the expectations of many marginalized patients entering the clinical interaction.

In addition to the past legacy of discrimination in the healthcare system, marginalized patients are also adversely influenced by their own experiences of discrimination. Experiences of discrimination influence minority patients’ rating of quality for health care received (Sorkin, Ngo-Metzger & Alba, 2010). These experiences of discrimination similarly adversely affect healthcare utilization, adherence to recommended treatment plans, and health outcomes. Casagrande, Gary, LaViest, Gaskin, and Cooper (2007) found that experiences of discrimination are associated with delays in seeking medical care and poor adherence to recommended treatment plans, “independent of need, enabling and predisposing factors, including medical distrust” (p. 394). Peek, Wagner, Tang, Baker, and Chin (2011) found that diabetic patients who self-reported discrimination from the healthcare system were more likely to have poor health outcomes. Clearly, previous experiences of discrimination influence how marginalized individuals consider when making decisions about healthcare utilization, which subsequently affects health outcomes.

Power and Resistance. Experiences of discrimination can foster a state of reactance or resistance among marginalized community members when interacting with health care providers. Marginalized community members that have experienced subjugation within larger social structures may enact resistance in an effort to redress the power disparity in the in the patient-physician relationship. For the purpose of this study, resistance and resistance strategies are understood using Foucault’s (1977, 1980)

knowledge/power framework. Foucault (1977, 1980) explication of the “relations” of power allows that the fluid nature of power allows both the powerful and the powerless to exercise power (Mulcahy, Parry, & Glover, 2010).

Acknowledging this, Foucault further explains that oppressed groups and individuals can use the acquisition of knowledge to claim power. For Foucault, power and knowledge are inextricably intertwined: knowledge is always a form of power, and power needs always needs knowledge in order to be exercised (Mulcahy et al., 2010). Mulcahey et al. (2010) explain how this binary works within the patient-physician relationship:

Doctors can exercise power because they control knowledge. Not only can they assert authority through their status as doctors, but they can also exercise power through their access to knowledge about the patient...doctors collect information from patients during tests and exams, but retain these charts for their own use. Here knowledge and power are intrinsically linked; doctors need these charts to exercise power, and yet they also need their authoritative position as doctors to collect the knowledge in the first place (p.1064).

Patients, Mulcahey et al. (2010) explain, are not “imbued with the authority to recognize their own behavior as powerful” and are expected to concede to the knowledge and power possessed by the physician (p. 1064). Foucault (1977, 1980), like Dutta (2001, 2005, 2007), warns against assuming that patients are powerless.

Collective resistance strategies are well documented in organizational and labor literatures. Observed forms of resistance in organizational contexts range from physically performed acts, such as striking, to more subtle discursive forms. Dutta

(2008) asserts, “current resistance literature in organizational communication examines the discursive practices in organizations to understand resistance as a routine yet complex social process that draws its meaning from the contextual aspects of organizing” (p.8). Tretheway’s (1997) further describes this dynamic, detailing the resistance strategies utilized by black community members participating in a social services organization, which included the parodying and refusal of confessional practices, fighting against bureaucracies, playing games and breaking rules.

Similarly, Ezzamel, Willmont and Worthington (2001) found that workers in a manufacturing plant used a variety of individual and collective strategies to resist the controlling techniques of their managers. Workers undermined the authority and credibility of their managers by accusing them of hypocrisy, constantly reminding them of any transgressions that were committed when they were workers, and rejecting collaborative team-based working practices (Ezzamel, Willmott, & Worthington, 2001, p. 1065). Sotirin and Gottfried (1999) identified secretarial “bitching” as a resistant act. In their study, secretaries strategically used gossip and mundane talk to maintain stereotypical gender attributes (while punishing those who refused to conform to them), to wield their collective knowledge as a defensive tool, and to challenge the prevailing assumptions about the identity of the idealized professional secretarial role (Sotirin & Gottfried, 1999). While the strategies may vary, resistance is present in both organizational and interpersonal contexts.

Likewise, resistance is present in patient-physician interactions as well. In her study of patient – physician interactions, Stivers (2005) identified “parent resistance” as a resource for negotiation of the treatment decision. Stivers (2005) noted that parents who

preferred antibiotics as a course of treatment for their children strategically withheld acceptance of treatment plans that did not include antibiotics, often moving to a more active form of resistance when the physician did not accede to their wishes. Koenig (2011) also describes a process of passive resistance, wherein patients enacted their agency by withholding acceptance of the treatment plans that physicians' presented in order to negotiate and collaboratively construct a mutually acceptable treatment plan. Ijas-Kallop and Ruusuvuori's (2010) conversation analytic study of patient-physician interactions found that patient's at times resisted the doctor's diagnostic information by referring to their present symptoms, past experiences in similar symptoms and information received in previous medical visits with similar illnesses.

Wright (2008) describes resistance as the product of a racialized reactance, where black patients may enter the clinical interaction with preexisting attitudes of mistrust influenced by historical and personal incidences of discrimination. Non-black physicians may similarly enter the interaction with implicit or unconscious biases. During the clinical interaction, black patients detect physicians' implicit biases. When faced with the paternalistic communicative styles and the subtle, unconscious biases of racially discordant physicians, black patients enter state of psychological reactance. In their reactance, black patients are more likely to resist the recommended treatment plans of the physicians, thus compromising their compliance and ultimately their health (Wright, 2008).

Patient activation lacks any mechanisms that could account for the complexity of communication processes such as these. These individuals do not require help or coaching in order to enact agency and participate. Rather, practitioners and scholars

(themselves a component of the larger structure) do not understand the ways in which marginalized patients are already active and exerting their will. As this is not understood, the intervention builds upon the assumption that the patient's power is inactive or inert. An intervention of this nature is not the best approach for addressing the various phenomena that are at work during interactions with marginalized patients because it does not address the larger issues of power. Subsequent interventions (and perhaps subsequent iterations of the patient activation intervention) should abandon the assumptions that marginalized patients require training, and that they must be persuaded to adopt idealized health behaviors. Rather, interventions should first understand what "good" health means to community members. As Dutta (2008) points out, individuals who are unable to obtain basic resources, such as food, will place less importance on eating the healthier foods. In order to be effective, interventions must first address the structural deficiencies that community members face as first step in improving health behaviors. In this instance, a more effective approach to intervention would consist of educating community members about programs or initiatives that provided food, provided transportation to food markets, or perhaps implementing a food bank – prior to attempting to administer an intervention that details the benefits of healthy eating. Cultural understanding is the very first step in developing a health intervention, and this understanding should be demonstrated by practitioners during interactions.

These findings call into question one of the underpinnings of patient activation that centers on patients' displays of passivity during the clinical interaction. Within the patient activation framework, patient passivity during the clinical interaction is undesirable and impedes the goal of an improved information exchange with the

physician. Whereas numerous studies have shown that marginalized and minority community members are more likely to display passive behaviors during the clinical interaction (e.g., Eggly, 2011), the underlying causes of this passivity are not fully understood or recognized within the patient activation framework. This is highly problematic, as it impedes the identification of a solution that truly addresses the real “problem” of patient-physician communication with marginalized individuals. Roter (1977) did attempt to address this issue by identifying a number of possible reasons for patient passivity, such as possible feelings of uneasiness when dealing with someone from a higher social class, an unwillingness to feel or appear ignorant, concession to the physician’s authority, or the physician’s reluctance to share control during the interaction; however, Roter’s review fails to account for reasons related to marginalization and discrimination. It fails to account for the fact that the health and communication behaviors of marginalized patients are largely shaped by the very fact that they are marginalized. It also fails to acknowledge that passivity does not always indicate a patient’s ignorance, intimidation, or disinterest. Instead, behaviors that appear passive may actually be acts of resistance.

The patient-physician relationship features an asymmetrical balance of power, but even in a subjugated position the patient may choose to enact resistance in different ways. As Foucault asserts, power is everywhere – it is omnipresent, “residing in every perception, every judgment, every act. In its positive, it enables and makes possible, and negatively it excludes and marginalizes” (Deetz, 1992, p.252). For Foucault, resistance always counters power. Deetz (1992) further explains, “Power relations are always met with resistance. Resistance is not external to configurations and its presence does not

denote the incompleteness or absence of power but its presence” (p.254). Halberstam (2005) similarly states that resistance is always embedded in power. Resistance may not be overtly demonstrated, but it is always present.

Whereas marginalized patients are often perceived as passive during the medical interaction, they often enact resistance in subtle, individualized ways that may not be readily recognized. Tretheway’s (1997) ethnographic study of low-income women participating in a social services organization illuminates the varied ways that marginalized individuals resist power structures. Tretheway explains that marginalized individuals are often perceived as being in need of the expert knowledge offered by the professional but are rarely passive in the face of this domination (Tretheway, 1997). Instead, Tretheway shows that individuals enact resistance in “complex, subtle ways” (p.284) by, for instance, maneuvering within the organization or structure in a manner that allowed them to manipulate the intended purpose of the organization in order to secure the resources they needed. They also rejected confessional practices, such as therapy, that could subject their verbalized thoughts to domineering experts (e.g., doctors, psychiatrists, managers, social workers) that could ultimately monitor, analyze, and control them (p.288). Thus, within Tretheway’s explication of resistance we can understand that the observed passivity in patients is not necessarily indicative of ignorance or disinterest but of resistance. As marginalized and minority patients are likely accustomed to facing subtle and overt forms of discrimination within systems of domination, it is hardly surprising that they might be reluctant to share personal details that could potentially be judged and used against them.

Acts of resistance could easily be overlooked due to their subtlety. For example, silence can serve as a vehicle through which individuals exercise their agency (Hundley, 2012), as can lack of adherence to prescribed treatment plans (Koenig, 2011; Beisecker, 1990; Cohn et al., 2009). Cohn et al. (2009) illustrates this when constructing the “narrative of resistance” of an African American, low-income, single mother of twin adolescent boys. Over the course of the year, the authors interviewed the mother, Sheila, twice and the physician once and observed the clinical encounter between the two. Sheila was initially thought to be noncompliant because she did not give her son a prescribed regimen of asthma treatment. After further exploration of Sheila’s health beliefs about asthma and the environmental factors that shape Sheila’s social world, the authors reinterpreted her noncompliance as a form of resistance.

Sheila demonstrated resistance during the interaction with the physician through overt ways by shifting power between their roles as she interrupted the physician to forcefully assert her concerns about her son. The authors describe a complex interplay between Sheila and the physician in which the physician focused on education and changed the topic when needed. Sheila retained control of the interaction, changing the topic when needed, emphasizing the needs of her son and using indirect comments to convey her doubt that the physician truly understood these needs: “I think you need a new stethoscope,” Sheila says, perhaps trying to indicate that the physician did not really discern what was happening with her son (p.34). The physician did pick up on this meaning and conceded that it might be time to purchase a new stethoscope. Sheila’s suspicion was perhaps justified when the physician confused her twin sons when discussing vitals.

Eggly and Tzelepis (2001) describe resistant behaviors in their study of relational control in “difficult” clinical interactions in which black patients and their physicians discuss pain management. As in Sheila’s case, the acts of resistance were more overt than silence or lack of adherence. The authors found that over half of the observed interactions were characterized by competition for control. During these difficult conversations, patients fought to assert their preferences for pain control and utilized strategies ranging from providing reasons for their preferences to explicitly rejecting or disagreeing with treatment recommendations provided by their physicians.

Mulcahy, Parry and Glover (2010) discussed the resistance strategies utilized by Canadian cancer patients. Patients who faced long wait times within the health care system actively resisted the “good” and “patient” patient roles (Mulcahy et al.). When faced with long waits, patients chose to actively seek cancer knowledge on their own instead of waiting for the physician. In many cases, patients presented this information to their oncologists when presenting their own dissenting perspectives. The authors explain that the long wait times only serve to further reinforce the traditional asymmetrical balance of power within the relationship, and the patient is therefore expected to assume the role of the compliant patient. As Foucault (1977) posited, acquiring knowledge independently and utilizing it during the encounter allowed patients to resist the traditional power structures. Mulcahy et al. (2010) note that these results clearly reflect a more complex depiction of patient power than what is typically reflected in literature: “The participants in this study were far more active than the role of passive patient traditionally dictates. Findings suggest a more complex reality, wherein the patient resisted the role of the patient patient” (p. 1068).

It should be noted that a patient's enactment of resistance has potential implications for the course of the interaction, including its outcomes. Enacting resistance in ways that challenge the physician's authority may result in the patient being perceived and judged in unfairly negative ways. Cohn et al. (2009) illustrates this in the previously discussed study of a mother used resistance strategies while interacting with her children's physician. When authors interviewed the physician after the encounter, he constructed the patient as "a chaotic person," (p. 34). This view sharply contrasted with the identity that the authors constructed after interviewing the mother at her home several times. The physician did not understand the mother also embraced the physician's agenda of resolving her son's asthma issues, but instead viewed her resistance strategies as a part of a chaotic identity. Physicians' perceptions of patients clearly have potential implications for clinical outcomes.

As the review indicates, negotiations of power between marginalized patients and physicians can be manifested in both subtle and overt ways. The actions (or inaction) of marginalized or minority patients could easily be interpreted by physicians as confirmation of a lack of intelligence, seemingly confirming physicians' beliefs or stereotypes and further contributing to a dominant power structure. But, as Foucault (1977) posits, power is constantly in negotiation, being claimed or ratified with the use of discourse. Health scholars and practitioners must move beyond the assumption that marginalized individuals require coaching in order to move out of passivity and begin inquiry into how they are potentially enacting agency in ways that are not yet acknowledged. Patients may exercise their agency in the clinical interaction by demonstrating behaviors (such as those espoused by patient activation) that foster greater

participation and influence the interaction. In some cases, patients may further enact their agency by resisting the physician through the use of less desirable behaviors, such as challenges or disruptions. These acts of resistance may serve as the vehicle through which patients advocate for themselves. As such, any approach that characterizes the marginalized as passive, “difficult” or “behaving badly” without fully understanding the socio-cultural context fails to acknowledge the covert and overt behaviors utilized by marginalized patients in order to enact their agency within interactions and larger structures.

A Culture-Centered Approach to Understanding Patient Activation

The above discussion illustrates the need to better understand how marginalized patients enact their agency and acts of resistance during clinical interactions. Patient activation interventions have proven to be effective in coaching marginalized patients to demonstrate active behaviors during the clinical interaction. What is missing from this approach, however, is a fundamental understanding of how these patients may already be active. This requires a comprehensive approach undergirded by an awareness of the historical, political, and contextual issues that have shaped the health experiences of marginalized individuals. Such an approach requires a culture-centered theory that attends to the interdependent relationship between culture and health.

Dutta’s (2001) culture-centered theory is ideal for examining the ways in which marginalized patients exert their agency and, at times, resist when navigating within the patient-physician dyad and the larger structure of the healthcare system. The culture-centered approach critiques the dominant approach in health communication, which is represented by the status quo, or the existing ideology that drives contemporary health

interventions intended to influence health behaviors and attitudes (Lupton, 2004). Lupton (1994) explains that these efforts “are typically based on the universal logic of scientific rationality, draw upon individualistic assumptions about the constitution of health risks and hence are ignorant of cultural contexts, and are unresponsive to the sociocultural-economic contexts within which health experiences are located” (p. 57). Within the framework of the culture-centered approach, any interventions intended to eliminate racial and ethnic health disparities must address “social, cultural and environmental factors beyond the biomedical model” (Dutta, 2008, p.561). Clearly, the culture-centered approach is ideal for interrogating patient activation. Before discussing the major tenets of Dutta’s conceptualization of the culture-centered approach to health communication, however, it is important to first examine Airhihenbuwa’s (1995) critique of the dominant discourse in health communication. This critique provided the foundation for Dutta’s approach.

While evaluating the persuasive communication techniques used to address health issues concerning HIV/AIDS, Airhihenbuwa (1995) determined that classical communication theories in the field of health communication failed to take into account the crucial contextual factors that shaped negotiated meanings of health within marginalized communities. Applying communication theories that are built upon Western principles, such as individualism and rational thought, Airhihenbuwa (1995) explains, are not appropriate in global communities that prize collectivism. An example of this is the Health Belief Model. That model, Airhihenbuwa explains, was developed to predict an individual’s response to potential health threats and subsequent utilization of preventative health care services in light of the perceived risks. This approach

presupposes the applicability of individual, linear, and rational perspectives. While this theory might prove to be effective in Western contexts that share these principles, it is not as effective in other global communities in which these concepts would be foreign. Identifying a culturally compatible approach to addressing health issues is imperative, especially when attempting to partner with populations with more collectivist orientations.

Airhihenbuwa (2000) also illustrates the need to problematize the ways in which culture is viewed and understood in dominant health communication approaches. Culture, according to Airhihenbuwa (2000), is:

...often appropriated as an exotic collective, is believed by many to exist only in Africa, Asia, and Latin America and in their descendants in the diaspora. Accordingly...beliefs are used often as a proxy for culture, such that beliefs and knowledge of illness become the focus of “culturally appropriate” messages and interventions. In fact, the term *belief* is often contrasted with knowledge, such that *belief* is used to connote ideas that are erroneous from the perspective of biomedicine and that constitute obstacles to appropriate behaviors (p.11).

Airhihenbuwa further explains that this ideology results in a binary that privileges expert, biomedical “knowledge” and positions cultural “beliefs” as attitudes that must be overcome. Airhihenbuwa provides the following example: “If you learned from your grandmother that chicken soup is good for your common cold it is a ‘cultural belief.’ However, if you were to learn the same health information from a physician, it is ‘knowledge’” (p. 7).

The privileging of biomedical knowledge characterizes much of health communication's theoretical approaches and campaigns, with cultural beliefs commonly considered ignorant and primitive. From this perspective, understanding cultural beliefs are valuable insofar as they allow practitioners to identify an entry point for persuasion and cultural members' subsequent adoption of the dominant biomedical knowledge. Airhihenbuwa (2000) urges us to understand culture as a strength and to "expose, deconstruct and reconstruct" those conceptualizations (p.267).

Dutta (2001) builds upon Airhihenbuwa's foundation by introducing culture, structure, and agency as tent poles for a culture centered theory. Culture, Dutta (2004) explains, is conceptualized as "the dynamic set of values that influences sociopolitical and economic structures and is embodied in a dynamic set of values that influences perceptions, attitudes, and behaviors of community members" (p.16). Structures are defined as channels of communication, community modes of transportation, medical services, health-enhancing services, and media platforms which serve to potentially constrain and limit the health potential of marginalized, underserved populations (p.38). Agency, according to Dutta (2001), "is enacted in its interaction with the structures and embodies communicative actions and processes that challenge, navigate, and attempt to change these structures" (p.38). All three constructs are interrelated, as marginalized individuals' interactions between structure and agency are "mediated through cultural processes and practices" (p. 16).

The interrelated nature of culture, agency, and structure provides insight into the process by which marginalized individuals strategically work to obtain healthcare services. Through the lens of culture, health scholars and practitioners should endeavor

to understand how individuals enact their agency in response to structure and also how structure influences the agency of marginalized individuals. Dutta (2007) explains,

Cultures are intrinsically linked to the social structures that surround them because the way resources are allocated and controlled significantly influences how meanings are created in the context of the life experience of cultural participants. In fact, cultures continually interact with these structures; on one hand, they shape structures and, on the other hand, cultures are shaped by structures (p.321).

This interconnected relationship influences the ways that marginalized individuals enact their agency, as they must contend with the existing social structures when attempting to solve health problems (Dutta, 2001, 2004, 2007).

Dutta and Basu (2008) clearly illustrate the interconnectedness of structure and agency in their ethnographic study of West Bengali men. When the authors asked participants to share their understandings of health during interviews, the participants indicated that they were perfectly aware of the health behaviors that were needed in order to achieve and maintain good health, such as eating fruits and vegetables. Due to constraining structural influences, such as poverty, substandard transportation, and scarce employment, however, the participants constructed health as “the absence of hunger.” The constraining influence of local structures made purchasing fruits and vegetables a luxury. Participants described the need to rely on the services of a pharmacist, who often did not have the medical expertise needed to correctly diagnose maladies and prescribe drugs, when acquiring drugs for a sick family member. Participants were very aware of the fact that the pharmacist was not the ideal choice, but they also explained that visiting

a clinic and physician would be too costly. Legislation intended to increase the accessibility of healthcare had only resulted in bureaucratic barriers and increased red tape, rendering community members unable to afford quality care.

When reviewing their findings, Dutta and Basu (2008) admitted feeling a degree of surprise in finding such a high level of health knowledge among their participants. Contrary to their prior expectations, community members were well aware of what constituted healthy habits. Their choice to pursue alternative means of healthcare or to avoid purchasing expensive produce was highly reflective of the constraining influences of the local economy and its health care system. Faced with these constraints, the participants were left to enact their agency by finding avenues through which they could obtain health services. This example clearly illustrates why interventions built upon assumptions that are shortsighted. In this case, the community members were already well equipped with health knowledge, but the nature of the overarching structure influenced the channels participants consulted when attempting to obtain health care. Failure to make an individual choice does not necessarily reflect passivity or a rejection of the message but rather is a reflection of the complex webbing of structure and agency that many marginalized individuals must work within. Dutta (2007) explains, “Rather than accepting the logic that members of cultures are passive receivers of messages directed at them, the culture-centered approach is committed to the articulation of an agency that is richly complex in its negotiation of structures” (p. 321).

Patient Activation: A Cultural Understanding

The findings of this review highlight the importance of understanding how marginalized individuals enact their agency and potentially resist during the course of

clinical interactions. As the culture-centered approach posits, marginalized individuals' enactment of agency cannot be solely attributed to personalized characteristics and individualized traits. Rather, marginalized individuals enact their agency in ways that are largely formed and shaped by the interconnected webbing of culture and structure that they exist within. As these systems are often less accommodating for the subjugated, marginalized community members operate in strategic ways that allow them to obtain resources that are often inaccessible. As Dutta (2008) notes, marginalized individuals adapt and utilize their agency in response to the inequities found in the larger structure. For instance, individuals consult may consult alternate sources of health care or find ways to circumnavigate health care and social services organizations when attempting to obtain health services. These ways of knowing become instinctive, developed in response to their marginalization.

This pattern can be easily identified in the instances in which marginalized individuals report previous instances of discrimination. Predictably, these previous experiences of discrimination impact the communication behavior of marginalized individuals during the clinical interaction. Hagiwara et al. (2013) found that high levels of perceived racism among black patients was associated with less nonverbal affect among patient and providers and with low patient ratings of provider warmth/respectfulness (p. 5). Additionally, the authors found that black patients with higher levels of perceived discrimination talked *more* during the clinical encounter when compared to other black patients with less negative racial attitudes. The authors suggest that the increased patient talk time was not the result of empowerment but rather an effort to control the interaction in order to prevent discriminatory treatment. The authors

admitted surprise at these findings, especially in light of previous studies that suggest that black patients are more likely to be passive during clinical interactions.

While these results may be surprising when viewed through the lens of contemporary patient-centered literature, they are perfectly supported by the culture-centered approach. In this case, marginalized individuals who reported experiencing discrimination within the larger social structures exhibited the adaptive behavior of talking more – at least, talking more than was expected for a group that has previously been deemed passive in health literature. In this way it is clear that the nature of the social structure has influenced the way that marginalized individuals enact their agency. As the authors posited, the increased talk is an effort to prevent further discrimination – an adaptive response that was acquired in response to previous experiences of discrimination within social structures.

Also supporting the need for a culture-centered approach to patient activation, Hagiwara et al. (2013) suggest future research that more closely examines how the discourse in their study interactions unfolded, reflecting,

Were patients with perceived discrimination talking more because they were telling physicians what they want for their treatment? In order to address these important conceptual questions, future studies should utilize theory-generating qualitative methods, such as content analysis and conversation analysis, to explore aspects of the interactions that exhibit larger or smaller physician-patient talk time ratios (p.130).

The authors clearly articulate the need for a culture-centered approach that explains their unexpected findings. Patient activation could not fully treat this scenario, but the culture-centered approach provides insight into these demonstrations of agency or resistance.

Goals of the Present Study

The previous discussion has demonstrated the need for a theoretical reconsideration of the underpinnings of the patient activation approach. The patient activation framework endeavors to undertake a worthy cause, but it lacks a fundamental understanding of the very communities that it intends to “empower” – and how these communities already use their power. More specifically, the conceptualization of active communication behavior that is espoused as an ideal for marginalized patients must be reexamined within a cultural context. Instead of coaching patients to demonstrate these idealized behaviors, scholars should endeavor to understand how patients, especially marginalized patients, might already be “active” in how they enact their agency. In fact, patients who are often considered “difficult” during the clinical interaction may in fact be enacting resistance in an effort to achieve the maximized outcome during the clinical interaction. Such a culturally grounded understanding would allow health scholars to develop health interventions that better address health disparities and how marginalized individuals cope in the midst of these inequities. Scholars should first gain an understanding of what is present before they attempt to introduce their “expert” knowledge in order to bring about change.

This lack of culturally grounded understanding represents a significant gap in patient activation literature. Dutta’s (2001) culture-centered approach counters several of the theoretical underpinnings of patient activation, especially the assumptions about

passivity. As stated previously, marginalized individuals are not predictably passive (Dutta, 2008) and may use strategies that range from the strategic use of silence to active resistance. This project endeavors to acknowledge the fullest possible range of marginalized individuals' enactments of agency, including behaviors that may be perceived as undesirable or difficult for the physician to manage. In a landscape of research that identifies the "deficient" communication behaviors of marginalized patients, only a minority of studies recast these behaviors as representations of complex power negotiations and adaptive responses to subjugating social structures. Clearly, there is a need for directed growth in this area of literature.

The present study directly addresses these gaps through the implementation of secondary analysis of clinical interactions involving marginalized patients and their physicians. The data set is comprised of the initial data previously collected and analyzed by the Hagiwara et al (2013) research team. The study uses Dutta's (2001) culture-centered approach as a guiding theoretical framework during the interpretation of results. As Hagiwara et al. (2013) suggest, a qualitative method (i.e., qualitative content analysis) is utilized to observe the nature of marginalized patients' enacted agency and resistance. Ultimately, this study proposes an extension of this intervention and related literature to provide a more culturally informed understanding of marginalized individuals and the nature of their enacted agency and resistance.

Dutta (2008) describes an interdependent, interrelated relationship between agency, culture and structure. This project endeavors to better understand how patients who have been forced to contend and navigate within inequitable, discriminatory structures interact with physicians when attempting to secure health care and health

resources. As Dutta explains, the nature of the overarching structure influences how marginalized individuals are able to use their agency when attempting to obtain health resources. How might these marginalized, underserved patients strategically enact their agency in response to the larger structures that further subjugate them? Hagiwara et al. (2013) note that these patients, who scored high in previous discrimination, ultimately were found to have poor adherence. With this knowledge in mind, it is important to first consider what additional structural or contextual issues patients experience, and how these might influence their interaction with the physician and perhaps their ability to adhere to the treatment plan. Thus, the following question is posed:

RQ1: What are the contextual factors that marginalized patients with a history of discrimination describe during the clinical interaction?

In his explication of patient activation, Street et al. (2003) identifies three specific behaviors (i.e., asking questions, expressions concerns and assertive responses). Additional research is needed to move beyond this narrow definition of “activation” and instead fully explore the range of behaviors that encompass patient agency. Thus, this study inductively builds typologies of observed agentive and resistance strategies among marginalized community members. The resulting typologies address a significant gap in patient-provider literature. Towards this end, the second question is as follows:

RQ2: What are the agentive strategies used among marginalized patients with a history of previous discrimination?

This project also aims to develop a typology of resistance strategies. Previous literature has explored client resistance strategies within larger organizations, specifically American social-welfare programs. Fraser’s (1989) typology is helpful when examining

the context of resistance in an organizational context, but does not address more micro forms of resistance within interpersonal interactions. Stivers (2003, 2005) discusses passive and active resistance and Ijas-Kallio et. al (2010) identifies three ways in which patients resist the diagnosis and during the clinical interaction, but neither offers the integration of a cultural perspective. This study seeks to fill this gap by providing a typology of resistance strategies used by marginalized patients with a history of discrimination in a clinical interaction. The observed patients in this study are medically underserved and report having experienced previous discrimination in the past. Are these patients more likely to exhibit resistance strategies during the interaction as a result of their lived experiences and limited access to health resources? This typology endeavored to provide insight by developing a typology of interpersonal resistance strategies that will be interpreted through the lens of the culture-centered approach.

RQ3a: What are the resistance strategies used among marginalized patients with a history of previous discrimination?

Finally, this project sought to understand how physicians responded when patients enacted resistance strategies. Much of patient activation literature confirms that patients who demonstrate agentive, “active” behaviors such as asking questions receive greater information provisioning (Cegala, Street Jr, & Clinch, 2007; Cegala, Chisolm, Nwomeh; Eggly, 2011). That agentive, “active” behaviors result in greater information-provisioning has been well established. Greater exploration, however, is needed in order to understand how physicians respond to behaviors that are not conventionally acceptable during clinical interactions, such as resistance. In many cases, these behaviors are negatively cast as “difficult” and often are not viewed positively. With this in mind, it is

important to understand how resistant strategies unfold and impact the process of decision-making during the clinical interaction. Stivers (2005), while acknowledging that resistance allows patients to fully participate during the interaction, ultimately views resistance negatively, indicating that it unduly pressured physicians and further contributed to the problem of over-prescribed antibiotics. Understanding physician response has even greater importance when considering the observed patient population in this study, marginalized patients with a history of discrimination. When these patients, who perhaps have had to push and strategize for numerous resources in their pasts, use resistance as a tool when negotiating with physicians, do they win? Does the physician persist in his or her own treatment plan? Or do they reach a mutually acceptable treatment plan?

RQ3b: How do physicians respond to the resistance strategies of marginalized individuals with a history of discrimination?

CHAPTER THREE

Methods

This chapter discusses the study design for the project, including the participants, data collection procedures for the original study, and a detailed account of data analysis. Justifications are provided for the chosen methodologies, which support the research questions, theories and topic as explicated in the literature review. In this project, a secondary analysis of previously collected data using qualitative content analysis was conducted in order to examine patient's use of agency and resistance strategies during the clinical encounter. The primary study, which originally produced the data, included both self-report survey data and video-recorded interactions at a primary care clinic to evaluate the efficacy of various interventions on patient-physician interactions. In the present study, the analysis focused on the videos and select measures from the survey to answer the four research questions guiding the investigation.

Qualitative Content Analysis

The term content analysis refers to a flexible and often varied approach to analyzing text data (Hsieh & Shannon, 2005). Bernard and Ryan (2010) refer to content analysis as “a set of methods for systematically coding and analyzing qualitative data” (p.287). More generally, Patton (2002) explains, content analysis refers to the processes of data reduction and sense-making efforts that allow for the parsing of a large volume of information in order to identify “core consistencies and meanings” (p.453). Content analysis is generally applied to the analysis of text, such as interviews, diaries of documents or transcripts (Patton, 2002). In addition to written texts, content analysis has been used to analyze videos and nonverbal behavior (Vrij, Edward, Roberts, & Bull,

2000). It may be utilized in a variety of contexts, such as describing attitudinal and behavioral responses to communication, reflecting cultural patterns in groups, institutions or societies and describing trends in communication (Weber, 1990).

Content analysis has a long history in research. Its roots can be traced back to the eighteenth century in Scandinavia, when the Church sought to monitor the spread of nonreligious content in newspapers (Krippendorff, 2004). In the United States, content analysis was utilized at the beginning of the 20th century (Hsieh & Shannon, 2005) when a surge in newspapers necessitated the development of ethical standards and inquiry that further examined “the phenomenon of the newspaper” (Krippendorff, 2004, p. 5). The second wave of growth for content analysis occurred in the 1930s and 1940s (Krippendorff, 2004) when radio emerged as a powerful new medium in communication, problematizing the appropriateness of research methods that were traditionally applied to newspapers. Later, content analysis proved to be instrumental before and after World War II, when researchers used it as a tool in order to understand the processes by which propaganda influenced audiences.

Content analysis provides a set of methods for the systematic coding and analysis of data. These procedures allow the researcher to make valid inferences from the text (Weber, 2010). The process of content analysis involves the tagging of texts or artifacts with codes. This might involve searching text for recurring words or themes (Patton, 2002), while developing patterns, themes and categories. Codes may be derived by prior information or theory (Bernard & Ryan, 2010) or emerge naturally from the observed text (Hsieh & Shannon, 2005). Content analysis methods may be used to explore manifest or

latent content (Bernard & Ryan, 2010) and may utilize inductive or deductive approaches (Patton, 2002).

Approaches to content analysis vary widely, ranging from impressionistic, intuitive, and interpretive analyses (Hsieh & Shannon, 2005). Weber (1990) explains that there is no right or wrong way to conduct content analysis; rather, the researcher must determine what methods are most appropriate. The type of content analysis chosen should reflect the “theoretical and substantive interests of the researcher” as well as the nature of the problem (Shannon & Hsieh, 2005, p.1277; Weber, 1990).

Content analysis offers both quantitative and qualitative approaches, and these branches are not sharply divided (Schreier, 2012). Krippendorff (2004) asserts that perceiving a dichotomy between quantitative and qualitative approaches is a faulty assumption, and explains that the demarcation should be considered as, “the explicitness and objectivity of scientific data processing on the one side and the appropriateness of the procedures used relative to a chosen context on the other” (p. 87). Indeed, a researcher’s decision to use either a qualitative or quantitative approach is largely reflective of the nature of the research question. Both approaches offer their own distinct advantages, and there are several distinct differences between the qualitative and quantitative approaches to content analysis.

First, Scherier (2012) suggests that the most important significant distinction is the degree to which the text is examined. While qualitative content analysis is concerned with latent meaning, quantitative content analysis focuses on the manifest, literal meaning of material. The quantitative approach to content analysis is well-suited to information that is highly standardized, while qualitative content analysis provides a

flexibility that allows the researcher to adhere to the tenets of the interpretive research tradition by considering various layers of situated meaning.

In addition, qualitative content requires a great deal of context. Schreier (2012) explains that qualitative content analysis is highly contextual, and allows the researcher to take the context into account while reviewing the material.

Third, quantitative analysis demands strict standards for reliability, while qualitative content analysis allows for a variety of approaches to reliability. This does not mean that qualitative content analysis lacks the rigor of a quantitative approach. Rather, the qualitative approach allows for more expansive criteria. Krippendorff (2004) notes that qualitative researchers tend to apply other criteria other than reliability. Denzin and Lincoln (2000) suggest alternative criteria, such as “trustworthiness, credibility, transferability, embodiment, accountability, reflexivity and emancipatory aims” (p. 13).

The flexibility that characterizes content analysis renders it an ideal approach for studies in the field of health communication. Recent years have shown a marked increase in the use of content analysis in health studies. Hsieh and Shannon (2005) reported that the use of content analysis grew from 97 studies in 1991 to 332 studies in 1997 and 6001 in 2002 (p. 1277). As Weber (1990) notes, content analysis allows the research to explore the intentions and characteristics of speakers, cultural differences in communication, and the attitudes and beliefs of an audience. This methodology is perfectly suited for the current project as it allows for the recognition of latent meaning, yielding results that are grounded within a cultural interpretation of the data, as expressed by participants. This project requires a largely interpretive process in order to identify the wide range of often subtle communication behaviors that point to larger phenomena,

such as agency and resistance. As such, content analysis is the ideal approach for health studies that seek insight in a wide range of topics, especially in clinical communication. In summary, the choice to use qualitative content analysis is driven by a number of factors, including its flexibility and ability to identify latent meaning. More specifically, qualitative content analysis is most appropriate when used during the course of a highly interpretive and intuitive process of analysis.

Given these factors, it is readily apparent that qualitative content analysis is the ideal methodology for this proposed study. First, the overarching goal of the study is to understand how marginalized individuals participate during the clinical interaction. Findings from this study are subsequently used to develop typologies for patients' enactments of agency and resistance. As little research has examined these phenomena using the approach undertaken by this project, the inductive data-driven coding frame that qualitative content analysis offers is optimal and further bolsters the study's ability to unearth previously misunderstood phenomena in data.

Indeed, qualitative content analysis supported the cyclical process of coding and analysis, whereby the codebook and coding frame constantly evolved. The new dimensions of meaning that emerged through the text allowed us to observe and properly classify the agency and resistance strategies that emerged from the data.

Second, the study is contextually bound within the broader area of health communication. Qualitative content analysis has proven to be an ideal method within the field of health communication, having been utilized in many different health-related and clinical contexts. Shuyler and Knight (2003) used qualitative content analysis to determine the information-seeking needs of patients on an orthopedic website. Similarly,

Cline, Rosenberg, Kovner and Brewer (2011) utilized qualitative content analysis in their exploration of registered nurses' perceptions of nursing care in hospitals. Additionally, Elwer, Alex and Hammarstrom (2010) applied qualitative content analysis to their study of the health experiences of employees providing elder. These studies clearly demonstrate that qualitative content analysis is an appropriate and ideal methodology for studies that are exploring communication dynamics within the contexts of clinical and interpersonal contexts.

Furthermore, the research questions are specifically focused on an even more narrow context – that of clinical communication between marginalized patients with a history of discrimination and their physician. This study uses a culture-centered approach as explicated by Dutta (2008) in order to understand the inter-related relationships of culture, agency and structure. Marginalized, medically underserved patients often must contend with a host of barriers and obstacles when attempting to obtain health resources. In response to these impedances, patients often act strategically as they attempt to navigate within the larger inequitable and often discriminatory overarching structures. Reciprocally, larger structures also potentially influence and shape the nature and degree to which patients enact their agency. Ultimately, culture serves as the foundation and common thread that undergirds these processes. Marginalized patients' values and beliefs not only shape their identity, but they also influence the ways in which patients interact with the world around them.

Using the framework of the culture-centered approach, one better understands the inextricably intertwined relationships of culture, agency and structure. Further, developing this understanding of culture potentially enables health scholars and

practitioners to understand that issues of health equity cannot be solved by simply addressing or changing individual behavior but rather starts with the recognition of the complex confluence of factors that impact patients and the ways in which they manage their health. The present investigation seeks to integrate this rich, multi-layered understanding to the analysis of the observed clinical interactions, and as such, it is imperative to use a research method that would allow for the recognition of often subtly expressed cultural understandings. As we are unable to personally interview the patients to directly inquire about their motivations and intentions when interacting with the doctor, correctly identifying and interpreting contextual clues is of the utmost importance. Attending to the surrounding context of these interactions provides insight into the lives of participants, and how their experiences ultimately affected their illness experiences and subsequent presentation of those issues to their physician.

In review, qualitative content analysis shares the goal of understanding personal or social meaning, and is typically applied to research questions that delve into these matters (Schreier, 2012). It is impossible to regard this text outside of the larger context in which it is embedded, a complex tapestry of distrust, discrimination and biases. Understanding the contextual cues requires not only an understanding of the manifest content of the text, but also of the latent, more subtle meaning that carried the weight of the surrounding context.

Data Collection

To answer the research questions, a secondary analysis of previously collected data was conducted. The principal investigator of the primary study, Dr. Louis Penner, received funding from the National Institute of Health (grant # 5R21 HD050) and the

SEMPAC (grant #U54 CA153606). Dr. Penner partnered with faculty in Family Medicine at Wayne State University's School of Medicine to gain access to the clinic and collect data from consented patient and physicians. The primary care clinic was located in a low-income neighborhood and allowed income-sensitive payments. In accordance with the study's aims to better understand various dynamics of the patient-physician interactions, the research team collected audio/video and survey data.

Primary Study Recruitment. During the primary study, participants were recruited prior to a clinical visit. A staff physician at the clinic worked closely with the research team to coordinate recruitment for the study. Prior to the physician's arrival, the research assistant met with patients in the examining room to share the details of the study. After receiving consent from the patients, the research assistant returned to the examination room and positioned two rolling cameras in unobtrusive locations in the corners of the room. Camera recordings captured the patient's visit from the time they entered the room until the time the patient left the room. At the close of the interaction with the physician, the research assistant returned to the examining room to administer the post-survey to collect attitudinal data. Each participant received a \$20 gift card. The research assistant also administered a post-survey for the physician. Data collection occurred over an eighteen-month period.

Consistent with the research design for the primary study, patient/physician dyads were randomized into control (general health information) and treatment (common in-group identity) groups. Participants (and their physicians) in the treatment group received an intervention designed to reduce intergroup bias. More specifically, the intervention sought to create common identity between the physician and patient.

Physicians who were assigned to the treatment condition were informed that their patients would be encouraged to “act as a team during the appointment with you” (p.3). The physicians were provided with examples of how to foster a sense of being on a team as well as a button that explained that they were participating in a team (identified by using a particular color). Patients that were randomized into the treatment condition received written instructions that introduced the concept of working in concert with the physician as a team. In addition, patients were asked to sign a contract stating their intent to work with the physician as a team, and they received a button that corresponded with the button worn by their physician. Patient-physician dyads that were randomized into the control condition did not receive the intervention; they did not receive buttons, pens or instructions/suggestions regarding teamwork with the physicians. At the close of recruitment, the video recordings of the patient-physician interactions were later transcribed.

Primary Study Participants. The participants of the primary study were patients who visited the clinic, as well as the residents who treated them. The primary study successfully recruited 112 low-income, self-identified black patients with an average age of 42.83 (sd =2.45). The racial composition of the participants closely matched the demographics of the surrounding neighborhood.

Present Study Participants. The present investigation seeks to observe the behaviors of the patients who reported significant previous discrimination. As such, I identified and selected patients that indicated a high degree of perceived discrimination. The perceived discrimination variable was measured using Brown’s (2001) scale of previous ethnic and racial discrimination. This instrument asks patients if they have

experienced discrimination across seven domains: jobs, medical treatments, job applications, police encounters, housing and dealing with neighbors (Hagiwara et al., 2013). Due to the high internal consistency of the scale (researchers found that the odd-even reliability with Spearman-Brown correction = .74), the researchers computed the sum of the yes/no responses across the seven domains (“yes (1)/no(0)”. Higher numbers, therefore, indicate a higher amount of perceived previous discrimination. During the primary study, 56.6% of the patients indicated that they had experienced discrimination in at least one domain.

In order to identify the “high previous perceived discrimination” patients, participants who scored above the mean number of incidents ($m = 2.43$, $sd = 11.03$) were classified in the “high discrimination” group. A total of 38 participants had a score of 3 or higher. Of those 38 participants, data was missing or thrown out during the primary study for 4 patients. There were no videotape recordings for 8 patients. In addition, one video recording was excluded from the data set because the patient had difficulty communicating with the physician due to experienced medical issues. The resulting 25 video recorded interactions were analyzed for the present investigation.

In order to assess an adequate number of patients who measured high in perceived previous discrimination, this study utilized data collected in both the first and second phases of the study. The participants in the first (control) phase of data collection consisted of 8 self-identified black patients with a mean age of 44.88 ($sd = 11.95$). Fifty percent of the participants in the first phase were male and fifty percent were female. Seventy-five percent of the participants in phase one made less than \$20,000 and 62.5% earned less than a high school diploma. Participants in the second phase of data

collection (intervention) consisted of 17 self-identified black patients with a mean age of 39.47 ($sd = 10.48$). Twenty-three and a half percent of the participants in the first phase were male and 76.5% of the participants were female. Fifty-two percent of the participants in phase one earned less than \$20,000 and 17.6% earned less than a high school degree. The resident participants consisted of fourteen non-black primary care physicians (6 from Indian/Pakistan, 6 from other parts of Asia and 2 whites) (Hagiwara et al., 2013).

This sampling of participants largely reflects the demographic composition of the larger parent study. All participants self-identify as black, as did 98.5% of the parent study. Also consistent with the larger study, participants were mostly comprised of women and earned less than \$30,000. This demographic make up of undereducated, low-income participants speaks directly to Dutta's (2008) conceptualization of structure, as participants' status demonstrates marginalization that potentially impedes their access to quality care.

During the second phase of the parent study, the researchers applied the intervention described above and also added a trust measure to the survey instrument. Given patients from both the control and experiment conditions were observed in the present study, there could be concern that patients in the two conditions may enact their agency and resistance differently. It should be noted, however, that Penner et. al (2013), found that the intervention related to past perceived history of discrimination. Instead, patient trust was the only significant finding from the treatment intervention, but not for patients that reported a higher history of previous perceived discrimination. Results showed that patient trust was significantly and negatively correlated with past

discrimination and that the curious higher talk times that Hagiwara et al. (2013) noted were reflected among patients with higher perceived past discrimination as opposed to lower perceived past discrimination. These findings seem to confirm that the experiment did not impact the variable of interest for the present study, perceived past discrimination. As such, I decided to analyze the transcripts from patients in both conditions.

Data Analysis

The texts for this study consist of 25 de-identified transcribed interactions of patient-physician encounters and the accompanying 25 video recordings of patient-physician interactions. After randomly checking several transcripts for accuracy, I concluded that the transcripts accurately represented the discourse featured in the videos. All transcripts clearly indicated changes in speaking turns between the physician and patient. The transcripts do not describe nonverbal communication, but they do identify noises such as sighs, coughing, etc. Transcription lengths reflect the highly varied lengths of interactions, with some transcriptions as short as six pages and other transcriptions as long as 26 pages for a total of 370 pages of double-spaced data in the present study.

In addition to the transcripts, video recordings of the patient-physician interactions were also utilized during the analysis in order to contextualize nonverbal communication. The recordings are secured on a protected server at the Karmanos Cancer Institute (KCI). These video recordings were accessed at KCI and coded in concert with coding software.

The study utilized qualitative data software. I entered all consensus-gained coding into the qualitative software program. Atlas.ti is an ideal qualitative software

package, as it accommodates an open coding frame and provides mechanisms for the development of flexible codes, categories and themes. Additional features such as conceptual mapping, advanced search options and statistical output perfectly complement the goals of this study.

Unit of Analysis

The unit of analysis for this project was the patient's utterance. For the purposes of this project, the utterance was defined as topic bound and determined by the patient's speaking turn. The utterance was the ideal unit of analysis for this study, as it is one of the most common units of analysis used in discourse studies (Van Dijk, 1972) and it is consistent with the unit of analysis used in several significant patient activation studies (e.g., Cegala & Post, 2009; Cegala, Street, & Clinch, 2007; Cegala, Chisolm, & Nwomeh, 2012). Maintaining uniformity within the measurement unit is beneficial, given that this project endeavors to compare and extend the patient activation framework. The length of the observed utterances ranged from a phrase (especially in instances in which the patient was interrupted or interrupted the physician), a sentence, or several sentences. In accordance with the project's design, not all utterances were codeable; only utterances that met the established criteria were coded, for a total of 525 utterances. Of these 525 utterances, 458 utterances were coded as expressions of agency, 34 utterances were coded as expressions of resistance and 33 utterances were coded for context.

Main Analysis

This project used qualitative content analysis to analyze the chosen texts. As this project sought to understand how forms of agency and resistance might manifest in this unique context, an inductive approach was used.

Data Preparation. Preparation for analysis began with the preparation of the SPSS file that contained survey data, including demographic and attitudinal data for patient and physician study participants. As this study seeks to understand how marginalized patients with varying degrees of previous discrimination enact resistance, the file was sorted according to the results of Brown's (1951) discrimination scale, as previously discussed. After identifying the appropriate patient cases, patient data was unitized into utterances in preparation for the coding process.

Coding. The coding process for this project is adapted from the constant-comparison process found in grounded theory (Strauss & Corbin, 1998; Glaser & Strauss, 1967). Grounded theory itself is an ideal tool for inductively generating categories and subcategories, which lends itself well to the goals of qualitative content analysis. The constant comparison process that grounded theory builds upon is an ideal tool for the analysis of this text and allowed the researcher to develop categories were driven by the text, interpreted within the specific context of the text, with the flexibility needed to capture significant distinctions and nuances.

Prior to the start of coding, I sought and recruited a coder that also self-identified as black. Due to the highly contextualized and interpretive nature of this study, it was ideal to have a researcher and coder who were racially concordant with the observed population. In this way, we were able to serve as cultural informants who were more

sensitized to subtle meanings and behaviors that nonblack researchers might not have detected. As Dovidio et al. (2006) and explain, “Whites and Blacks are more accurate in decoding the nonverbal behavior of members of their own race than they are of other races” (p.484). During the coding process, we found that our cultural backgrounds enabled us to identify verbal and nonverbal behavior that was rife with multi-layered meaning. This in-group understanding and familiarity with the patients’ communication enabled us to more effectively mine latent meaning.

Research Question 1. As we reviewed the data, we identified any instances in which patients shared contextual and psychosocial information while interacting with the physician. After coding all patient interactions, we re-examined previously identified instances of patient provided context and applied thematic analysis processes to identify the emergent themes.

Research Questions 2 and 3a, Phase One. In preparation of the start of coding, we closely reviewed the codebook and devised a plan to become sensitized to the key coding elements, specifically, agency and resistance. As agency is a broad terms that potentially encompasses a vast number of observed behaviors, the researcher and coder met to discuss how agency would be defined and subsequently recognized during the clinical interactions. To accomplish this, we reviewed previous definitions of agency in patient-provider and critical literature. Next, we applied their shared understanding during a period of pilot coding which used video recorded interactions (and the accompanying transcripts) from a different Karmanos data set that also featured patient-physician interactions. Using the guidelines that they had previously discussed, we coded for agency in two video recorded clinical interactions. After coding the interactions

separately, we met to compare the identified utterances and the codes assigned to them. During the course of this discussion, we engaged in spirited debate as we sorted any discrepancies in meaning for the assigned codes (Cline, Rosenberg, Kovner, & Brewer, 2011) and ultimately settled on an initial coding tree that captured agreed upon codes. This iterative process continued, as we were constantly questioning, scrutinizing and amending existing and newly created codes until a process of consensus was reached. We then repeated this process and coded a third video/transcript text, after which we found that we were of one accord regarding the criteria for patient agency. Patient agency, therefore, was defined as a meaningful act (verbal or nonverbal) that serves to influence the interaction by communicating/conveying the patient's will, desire, opinion, feelings or perceptions.

Next, we repeated this process in order to gain a shared understanding of what agentive acts functioned as resistance. We decided to use Stivers' (2005) definition of passive resistance (i.e., withholding approval of the physician's plan) and active resistance (i.e., "a sequence of action regarding the treatment such as a challenge, queries about the effectiveness of appropriateness of the medication or about alternative treatments") as a guiding influence as we reviewed texts. During the second round of pilot coding, we worked to identify whether or not any enactments of agency identified in the previously reviewed transcripts functioned as resistance. To accomplish this, we repeated the process described above, constantly comparing and communicating about what resistance "looked like" according to the guidelines presented by Stivers. Ultimately, we decided to use Stivers' definition for resistance, with the understanding that definition would likely evolve in concert with the inductive process to include other

related phenomena that we observed. Resistance, therefore, was defined as “behavior that didn’t align with the patient’s treatment plan...that challenged or queried the effectiveness of medication or alternative treatments” (p. 980).

After establishing operationalized definitions for agency and resistance, we once again turned to the previously reviewed transcripts to test the process of inductively coding nonverbal communication. This was done to provide further contextualization of the verbal utterances. After coding two transcripts and noting the pattern of nonverbal behavior, we discussed and decided upon a coding rule that would detail nonverbal communication only when patient agency or patient resistance was occurring.

As Knapp, Hall and Morgan (1972) explain, it is impossible to separate verbal and nonverbal communication into different, distinct channels. As such, we were careful to examine the nonverbal and verbal communication as parallel texts that ran together simultaneously. We identified “significant” nonverbal communication by identifying meaningful changes in nonverbal communication that coincided with the enactment of agency and resistance. For example, if a patient held the same posture for prolonged amounts of time during the interaction, and subsequently, maintained it during an enactment of patient agency or resistance, this nonverbal behavior was not considered meaningful and therefore was not coded. If, however, a patient changed his or her posture and/or expression from his or her previous repose while demonstrating patient agency or resistance, this behavior was considered meaningful and therefore coded. Using an inductive approach, we coded a range of behaviors ranging from silence, facial expression, posture, vocal tone, body orientation and movement.

We utilized this process of consensus gaining throughout the course of the entire project. During the first phase of the investigation, we used a consensus gaining approach to develop, refine and settle upon the operationalized definitions of the key concepts and other coding rules. During the second phase of the coding, where we applied our decided upon coding system, we used this process to constantly question the appropriateness and “fit” of the coding scheme, and adjusted and tailored our coding hierarchy as the data required.

This approach was ideal for this project, given the inductive nature of the study. As opposed to quantitative approaches, which calculate the statistical degree to which coders agree, the consensus-gaining process accommodates that recursive, iterative nature of the constant comparison process. During the coding process, we constantly compared data to determine if existing coding and categories were applicable, or if new codes were necessary. This process required a great deal of ongoing, frequent interaction between the coders in order to appropriately tailor the coding process. Judging validity using consensus gaining was the most appropriate method for ensuring consistency and agreement. Several health related studies that used qualitative content analysis as a methodology have utilized this consensus gaining as a means of achieving validity (Cline et al., 2011; Elwer, Alex, & Hammarstrom, 2010; Harris et al., 2015; Spencer, Wambach, & Domain, 2014).

Research Questions 2 and 3a, Phase Two. Prior to the start of analysis we familiarized ourselves with the observed texts by performing an initial walk-through of each transcribed interaction, with the goal of understanding, “What is happening here? How is it happening? Who is involved?” (Schreier, 2012; Strauss & Corbin, 1998. Both

coders reviewed each transcript closely before watching the related video recorded interaction in order to get an initial feel for “what was happening” over the course of the interaction.

Next, we began coding with the comparison of incidents. Coders watched the entire patient-physician interaction, beginning with the physician’s entrance and ending with the physician’s departure. Both coders began the open coding process by identifying patient utterances that met the criteria for agency – and if so, how it functioned - and applied descriptive codes. For each identified patient utterance, the coders further determined if the instance functioned as an act of resistance – and if so, how? - and subsequently coded any significant nonverbal communication. This process continued, with the coders constantly comparing new instances to instances that had previously been coded. When necessary, new codes were added and previously identified phenomena were added to existing codes. As this iterative process continued, we adhered to Strauss and Glaser’s (1967) rule for coding through constant comparison: “While coding an incident for a category, compare it with the previous incidents in the same and different groups coded in the same category” (p. 106). Glaser and Strauss (1967) note that the actual process of coding can be done as simply as scribbling on the margins, or more elaborately with notecards. In this case, we wrote our codes on the margins of the printed transcripts. During this phase of analysis, researchers are also encouraged to create memos, a practice which is helpful when collecting initial impressions and observations (Charmaz, 2006). While coding the clinical interactions using the constant comparison process, we created memos that reflected any influences or external contexts that influenced the interaction, or more specifically, influenced the way

that the patient relayed communication and the physician in turn responded. These memos were added at specific inflection points in the text, and were also added to note the overall course of the interaction. We then reviewed each transcript/video independently and then met to review the contents of their coding. Any disagreements were settled through vigorous, spirited debate until consensus was met.

The next phase of coding involved the integration of categories and their properties (Glaser, 1967). This phase occurred concurrently with the constant comparison process. During this stage of coding, we worked together to constantly refine existing categories, taking care to identify instances in which similar or related properties could be integrated or collapsed in order to represent an integrated whole (Glaser, 1967). After meeting to reach consensus for each transcript, I updated the codebook and each continued coding according to the contents of the updated text. We analyzed all 25 transcripts. Once the inductive content analysis was completed, I entered all of the manual coding into Atlas.ti, a qualitative data software program. During this process, I used the automated coding features of Atlas.ti to identify all of the coding identified in the printed pages. After entering all of the coding, I used the program's sorting and compilation functions in order to gain a comprehensive understanding and theoretical rendering of the processes depicted in the data.

Using the output results from Atlas.ti, we then examined the established categories with their associated quotations for shared underlying meanings. Consistent with thematic analysis techniques, we used an inductive process of analysis to move from the meaning expressed in our previously coded categories to representative themes. After closely examining each category, we worked to determine how many categories were

similar. The resulting themes represent the strands of shared meaning that occurred throughout the domain of our categories (Montgomery & Duck, 1991).

Thematic analysis perfectly suited our analysis process and the presentation of our data, as its complexity accommodates interpretations based on a holistic analysis (Montgomery & Duck, 1991). Our categories, and the resulting themes, seek to describe and explain highly contextual and nuanced meaning reflected from patients during their interactions with physicians. Thematic analysis allowed for the richness and depth of description needed to fully convey our findings. Sandelowski and Leemon (2012) urge researchers to present the findings of their qualitative study with thematic statements, which would ultimately be translated into “the language of intervention and implementation” (p.1404). In addition, thematic analysis has proven to be a useful tool for several health-related studies using qualitative content analysis (Amorim, Ramos, Brito, & Gazzinelli, 2014; Reutter et al., 2009). Perhaps most notably, Reutter et al.’s (2009) use of thematic content analysis to report on low-income people’s perceptions and responses to “poverty stigma” illustrates the utility of thematic analysis when reporting results. The authors’ descriptions of their participants’ personal and social strategies were deeply rooted within a cultural understanding of the participants’ understanding and the context provided in their responses. Likewise, this study provides a culturally informed accounting of the strategies that marginalized, underserved patients utilize while interacting with their physicians.

Research Question 3b. After identifying themes, we then revisited instances in which patient resistance was enacted in order to identify the larger “sequence of resistance” (Stivers, 2005). Because these patterns of resistance often were interrupted

by landmarks in the clinical interaction (i.e., talk was distracted by the clinical examination, the resident left the room to consult with the attending physician), interactions characterized by resistance were not always introduced and resolved in a linear fashion. As such, it was most appropriate to define a “sequence of resistance” as a unit of analysis that started with the first topic-related enactment of resistance and ended with the physician’s pronouncement of the treatment plan or other related decision going forward. Often, these sequences featured other discourse and activity that were unrelated, but they adequately captured the conversational movement from the initial discussion to the resolution of resistance.

Using an inductive process, we reviewed each identified sequence of resistance subsequently reached consensus in order to classify and describe the outcome of patient resistance. Ultimately, we found that outcomes fell within three categories: 1) the patient and physician reached a mutually acceptable decision regarding treatment, 2) the physician conceded to the patient’s resistance or 3) the physician persisted with his or her own recommendation. Using the analysis tools in Atlas.ti, I subsequently identified the nonverbal and verbal communication that frequently co-occurred with patient resistance.

While there is another coding system that measures and observes the degree and direction of enacted power within interactional relationships (Rogers & Ferace, 1975) it was not the most appropriate tool for interpreting and understanding the nature of physician response for this investigation. Sequences of patient resistance were often long and unwieldy, and sometimes lacked the order and predictability that would have suited the relational control coding system. In some instances, the patient’s sequences of resistance featured an intermingling of issues that required consensus gaining from the

coder to in order to classify the physician response, given the numerous issues presented at one time. The nature of this data, as well as the unique context that is situated within, clearly required a descriptive, inductive approach such as that utilized during the previous stages of coding. As such, we reviewed the previously identified sequences of resistance and described how the physician's ultimate decision, as well as the topic that prompted the conflict. In addition, Folgers and Poole (1982) have raised questions about the validity of Rogers and Ferace's coding scheme, identifying issues with the need for empirical validation of the control code assignments ("dominance, submission, neutrality") and the coder's inability to truly discern the intent of the message and verify this interpreted meaning with the native audience.

Validity. Denzin and Lincoln (2000) assert that qualitative content analysis allows for more expansive criteria of reliability, such as trustworthiness, transferability, reflexivity and accountability. We met these requirements in several different ways. Long and Johnson (2000) posit that the terms validity and reliability have "the same essential meaning," explaining that the nature of qualitative data often requires a different demonstration of reliability. Therefore, we endeavored to meet the requirements set forth by Denzin and Lincoln (2000).

Building upon previous research concerning trustworthiness (Guba, 1981; Guba & Lincoln, 1981), Graneheim and Lundman (2004) describe transferability and credibility as key requirements in demonstrating trustworthiness. According to Graneheim and Lundman (2004), credibility "deals with the focus of the research and refers to confidence in how well data and processes of analysis address the intended focus" (p.109). Our analysis process met this requirement in several ways. First, the

project's participants perfectly suited the aims of the project, which was to better understand how marginalized individuals participated during the medical visit. The observed individuals provided a range of gender, age and various perspectives that provided a richness to the data (Graneheim & Lundman, 2004).

Next, the project addressed another critical issue for achieving credibility by selecting the most suitable meaning unit. As Graneheim and Lundman explain, meaning units that are too broad (such as paragraphs) or too short (such as a single word), may result in unwieldy or fragmented data. The selection of the utterance was ideal, as it allowed provided specificity in terms of the discussed topic, but also allowed flexibility in length, such as in cases where patient's had more lengthy explanations and/or interjections. The ideal size of these meaning units allowed researchers to easily find unitized data in its context during later phases of analysis, and easily lends itself as an ideal, accessible unit of data when reviewing the results.

Third, the project enforced the requirement of agreement between researchers when determining the degree to which categories and themes covered data. The coder and I worked closely together to ensure that, in all cases, consensus was met during all phases of the analysis. In this way, the results are not merely the result of my own interpretation, but have been confirmed and enhanced by the contributions of the coder. Graneheim and Lundman (2004) "defend" the value of dialogue among co-researchers, explaining that this process aids in confirmability, or the degree to which various other researchers would agree with the way that the data is labeled and sorted (p.110).

Next, this project has transferability to other settings or groups. Graneheim and Lundman (2004) explain that transferability can be facilitated through clear description of

“culture, context, selection and characteristics of participants, data collection and process of analysis....a rich and vigorous presentation of the findings together with appropriate quotations will also enhance transferability” (p. 110). This project has provided a detailed, transparent account of the participants for both the primary and secondary study, as well as detailed accounting of the data collection and analysis processes. In addition, the clear explication of this project’s emphasis on understanding the communication of marginalized, underserved community members during medical interactions allows other researchers to easily apply the tenets of this study to another population of marginalized, underserved community members that are geographically, racially or ethnically different.

Finally, this project demonstrated validity as we honored the process of reflexivity during the phases of data analysis. As this project endeavored to interpret and understand data within a cultural framework, we were particularly attuned to contextual and cultural information provided by the participants. While we understood that our standpoints, which include our identities as black women, might aid us in identifying meaning and behaviors that might otherwise be missed by nonblack researchers, we were careful to examine the other aspects of our selves that might unconsciously influence our interpretation of data. Porter (2003) describes reflexivity as the process by which researchers make explicit and take into account their own beliefs and values, in the same manner in which they would observe those of their participants, in an effort to understand them. During the analysis, our identities as black women proved to be helpful in identifying in-group behavior, but we understood that we could not selectively eliminate the effects of layered understanding that this identity potentially introduced to the analysis process. In light of this knowledge, we engaged in constant dialogue about our

perceptions and understandings of observed phenomena, and how our own lived experiences and understanding potentially contributed to them.

Our study did not apply the standards of reliability that are typically attributed to quantitative data, but those standards were not necessarily the best suited given the highly interpretive nature of our data analysis. Our commitment to demonstrating validity ensured the rigor for this research and has produced in our method and resulting results and conclusions.

CHAPTER FOUR

Results and Discussion

This chapter provides an overview of the findings that resulted from the analysis, as well as a discussion of these findings and their implications. We conducted a qualitative content analysis of written and video texts of clinical interactions with patients with a history of previous discrimination, examining the contextual issues that patients described, verbal and nonverbal enactments of agency and resistance, and physicians' responses to enactments of patient resistance. The results and subsequent discussion of this analysis will be presented thematically, according to each research question.

RQ1: What are the contextual factors that marginalized patients with a history of discrimination describe during the clinical interaction?

Participants' discussions with their physicians often featured descriptions or explanations of circumstances that affected their health and their ability to manage their health. During their interactions with physicians, participants' history-giving, explanations of symptoms and concerns were inextricably intertwined with their disclosures of hardship. Participants described difficulty coping with inadequate insurance coverage and financial hardships including lack of housing, unemployment and underemployment. Though these factors were external to the clinical interaction, they often influenced the communication within the interaction as the participants and the physicians grappled with ways to preserve patients' health in the midst of often devastating circumstances.

Inadequate Insurance Coverage. Inadequate insurance coverage was a consistent source of distress for many patients, especially those insured through Great

Lakes, a Medicaid plan. Participants with this plan often described difficulties obtaining their medication, receiving referrals and finding providers for certain specialties. Acknowledging this insufficiency, a physician commented to a patient prior to providing a referral: *Your insurance very tough, okay, so they will tell you oh this doctor goes in the area.*

In the excerpt below, a participant explains how his insurance does not cover his seizure medication:

Patient: Yes, uh uh I've got to change from the Great Lake insurance.

Doctor: Yes.

Patient: I'm trying to change from the Great Lake Insurance to this insurance because =

Doctor: Yes.

Patient: Do you accept that insurance?

Doctor: You have to ask, you have to ask on the front desk. =

Patient: Uh

Doctor: You have to check with them.

Patient: Okay, because the Great Lake is not paying for my medication. And I need uh uh dental and I need vision and it doesn't cover it, xxxx xxxx xxxx =

Doctor: Okay, but are they covering your seizure medication?

Patient: Uh uh uh they didn't cover the original; they covered the Dilantin.

Doctor: Okay.

Patient: But I can't take Dilantin.

Doctor: Why?

Patient: It makes me sick.

Doctor: Uh uh you took Dilantin for 16 years, right?

Patient: No, I took the original Dilantin, not the generic.

Doctor: Yes.

Patient: See, uh I can take the original but I can't take the generic.

Doctor: I wrote you Dilantin, right?

Patient: Yes, you gave me that.

Doctor: But they're not giving you the Dilantin, the original one?

Patient: They're not, the insurer won't pay for the original one. The insurer will only pay for the uh uh generic.

Doctor: Yes. And that you can't =

Patient: I can't uh uh take that. That makes me =

Doctor: So are you on any medication at this time?

Patient: I'm taking uh, I'm still taking the uh uh uh, I bought some, I bought some, uh some uh Dilantin. The original Dilantin?

Doctor: Yes.

Patient: I bought it myself. Uh uh I bought some.

Doctor: You bought yourself.

Patient: Yes, I bought it myself. (Case #132)

As the interaction continues, it becomes increasingly clear that the patient's practice of buying the medication himself has become untenable. He is only able to afford a certain number of pills (less than the recommended dose), and that purchase is only made possible with the financial support of his siblings. Meanwhile, he has consulted the physician to address his steadily worsening symptoms. It is clear to see that this contextual factor has a clear effect on his health, and must be addressed.

Financial Hardships. Participants also discussed financial hardships experienced as a result of inadequate housing, unemployment and underemployment. For example, one participant, who visited the physician to address the issues of uncontrolled diabetes and high blood pressure, described the stress of homelessness:

Doctor: Okay, just hold on. Your blood pressure is very high, don't know why. Your blood pressure is supposed to be =

Patient: Because I know because I'm stressing.

Doctor: What makes you stress out? Why don't you go to all your physician and =

Patient: Because it's hard for me to get here, like I said. The way the transportation is setup, like I said, I'm homeless so I go from house to house. And the address that I'm using, that's the only address I can be picked up at. And right now that house is flooded and stuff. So I =

Doctor: Flooded with what?

Patient: Pipes busted, so the whole house is flooded. (*Sigh*) So the only address I'm using is the xxxx. And they won't pick me up anywhere. They said that's the only place they can pick me up at.

Doctor: And initially you were staying with a sister, right? Now you don't stay with your sister?

Patient: I stay with my other sister now. But I still use the xxxx address and stuff. That's here I get all my mail and stuff. And right now I'm trying to find a place near my son and them, so. (Case # 172)

This patient's narrative is telling, especially in light of the fact that she is unable to manage her blood sugar and blood pressure, both of which are dangerously high. While provisions have apparently been made for transportation to see a physician, the participant no longer has shelter at the approved address. Lack of a stable environment often impeded regular monitoring of her blood sugar with a glucometer. The physician,

sensitive to the participant's dilemma and seemingly alarmed by the patient's high blood pressure, briefly leaves the examining room to investigate any other resources that prove helpful for the participant. Ultimately, however, he is only able to offer the short-term solution of "something to eat."

In another example, a participant requests a prescription for a walking aide, explaining that a particular model is more financially accessible for her:

For the wheelchair. They had a wheelchair that you can it's not a wheelchair, it's a walker, but you can sit down on it, and go like they, you know, I can't afford it. And maybe I can afford that one, it's like \$99. (Case # 170)

In the following example, a participant describes the stress he experienced as a result of his recent divorce and inconsistent employment:

Doctor: Do you work right now?

Patient: Yeah, they have me laid off this week.

Doctor: This week?

Patient: Right, I have been laid off, off and on from where I work for a week and they'll lay me off for a week. I work two weeks = (*gesturing*)

Doctor: Okay.

Patient: = laid off a week, you know. (Case #156)

The participant goes on to explain that his sharp decrease in income, coupled with his customary bills, makes it difficult for him to buy food. Food, he explains to the physician, is a luxury: "Something has to give, so the luxury of food in the house is not an option" (Case #156).

Discussion of Contextual Factors. The contextual factors that these patients discuss perfectly illustrate Mishler's (1984) description of the voice of the lifeworld:

“The voice of the lifeworld refers to the patient’s contextually grounded experiences of events and problems in her life. These are reports and descriptions of the world of everyday life expressed from the perspective of a ‘natural attitude’” (p.104). In the previous excerpts, it becomes readily apparent that both the voice of the lifeworld influences communication within the interaction. Understanding the contextual factors that foreground patients’ health experiences better equips physicians to provide care. Barry et al.’s (2001) study of communication behaviors in general practice cases confirms this, as results showed that when patient and physician engaged in the lifeworld, more of the agenda was voiced and physicians were more apt to recognize the physical and psychological issue that patients presented. Conversely, the poorest health outcomes occurred when patients used the voice of the lifeworld but were subsequently blocked or ignored by their physician. The authors assert that these findings serve to further support the notion that increased use of the lifeworld promotes better outcomes and more humane treatments of patients.

In our study, physicians were open to learning about participants’ lifeworlds, often asking probing questions in order to better ascertain how the patient could learn to cope in adverse environments. In some cases, physicians provided instructions that were tailored to the constraints in access that many patients experienced. As Barry et al. (2001) suggest, physicians often attempted to address some of the structural issues impacting healthcare but were ultimately unable to provide any solutions that could effect long-term change.

These findings mirror Dutta’s (2008) description of the confining influence that structure has upon marginalized individuals attempting to obtain health care. Just as

Dutta and Basu (2008) found that their West Bengali participants described health as a lack of resources, our participants described the structural barriers that often impeded their attempts to gain an optimal quality of healthcare. Participants informed physicians that they had the desire to be adherent and monitor their health, but they often lacked the resources needed to facilitate these practices. Participants who had Medicaid, a state funded insurance, were unable to afford their prescribed medications or receive referrals for physician's preferred specialists due to inadequate coverage. While these insurance and health care services were put in place in order to assist the marginalized, it is readily apparent that they further contribute to a gaping inequity. The patients, already ensnared in hunger, homelessness, stress and unemployment, must turn to a highly flawed system in which they must fight for resources. As our findings prove, context *matters*, and for marginalized patients, context often shapes their illness experience and influences the ways in which they demonstrate agency.

RQ 2: What are the agentic strategies used among marginalized patients with a history of previous discrimination?

Participants demonstrated many different participatory behaviors during the clinical interaction as they sought and provided information to their providers. We reviewed the 29 categories of agentic tactics that resulted from our inductive qualitative analysis and applied thematic analysis techniques to identify shared underlying meaning. The resulting five themes, or overarching agentic strategies, emerged following the analysis of patients' agentic acts: interrupting the physician, expressing needs and desires, observations of care, construction of identity and agenda/goal setting management. The following table reflects each strategy and the tactics that comprise them.

Table 1.

Patients' Agentive Strategies

Strategy 1: Interrupting the Physician				
Name of Tactic		Tactic Definition	Example of Tactic	Counts
Interruption (<i>occurs outside of the patient's speaking turn</i>)		Patient interrupts the physician; this interruption consists of only a few words and intended purpose is not known.	"XXX XXXX"	17
Interruption Question	–	Patient interrupts the physician to ask a question/clarifying question.	"What about the psychologist?"	28
Interruption Knowledge	– Other	Patient interrupts (not during his speaking turn) physician to provide/explain/share an information resource external to the interaction and the doctor's explanation, i.e., information gleaned from websites, journals, newspapers, family members' experiences, information relayed during an encounter with a previous physician, etc.	"But the other doctor said that was taking too many meds and needed to go off of that."	1
Interruption Context/Psychosocial	-	Patient interrupts the physician to provide some information that is contextual or psychosocial in nature in order to further support the process of clinical communication. This could include sharing external circumstances that complicate adherence or compliance, or details that better contextualize how external factors shape the patient's physical or mental	"Like I told you, I been homeless and moving from house to house and I can't always check my blood sugar."	1

	well-being.		
Interruption Demonstrating Understanding	- Patient interrupts the physician in order to demonstrate that he understands what the physician is conveying. This is beyond a continuer, and must consist of a clearly explicated statement.	= "I understand that, I understand that."	3
Interruption- Concern	Patient interrupts the physician in order to express a concern to the physician. This could consist of 1) emotions/feelings/concerns that the patient is experiencing about the state of his/her health or the diagnosis or 2) physician pain or discomfort that the patient is experiencing.	Patient: So I have to take the cholesterol pills? Doctor: ...If it is going up. If it's not going up, if it is same = Patient: I see here my cholesterol is going up.	6
Interruption Preference	- Patient interrupts the physician to state her preference/preferred choice for a particular course of action/treatment.	= "Wish you could do all of them at the same time."	5
Interruption Acceptance	- Patient interrupts the physician to indicate that she now accepts the physician's proposed treatment plan/proposal/assertion.	= "You can poke me today."	1
Holds Floor/Persists through Interruption	Physician attempts to interrupt patient, but continues speaking, successfully holds floor.	Patient: And I try to hold on, try to hold on to it and = Doctor: And yeah, no =	11

Patient:= meet my expectations.		
Strategy 2: Expressing Needs and Desires		
Name of Tactic	Tactic Definition	Example of Counts
Question- Direct	Patient <i>directly</i> poses a question that is <i>generally related to the treatment</i> , his/her condition, or the clinical encounter. This general question <i>serves the sole purpose of seeking information and/or clarifying provided information, and is delivered during the patient's speaking turn (not an interruption) and is not identified as any other form of agency.</i>	"Doctor, can you tell me why I'm still feeling dizzy?" 150
Question - Indirect	Patient <i>indirectly</i> poses a question that is generally related to the treatment, his/her condition, or the clinical encounter. This general question serves the sole purpose of seeking information or clarifying previously provided information, and is delivered during the patient's speaking turn (not an interruption) and is not identified as any other form of agency.	"I don't know if my iron low again." 14
Express Concern	Patient shares feelings or concerns related to his/her condition and/or symptoms and/or proposed treatment plan. This category includes expressed feelings as well as medical issues/symptoms.	"And I don't like that, because they say bruises and stuff like that can lead to diabetes. I don't want 42

			that.”	
Direct Request		Patient directly petitions physician for services, information, assistance, etc.	Is it possible to have another copy of the script you gave me for the optometrist?	48
Indirect Request		Patient indirectly petitions physician for services, information, assistance, etc.	I don't have no uh uh refills on that.	7
Express Preference		Patient indicates that he prefers one course of action/treatment proposal over another. Both or one options may be provided by physician, or patient my present alternative course of action.	"I'd rather try to go off of the Wellbutrin before I try a different one."	18
Reference Knowledge	Other	Patient inquires with physician (during his speaking turn) about information gleaned from external sources (sources can vary in reliability, from health websites, journal articles, etc) and may also include knowledge gained from friends and family members or information shared during previous interaction with health care professional.	"My sister says she has trouble feeling her feet and she has diabetes, too."	16
Strategy 3: Observations of Care				
Name of Tactic		Tactic Definition	Example of Tactic	Counts
Expressing Feedback	Positive	Patient provides positive feedback to the physician. This includes explicitly thanking the physician for quality of care at the end of	"I know, I know I can trust what you say, Dr. PXX."	1

	the intervention (more than simply saying "thank you" or "take care" at the end), remarking on a positive history with the doctor, expressing trust, expressing appreciation, etc. This must be an explicit statement.	
Expresses Displeasure/Complaint	Patient expresses anger, frustration (negative emotion) about treatment by clinic health care professionals/clinic processes, procedures, etc.;	"I been 3 waiting a while... thought you forgot about me."
Misinformed/Lack of Information	Patient explains/complains that she previously received health information from a previous health care provider that was either 1) nonexistent; previous HCP dd not explain or provide information during previous clinical interaction or 2) not clearly conveyed or adequately explained during previous clinical interaction.	"The last time 8 I was here, the doctor said he was gonna drain it."
Strategy 4: Construction of Identity		
Provides Context/Psychosocial Information Unprompted	Patient provides contextual or psychosocial information - to further support/explain clinically related issues without prompting or questioning to the physician.	D: "Your 17 blood pressure is really high. P: "I been stressing...."
Provides Context/Psychosocial Information Prompted	After prompting from the physician, the patient - provides contextual or psychosocial information to further support the manifestation or management of clinically related issues.	Doctor: 2 Okay. So how is the depression part going on? Patient: It's all right.

Admitting w/Compliance	Issues	Patient voluntarily (without prompting) relays that he/she is aware of the proper health behavior but is struggling with adherence with treatment recommendation.	"I know that I need to lose weight, I know that I need to do better, I just been struggling."	6
Explanation of coping mechanisms	Patient shares with the doctor techniques, approaches or perspectives that she uses in order to physically and mentally manage the burden of her malady.	"It's pain right now but I done learned how to make myself happy throughout it."	4	
Self as Expert	Patient presents him/her self as an authority or expert on the workings and processes within his/her body, with the ability to discern changes in health and determine what forms of care/medication/treatment are best suited for him/her.	<p>Patient: But it never, it don't ever be like that. It always stays bright red.</p> <p>Doctor: Yes.</p> <p>Patient: Always.</p> <p>Doctor: Okay.</p> <p>Patient: And that's how I know something wrong.</p>	7	
Strategy 5: Goal and Agenda Setting/Management				
Agreeing/Acceptance	Patient accepts or agrees to physician's proposal or solution. This is an active act, and not merely active listening or continuers. This occurs after the physician has presented (and perhaps	"Ok, doc, I'm fine with that."	19	

	explained) the proposed treatment and signals (with some finality) that the physician's proposal has been accepted after discussion.	
Demonstrates Understanding	Patient indicates that she/he understands the information that the information is conveying. This is an active, unprompted act, (does not include any continuers) and consists of the patient clearly stating that he/she understands what the doctor is saying.	"I see what 6 you're saying."
Concession	After negotiation, the patient willfully decides to compromise and settle upon a treatment plan or course of action (does not have to be the physician's originally proposed plan, can be mutually agreed upon). This agreement or acceptance of the proposal/solution/treatment plan is granted after a presentation of the available options, after a negotiation or compromise.	"Ok then, 10 well, I guess you can just mail it to my house if you don't have time now."
(Re)Direct Agenda	Patient (re)directs discourse in the clinical interaction in order to fully address his/her concerns.	Now how 6 about this ulcer? This is my big deal right now.
Corrects Physician	Patient corrects physician and provides the correct technical/factual information.	3

Interrupting the Physician

This strategy consisted of patients' interruptions of physicians' speaking turns, as well as patients' unwillingness to relinquish the floor when physicians attempted to interrupt them. Interruptions were defined as an individual's bid to stop the progress or continuity of another's individual's speaking turn. Two subthemes, patient interruptions and holding the floor, emerged during the analysis. During 44 instances of patients' interruption, patients routinely interrupted physicians in order to ask questions and provide additional information. In 11 instances, patients successfully held the floor when a physician attempted to interrupt them. During these instances, patients did not yield to physicians' attempts to interrupt their speaking turn and continued to steadfastly complete their speaking turn.

Unlike the previous theme, this strategy consists of patients expressing their needs and desires outside of their speaking turn, signaling a clear attempt to claim (and often maintain) the floor. Thus, the focus is on the process, rather than the content, of the utterance. Interruptions most often occurred in the form of an interjected question. In these cases, patients frequently interrupted the physician's speaking turn in order to request additional information provisioning about the physician's proposed diagnosis or treatment plan:

Doctor: If um there is no thickening, then we would have to, you know, try some alternate um, you know, methods um or medications. But he said we could =

Patient: Like what? (*frown*)

Doctor: Um see, you tried the oral contraceptions. Straight estrogen can work. Um so, basically we need, I guess the way insurance is playing out, we need baseline tests before referring you out or insurance will not = (Case #176)

Doctor: That's good, that's uh uh reassuring. But still this could potentially be quite serious.

Patient: So don't take this any more?

Doctor: No sir. I don't think you're ever going to take that again. (Case #104)

Participants also interrupted the physician to provide additional information, often during the physician's history taking:

Doctor: Okay, so about seven days. And when did you start on that? Thursday or Wednesday?

Patient: I don't know.

Doctor: Not sure, but it was in this week that you started.

Patient: Yes.

Doctor: Okay. So, I'll put that you =

Patient: And I bled so heavy, I had to wear diapers. (*Avert gaze*)

Doctor: Okay. So, you actually wore diapers. How many diapers were you soiling?

Patient: Um every time I changed my, maybe about four or five a day. (*Rising tone*)

Doctor: Okay. Wow. Uh that is pretty heavy. (Case #176)

In this example, the participant's interjection effectively interrupts the physician's assessment ("I'll just put...") and provides additional information conveying the severity of her symptoms. The physician shows an improved understanding of her condition when he remarks that her bleeding is indeed "pretty heavy." The participant's interruption clearly serves as a timely contribution of information that influenced the interaction and powerfully demonstrates how patient agency influences internal processes within the clinical interaction.

While participants frequently interrupted patients, physicians also interrupted patients during their speaking turn. In many cases, however, participants did not yield their speaking turn to the attempted interruption and continued speaking, successfully holding the floor:

Patient: So what if it keep continue bothering me? I mean, I'll be, I don't want to keep being in pain and being uncomfortable, you know what I'm saying? Whatever I need to be done I want to go get it done. I mean I've taken = (*rising tone*)

Doctor: Yeah, I understand but give =

Patient: = all this different medicine =

Doctor: Give it time. You know =

Patient: I've taken medicines, I had Naproxen before. (Case #121)

In this example, the physician attempts to interrupt the patient's by countering concern about the potential efficacy of the proposed treatment twice ("Yeah I understand but give ="; "Give it time. You know=") but the patient does not yield to this attempt to reclaim the floor. Instead the patient retains his speaking turn and does not relinquish it until he has successfully conveyed his concern: "I've taken medications, I had Naproxen before." The patient's ability to thwart the physician's attempted usurpation of this speaking turn reflects patient agency.

Discussion of Interrupting the Physician. These findings illustrate a dynamic and often fluid flow of power throughout patients' interactions with their physicians. In many cases, patients' interruptions serve as a source of power-claiming discourse (Ainsworth-Vaughn, 1992). Kettunen, Poskiparta and Gerlander (2002) further support this notion, explaining that patients often counter the expert power of providers by using interruptions as power messages. The authors provide an example of this by describing

how a nurse practitioner's attempt to interrupt a patient fails as the patient steadfastly holds the floor. The findings from this study resonate with our own findings, as several patients in our study also refused to relinquish their speaking turn when the physician attempted to interrupt them. In many of these cases, patients demonstrated a determination to provide an exhaustive accounting of their symptoms or concerns, especially in cases where the participant had visited the clinic previously to address the same issue or was previously misdiagnosed.

Interruptions clearly function as power-claiming discourse. It is also important to note however, that interruptions do not *always* function as a bid for power. As Kettunen, Poskiparta and Gerlander (2002) note, while interruptions can function as dominance, one should keep in mind that interruptions are a "many-sided phenomenon" that should always be considered within the larger context of the interaction. Other authors have explored the complex nature of interruptions (Li, 2001) and proposed distinctions such as "intrusive or cooperative and "power" and "nonpower." Our findings support this, as there were cases in which interruptions served to interrupt the physician's speaking turn, but there were also instances in which patients' interruptions served a supportive function.

When viewed within the context of the interaction, interruptions carried an intent that can be interpreted as more than the observed technical violation of the physician's speaking rights. In these instances, participants do disrupt the physician, but with the intent to aid in the diagnostic process by providing as much relevant information as possible. Murata's (1984) definition of "assistance," a cooperative form of interruption, states that one speaker discerns that another speaker needs assistance and interrupts to

provide the speaker with words, phrases, sentences or ideas (Li, 2001). From this perspective, we understand some participants' interruptions are not intended only as power moves or impolite behavior. This is especially true for our participants, several of whom had not yet received an effective treatment plan or correct diagnosis after several visits to the clinic.

These findings are significant for several reasons. First, the findings demonstrate that the participants, low-income black patients, are capable of vying for dominance during the interaction and often use interruptions and persistence as a vehicle for claiming this power. Second, participants often used interruptions and persistence as a means of "helping" the physician identify the best course of treatment for their care. The implications of this point are worth noting: In cases where patients may be perceived as disruptive or difficult, they may in fact be advocating on their own behalf as they attempt to assist the doctor in delivering a better quality of care. In our study, participants consistently described feelings of frustration when relaying the winding road towards a correct diagnosis. In these cases, the participants are not necessarily intending to supplant the power of the physician during the physician's attempt to diagnosis their condition – they are, in fact, dependent on the physician's expert knowledge and ability to render the correct diagnosis and address their health issue. Rather, they are using their agency to ensure that the physician has all the pertinent information in order to render the best informed diagnosis and treatment plan. In this context, we can understand that patients who may be perceived by physicians as "difficult" are in fact using their agency to fully participate during the interaction and hopefully, obtain the health services that they need.

Expressing Needs and Desires. This strategy was the most commonly identified ($n = 295$) and consisted of patients petitioning their physician to address their needs and desires. Three subthemes emerged during the analysis: Asking questions ($n = 164$), making requests ($n = 55$) and expressing concerns and preferences ($n = 76$).

Patients' needs were often related to information and treatment provisioning, such as information about a diagnosis and/or treatment or refills of medications. Patients' desires most often centered around requests for preferred modes of treatment, such as referrals to see a specialist or a preferred course of treatment.

Participants commonly expressed their needs and desires during the clinical interaction by asking questions, stating concerns and making requests. Asking questions ($n=164$) consisted of patients' direct and indirect inquiries to physicians requesting additional information provisioning. First, while questions were posed in both an indirect and direct form, participants more often used a direct construction when seeking information from the physician. Direct questions assumed the interrogative role of a question, while indirect questions were most often posed as statements that successfully elicited additional information from the physician. Direct questions comprised 150 utterances. Examples include:

And is the medication cut then or is it taken off completely? (Case #121)

So he probably wouldn't take my insurance, right? (Case #118)

What kind of a medication? What would it be? (Case #162)

Conversely, only 14 questions took an indirect form, where participants indirectly sought knowledge or confirmation from the doctor, but did not pose these questions in a direct manner:

Yes, I've never had to use one before (Case #169)

I was thinking too, it might be my mattress. I might need a new mattress. Maybe that might, you know. (Case #111)

Question asking, therefore, occurred in both direct and indirect forms.

In addition to asking questions, participants also shared their feelings of fear or worry (n=42) when discussing their health conditions or diagnoses:

And um it hasn't really gotten any better. (Case #121)

I could have a heart attack. (Case #170)

Participants also expressed concern about physicians' recommended treatment plans, or processes required to reach a diagnosis: "I'm nervous" (Case #170); "Very frustrating" (Case #164). Sharing overall concerns about their health as well as specific worries over treatment plans allowed patients the opportunity to give voice to the issues that concerned them and potentially receive feedback from physicians.

Lastly, participants frequently made requests of their physicians. These requests varied, as participants presented a range of healthcare needs. Participants frequently explained that they were out of medications and other related medical equipment, such as glucometers. In several cases, participants indicated that they were out of medications or materials because they had not received healthcare or visited the clinic for follow-up for a prolonged amount of time. Lapses in care also prompted patients to request additional testing or services that had not been performed at previously recommended intervals. For these reasons, participants often presented several requests to their physician for refills, tests, referrals and supplies over the course of the clinical interaction.

As with questions, participants more often used a direct construction when making requests of their physicians. Forty-eight utterances were identified as direct

requests, which were constructed as a patient's clear, explicit and specific request for the physician to take action, in either declarative or interrogative forms:

Okay. Doctor uh uh, will you, check my uh uh cholesterol? (Case #132)

I do need something for pain too. (Case #162)

By contrast, patients' indirect requests followed a more circuitous route and were conveyed in an implied or implicit manner. Only 7 patients utterances were classified as indirect requests:

And also I was wanted to see if I could get a prescription for the bathtub thing. Because I can't hardly get out the tub. (Case #170)

I'm running out of those orange pills. (Case #112)

Discussion of Expressing Needs and Desires. These findings resonate with existing literature that describes the various forms of patients' information-seeking. Street (2003) previously identified asking questions, expressions of concern, and assertive responses as the cornerstone of patient activation in his ecological model of communication. Our findings further enforce the veracity of these strategies, as we have also identified three tactics that fall under the agenic strategy of "expressing needs and desires": question asking, expressions of concern, and "making requests" (which is a type of "assertive response; see Street, Gordon, Ward, Krupat, & Kravitz, 2005, p. 968). Clearly, the "active" behaviors that Street and subsequent authors describe fall within the purview of patient agency. As Street et al. (2005) assert, "These behaviors are active forms of participation because they interject the patient's perspective into the interaction and can have a powerful influence on the physician's behavior and decision-making" (p. 961). We found this sentiment to be true during our investigation of these behaviors. Participants who asked questions of their physician, shared concerns, or requested

information or services consistently received a response that most often included further provisioning of information. The results of our investigation show that, as previous patient activation intervention research has reported (Cegala, Street Jr, & Clinch, 2007; Street et al., 2005), patients who actively participate by demonstrating these behaviors receive additional information provisioning.

An interesting outcome concerns the fact that the participants *did* commonly demonstrate these behaviors. Previous literature has described black patients as displaying fewer participatory behaviors during the clinical interaction. Street, Gordon and Haider (2007) found that physicians demonstrated fewer participatory styles and considered black patients to be less effective communicators. As such, interventions such as the Question Prompt List (QPL) have been identified as an ideal tool to foster more participatory behaviors during the clinical interaction. Noting the benefit of patient activation interventions for chronic care and among older patients, Epstein (2006) suggests that the intervention would benefit marginalized patients: “Presumably the same would be true of poor, immigrants, non-English speakers, and other marginalized groups. Even though they might not want to be activated, it seems that they need to be in order to optimize outcomes that are of value to them” (p. 276). This statement reveals several assumptions that our findings have countered.

First, we found that all of our participants, who consist of low-income, black patients with a history of discrimination, consistently posed questions, requests and concerns to their physician – without the prompting of an intervention that specifically promoted these behaviors. While some of the patients who were recruited during the second phase of the study received team buttons and pamphlets that broadly encouraged

“being a team”, this intervention did not encourage the use of asking questions, expressing concerns or making requests. Also, patients in both the control and the experimental phase of data collection enacted agency. Contrary to Epstein’s (2006) assertion, these patients did not “need” to be activated in order to demonstrate “activated” behaviors, nor did they seem to “dislike” actively participating during the interaction. Our participants demonstrated that they already had the ability to exercise their agency when interacting with the physician.

Our findings show that participants most often used a direct construction when posing questions and requests in both groups - possibly indicating that participants were already comfortable exercising their agency and intent on securing the resources needed to address their health concerns. Eggly et al. (2011) explain the larger implications for interactional power when posing direct versus indirect questions:

Asking direct questions may also indicate an attempt to assert power in an interaction. Some patients prefer to avoid directly asserting power when interacting with their oncologist, especially when they consider the oncologist to have greater authority in the traditionally hierarchal physician-patient relationship. As a result, these patients ask fewer direct questions, thus communicating their intention to gain information with more ambiguity (p. 64.)

In their study of black and white oncology patients, Eggly et al. (2011) ultimately found that black patients asked fewer questions when compared to whites, with a smaller proportion of direct questions. While this study does not compare our participants with white patients and does not take place within an oncology setting, the divergent results of our study are still telling. Within our study, the largest proportion of questions asked by

our (black) participants was directly stated. Given Eggly et. al's explanation of the difference in power dynamics for direct and indirect questions, it becomes apparent that our participants were comfortable exercising their agency by expressing their needs and desires when compared with the participants from Eggly et al.'s and others studies.

Observations of Care

In this strategy, participants shared their observations regarding the quality of their health care and their providers when interacting with physicians. Two subthemes emerged from this strategy: providing feedback about the quality of care ($n = 4$) and citing instances of lack of information or misinformation ($n = 8$).

Patients provided their physician with feedback regarding the quality of care received. While this feedback was sometimes in positive in nature ("Thank you for listening"; Case #167), in most cases participants complained about the quality of care that they received, describing issues that ranged from long wait times, inadequate explanation and/or patient education and potentially inaccurate diagnoses. For example, after an extensive wait for the physician's arrival, a participant noted, "Thought you forgot about me" (Case #170). The physician, in response, apologized and explained why he was detained.

More often, participants described issues with care that necessitated return trips to the visit and seemingly contributed to a growing feeling of distrust in their physicians and their physicians' ability to effectively treat them. Participants often shared these observations and/or experiences with physicians at the onset of the clinical interaction while simultaneously providing clear expectations for the physician during the present

visit. In the following example, a participant relays her first experience in the clinic, which she found to be highly dissatisfying:

Patient: Well, my first encounter um here uh uh, it wasn't real pleasant and um =

Doctor: What happened?

Patient: Well, because for one it was my first time coming here and uh I overheard them over talking that they'd scheduled a new patient at 4pm and obviously they don't usually do that, new patient, so at 4pm I guess everybody was getting ready to go home or there was =

Doctor: Well we, the thing is =

Patient: = no time for it =

Doctor: No. Like we usually don't schedule new patients after 4pm but that's only because then we don't get enough time, as much time as we would like to dedicate, you know. Uh, we're here till 5pm, at least 5pm, but usually we don't take =

Patient: Exactly, yeah

Doctor: = even established patients after 4:30pm and no new patients after 4pm but I'm sorry to hear that. Uh uh, I didn't know that that had happened.

Patient: Yeah, so I felt like kind of rushed.

Doctor: Okay.

Patient: I mean uh uh you fill out the new patient questionnaire where you have, put your concerns, provide any history and stuff like that. None of that was discussed =

Doctor: It wasn't addressed, okay.

Patient: I told her that I took Lisinopril, I took my last pill yesterday. I needed a refill. She said, "Okay," gave me a refill, nobody took my vitals, nothing.

Doctor: Okay.

Patient: You see there's no vitals on there initially, just today.

Doctor: Uh, okay, yeah I see that. Okay.

Patient: So I saw her every bit about three minutes and that was it.

Doctor: Okay.

Patient: Gave a script for Lisinopril, asked me did I need anything else. I said, “No,” and that was it. (Case #152)

As the participant explains, her previous encounter with a physician was rushed because of her arrival time, and as result, the interaction was rushed and her concerns were not fully discussed. Although the previous physician fulfilled her request (a new script for Lisinopril), the participant was aware of the fact that standard procedures had not taken place. She voiced this dissatisfaction at the very beginning of her next clinical interaction with the new physician, preemptively setting her expectation for an improved quality of care during the present visit.

In other instances, participants directly questioned their physician’s competence and/or technical skills and acumen during the clinical interaction: “Dr. Sxxx you did this before you came here, didn't you? Okay” (Case #170). This questioning could be attributed to a distrust of their treating physicians. Participants were aware that their physicians were residents who needed final approval from the attending physician and often questioned their ability and competence. These repeated questions signal an awareness of the fact that their treating physicians were less experienced, which potentially yielded lesser quality of health care.

Discussion about Observations of Care. The issues with care quality that participants identify and describe are often characteristic of the health services typically provided for black patients. This is especially true for marginalized patients who are reliant on poor performing health care plans and under-qualified physicians (Hasnain-Wynia R, Baker DW, Nerenz D, & et al, 2007). For example, Bach et al. (2004) found

that when compared to white patients, black patients are more likely to be treated by physicians who are less well trained clinically and have less access to important clinical resources. In addition to underperforming and undertrained physicians, an additional factor that contributes to the disparity in healthcare quality for blacks are the underperforming hospitals where black patients often seek care. Bernato et al. (2005) found that on average, blacks went to hospitals that lower rates of evidence-based medical treatments. Lucas et al. (2006) reported that black patients have higher operative mortality risks when compared to whites because they attend hospitals with higher mortality rates for several procedures, such as coronary artery bypass, aortic valve replacement, abdominal aortic aneurysm repair, carotid endarterectomy, radial cystectomy, pancreatic resection and esophagectomy.

Hassnain-Wynia et al. (2007) also noted these disparities in healthcare between minority and minority patients, as well as a pronounced disparity in counseling. Acknowledging that counseling requires resources such as time and documentation, the authors still advocate communication training for physicians. These findings are especially pertinent, given the findings of our study. Participants expressed a sense of frustration and bewilderment as they discussed their multiple visits to the clinic, and it becomes increasingly clear the physicians have not (in previous or present visits) provided sufficient education and counseling when providing the treatment plan. Perhaps some of the communication “disconnect” could be attributed to the fact that the residents in most cases are foreign-born, South Asians who speak English as a second language. As Mertz, Jain, Breckler, Chen and Grumbach (2007) note, South Asian U.S. medical graduates are more likely to work in medically underserved communities, with low-

income minority patients such as our participants. While only a few of the participants appeared to have difficulty understanding the physicians' use of English, they often expressed a desire for additional details concerning diagnosis and treatment plans.

These findings clearly demonstrate that black patients experience a disparity in healthcare quality, and our participants consistently spoke to these observations of disparity during the interaction. It is interesting to note, however, that our participants not only were aware of and noticed these differences, but they also shared these observations with their treating physicians. These shared observations are clearly agentic and are conveyed in order to let the physician know that they are dissatisfied with a type of treatment and that they do not wish to repeat the experience.

As the literature demonstrates, it is not uncommon for black patients to receive substandard care. What is noteworthy, however, is that the participants in our study were unabashed in enacting their agency in order to share their grievances, dissatisfaction and observations with their physicians. As Lim, Tan and Goh (1998) note, patients' complaints are indicative of patient dissatisfaction and point to the need for healthcare personnel to give greater attention to service dimensions such as wait time, professional skill, patient expectations and conduct. As the participants demonstrated, complaints serve as agentic acts that function strategically in an attempt to improve the outcome of the interaction.

Construction and Explanation of Identity

This strategy consisted of instances in which participants provided information and supportive details that functioned to construct and explain their identity ($n = 36$). Two subthemes emerged: sharing of personal narratives ($n = 29$) and positioning themselves as

experts of their own bodies ($n = 7$). While providing history and discussing symptoms and possible treatment plans, participants provided contextual information that allowed doctors to better understand how they were socially positioned both within and outside of the contexts of their illness. Participants also commonly constructed an identity as the expert of his or her own health and body.

I'm for real, I mean this is not you. I'll be in pain and I know what helps me, you know what I'm saying? (Case #129)

Me, I'm the only one that knows what I feel and what's going on. (Case #180)

In another instance, a patient explains that her familiarity with menstrual cycle allows her to be especially attuned to changes in her reproductive health. When sharing her suspicions of an ailment, she offers the physician the following evidence:

Patient: But it never, it don't ever be like that. It always stays bright red.

Doctor: Yes.

Patient: Always.

Doctor: Okay.

Patient: And that's how I know something wrong. (*direct stare*) (Case #174)

When sharing information about their health concerns, participants often shared related contextual information with the physician in order to better construct their identity and perhaps influence the physician's perception of them. A common sentiment that united these disclosures was the narratives of strength and survival. Participants described the trying circumstances that they were forced to contend with, ranging from caring for parents and disabled children, and managing their health in the midst of physical and mental illness.

One participant, who experienced a fall during a shopping trip and experienced undiagnosed pain as a result, describes the personal challenges that she faces in the midst of her pain:

Patient: Like I say, I have four kids. I gotta be strong... I just got my MRI this year. So throughout that I had to get strong in the mind and work with myself in order to be able to maintain. Like I said, my youngest who is disabled is three. I got to take care of him and yes, there's pain, but I'm going to do what I've got to do because I got to.

Doctor: All right. Have you applied for anything like disability or anything, anything?

Patient: No, the reason why I haven't is because I don't want nobody to feel, I mean I don't want to feel like I can't take care of my child.

Doctor: Yes.

Patient: Because he's already disabled. He gets Social Security and stuff. So it's like, I want to be stronger so that, you know, I won't have to go through that. But no, I haven't. Right now I'm getting just help from the state. (Case #180)

Another participant discusses the stress that accompanies her role as caregiver for her mother:

Yeah, taking care of the mom, uh that's the main thing. Um you know, I'm her caregiver and I'm getting ready to go on a little vacation and uh everyone in the family know it but right about now the person that was supposed to take over uh is acting very overwhelmed about it as the day approaches. So now I have to do other things, make uh other accommodations for her care, you know, and it's just kind of real stressful because I like to be prepared uh uh you know, for things and that's been having a lot to do with my mood changes, you know. (Case #118)

In both cases, the patients self-identify as having strength in the midst of difficult circumstances and a strong commitment to those dependent on them. Both narratives share themes of survivorship and allow the patients to construct their identity as competent, strong women that capable of managing their personal struggles in the midst of health challenges.

Discussion of Identity Construction. Tretheway (1997) asserts that organizations are sites of identity formation, and this notion is certainly reified after examining the findings from our results. While Tretheway observes how marginalized individuals enact agency in a social services organization, our findings show health care organizations, especially the medical visit, are also a site for identity formation. Tretheway explains that organizational discourse allows the introduction of meanings, personal identities, values, knowledge and modes of reasoning – all of which can be conveyed with strategic influence.

Goffman (1952) describes this strategic process as “self presentation”, a process by which individuals seek to manage their impression and the way that others perceive them during social interactions. Humans, Goffman notes, are social creatures that try to behave in ways that tell others who they are and how they should be treated. Within this framework, first impressions are important – especially for interactions involving individuals with different socioeconomic status. Citing the example of a waitress and her customer, Goffman explains that the individual with the lower status must be active and decisive in setting the best impression during initial interactions, which often serves to define the relationship: “The work adjustment of those in service occupations will often hinge upon a capacity to seize and hold the initiative in the service relation, a capacity that will require subtle aggressiveness on the part of the server when is of lower socioeconomic status than his client” (p. 142). Goffman further explains how the waitress’s deft handling of the customer (e.g., clearing a dirty table where the customer is seated without waiting for permission) can firmly establish power dynamics within the relationship so that there is never any question as to “who is in charge” (p.142). For

Goffman, self-presentation is not only strategic, but it is necessary for those of lower socioeconomic status who wish to establish a foothold of power.

While the patient-physician relationship is in some ways different from the consumer/service dynamic that Goffman (1952) describes, the power differential is directly applicable to the context of the clinical encounter. As previously discussed, power within the patient-provider dyad is inherently asymmetrical, yet patients may lay claim to power with power-claiming discourse. In our study, participants attempt to shift this balance by discursively managing this process of self-presentation, and thus, the physician's perception and subsequent treatment of them. Though their maladies varied, participants were often consistent in their presentation of beleaguered yet empowered, enduring individuals that survived despite the odds. One participant explains, "It's pain right now but I done learned how to make myself happy through it" (Case #180). Another remarks, "Well, I've just been dealing with it thus far" (Case #118). The narratives that these participants share as well as the information that they choose to include and discard during the telling, are strategic as they potentially set the stage for the physician's expectations of who they are, how they should be treated, and the role that they will play during the course of the interaction.

Cohn et al. (2009) describes this phenomenon in their description of a clinical interaction involving the single African American mother of two asthmatic children. The mother, who lives in poverty, performs her identity during the clinical interaction in a way that allows her to negotiate for the best outcome for her children. Cohn et al. explain, "The stories she chooses to tell and how she tells them are means for her to show us how she would like to be perceived...Ultimately, such understanding might assist

practitioners in co-constructing an intervention that honors her sense of self and empowers her to manage her children's asthma..." (p. 28). In this same way, our participants perform their identity through their strategic use of self-disclosure and narratives.

The need to manage self-presentation is especially acute for our participants – black primary care patients who are of a lower socioeconomic status and at the undesirable end of a power differential. For these patients, it is crucial to create the impression of an engaged, intelligent and motivated patient. Research has clearly shows that physicians' implicit and explicit biases influence the way the ways in which they perceive black patients and often influence their decision-making concerning treatment plans (Dovidio et al., 2008; Stepanikova, 2012). Further, research has shown that black participants are often sense these biases – both explicit and implicit (Penner et al., 2013). Participants' recognition of these cues could motivate patients to carefully cultivate the identity shared during the clinical interaction as it could have a direct influence on the physician's diagnosis and suggested treatment. Clearly, this process of constructing identity during the clinical interaction represents a very subtle yet deliberate enactment of agency that potentially influences the interaction and the resulting communication and outcomes.

Goal and Agenda Setting/Management

This strategy consisted of patients' shaping the progression of the clinical interaction by influencing and directing the agenda ($n = 44$). During this strategy, participants closely followed physicians' communication concerning diagnosis and treatment, often interjecting and objecting in an effort to optimize the visit's outcomes.

Participants also worked in concert with physicians to ensure that their physicians received and understood all of the information that they conveyed. Reciprocally, participants also ensured that they had an accurate understanding of physicians' explanations and treatment recommendations, regularly providing feedback and reminding physicians of potentially contradictory symptoms or experiences if they did not understand the physician's decision. This ongoing process of "checking in" allowed participants to monitor the decision making process by ensuring that their physicians fully understood the information they conveyed and integrated it in the resulting treatment decision.

Participants' partnering behaviors ranged in form and content, sometimes evidenced in the form of setting expectations for the interaction's agenda, demonstrating understanding, and conveying their agreements, or concessions to recommended treatment plans. Throughout the interaction, patients were vigilant in their monitoring of the interaction, reminding the physician of what they wanted to accomplish during the interaction, and if they did not understand or agree with the physician's plan.

Several participants used their agency in order to establish a mutually agreed upon agenda, often simply stating what they planned to accomplish during the visit:

I have three concerns today. (Case #176)

Okay, because that was another concern I wanted to, I told her that I was having some, sometimes I felt dizzy. (Case #132)

Let me show you something. (Case #112)

When necessary, patients also redirected the agenda and returned the physician's attention to the desired topic: "Now how about this ulcer? This is my big deal right now" (Case #121). These efforts to direct and manage the progress of the agenda at the

beginning of the agenda and throughout during the medical visit represent a clear enactment of patient agency, which was often motivated by patients' needs to address multiple pressing issues during a limited time provided during the intervention.

Participants also stated their preferences when presented with options, and offering their concession after negotiating over certain treatment-related terms:

No problem, I understand, I understand. (Case #115)

Okay. Okay, that'll be fine, Doctor. (Case #132)

Okay, rrwel, we'll see how it goes. (Case #118)

That's true. Okay, yeah, go ahead and I'll just like one refill... (Case #164)

No, I'll try the diet thing first, let's do that first. (Case #162)

Discussion of Goal and Agenda Setting/Management. Participants' demonstrations of patient agency throughout the diagnosis and treatment sequences of the interaction signal a clear intent to participate and partner with the physician. Previous literature has examined how the process of setting the agenda during the medical visit often disadvantages the patient, as the physician often chooses a patient problem to discuss without fully exploring the patient's full spectrum of concerns (Marvel, 1999). Manny and Ray (2002) for example, describe a pattern of agenda setting that often consists of the physician initiating the opening sequence with a name exchange/check, brief pleasantries and a first topic initiator. As the interaction continues, the authors note that the inherent power imbalance within the dyad becomes evident as the physician assumes his prerogative to speak first and then manages the agenda for the duration of the interaction. Our findings, however, demonstrate that participants were comfortable exerting their agency in order to influence the unfolding of the interaction and shepherd

the physician back to their previously identified topics of interest as needed. This vigilance and focus is understandable when interpreted within the larger context of the interactions. Several participants reported not having received medical care for an extended period of time, and as a result, several health issues that required treatment had accumulated. Participants were aware of the time constraints of the medical visit and therefore worked strategically to ensure that all of their needs could be addressed during the interaction.

In addition to setting the agenda, participants demonstrated a clear desire for partnership with their physician when reviewing treatment plans and determining their suitability. While literature shows that not all patients want to participate in decision making (Levinson, Kao, Kuby, & Thisted, 2005) and that physicians often underestimate black patients' desire for partnership during the interaction (Street & Haidet, 2011), our findings clearly show that some patients desire partnership from their physicians when reviewing, discussing and deciding upon diagnosis and treatment.

Participants in our study consistently pressed physicians for additional information and details concerning their decision-making during clinical interactions, and these findings mirror some findings in existing literature. Cooper-Patrick et al. (1999) reported that black patients rated their medical visits as less participatory when compared with white patients. However, participants in our study assumed a more active role when discussing diagnoses and treatments, often in response to a minimal education and explanation on the part of the physician. The vigilance that participants demonstrated during these interactions is justified as participants identified instances of misinformation and inadequate understanding of patients' health concerns. Our findings show that black

primary care patients can actively participate and partner with the physician during the clinical action, and perhaps are more motivated to do so when attempting to optimize the visit's outcomes.

It should be noted that all of our participants, who consist of low-income, black patients with a history of discrimination, demonstrated agency during interactions with physicians. The nature of these interactions, coupled with participants' explanations of how information, services and resources were often badly needed, show that these patients were proficient in demonstrating "active" or agentive behaviors in order to obtain health resources. In fact, it is safe to assume that these patients were *already active*, or already equipped to exercise their agency when interacting with the physician. This is compelling, given that much of patient-centered literature does not reflect this population in this way. These findings show that these marginalized patients are capable (without prior prompting) of demonstrating active behaviors, and as a result of having to endure constraints in access to healthcare and health services, they may become more proficient or likely to exercise their agency.

RQ 3a: What are the resistance strategies used among marginalized patients with a history of previous discrimination?

Resistance strategies consisted of participants' efforts to challenge and reject the physician's recommended diagnosis or the recommended treatment plan. We reviewed previously identified instances of patient agency in order to identify the instances in which patients' enactments of agency simultaneously functioned as resistance. As Koenig (2011) discusses, resistance is a manifestation of patient agency. Building upon this conceptual understanding, we identified the instances of agency in which patients used both active and passive tactics for enacting resistance to the physician's treatment

and/or diagnosis. Using context and Stivers' (2005) definition as a guide, we identified instances of passive resistance (behavior that didn't align with the physician's treatment plan), and several instances of active resistance (behavior that challenged or queried the diagnosis as well as the effectiveness of medication of alternate treatments, p.950).

Participants used a variety of tactics during sequences of resistance. Four patients resisted their physician's diagnosis, with a total number of 14 resistance tactics instances that include presenting other knowledge to the physician, questioning the diagnosis, presenting a different diagnosis, and questioning the physician's competence. Three patients resisted their physician's treatment plan, with a total of 21 resistance tactics instances that include questioning the treatment plan, proposing a different treatment plan, stating values/beliefs and withholding approval. Whereas we identified two instances in which participants used passive resistance tactics to resist the treatment plan, patients most often used active resistance tactics when resisting the diagnosis and/or treatment plan. The following table details participants' resistance strategies:

Table 2.

Patient Resistance Strategies

Resisting the Diagnosis			
Name of Tactic	Tactic Definition	Example of Tactic	Counts
Referencing Other Knowledge	Patient cites other external source (reading, article, previous HCP, family member) to refute the physician when discussing clinical elements	“Now, another doctor that I was dealing with, he told me he think I passed a kidney stone once.”	1
Presenting Different Diagnosis	Patient suggests a different diagnosis that counters the physician's diagnosis.	<p>Patient: But you know what I believe? I believe it's the kidney, though.</p> <p>Doctor: Okay, okay. Why do you think that?</p> <p>Patient: Because it, rrlike, okay. Sometimes I, uh it be rrlike, sore, but not outside. You know what I mean? Not like a muscle, youknow.</p>	5
Questioning Diagnosis	Patient questions the accuracy of the diagnosis that the physician has provided.	<p>"This don't look like a gas."</p> <p>“But it's recurring.”</p>	5
Questioning Physician's Competence	Patient questions the physician's ability (competence, sufficient experience) to correctly complete a clinical function, such as diagnosis, treatment plan, etc.	"Do you know how to read that? How long have you been doing it? Is there someone else here who has been doing it longer?"	1
Refusal	Patient rejects physician's proposed plan and refuses to comply	<p>“Uh, I can't. I can't.”</p> <p>“Give me the prescription. I want some Vicodin. This</p>	2

is crazy.			
Resisting the Treatment Plan			
Name of Tactic	Tactic Definition	Example of Tactic	Counts
<i>Active Resistance Tactics</i>			
Questioning Treatment Plan	Patient challenges physician by stating disbelief in proposal or suggestion, contradicts physician explanation.	"What were people during before Lipitor?"	11
Propose Different Plan	When presented with the treatment plan, patient proposes a different/alternative treatment plan	"Can't I just stop taking the pills for a few days until my potassium goes down?"	7
State Values/Beliefs	Patient cites personal values, (dis)beliefs when refusing/countering physician's suggested treatment plan	<p>Patient: I'm not a big medicine guy. I'm going to tell you that =</p> <p>Doctor: You're right, I'm not either, but =</p> <p>Patient: Uh I'm really against it. Uh uh my family has done this medication thing all their lives and none of them gotten better. I mean I'm just going to be honest with you. Uh, I'm not a big medication guy. For the most part, most of my life I've stayed pretty healthy =</p>	1
<i>Passive Resistance Tactics</i>			
Withholding Approval	When asked/prompted to approve or give permission for the commencement of a treatment plan/suggestion, patient strategically avoids giving the approval or acceptance that the	(silence) "I will still have to think about that."	2

physician seeks

Resisting the Diagnosis

Patients used only active resistance tactics to question the physician's rendered diagnosis. Participants used 5 different tactics when resisting the diagnosis, including referencing other knowledge ($n = 1$), presenting a different diagnosis ($n = 5$), questioning the diagnosis ($n = 5$), questioning the physician's competence ($n = 1$) and refusal ($n = 2$). Participants who questioned their physician's diagnosis often used a variety of resistance tactics during sequences of resistance.

Proposing a Different Diagnosis. When proposing a new diagnosis, participants suggested alternative diagnoses that they perceived as a better "fit", often with an explanation. In the following excerpt, a participant visited the physician to discuss his back pain. When the physician suggests that the pain was likely muscular in nature, the patient demurred and shared his own suspicion that the pain was related to his kidneys:

Doctor: Ninety percent of the time, it's a muscular pain. You know, muscular strain just kind of comes and goes with certain movements. You can =

Patient: But you know what I believe? I believe it's the kidney, though. (*Smiling; head inclined*)

Doctor: Okay, okay. Why do you think that?

Patient: Because it, like, okay. Sometimes I, uh it be like, sore, but not outside. You know what I mean? Not like a muscle, you know.

Doctor: Okay.

Patient: It be like, just a sore feeling, you know?

Doctor: Okay, okay.

Patient: But uh uh it seemed to not last. Now =

Doctor: It doesn't last, what?

Patient: = uh a few months ago, I had some sharp, real sharp pains go through there, you know?

Doctor: Okay.

Patient: And it made me sort of start to realize that it was really hurting, you know, but that went away. So, I don't know, you know.

Doctor: Ok.

As the interaction continues, the physician agrees to order additional testing in order to test the patient's kidney function. (Case #143)

In another instance of resisting the diagnosis, a participant disagrees with the physician about existing pain and a possible correlation with an image on a previous scan. As the participant held the scan, she referred to the shape of the previously identified abnormality and provided her own interpretation of the image. Though the physician recommended additional testing to clarify the image, the participant persisted in her belief that the image indicated pregnancy:

Patient: Okay, because where I feel it, it's on this side, and I feel it like right up in here. (*lean forward; direct stare*)

Doctor: It's in there, it's inside there, but you cannot feel it.

Patient: No, I'm talking about where I feel the pain at sometimes.

Doctor: Yes.

Patient: Could, could it be possible for it to be, uh, okay, I still have milk. Could it be possible that that could be fluid just up under there?

Doctor: No, I don't think so. Because it is inside the chest.

Patient: Right, right, right, right, right.

Doctor: So milk does not go there. Milk generally stays out of the — you are having ribs over there, right?

Patient: Right. But's its =

Doctor: But milk does not go in, inside the ribs. Milk generally stays out of the ribs. These are the ribs, and this is your breast here =

Patient: Right because she, when Dr. Axxx said that she seen it was like could be fluid.

Doctor: It is, it is less likely to be fluid. It is a solid mass. Solid, not like a fluid.

Patient: Something hard.

Doctor: Something hard. Correct. So that's the reason we have to get this PET scan done. This is the script for the PET scan. I know it's like too much, but once we get this scan, the PET scan, we will be quite sure what it is, okay? Because CT scan, even though it tells that, you know, it is kind of a mass it doesn't tell you what exactly it is.

Patient: Right, but I have my own condition and what I might think it is.

Doctor: Yes. And what do you think?

Patient: And I don't know, I'm not trying to say this to be =

Doctor: Yes.

Patient: = because I know =

Doctor: No, it's, no that's fine, I would like to know =

Patient: The image, that image right here look like a baby. (*head lowered; directed stare; Case #180*)

Questioning the Diagnosis. Participants who questioned the diagnosis clearly communicated their skepticism and rejection of the physician's recommended diagnosis.

In one example, a patient who experienced recurrent symptoms failed to endorse her physician's initial diagnosis and continued in her inquiries concerning ongoing

symptoms. When the physician indicates that the results of preliminary tests indicate the absence of any condition, the patient challenges the diagnosis:

Doctor: So we'll check your pap smear today; uh, we did some culture, you know, it takes a bit of time for the cultures to come back, the results to come back. But I don't suspect anything bad.

Patient: So with me having the irritation to my cervix, what could that come from?

Doctor: Um, it could just be uh, I'm not so sure. Um, I couldn't say for sure. I can't point out what exactly is irritating that's causing your cervix to cause a little bit of pain. I'm not sure. That's why I'm getting the ultrasound.

Patient: Okay.

Doctor: Like I'm not, I don't think it's a bacterial infection that's causing the, you know, the pain the vagina. There's no urinary tract infection; I check you for that so there's no urinary tract infections. There's no bacterial infection in the vagina. Um but an ultrasound can help us um, you know, some things that we can't catch under the microscope, the laboratory also catches it. So if I'm not able to catch something um, you know, the results if they're, I don't think they're going to be...

Patient: That's like the third time I heard that and – (*directed stare; touching face*)

Doctor: Alright, but the thing is I'm not going to treat you. I don't think so it's anything –

Patient: Right, right, I understand.

Doctor: That needs to be treated today.

Patient: I understand but the whole thing is that I know my cervix =

Doctor: And why does it come back –

Patient: Yeah. (Case #174)

Whether this patient previously received an ultrasound during the previous visits is unclear, but her frustration regarding the physician's tentative pronouncement that everything would be fine is easily apparent. As the physician rules out probable causes

for her pain, the participant counters, “That’s like the third time I heard that,” indicating that her pain has not been adequately addressed over the course of the present and previous clinical interactions. In this instance, the participant questions the tentative diagnosis in an attempt to emphasize the unresolved, ongoing nature of her pain.

In another instance, a participant questioned the diagnosis that the physician proposed, interjecting with a reminder of his symptoms. The participant, who had visited the clinic twice before to address the issue recurring abdominal pain, listens closely as the physician reviews the possible causes and then objects:

Doctor: Uh, it could be a simple gastroenteritis. That is an infection of the stomach, uh, because of some bug and stuff, maybe, you know, you ate something that, you know, nobody else did.

Patient: But it's recurring. (*gesturing; head inclined*)

Doctor: Right. No, I am just listing some possibilities; that's one of the possibilities. (Case 103)

In a clear demonstration of resistance, this patient challenges the physician’s assertion with his own assertion: “But it’s recurring.” While the physician goes on to recommend a scan of his abdomen, the role of patient agency in guiding this process is clear. Though the doctor acknowledges that she’s simply “listing possibilities,” it is unclear why she suggests a diagnosis that did not fit the ongoing, intermittent nature of the patient’s symptoms. Perhaps the physician would have ruled out this particular with the testing, but the patient’s frustration (conveyed with a rising tone and volume) is understandable. After multiple visits to the clinic to address his abdominal pain, he reacts quickly and decisively to shape and influence the physician’s ruminations about possible causes.

Referencing Other Knowledge. Participants also referenced knowledge from external sources during resistance sequences. When wielding this tactic, participants

discussed information (often contradictory in nature) that they had gathered from sources external to the clinical interactions, such friends, family, and other health practitioners. The participant who contested the source of his back pain attempted to advance his own theory about his kidneys by referencing information previously provided by another physician: “Now, another doctor that I was dealing with, he told me he think I passed a kidney stone once” (Case #143.) Likewise, the participant who disagreed about the source of an x-ray image cited a family member when the physician provided inaccurate information about menstruation and pregnancy:

Doctor: No, I don't think so, and if it is there then it won't be — you are having your periods?

Patient: Yes.

Doctor: When was your last period?

Patient: Just recently.

Doctor: Okay, so you are not pregnant, right?

Patient: That's not true, though. (*chin on fist*)

Doctor: Why?

Patient: Because my cousin =

Doctor: Yes.

Patient: = was having, just had — she had been on but had one for six months.

Doctor: She had a period =

Patient: For six months, right, no letup, and after six months found out it was something.

Doctor: So she was having some problem xxxx. But the exam does not show anything, and =

Patient: Right, but see, they didn't go and look for that. (*Smile; directed stare;*

hands punctuating words; Case #180).

Challenging Physician's Competence. In one instance, the patient who quarreled with her doctor regarding the unknown object on her scan finally questions the physician's ability to read the scan:

Patient: Right, right. Well, are you, uh, how do I put this, you are able to read these?

Doctor: Yes.

Patient: With knowing exactly what you see?

Doctor: Yes, most of the part, but the thing is, I'm not an official one. I'm not a specialist.

Patient: But is there someone here? (Case #180)

The physician indicates that he is able to read the scan and notes that he is not a specialist [referring to the location of the mass, in the chest region]. The patient, in turn, asks if someone else is present to read the scan. The participant uses this tactic in an effort to further undermine the physician (and his expert ability) as he attempts to quell her protestations regarding the source of the object.

Discussion of Resisting the Diagnosis. These excerpts show instances in which participants resist the diagnosis that their physicians present and, in some cases, advocate for their own diagnosis. Interestingly, patients used only active resistance strategies when resisting their diagnosis. Patients' admissions that they preferred to endorse their own their own diagnoses ("*I believe it's the kidney*"; "*But I have my own condition and what I might think it is*") signal a clear misalignment with the physician's diagnosis. In these cases, the participants cite information that was provided by another physician during a previous interaction in order to bolster their claim.

While participants have their own reasoning and present their own clues and evidence to support their beliefs, one should note they are perhaps not necessarily correct in their assertions. It is unlikely that the participant in the second excerpt had a baby floating in her chest region. The results from the second participant's testing of his kidneys were probably shared during a subsequent visit, yet the possibility exists that the source of this pain originated from his muscles as the physician suggests. Despite one patient's frustration, it is entirely possible that ultrasound results revealed that nothing was amiss, as her physician suggested. Accuracy aside, these self-derived diagnoses reveal a remarkable display of assertiveness. These patients not only assert their agency by questioning the diagnosis – they challenge the physician and reject the proposed diagnosis. These participants presented their physician with symptoms that seemed to counter the diagnosis that their doctor provided, perhaps indicating that greater explanation or education was needed in order for the participants to endorse the physician's treatment plan. Interestingly, physicians in all four cases agreed to further testing to rule out the diagnoses that the patients offer. While this physician response does not validate the patient's proposed diagnosis, it does demonstrate the effectiveness of patient resistance. Resisting the physician's diagnosis resulted in further exploration of their symptoms with the aid of testing, which potentially provided a diagnosis that the participants would be more willing to endorse.

While there is a dearth of research concerning interactional resistance, our findings confirm existing previous findings. Our participants did indeed resist diagnoses that they deemed inappropriate (Stivers, 2005). Just as Ijas-Kallio, Ruusuvuori, and Perakyla's (2010) findings indicate, our participants also referenced their immediate

symptoms, past symptoms and information provided during previous medical visits as resistance tactics when resisting the physician's recommended diagnosis. However, the resistance tactic of questioning the physician's competence is a new contribution to interactional resistance research. This tactic may be owed to a number of unique circumstances, specifically, the composition of this study's participants. Unlike Ijas-Kallio's study (2010), which consisted of Finnish patients in a primary setting, our participants are comprised of low-income black patients. The act of questioning a physician's competence is a clear resistance tactic, but is also indicates distrust. This finding is hardly surprising in light of the fact that this study's participants reported a high degree of previous perceived discrimination. Given the unique findings generated from this population, future research should examine the patterns of resistance that emerge from this and similar populations of minority and marginalized individuals.

Resisting the Treatment Plan

Of the small body of literature that examines interactional resistance, much of it concerns resistance enacted during discussions of treatment and treatment-related modalities. Our findings confirm this, as treatment-related discussions served as the sites for patient resistance. When presented with their physicians' treatment plan, four participants enacted resistance as a negotiating tool, sometimes proposing an alternative to that plan, or suggesting a new treatment plan altogether. The two patients who resisted their physician's treatment plan used an assortment of active resistance tactics, including proposing a different treatment plan ($n = 7$), questioning the treatment plan ($n = 11$), and sharing values and beliefs ($n = 1$). In two instances, two patients used a passive resistance tactic, withholding approval for the proposed treatment plan ($n = 2$).

Withholding Approval for Treatment Plan. In two instances, participants used passive resistance strategies by strategically withholding their approval of the physician's recommended treatment plan. In the first instance, a patient experiencing knee pain requested a stronger painkiller instead of the Naproxen that his physician recommended. As the physician demurred he offered explanations for why the Naproxen was more appropriate for his injury. As the interaction continued, the participant used a lengthy period of silence to withhold his approval of the physician's treatment suggestion. In the second instance, a patient refused to endorse his physician's treatment plan, which consisted of taking cholesterol medication:

Doctor: But at this point I think you need the medication. Still your decision.

Patient: I will have to still think about that.

Doctor: Ok. You still want to think about it?

Patient: Yes, I would rather think about that one. Uh and then maybe, you know, I can do another follow up. (*Head bowed*) (Case #121)

Questioning the Treatment Plan. Participants who utilized this strategy most often challenged the appropriateness of the physician's suggested treatment plan. In one instance, a patient questions his physician about the treatment recommendation that he's been given for managing an ulcer on his foot. The physician recommended that the patient wear a pressure sock, but the patient contended that the wound fared better without use of the sock:

Patient: Yeah, like I said it actually, when I was wearing the sock it was like =

Doctor: Yeah.

Patient: = I was like I just don't you know =

Doctor: Any stuff coming out of it?

Patient: Yes, especially with the sock.

Doctor: Yeah. Okay. Because I remember it was uh =

Patient: A little bit smaller.

Doctor: Smaller, it was kind of healing at that time =

Patient: But once again I'll say Dr. and once again, I wasn't wearing the pressure sock before = (*directed stare*)

Doctor: Yes.

Patient: = and it seemed like it was getting better =

Doctor: Right, right.

Patient: = and then when I put the sock on I decided, no I'm like, "It's like it's getting worse," but I kept wearing it because I uh uh just wanted to make sure. (Case #129)

After a lengthy discussion of how to treat the ulcer, the patient's protestation clearly functions as a challenge: "*But once again I'll say Dr., and once again...*" The patient is clearly distrustful of the physician's recommended treatment plan and maintains a sustained objection as the physician attempts to deliver and finalize the treatment plan.

Proposing Different Treatment Plan. The participants who utilized this tactic proposed different plans in response to the physician's recommended treatment plan. In one instance, a participant rejected the physician's recommendation to use over the counter medication to manage his pain and instead forcefully lobbied for the use of stronger pain medication to manage his knee pain:

Patient: Any alright, can you give me something besides the Naproxen. I don't want that because don't want my body dehydrated. (*leans away; fidget; turns head; avert glance; looks at floor*)

Doctor: Hmm? Naproxen is the best. It doesn't hurt your stomach so much as Motrin because you can take it only twice a day.

Patient: Why I can't have Vicodin is for pain, that's relaxing. That's keeps me not being in pain. All that other stuff I had I'd be in pain = (*shaking head; gesturing*)

Doctor: But Vicodin, you know, it doesn't decrease the swelling. Vicodin =

Patient: Uh, I can elevate that. I just want something stronger then for the pain = (Case #129)

In this excerpt, the patient rejects physician's recommended treatment plan for Naproxen, despite the physician's pronouncement that the Naproxen is "best". The patient begins a process of resistance in response to the physician's adamancy as he addresses the physician's concern about his knees swelling. The physician does not immediately address the patient's claim that the Naproxen does not provide adequate pain management for several turns and the interaction continued in a particularly contentious manner, with the patient continuing to press for a more potent painkiller through the use of demands and an aggressive tone.

The following excerpt shows the sustained resistance efforts, as the patient continues to challenge the physician's treatment decision as he petitions for stronger pain medication:

Patient: So what if it keep continue bothering me? I mean, I'll be, I don't want to keep being in pain and being uncomfortable, you know what I'm saying? Whatever I need to be done I want to go get it done. I mean I've taken = (*head nod; shaking head; scratched nose*)

Doctor: Yeah, I understand but give =

Patient: = all this different medicine =

Doctor: Give it time. You know =

Patient: I've taken medicines, I had Naproxen before.

Doctor: Yeah, but uh uh let's take because uh you do not use immobilization. You know what I'm saying? Uh you continue moving around with this thing and uh, you know, it uh =

Patient: That's why xxxx these medicines.

Doctor: Yeah, you have to give it a rest.

Patient: Yeah, and I do Naproxens, I had them before for I don't know what, for my foot. I had my foot crushed and then in = (*shaking head; fidgeting*)

Doctor: But this is different stuff. This is the best medication for this thing.

Patient: But I had the same doctor say that same stuff. I mean y'all start keep giving me that garbage for my leg I'll be in pain. Y'all don't understand. (*Avert gaze; lean away; shaking head; sigh; looking down at ground; Case #129*).

Here the patient continues to persist in his quest for a different treatment plan, each of his conversational moves countering the physician's attempt to defend his treatment plan. As the patient continues to resist, the physician is unable to end the treatment sequence and continues to work towards alignment as the interaction continues, ultimately consulting with the attending physician.

In another instance of patient resistance, a participant who suspected a pregnancy relentlessly voiced her dissent over the type of pregnancy test that the physician wished to prescribe, and the timing of the test's administration:

Doctor: What we are going to do right now, we'll do a urine pregnancy test and when you come after two weeks we will do the other pregnancy test, okay?

Patient: What's the other one?

Doctor: Blood. We will check the blood. That's a very good test.

Patient: So why don't do that first, the blood?

Doctor: Because I don't think you're pregnant.

Patient: I want to know. I don't, uh, I want to know for my own =

Doctor: All your convenience.

Patient: Yes, because like I said, my body's changing and it's and then you saying that, and I just want to make sure that it ain't nothing that if I'm taking medicine, it ain't nothing that's harmful that I'm doing. Because it did look a little suspicious to me = (*lean forward; direct stare*)

Doctor: Yes.

Patient: = the feeling ain't too good, you know =

Doctor: Okay. We'll get to your blood, okay? (Case #180)

The patient's rejection of the physician's planned course of treatment for investigating the pregnancy proved effective, as the physician ultimately yielded to her resistance efforts and ordered a blood test.

Stating and Defending Beliefs. Participants often expressed their preferences and values during interactions when discussing acceptable treatment plans. This tactic clearly functions as a resistance strategy in the instance below, where the physician offered his values and beliefs as a defense against endorsing her treatment plan. The participant resisted his physician's recommendation to start cholesterol medication, explaining that he was "against" the idea of taking medication on a regular basis:

Patient: Uh I'm really against it. Uh uh my family has done this medication thing all their lives and none of them gotten better. I mean I'm just going to be honest with you. Uh, I'm not a big medication guy. For the most part, most of my life I've stayed pretty healthy =

Doctor: Okay.

Patient: without doing medications. (Case #129)

As the interaction unfolded, the physician continued to press for acceptance of her treatment plan, citing the dangers of uncontrolled cholesterol levels. The participant refused, explaining his conviction that his low cholesterol could be managed with diet

and exercise. When the physician countered that his high cholesterol levels were possibly owed in part to a genetic component, the participant rejected her claim, recounting a history of longevity in his family:

Patient: My grandmother lived, uh my grandmother now is 79. And my other grandmother, well she uh was a diabetic and back then because she died in her fifties, because back then they just didn't have anything.

Doctor: Right.

Patient: But um uh, you know, they just didn't have anything and of course black patients really had a really hard time back then. So uh we attribute that to a little bit of that too. But um all the rest of my, I look at all the rest of my family members, I'm like, they lived too doggone long.

Doctor: Now your father was hypertensive as well =

Patient: Now my father, yeah, now my father, in particular my father was also a drug addict for 25 years so you know, and an alcoholic so I have to, you know, I have to look at some of those things, um.

Doctor: Yeah, but that should not give you high blood pressure or diabetes.

Patient: Well, if you eat pig's feet every single day = (smile)

Doctor: If you what?

Patient: Pig's feet =

Doctor: I see.

Patient: = and chitterlings and all the terrible foods all of your life =

Doctor: Yes.

Patient: = that's what he's done along with being a drug addict. You know, he just ate the worst and worst of foods and he smoked all his life. He smoked since he was 12 years old. See a lot of these things I just don't do, I've never smoked a cigarette in my life and I don't eat like my dad. You know, uh uh I have in the past but I've changed my diet over the last three to four years and um = (*Gesturing*; Case #129)

The participant's detailing of family history serves as further evidence as he continues resist the physician's plan. The participant constructs the early death of his grandmother as the result of black patients "having a really hard time back then." Exactly what he is describing is not clear here (whether stress or lack of access to health care), but the physician quickly counters this narrative of ancestral longevity with the reality of the patient's father, who also suffered from chronic health issues. Confronted with this example, the participant offers the excuse of poor diet.

Discussion of Stating and Defending Beliefs. In this excerpt, the patient's aversion to developing a dependence on medication, which is predicated on his belief that medication has been ineffective for other family members, serves as a resistance strategy. Research has shown that racial and ethnic minorities often have cultural beliefs about medical treatments. For example, Cooper et al. (2003) found that blacks were less likely than whites to find antidepressant medication acceptable. In this instance, the patient produces his belief as a defense against the physician's recommendation for treatment of his high cholesterol.

Refusal. Similarly, participants used active resistance to refuse treatment plans. In one example, a physician urged a patient to visit the emergency room to receive treatment for his elevated potassium levels and the patient initially refused: "*Uh, I can't. I can't.*"

In another instance, the patient with unresolved knee pain held steadfastly to his resolve when the physician asked him to consider taking the Naproxen. As the negotiation over the treatment plan reached a critical point, the physician made one last attempt to persuade the patient:

Doctor: I know, you are not, you know, uh uh uh why you need this Vicodin? It's not, you know, it's not going to help =

Patient: Who's the patient me or you?

Doctor: Hmm?

Doctor: Who the patient me or you? I'm for real, I mean this is not you. I'll be in pain and I know what helps me, you know what I'm saying? (*hands gesturing; hostile tone*)

Companion: He think you addicted, right?

Patient: I ain't no addicted to a goddamn Vicodin. Xxxx, I know what the xxxx do more for my leg.

[Silence]

Patient: Give me the prescription. I want some Vicodin. This is crazy. (*Avert gaze; looks at floor*) (Case #129)

This enactment of active resistance carries significant force, as the patient ignores the physician and repeats his demand. His refusal briefly ends the negotiation over the treatment plan and physician in turn retreated from the room and indicated that he would, "Talk to his supervisor."

Discussion of Resistance of the Treatment Plan. Participants resisted the treatment plan using both passive and active tactics. In both cases, the participants chose not to endorse the recommended treatment plan. As Heritage and Sefi (1992) explain, withholding acceptance to medical advice is classified as passive resistance because it signals the patient's unwillingness to follow the advice offered (p. 395). In both cases using passive tactics, the participants demonstrate an unwillingness to follow their physician's advice and this unwillingness is signaled in an indirect, passive way. In the first instance, the participant uses silence during a key juncture in the interaction when he would have otherwise agreed to the physician's plan. In the second instance, the

participant does not give a direct or outright denial of the treatment plan. Instead he delays (and ultimately does not give) his approval, requesting more time to “think that one.” Both instances meet Koenig’s guidelines for passive resistance, which include, “behavior other an acceptance where an acceptance is normative due, including: allowing a gap of silence” (p. 1108). Whereas these tactics signal “passive” resistance, they proved effective in signaling patients’ unwillingness to endorse the treatment plan.

Interactions using active resistance tactics show a relentless, often contentious process of resistance in which participants push for their preferred treatment plan. The content of these examples, however, inevitably raises questions about the appropriateness of their requests. To the practiced practitioner, the participant’s dogged pursuit of a potent painkiller (Vicodin) instead of the recommended Naproxen might signal drug-seeking behavior. Likewise, the participant’s insistence on receiving a blood test to rule out pregnancy instead of the urine test might be perceived as the patient’s incomprehension. These examples, especially in truncated form, show why marginalized patients who are “difficult” during the behavior are often negatively perceived.

Closer examination of the texts and their contexts, however, provides a more informed understanding of the circumstances that have likely motivated these enactments of patient resistance. In the first excerpt, the patient has visited the clinic for the second time, having been promised that his knee would be drained, thus alleviating his pain. After meeting with the present physician, the previous physician’s diagnosis is discarded and the patient is told that the knee simply requires an over the counter pain reliever and elevation. In response, the patient informs the physician that he is still in pain, unable to work (and needing to return shortly). After his hopes for pain relief are dashed, he

further informs the physician that he has Vicodin helpful in alleviating his pain, and requests “something stronger” than the Naproxen to assist in managing his pain so that he can once again sleep and return to work.

In the second example, the participant evinces feelings of distrust towards her physician when he provides her with technically incorrect information. While attempting to convince the patient that the indistinct object in the scan was not a pregnancy, the physician advised her that she could not be pregnant because she had recently menstruated. “That’s not true!” The participant retorted, and went on to relay the experience of a friend who had indeed been pregnant despite regular periods (Case #180). The physician’s misstep further complicated his attempt to prove that she was not pregnant and seemed to strengthen the patient’s resolve as she continued to press for testing.

While these excerpts show the process by which patients resist treatment plans, the overall interactions point to a gaping chasm in understanding and perspective between the patient and physician. It is, perhaps, safe to assume that these physicians want the very best for these patients and as such have provided plans that seem most appropriate for addressing their needs. In spite of this, the previous health care experiences of the patients have taught them to closely examine the physicians’ offerings, and in some ways, their suspicions are justified. The patient in the first interaction was met with the news that he was previously misdiagnosed and his expectation for pain relief would not be met that day. The second participant, who had previously aired her suspicions of misdiagnosis, persisted in her resistance of the physician’s treatment plan when she identified a flaw in his reasoning.

It is hardly surprising, therefore, that patient resistance occurred during these interactions. When understood with a foregrounding of the contextual circumstances that shaped these interactions, and the resistance that the patients ultimately enacted, resistance can be understood as a means of advocating for one's self. These participants are not only resisting the physician's treatment plan, they are attempting to minimize or eliminate any chance that they will not receive the care they deserve and potentially leave the interaction with their needs unmet.

While there is a dearth of research concerning interactional resistance, our findings confirm existing previous findings. Participants did indeed enact resistance when they deemed their physician's treatment plan to be inappropriate. While Stivers (2002) discusses the resistance tactics that parents often use when advocating for antibiotics, our study shows that patients resist treatment plans across a variety of topics. In addition, participants in this study used both active and passive resistance strategies when challenging the physician's plan. A participant's use of silence to resist the treatment plan was especially noteworthy, and confirmed research that frames strategic silence as a tactic for enacting resistance (Koenig, 2011; Wagner, 2012). Future research should examine the ways in which marginalized participants may utilize both active and passive forms of resistance tactics.

RQ3b: How do physicians respond to the resistance strategies of marginalized individuals with a history of discrimination?

Several participants in our study initiated resistance sequences when discussing their diagnosis and/or treatment plan with their physician. In our investigation of the five patients who enacted resistance, we found that these enactments often influenced the

outcome of the interaction. Physicians responded to patient resistance in one of three ways: 1) The physician offered a compromise with the patient that allowed for the emergence of a mutually acceptable treatment plan, 2) The physician conceded to the patient's request and granted the patient's request, or 3) The physician denied the patient's request. In three cases, the physician offered a compromise that produced a mutually acceptable treatment plan. In one case, the physician denied the patient's request, while in another case the physician conceded to the patient. The following table below provides an overview of these conflicts, as well as the physician's response to the patient's resistance.

Table 3.

Physicians' Responses to Patients' Resistance Tactics

Case Number	Topic of Resistance	Physician Response
174	Patient refuses to endorse physician's tentative diagnosis; complains that she has been given the same information in previous visits.	Physician denies request Physician maintains that she cannot treat her for cervicitis or any illness without a manifestation of illness; continues with plan to order ultrasound.
104	Patient refuses when physician advises him to immediately check into the ER to receive treatment for dangerous potassium levels; explains personal responsibilities and duties and negotiates for a delayed visit on the following day.	Physician Compromises Patient agrees to check into ER after running an errand.
129	Patient demands Vicodin for his knee pain. Physician advises that Vicodin will not adequately address inflammation and instead	Physician Compromises Physician offers treatment plan that consists of Vicodin and Naproxen.

	recommends Naproxen.	
143	Patient complains of back pain, shares his belief that his kidneys are the source of his discomfort. Physician advises that the pain is likely muscular in nature.	Physician Concedes Physician orders diagnostic tests to assess patient's kidneys.
180	Patient brings film from previous scan, insists that suspicious site on scan is pregnancy; physician explains that it is not a possibility and recommends additional scans.	Physician Compromises Physician orders pregnancy test, patient agrees to follow up with additional scans.

These results show that physicians in our study did adapt their treatment plans in response to patient resistance. These results raise questions about the larger implications surrounding patient resistance. While patient agency and “activation” is ideal during clinical interactions – especially for marginalized patients – could patient resistance interfere with physician’s administration of the best treatment plan? In each sequence of resistance, patients delivered impassioned requests and pleas to their doctors. Despite the surrounding context clues, we can never be completely sure of the patient’s intent. While one patient provided a compelling rationale for his Vicodin request, another patient’s request aroused the physician’s suspicion. These examples show the dilemma that physicians face when attempting to render the best treatment plan while acknowledging the needs and wishes of the patient.

In addition to the question of assessing patient honesty and intent, physicians also experienced difficulty when attempting to persuade patients to pursue the best course of treatment for their health. In one instance, the bargain that a physician struck with a patient (allowing him to delay his arrival at the ER) reflected an acknowledgement of the

patient's contextual circumstances and engagement in the patient's lifeworld. In spite of this, the patient's decision to delay medical care was clearly inadvisable. Similarly, another patient's demand for Vicodin complicated a physician's efforts to treat the inflammation associated with his knee injury. While patient resistance is effective and allows the patient a greater measure of power during the interaction, it might not always result in the best outcome for the patient.

It should also be noted that patients do not have the same expert power as the physician, as such, might press for diagnoses or treatments that are not technically correct. This possibility is highlighted in the case of patient who suspects that an abnormality in a scan of her chest is a pregnancy. It is safe to assume that that the physician's explanation of anatomy proved to be true, but the patient's resistance in this case is problematic. As the physician persisted in his request to have follow up scans completed, the patient initiated a lengthy and often contentious sequence of resistance as she defended her self-diagnosis. Similarly, another patient rejected his patient's suggested diagnosis of back pain and insisted on further exploration of his kidney. Given the content of these cases, patient resistance can be understood as a potential drain on clinical resources.

Stivers (2005, 2007) speaks to this dilemma, identifying patient resistance as a challenge for physicians as they attempt to render the most appropriate treatment plan for patients. Stivers discusses resistance as a contributing factor to the overuse of antibiotics, as parents often pressed physicians to prescribe unnecessary antibiotics for their children. Her assertion has merit, especially as our findings shows that patients initiated lengthy clinical sequences for diagnoses and/or treatment plans that were perhaps incorrect or

unnecessary. It is unlikely that a patient experienced a pregnancy in her chest region, and the additional testing that she and other patients demanded potentially represent unnecessary tests and expenses that would not have occurred without the patients' relentless intervention. While patient resistance allows patients to claim power during the clinical interaction, it is clear that such efforts may work against clinical efficiency.

General Discussion: Revisiting the Culture Centered Approach

This investigation used a culture-centered approach in order to produce a contextualized, culturally informed understanding of how marginalized patients demonstrated agency and resistance when interacting with physicians. Our findings can be further interpreted using Dutta's (2008) culture-centered theory, which describes how the interdependent relationships between culture, structure and agency often influence and shape how marginalized obtain health services. The results of this study fit neatly within this model, providing insight into the communication processes that occur in clinical interactions with marginalized individuals.

The roles of culture and structure are immediately recognizable within our results. Discriminatory and inequitable practices of larger overarching structures ultimately influenced the patients' cultural beliefs and practices. Participants reported previous discrimination across several domains, including health care, housing, education and law enforcement. These previous experiences most likely shaped pre-existing attitudes and beliefs of participants, who often seemed to enter the clinical interaction prepared to directly or indirectly address any discrimination or inequity meted from their physician. These expectations were perhaps justified, as several participants indicated that they had

previously visited the clinic and received inadequate care. Dutta (2007) explains this reciprocal process:

Cultures are intrinsically linked to the social structures that surround them because the way resources are allocated and controlled significantly influences how meanings are created in the context of the life experience of cultural participants. In fact, cultures continually interact with these structures; on one hand, they shape structures and, on the other hand, cultures are shaped by structures (p.321).

This dynamic is clearly at work among our participants, as they seek to obtain health resources within a system that continues to disenfranchise them with under qualified physicians, inadequate health care coverage and insurance and insufficient resources. These circumstances likely influenced the perceptions and behaviors of our patients.

The cultural values and beliefs of our participants, in turn, shaped and influenced the ways in which our participants enacted their agency within the structure of the clinical interaction. Findings from the primary study indicated that individuals who scored highest in previous discrimination featured in clinical interactions in which patients talked more than their physicians. Penner et. al (2013) theorized that this perhaps pointed to an effort by participants to avoid further discrimination during the interaction. Our results support this finding, as we found that participants often showed suspicion and distrust during the medical interactions, as voiced in their skepticism of their physicians' qualifications and decisions concerning diagnosis and treatment. Participants often directly shared their perceptions and beliefs concerning the intent and efficacy of the clinical and its staffing physicians, in several instances advised physicians that they

trusted their own expert knowledge of their bodies. Many participants did not hold the belief or opinion that their physician's would provide the best quality of care, and initiated action intended to produce the best possible outcome.

As such, the interdependent relationship between culture and agency was clearly evident during observations of patient agency and resistance. Patients managed their presentation to the physician, carefully constructing their self-image in an effort to be positively perceived. Patients were adept at enacting agency, often surprisingly so. Participants routinely questioned the qualifications of their physicians, and closely monitored the physician's progress during the interaction in order to ensure that all the pertinent information was considered and processed during the construction of the diagnosis and treatment. Objections and interruptions were utilized to ensure that the adequate consideration was given to all of the key pieces involved during the identification of the diagnosis and treatment plan. Patients consistently asked questions of their physicians, clarifying information when needed and expressing their concern when the treatment plan did not resonate with their own expectations or desires. Patients worked as advocates in their own interests, displaying vigilance as they monitored the progression of the clinical interaction, as well as the physician's comprehension of their illness and related symptoms. Patient resistance represented this same process of advocacy, as patients pressed physicians in an effort to ensure that they had received the most accurate, appropriate diagnosis and treatment plan. While patients were perhaps not always correct in their assertions, their actions are perhaps understandable given the context of a history of misdiagnoses and inadequate patient education. The link between enactment of agency as a result of cultural values are clearly shown in our findings.

The reciprocal relationship between structure and agency is also on display during observed interactions with our participants. The same dialectical tension between structure and agency that Dutta (2008) discusses in his study of West Bengali men is also apparent in the lives of these black, low-income patients. Just as a participant in Dutta's (2008) study remarked that health was the absence of hunger, a patient within this investigation commented to his physician that food was a luxury. Findings from this study showed that participants contended with devastating contextual factors in the midst of their efforts to secure health services. Personal struggles such as unemployment, homelessness, inadequate insurance coverage and poverty were formidable obstacles for several patients, and often constrained and shaped the ways in which patients enacted their agency when attempting to manage their health independently or with a physician's assistance. As our study shows, patients' efforts to obtain health care from physicians were often further stymied by the inferior quality of health care resources provided. Insurance coverage through Medicaid and other government plans often did not provide adequate access for prescriptions, medical supplies, and referral for specialists. In addition, the physicians that provided care for patients were residents who were still receiving training under the supervision of an attending physician. The findings from this study show that issues of patient agency and resistance go beyond the dyadic relationship of the patient and physician and represent a persistent system of oppression and subjugation that often shapes how patients' perceptions and beliefs, as well as the ways in which they enact their agency when attempting to manage their health.

CHAPTER FIVE

Conclusion

In this project, I sought to understand the nature of agency and resistance among black primary care patients. This investigation interrogated several of the assumptions that guide current contemporary health interventions. Health scholars and their subsequent health interventions have asserted that marginalized patients are generally less active and may require “activation” in order to demonstrate the ideal participatory behaviors during the clinical interaction. This approach fails to consider the complexity of factors that influence the health behaviors and beliefs of marginalized and minority patients. It is therefore crucial for health scholars to understand the interdependent relationship between culture, structure and agency. This approach seeks to establish a starting point of inquiry for this research imperative by exploring the ways in which black primary care patients *do* enact their agency, and in some cases, resistance, during the clinical encounter. This line of research potentially offers an important contribution to behavioral research as it offers a new perspective for understanding how marginalized patients are already active, and strategic in their enactment of agency. Such an understanding can ultimately provide a cornerstone for accurately identifying and targeting the factors that contribute to health disparities.

Summary of Findings

The first research question asked, “What are the contextual factors that marginalized patients with a history of discrimination describe during the clinical interaction?” After the analysis, I found that participants described a myriad of contextual issues, including insurance coverage issues, homelessness and job loss. In several instances, these

contextual and psychosocial issues influenced participants' health behaviors. More specifically, participants advised physicians that external circumstances influenced health management behaviors such as seeking help from a specialist, gaining access to medication or attending doctor's appointments.

The second research question asked, "What are the agentic strategies used among marginalized patients with a history of previous discrimination?" Following the analysis, I found that study participants enacted agency in a plurality of ways. The observed enactments of agency served a variety of functions during the clinical interaction, ranging from questions and requests that addressed instrumental needs and more subtle, strategic tactics that attempted to influence the physician's perceptions. These results showed that marginalized patients are not generally passive, as has been previously supposed, but are often mindful and strategic in their enactment of agency. In fact, the previous experiences of discrimination participants reported may have primed participants to display more participatory behaviors in an effort to prevent additional discrimination.

Research Question 3a asked, "What are the resistance strategies used among marginalized patients with a history of previous discrimination?" Following the analysis, I found that a few study participants did indeed enact resistance as they resisted the physician's diagnosis and/or recommended treatment plan. During these sequences of resistance, participants employed multiple tactics, such as questioning the diagnosis/treatment, proposing a new diagnosis/treatment, withholding acceptance of the treatment plan and stating values and beliefs. Resistance efforts functioned as the vehicle through which patients pressed and persisted in their effort to secure a mutually

acceptable treatment plan and/or diagnosis. Study results suggest that marginalized patients have the capacity to enact resistance strategies, and often launch resistance strategies in an attempt to secure a better quality of health in the midst of a vastly imperfect health care system.

Research Question 3b asked, “How do physicians respond to the resistance strategies of marginalized individuals with a history of discrimination?” I found that patients’ resistance tactics proved effective in several instances in which physicians compromised with the physician and tailored their treatment plan in order to receive the patient endorsement. Patient resistance strategies were not always successful, however, and in several instances consumed clinical resources (such as time and additional testing) as the physician attempted to address and assuage patients’ requests and demands.

These findings, when viewed comprehensively, provide a more fully fleshed understanding of the ways in which marginalized patients participate during the clinical interaction. The culture centered approach provides the ideal framework for interpreting the study results. Study participants were often mired in structural issues such as joblessness, underinsured status and mental health challenges. These challenges subsequently compelled patients to enact their agency strategically during the clinical interaction. Displays of patient agency and patient resistance often functioned to optimize clinical outcomes, especially in light of structural constraints such as less qualified physicians. Within this framework, marginalized patients’ participation in clinical interactions can be understood as the product of inextricably intertwined factors.

Conclusion/Implications

The understanding of patient participation as complex, especially in the case of marginalized individuals, calls for a recasting of the principles that undergird contemporary health interventions. While personal choice exists for every patient, it is clear that the phenomenon of patient-physician communication does not exist in a vacuum. Marginalized patients, in this case, low-income black primary care patients, are not able to emancipate themselves from a complex webbing of discrimination and inadequate resources with personal choice.

In addition, the patients in this study demonstrated patient agency and patient resistance without the aid or prompting of a question prompt list. Contrary to Epstein's (2006) assertion that marginalized individuals "might not like to be activated," patients in this study demonstrated agentive behavior. In fact, these demonstrations represented patients' attempts to obtain the best possible care amidst substandard health care resources. Clearly, there is a lack of understanding concerning marginalized patient's motivations and the strategic nature of their enacted agency and resistance. Participants in this study demonstrated – unprompted- the three behaviors that form the cornerstone of patient activation: asking questions, expressing concerns and assertively stating their needs. These displays of "activated" behavior occurred consistently among participants. In some cases, patients moved behind "activated" and agentive behaviors and challenged the physician.

The observed interactions in this study show that marginalized patients are capable and adept at enacting their agency. In fact, larger structural and contextual issues may have motivated these patients to display more agentive and resistant behaviors as

they fought to obtain the best level of care amidst lower levels of quality. These demonstrations of enactment and resistance are also representative of an adaptive response to the systemic inequity. From a culturally informed perspective, patient activation stands a yet another failed recipe for “empowerment.” As our study shows, true change can only be brought about when disparities are examined not only from an individual perspective, but also with a commitment to addressing the structural inequities that perpetuate these disparities in care.

Limitations. Using a culture-centered approach, this study explored the nature of patient agency and patient resistance during clinical interactions with marginalized patients. While this study yielded original and actionable results, there are several noteworthy limitations to the study and its design.

This study conducted a secondary analysis of data collected during the larger primary study. As such, the data was constrained according to the goals and data collection procedures of the parent study. For example, this investigation used patients from both the control and experimental arms of the parent study. Ideally, a study of this nature would observe only the data in the control condition to ensure that the intervention from the primary study did not influence communication. Also, the amount of time that elapsed since the closure of the study until the present study was considerable, and would not have allowed for follow-up interviews with participants. Given the critical nature of the culture-centered theory, participant interviews would have been the ideal method for exploring the motivations of study participants. Future studies should redress this limitation by conducting extensive interviews before and after the clinical interaction.

In addition, this study relied primarily upon the video recorded and self-reported data for supporting contextual information. As such, context could only be derived from information that patients provided to physicians during the interaction. This also limited the extent to which inferences could be made about the patient's intent, a considerable limitation given the culture-centered perspective of the study. Future studies should ideally include interview data.

Future Studies. Future studies should build upon the findings of this study by using several different approaches. First, this study and its typology should be expanded and applied in specialist medical settings as well as primary care settings to determine if there are any differences in patient agency or patient resistance strategies emerge depending on specialty. Patients in our study were overwhelmingly active, and in some cases, resistant. These findings might differ in a specialty setting, such as oncology, where the nature of one's health condition might influence the degree to which a patient might rely more fully on the expert knowledge of the physician.

Second, future studies addressing patient resistance and patient agency should utilize ethnographic methods that allow for the observance of not only the clinical interaction, but the integration of interview data that reflects the perspectives of the patient and the physician before and after the intervention. Such an approach would allow for a richer, more comprehensive understanding of patients' cultural beliefs, attitudes, perceptions and intent during the clinical interaction. The present study relies upon contextual clues derived from the interaction, such as the patient's stated intent. Utilizing ethnographic methodology at various points in time, both before and after the

interaction, would provide a fuller understanding of culture, as well as the degree patients are aware of their strategic use of agency and resistance.

Third, subsequent studies should include the interviews with patients that occur as the patient is watching a video recording of the clinical interaction and providing feedback. This present study examined enactments of agency and resistance, as defined by existing literature. An important contribution to this area of study would involve the patient's identification of his or her own strategic moves, with an explanation of why those moves were enacted. Data collection resulting from this methodology would come the closest in assessing the values, beliefs and intents of marginalized patients, from the perspective of a cultural insider.

Fourth, future studies should develop and implement health interventions that address the various dimensions of need that influence the health of marginalized individuals. Such an intervention would consist of a multidisciplinary team of practitioners, including social workers, nutritionists, patient navigators, therapists and Medicare/Medicaid liaisons and life coaches. Under the auspices of this intervention, patients would receive services from each practitioner in order to address any factors that might impede the patient's ability to successfully manage his or her health. An intervention of this nature acknowledges and attempts to treat the interdependent nature of culture, structure and agency.

Fifth, future studies should adopt a more dyadic approach to observing the interplay between both the patient and the physician during instances of agency and resistance. This study endeavored to produce an exhaustive report of patient agency and resistance from the perspective of the patient. Future studies should expand this approach

in order to understand the iterative nature of patient agency and resistance, such as the observing the ways in physicians respond to patients, and how patients respond to these reactions.

Finally, future studies should apply this typology to different kinds of marginalized groups to determine if patterns of patient agency and patient resistance vary according to race, ethnicity or socioeconomic status. The typology that resulted from this investigation is built upon observances of clinical interactions involving low-income primary care black patients. Participants with different sources of marginalization may face different challenges and obstacles, and as such, may enact resistance and agency in different ways. Application of this typology in various contexts is essential, as theory-driven research is needed to address the dearth of interactional agency and resistance research.

In closing, patients in this study enacted agency in both subtle and overt ways, both verbally and nonverbally. Our findings counter previous studies that conceptualize marginalized individuals as passive and non-participatory during clinical interactions. Future studies should continue to examine how marginalized patients strategically enact agency and resistance in an effort to obtain health services.

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ABSTRACT**AGENCY AND RESISTANCE STRATEGIES AMONG BLACK PRIMARY CARE PATIENTS**

by

JANELLA HUDSON**August 2015****Advisor:** Dr. Katheryn Maguire**Major:** Communication Studies**Degree:** Doctor of Philosophy

Research has identified marginalized and minority patients as displaying fewer participatory behaviors during the clinical interaction. Using a culture-centered framework, this study examines the process by which patients with a previous history of discrimination employed agency and resistance strategies in order to influence the outcome of their clinical interactions. This study conducted a secondary analysis of the video taped interactions of 25 black primary care patients in an urban low-income clinic. Using qualitative content analysis, I identified five emergent themes for patient agency: interrupting the physician, stating observations of care, expressing needs and desires, constructing identity, and agenda/goal management. Participants also used both active and passive forms of resistance tactics in an effort to influence the diagnosis and treatment plan, including questioning the diagnosis/treatment plan, proposing a new diagnosis/treatment plan, providing values and beliefs, questioning the physician's competence and refusing to endorse the treatment plan. Results from this study indicate that black primary care patients with a history of previous discrimination displayed

highly participatory behaviors during the clinical interaction, with displays of patient agency and, in some instances, patient resistance. Future research should examine the role of patient resistance as an attempt to negotiate within the interaction.

AUTOBIOGRAPHICAL STATEMENT

I am a communication scholar conducting behavioral research within interpersonal, family/relational and community-based contexts using qualitative research methods. More specifically, my research has examined interpersonal communication between physicians and marginalized patients, family/relational processes of disclosing genetic risk to genetically-related family members, and community-based research to explore cultural values and beliefs that influence cancer behaviors, such as screening and adhering to treatment recommendations. My overarching research goal is to utilize culturally grounded understanding to address and improve health disparities that disproportionately affect minority and underserved communities.