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AFRICAN AMERICAN PARENTS' EXPERIENCES
IN THEIR CHILDREN'S HEALTH CARE
ENCOUNTERS

By

Rebecca D. Green

A Dissertation

Presented in Partial Fulfillment of Requirements for the

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DEDICATION

I dedicate this work to my husband, Mike, and my son, William, who gave me the time, space, support, and encouragement to pursue doctoral studies.

I dedicate this work to the school nurses in the Valdosta City School system, who work tirelessly every day to care for the most vulnerable children in our community.

I dedicate this work to the women who participated in this study, who overcome difficult circumstances and navigate barriers every day to provide opportunities for their children.

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ABSTRACT

AFRICAN AMERICAN PARENTS' EXPERIENCES

IN THEIR CHILDREN'S HEALTH CARE

ENCOUNTERS

By

Rebecca D. Green

Persistent disparities in African American child health may be the result of the intersection of many social determinants of health and other factors, such as health care relationships. A review of the literature revealed a gap in understanding of African Americans' perceptions of care; and a gap in understanding of dimensions of relationship-centered care between African American patients and health care providers. The purpose of this qualitative study was to interview African American parents about their encounters with their children's health care providers; in order to generate new understanding that could lead to interventions that can measurably improve health outcomes for African American children. The author employed an interview guide to interview 18 African American parents in a small south Georgia town about encounters with their children's health care providers. The data were analyzed within frameworks of social phenomenology, critical ethnography, and intersectionality. Data fell within two main content areas: precursory parental relevances, and we-relationships. Precursory parental relevances included: symbolism of illness and wellness, typifications of health care providers, and various in-group/out-group memberships. Membership in the

insurance out-group was particularly important in parents' perceptions of health care encounters. Parents' descriptions of we-relationships with children's health care providers were categorized as routine, problematic, or transformative and were characterized by parents in terms of how patient-centric provider role expectations, relevances, group memberships, and knowledge affected the relationships. Practical recommendations include concrete relationship-centered interventions for health care providers. Recommendations for health professions education include a call for development of cultural competence curriculum with greater emphasis on understanding how health care language, mores, customs, values, codes and practices serve to alienate those persons it purports to serve; and inclusion of intersectionality as a framework for consideration of environmental macrofactors that contribute to health disparities.

Keywords: African American health, patient-provider relationship, relationship-centered care, social phenomenology, intersectionality, health care culture

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CHAPTER 1: INTRODUCTION

1966 was a busy year for African Americans and Whites in Atlanta. The “city too busy to hate” was reeling in the face of civil rights legislation and the following race riots, and African American leaders and students were organizing in order to achieve a vision of African American control over African American communities (The New Georgia Encyclopedia, 2011). It was also the year I was born at St. Joseph’s Infirmary, on Courtland Street in downtown Atlanta. Ironically, that historical site of St. Joseph’s, the current Martin Luther King, Jr. memorial, and the Margaret Mitchell House all are within two miles of one another. Ironic, because these very symbolic physical locations represent tensions of internal positionality for me, a White southern woman of slave-owning ancestry. Elsewhere in Georgia in 1966, the reality of civil rights was slower to take hold. At the time, some civil rights activists ruefully suggested that the movement stopped at Perry, south of Macon (New Georgia Encyclopedia, 2011). In one small south Georgia town, the biggest news of 1966 was not the civil rights activity happening in Atlanta and other large metropolitan areas, but the local opening of an international clothing manufacturing plant. This plant would bring economic prosperity to many residents both African American and White, and to a town that historically had depended on agriculture. In that year of my own birth, 1966, my mother never knew a thing about the small south Georgia town or about the new factory, both of which will be pivotal in

the pages ahead. If she had known about them, she never would have imagined that they would prove meaningful to her brand new daughter some forty-five years later.

My mother, now deceased, frequently referenced those volatile days of marches and protests in Atlanta, wondering “where she was” during that period of time. She felt guilty that she was not an active participant in lunch counter sit-ins and other active non-violent protest. The reality is, though, that she was tucked safely away in a white suburb of Atlanta, with a 5 year old and brand new baby, her husband a freshly minted attorney. Her feelings of guilt, however, lasted her entire life, and resulted in redoubled efforts to “help the disadvantaged.” As my sister and I got older, my mother established girl-scout groups in Capitol Homes downtown and taught Sunday School every Sunday for twenty-five years in the Girls’ Juvenile Detention facility downtown. We often got taken along. Her efforts continued throughout her life and up until the day she died. In her retirement, she led a weekly women’s song and music fellowship in a women’s detention facility in North Carolina.

Needless to say, my mother profoundly influenced me. She grew up in genteel poverty just off the Natchez Trace in central Mississippi, where her closest friends and playmates were the children of the African American tenant farmers across the road. The two families “did for each other” in times of stress and need and shared and celebrated together in times of plenty; but her friends always used the back door and referred to her as “Miss Trudy.” My mother and her nine siblings, poor descendants of wealthy slave-owners, grew to adulthood expressing vastly different attitudes about race and race relations. Some were outwardly prejudiced, others more like my mother. It is people like my mother, and their children, products of the Civil Rights era, who have struggled and

continue to struggle with their own legacy and White privilege, in the form of *White guilt*, the guilt experienced by Whites regarding the history of slavery and continuing white privilege (Katz, 1978; Collier & Horowitz, 1997; Smith & O'Connell, 1997).

White privilege is the unearned advantages of being White in a racially stratified society (Neville, Worthington, & Spanierman, 2001).

On a personal level, I concede that a certain amount of White guilt (Katz, 2003) colors my worldview. One of the primary reasons I chose to go into nursing as a young adult was the personal compulsion I felt to “help others,” particularly African Americans. Having grown up in a White community in the deep South, and having liberal parents who made a special point of “helping the disadvantaged” created a certain amount of paternalism in my ideas and attitudes. Like many in the helping professions, I feel as though I have an obligation to care for others, as if others are somehow not capable of caring for themselves. In pursuing this topic of inquiry, the stated purpose of which has to do with consideration of equity and examination of power imbalances in health care relationships, I must acknowledge that my own attitude contributes to the very dynamics I attempt to identify. I also must confront the legitimate question of whether a White scholar is able to really understand and interpret the African American experience.

On a professional level I have bias as well. Practically, I have engaged in many discussions with other clinicians about our frustrations with parents of all ethnicities and why they “don’t just do what they ought to.” “What they ought to” inevitably refers to what we are telling them to do! On a more sensitive note, this conversation most often occurs in reference to families of minority ethnicities or social class; in the South, most often poor African American families. Clinicians are often wedded to a belief that their

clinical solution or approach to a problem is the correct one. Concern for children who are dependent on their parents creates clinician indignance when it is perceived that their parents do not apply the prescribed solution. Health care encounters in the United States are both voluntary and compulsive. Parents are required to comply with immunization law, for example; but not required to seek treatment for strep throat. Why are some so hesitant to comply with what is required by law, yet so over-quick to utilize emergency care for non-emergent situations? There are many answers to these questions available in scholarly literature and research; but it is safe to say that the health care encounter is often fraught with social, economic, gendered, and professional inequity. This inequity may establish professional bias and may lead to unquestioned assumptions that the professional practitioner may not be aware of in daily encounters and interactions with patients.

It is one of the primary premises of this dissertation that the professional bias and assumptions that may go unquestioned by the practitioner are reflective of not just White ethnocentrism, but of professional ethnocentrism. Ethnocentrism is “the tendency of an individual or group to hold the feelings and beliefs that one’s own values, beliefs, and practices are the most desirable, acceptable, or best, and to act in a superior manner to another culture’s values, beliefs, and practices” (Jeffreys, 2001, p. 45; Leininger, 1991). Zoucha (2000) acknowledged that ethnocentrism and resultant stereotyping, prejudice, bias, and discrimination adversely affect interactions and relationships between clinicians and patients. It is often the case, as well, that the things we most often value as professionals are prioritized differently by patients. These priorities may differ even more when ethnicity is considered. As clinicians, practice may improve as we move

from ethnocentrism toward ethnorelativism, “the experience of one’s own beliefs and behaviors as just one organization of reality among many viable possibilities” (Bennett, 2004). The ethnocentrism that normalizes behaviors and family structures according to white nuclear-family middle-class norms is evident throughout literature from a variety of disciplines.

The Moynihan report of 1965 is a classic example which portrays “the tangle of pathology” in the African American family structure as responsible for gaps in income, standards of living, and education in the African American community (Moynihan, 1965). The irony of the Moynihan report (1965) is in its well-meant attempt to improve outcomes for African Americans through a concerted government effort. The glaring assumptions and paternalistic attitude of the Moynihan report seem obvious to those reading it today, but it is precisely this dynamic of well-meaning ethnocentrism that I believe still exists in clinical relationships between health care professionals and patients of all ethnicities; and is even more divisive in the relationship with ethnic minorities like African Americans. Just as the Moynihan Report sought to rectify social and economic disparity through repair of perceived dysfunction in family structure, the Western health care approach seeks to rectify health disparities using ethnocentric approaches to repair dysfunctional human bodies and alter dysfunctional responses to illness. This approach is a complex one that makes assumptions about deviance from norms on both the level of fundamental functional bodily norms, as well as on ethnicity-based societal norms. I believe this is a complexity that health care professionals do not yet fully recognize, and one that is responsible for a great deal of the way we identify and address (often unsuccessfully) health disparity.

Bryant and Coleman's (1988) review of the portrayal of African American families in college-level marriage and family textbooks from the 1980's identified 25 textbooks that included discussions of African American family life and identified the text's perspectives as either cultural deviance (African American family life as deviant from a White norm), cultural equivalence (legitimizing African American families that adhere to a White norm, and making references to characteristics like extended kin networks as positive but *different from* White norms; and acknowledging racism and discrimination as reasons for deviance), or cultural variance (no comparison of African American family structure to White family structure). They found that even textbooks that legitimized African American family structure as positive often did so while assuming a nuclear white middle-class norm, using concepts like *legal marriage* and *two-parent families* as desirable and good. All of the textbooks used a deviance, equivalent, or mixed approach; none used a totally variant perspective. While this may have changed since the 1980's, Bryant and Coleman's study is reflective of a long history of ethnocentrism in the academic milieu in which currently practicing professionals were trained (Davis, 1995; Teo & Febrarro, 2003). Bryant and Coleman's study (1988) certainly provided some insight into the way a disciplinary approach can embrace norms without thought to whether the very idea of normal is itself a barrier. This insight has major implications for the conceptual norms with which health care professionals associate illness and wellness, in assumed values related to fundamental concepts like *blood pressure, weight, diet, and exercise*. Bayne-Smith (1996) stated it succinctly when she said that "the difficulty most people experience is that culturally conditioned behaviors, responses, and ways of interacting become at the most profound levels the

total framework out of which they not only operate but also interpret and judge the behaviors of others” (p. 36). I hope to illuminate this perspective of norms and cultural ethnocentrism in the discussion section.

As a nurse practicing in the pediatric arena for most of my career, I have encountered many African American children and families. Given that there are limited numbers of African American clinicians, it is most often the case that African American patients and families are cared for by White health care providers. While this may not be ideal, it is essential that all patient populations receive the highest level of care regardless of race, class, or ethnicity. Without exception, every clinical milieu in which I have practiced has demonstrated that the relationship between African American clients and White clinicians may not be optimal. With any ethnic group, clinicians from ethnic or social backgrounds different from those of their patients may stereotype and make unfair assumptions, and patients may rightfully resent what they perceive to be judgment, prejudice, and lack of understanding. Because African Americans constitute such a large minority, especially in the southern United States, they are the group most often at risk for stereotyping and unfair assumptions by clinicians.

Purpose

In my practice as a pediatric nurse, I am concerned about clinician relationships with parents and how those relationships affect the health of the child. The purpose of this study was to interview African American parents about their encounters with their children’s providers, in order to generate new understanding that may lead to interventions that can measurably improve health outcomes for African American children. I was also interested in comparing themes that emerged from interviewing

African American parents from different socioeconomic backgrounds. The overall aim of this study was to gain understanding of the personal, familial, and sociocultural forces that shape African American parents' encounters with health care providers and the health care system. It was anticipated that the understanding gained in this study would facilitate the creation of culturally sensitive approaches that health care providers and institutions can implement in relationships with African American parents, with the ultimate goal of improving the health outcomes of African American children.

Significance

This topic is significant in regards to both African American health and to nursing and other health care professions, as well. Relevant identified gaps in current research are delineated in this section. Quantitative evidence available in the literature demonstrating the significance of health and other disparities among African Americans is also reviewed in this section. In addition, nurses' and other health care professionals' encounters with patients in health care settings are considered as key factors in understanding and addressing these disparities. Nurses, in particular, are culturally situated to act as advocates and brokers between the cultures of western health care systems and culturally diverse populations, and are thereby uniquely positioned to improve overall patient care and general health of individuals and populations.

Cooper et al. (2006), in their literature review of research related to the role of social relationships in the health care system, concluded that less is known about how race and ethnicity influence clinical relationships in terms of health disparities, and suggested that future research include "relationship-centered" (p. S21) frameworks for addressing health disparities. Cooper et al. (2006) specifically recommended

consideration of less visible demographic characteristics, investigation of concepts related to mutuality in the health care relationship, and enhanced understanding of dimensions of relationship-centered care: all for the purpose of providing new knowledge to inform the development of approaches to health systems, health professions education, and community based interventions meant to reduce racial and ethnic health disparities and improve health outcomes. Knowledge from the study I conducted contributes to enhanced understanding of these dimensions of relationship-centered care and may elucidate relational avenues through which health disparities may be addressed, and has the potential to improve African American pediatric patient health and health care.

Fongwa (2001) identified a gap in the literature related to African Americans' perceptions of the dimensions of quality of care, and suggested that clinicians increase the effectiveness of their interventions "by familiarizing themselves with African Americans' health care issues and allowing African Americans to participate in defining, participating, and evaluating their own care" (p. 47). Similarly, Johnson et al. (2004) identified a gap in the literature in regards to patients' perceptions of the cultural competence of their health care providers, and recommended further investigation into mechanisms through which either cultural competence or experiences of bias impact health and health care that incorporate the patient perspective. My study was designed to illuminate some of these dimensions of care from the African American perspective, specific to a small south Georgia community. The results could facilitate clinician familiarization with issues identified by African American patients as important to their perceptions of health care encounters, and may identify components that should be included in professional education and practice, and policy and systemic interventions

designed to reduce disparities in health and health care. Such interventions are directed at both acquiring a better understanding of African Americans' perceptions of care, but also in providing a medium for critical examination of professional practice and professional cultural bias.

Kawachi, Daniels, and Robinson (2005) identified the lack of reporting of health statistics on the axes of both ethnicity and class as an issue that has led to a gap in understanding the multidimensionality of health disparities. They suggested that race and ethnicity have been used in the discussion of health disparity in order to "suppress class-based discourse" (p. 343). Becker and Newsom (2003) reiterated that gap in understanding of African Americans' perceptions of care related to socioeconomic status, particularly in the understanding of socioeconomic status as "not just a confounder of racial differences in health but part of the causal pathway by which race affects health" (p. 742). The study I conducted considered issues of both ethnicity and class in health care relationships, and may clarify which is more relevant for the participants in my study, or how the two may intersect in health care relationships. These sorts of understanding and discourse are imperative in addressing race and class related disparities in health and health care at a systemic and policy level.

Lillie-Blanton, Martinez, and Salgonicoff (2001) stated that though the documentation of health disparities is great, the underlying factors that cause them are poorly understood. Their recommendation was to design future investigations to enhance knowledge about "the extent to which racial/ethnic differences persist in the site of medical care" (p. 15); and how these differences relate to health disparities. They specifically mention differences in the sites of care, content of care, the patient-provider

relationship, and financial barriers, or any combination of these as contributors to health disparities. Similarly, Smedley, Stith and Nelson (2003) in their Institutes of Medicine report found that stereotyping, bias, and uncertainty in the health care relationship can contribute to unequal treatment of patients. Their summary stated that there are specific gaps in understanding how disparities emerge in the structure and process of care.

Finally, Copeland's evaluation of the literature identified that "very few investigations examine the perceptions that African Americans have about the services they receive"; and that "little literature exists regarding the personal and nonstructural barriers to access and utilization of services as perceived by ethnic and racial minority consumers" (p. 267).

These authors also suggest that a better understanding of the sociocultural context of African Americans may reduce barriers to care. My study was designed to provide detailed information about the patient-provider encounter and factors associated with parent's experiences of the care provided to their children, and begins to illuminate where and how relational complications emerge in the intersections of race, income, and other factors.

The importance of African American's experiences with health care is evident in the quantitative data that demonstrate significant health disparities, and in a review of the literature that is indicative of the focus that these disparities have generated in many disciplines. Chapter 2 provides a comprehensive literature review, divided into categories of theories and concepts that have informed my interest and my understanding of African American children's health and the experiences of their parents in health care settings. I encourage the reader to consider the literature review of Chapter 2 as further evidence that bolsters the significance of a study that may deepen the understanding of

African American's interactions with the health care system. There is also, however, a great body of quantitative data that demonstrates overall health disparities and other disparities of African Americans, and perhaps provides the most persuasive evidence that the study I proposed was significant. In the following section, data from a variety of landmark sources are used to describe what authors have identified as significant health disparities of African Americans in comparison with White Americans over the last ten to fifteen years. The section concludes with the most recent data from the CDC Health Disparities and Inequalities Report, released in 2011.

There are many health disparities associated with African Americans. African Americans make up approximately 13.5% of the population (Dayer-Berenson, 2011). Past research has revealed many disparities in the health of African American children when they are compared to White children. Historically, African American children have had lower rates of immunization than White children (Neiderhauser & Stark, 2005). Some research has indicated that African American children suffer asthma at up to twice the rate of White children (Gold & Wright, 2005). As infants, they are almost twice as likely to be low birthweight and have more than double the infant mortality rate of White infants (Children's Defense Fund, 2010). In 2005, the CDC (2005) reported that the obesity rate for African American children ages 6 to 19 was about 22%, versus a rate of 12% for White children.

Historically, African American adults have also appeared to be less healthy as a population than Whites. In 2006, African Americans were reported to be 25% more likely to die of cancer and twice as likely to die from complications of diabetes than were Whites, and were less likely to receive effective treatments (NAACP, 2006). In 2005,

though the top three causes of death for African Americans, heart disease, cancer, and stroke, were the same as those for Whites, the Centers for Disease Control (CDC, 2005) reported that “the risk factors and incidence, morbidity, and mortality rates for these diseases and injuries often are greater among African Americans than whites” (p. 1). In addition, three of the top ten leading causes of death for African Americans in 2005 were not leading causes of death for Whites: homicide (sixth, for Whites), Human Immunodeficiency Virus (seventh, for Whites), and septicemia (ninth for Whites). Among African American women, the incidence per 100,000 of colo-rectal cancer (54 versus 43.34), pancreatic cancer (13 versus 9), and stomach cancer (99 versus 4.5) was substantially higher than that of White women; and among African American men, the incidence of prostate, lung, colo-rectal, and stomach cancer per 100,000 was significantly higher than that of White men (CDC, 2005).

There are disparities between African Americans and Whites in access to care, insurance coverage, and mental health treatment as well (Briscoe et al, 2010). In 2005, African Americans (81%) were reported to lag behind White Americans (87%) in percentage of persons less than 65 years old with health insurance (CDC, 2005). In 2000, African Americans (16%) were more likely to rely on hospitals and clinics (as opposed to a primary care provider) than were White Americans (8%) (United States Department of Health and Human Services, 2000a, b). Despite the obvious contributors to reduced access to care, lower rates of health insurance, and lower incomes of African Americans, there are more insidious processes at work. One study found that African Americans received poorer quality of care during hospitalization for congestive heart failure and pneumonia; another study showed that African Americans were one third less likely than

Whites to be referred for cardiac bypass, with similar symptoms; and another study indicated that the length of time between an abnormal mammogram and diagnostic follow up for African American women was double that of White women (USDHHS, 2000a, b). These examples are only a few of many cited in the literature of the past ten to fifteen years.

More recent statistical data available in the CDC Health Disparities and Inequalities Report (2011) demonstrate that while minor progress has been made in some areas, such as an overall improvement in immunization rates for various age groups and specific immunizations, other gaps have widened when African American health is compared with the health of Whites. The CDC's findings were divided among several categories, which included social determinants of health; environmental hazards; health care access and preventive services; and health outcomes in terms of mortality, morbidity, and risk behaviors. The most significant areas of health disparity, as detailed in this most current report, are outlined in the following paragraphs.

Significant social determinants of health were identified by the CDC (2011) to be education and income. Income and education directly affect health outcomes by their influence on living standards, access to high quality food and better housing, and health care services. In 2009, according to the CDC report, 18% of African Americans did not complete high school, as compared to 9% of Whites. There are also racial disparities in terms of adults living below the poverty level, with 8.4% of White adults living below the poverty level, as compared with a staggering 21% of African American adults.

The CDC (2011) also reported that environmental hazards related to substandard housing and air quality were greater for African Americans than for any other ethnic

group, with African Americans demonstrating the highest number of householders living in inadequate, unhealthy housing. The overall health of housing was described as being related to exposure to chemicals and allergens, square footage, physical repair, proximity to parks and services, and adequacy of the physical status of the building (paint, plumbing, electrical, presence of pests, etc). African Americans were 2.3 times more likely to occupy inadequate housing than were Whites. The likelihood of living in substandard housing increased as household income decreased, a significant statistic when considering the income disparity that exists for African Americans when compared with Whites. Outdoor particulate matter concentration and ozone pollution are measures of air quality that are strongly related to poor health outcomes such as premature death, lung cancer, and respiratory and cardiovascular disease. African Americans were more likely to be exposed to both more particulate matter (15.2%, 9.7%) and ozone gas (40%, 32%) than were Whites, because of their likelihood of living in or near metropolitan areas.

The CDC (2011) also identified access to insurance and preventive services as areas in which health disparities still exist between African Americans and Whites. Disparities in insurance rates were described by the CDC (2011). The uninsured rate for African Americans was 23%, for Whites it was about 14%. Disparities in preventive health services like flu vaccination and colorectal cancer screening were reported, as well. For example, the H1N1 immunization rate for African American children aged six months to seventeen years was about 49%; the rate for their White counterparts was about 54%.

Mortality rates reported by the CDC (2011) showed disparities that exist between African Americans and Whites. The infant mortality rate for infants of African American women was 2.4 times higher than that of infants of White women. A higher percentage of African American women (40%) than White women (19%) died before age 75 from complications of coronary heart disease. This difference was true for African American men as well, and for both African American men and women for deaths from stroke. Homicide rates were also significantly higher for African Americans (23.1 per 100,000) than for Whites (2.7 per 100,000).

Morbidity rates also are indicative of health disparities (CDC, 2011). African Americans of all ages continue to have higher rates of obesity (21%) than their White counterparts (14%). One in five births to African American women is preterm, versus about one in nine of those to White women. The rate of preventable hospitalizations was higher among African Americans than among Whites. Asthma rates were also higher among African Americans when compared to Whites; but the most significant difference is evident in comparing current asthma among African American children (14.6%) and White children (8.2%). HIV rates are higher for African Americans than for Whites: The rate of infection diagnosis was 73.7 per 100,000 among African Americans, as compared with 8.2 per 100,000 among Whites, with a relative percentage difference of 799%. Diabetes remains more prevalent among African Americans (11%) versus Whites (7%). The percentage of African American adults with hypertension remains higher (42%) than that of Whites (about 29%).

Disparities in areas other than health exist between African Americans and Whites. Some of these include income, educational, and employment disparities; as well

as higher rates of incarceration and homelessness (Hopps, Tourse & Christian, 2002; Utsey, Geisbrecht, Hook & Stanard, 2008). African Americans also have lower wages and more often live in substandard housing than Whites (Brody, Dorsey, Forehand & Armistead, 2002). In addition, some research has found that African Americans suffer from race-related stress and resultant poorer mental health functioning, and that racism may result in greater psychological distress than even stressful life events (Utsey, Geisbrecht, Hook & Stanard, 2008). African American children, particularly, suffer from social disparity. In comparison to White children, they are three times as likely to be poor and to live in extreme poverty; more likely to be born to a teen mother, to live in a single-parent household, to live with neither parent or live in foster care; and seven times more likely to have an incarcerated parent (Children's Defense Fund, 2010). African American children suffer from educational disparity, as well. They are half as likely to be identified as gifted, one and a half times more likely to be identified as having behavioral or developmental problems, two and a half times more likely to be retained in a school grade, and three to four times more likely to be suspended or expelled from school (Children's Defense Fund, 2010). Finally, African American children are five times more likely to have interactions with the criminal justice system at earlier ages, twice as likely to be arrested and detained by police, and five times more likely to be victims of violent crime when compared to White children (Children's Defense Fund, 2010).

A great deal of literature exists that establishes quantitative evidence that race-related and socioeconomic health disparities exist for African Americans and the poor as compared to Whites and middle class people as a whole (Centers for Disease Control and

Prevention, 2005, 2011; National Institutes of Health, 2006). The interaction of race and socioeconomic status in affecting the health status of African Americans was the topic of an extensive literature review by Williams and Collins (1995). Their landmark work reviewed the majority of the current literature of the time to determine how socioeconomic status, race, and major social structures and processes produce inequalities in health. They concluded that social class position (which can be measured in a variety of ways, including income), is a key variant in the distribution of disease; and that improving health of populations is contingent upon understanding macrosocial dynamics. Williams and Collins (1995) also suggested that race and class have a magnifying effect on health disparity, and that understanding this interaction within racial and ethnic groups is critical for future research. Their recommendation holds true today (Drexler, 2007), and the trend is evident in the most recent health disparities data reported by the CDC (2011) in terms of social determinants of health like education, income, housing, and insurance status as they relate to measurable health indicators like preterm birth, substance abuse, asthma, and diabetes; all along the axes of gender and ethnicity. And while indicators like income and education are now widely considered and accepted as factors in health disparity, there is less quantitative evidence that specifically links class or socioeconomic level to health disparities *within* racial and ethnic groups; although this is becoming more and more a topic of interest (Robinson, 2010). Understanding differences in experiences among African Americans with consideration to social differences may be a step forward to understanding resultant disparities. The study I designed considered socioeconomic status as it affected African American parents' experiences of their children's health care encounters, and my findings

confirmed the multidimensionality of socioeconomic status and the intersecting factors related to it.

Evidence that health and other disparities exist for African Americans when compared with Whites is clear and well-established. The purpose of this study was not to generate further evidence of disparity, however, but to investigate how the experiences African American parents have in their children's health care encounters may contribute to an environment in which health disparities may be exacerbated or meliorated, and the overall health of African American children improved.

In short, there are many complex factors at work in disparities experienced by African Americans. Copeland (2005) described the sources of these disparities as multivariate and complex, with contributing factors such as "lack of access to care; barriers to care; increased risk of disability and disease resulting from occupational exposure; biologic, socioeconomic, ethnic and family factors; cultural values and education; social relationships between majority and minority population groups...; and culturally insensitive health care systems" (Copeland, 2005, p. 265).

This reference to culturally insensitive health care systems is the factor that most interests me and which justifies this study as significant to nursing and other health care disciplines. There is an identified gap in the literature in terms of perceptions that African Americans have of the care they receive and health care barriers perceived by minority consumers themselves (Copeland, 2005). Few studies have investigated the experiences and perceptions of African American parents regarding their children's health care encounters. Much of the past research seems to be focused more on the cultural competence of clinicians, and less on the perceptions of minority patients

themselves. Past research is also almost exclusively focused on race and ethnicity or on socioeconomic status, as opposed to socioeconomic or class factors within minority groups. Finally, very little attention has been given to the contributing factors of parents' perceptions about their children's health and health care. People who may choose to eschew the health care system for themselves may not feel as free to do so when the health of their children is involved; and yet their attitudes and perceptions of the health care system are likely to be communicated to their children and may directly affect their children's health.

If a clinician does not understand a parent's history and perspective, and the parent does not trust the clinician, then the child's health needs cannot be adequately addressed, and health disparities will remain. Problems with communication, understanding, and adherence to treatment will characterize the parent/provider relationship. It is therefore critical that clinicians try to understand and change negative dynamics that may exist in this relationship and within the health care system. I believe clinicians' lack of understanding of a patient's biographical history and perspective is indicative of the intersecting cultures and conflicting relevances of practitioners and patients. Culture and trust will be considered in Chapter 2 as concepts foundational to my interest and understanding of African American parents' experiences in their children's health care encounters. Conflicting relevances will be explained further in Chapter 3 as a concept from the social phenomenology of Alfred Schutz.

Nursing's major constructs are those of human, nursing, environment, and health. As nurses we assume that the interactions between and among these elemental constructs is ongoing and complex. Health disparities truly exist at the intersection of human,

environment, and health. Disease and illness models (the traditional western cultural approaches to health care) identify and define what are considered to be health disparities. Nurses make assumptions that responses to disease or illness (health) can be mitigated through manipulation of nursing, human, and environment. Nursing's situated role within the culture of western health care creates an opportunity for nurses to function as cultural brokers. *Cultural brokering* is defined as the act of bridging, linking, or mediating between groups or persons of differing cultural backgrounds for the purpose of reducing conflict or producing change (Jezewski, 1990). The National Center for Cultural Competence (NCCC, 2010) stated that "almost anyone can fulfill the role of a cultural broker. Most cultural brokers assume multiple roles within health care and other settings and their respective communities. Although cultural brokers serve the same function, they come with different expectations and have divergent experiences, yet aim to create a cultural connection" ("Who can fulfill the role of cultural brokers in health care settings" section, para. 1). It is because of nurses' potential to facilitate understanding which may enhance health and reduce disparities within the populations we serve, that this inquiry is significant to nursing: "Whatever their position, cultural brokers aim to build an awareness and understanding of the cultural factors of the diverse communities they serve and of the ways in which such factors influence communities" (NCCC, 2010, para. 1). This sentiment is echoed in *The Handbook of African American Health* (Hampton, Gullotta & Crowel, 2010). These authors recommend that health care providers and researchers interested in improving the well-being of African Americans be involved in research and interventions designed to improve specific understanding of African American experiences and culturally competent care.

In short, the significance of this study was established by the evidence of health disparities that many African Americans face, and by the role that health care practitioners may have in ensuring that the encounters that occur in health care settings reflect an understanding of the many factors that affect the health of their patients. Culley (2006) stated: “Nursing and other health care discourses need to overcome their ‘structural blindness’ and to seek ways of bringing issues of ethnicity, gender, and class (and their intersections) to the forefront of the research agenda. Researchers also need to be reflexive about how their social location may influence the way in which they represent ‘Others’ and be wary of reproducing unequal social relations in their representations of meanings” (p. 150). Culley (2006) also suggested that conceptual tools for achieving these recommendations may be lacking. Culley’s (2006) recommendations highlight why I believed that a critical qualitative study of African American parents’ experiences in their children’s health care encounters was important and significant.

Theoretical Frameworks

I approached this qualitative study with the assumption that the interaction of health care professionals and African Americans represents the interface of at least two differing cultures (health care culture in interaction with those outside health care; and sometimes the interactions of differing ethnic cultures). Chapter 3 provides an explanation of the philosophical and methodological approach proposed for the study. The social phenomenology of Alfred Schutz is used to justify the appropriateness of the qualitative approach for this particular study and as a foundation to the overall consideration of culture and human interaction. I also framed my inquiry from a perspective of critical social theory, assuming that there are fundamental power inequities

that exist in the relational dynamics present in many interactions between health care providers and African Americans. From the critical paradigm I specifically considered the concept of intersectionality, the ways in which race, class, and gender may shape the interactions that African American parents have with their children's health care providers. I also integrated my understanding of current concepts and trends (outlined in Chapter 2, *Literature Review*) gleaned from human ecology theory and literature, vulnerability and resilience theory and literature, and cultural competence theory and literature to link the social phenomenological explanation of individual experience and personal relationship to the broader dynamics of power and equality that exist within health care institutions and within the patient-provider relationship.

The specific methodology and method chosen for this study was critical ethnography. I sought to describe and understand the experience of African American parents through information gleaned from narrative accounts of their experiences and perceptions of their children's health care encounters. Like other qualitative methodologies, critical ethnography is used to find meaning and understanding through people's life experiences, but introduces an ethical dimension to the study. The ethical dimension requires that the human nature of the researcher and his or her interconnectedness with participants results in a response; a response in which the participants' voices are heard. It is this ethical dimension of experience and participant narrative that pulls in the component of critical ethnography and makes it appropriate for my topic of interest. According to Madison (2005) "critical ethnography begins with an ethical responsibility to address processes of unfairness and injustice within a particular lived domain" (p. 5). It is the interaction of researchers with Others that grounds the

inquiry into social conditions that limit choice, exacerbate power differentials, and “constrain meaning” for individuals and communities (Madison, 2005, p. 5).

Assumptions

My introduction detailed many of the personal assumptions and biases that led me to pursue this topic of study, and which may color my approach to and interpretation of African American parents’ experiences in their children’s health care encounters. But beyond my personal history and perspective, there are many assumptions and biases that affect interpretation of the topic. Even the scholarship that undergirds frameworks of and approaches to racial disparity reflects bias that is often unquestionably assumed and consumed by interested scholars and professionals. The disparity data reported earlier in this introductory chapter, and the literature I cite in the following chapter, while seemingly objective and well-intentioned, insinuate that African Americans are somehow deficient, or less-than their White counterparts. This insinuation is the ever-present conundrum that exists when one group is compared to a societally defined norm. What is normal? Who is normal? These are questions that are grounded in the statistical analysis inherent to a positivist, quantitative approach (Stigler, 2010) that is assumed in much Western health care education and practice. While postmodernism has provided a variety of new ways to view the world, the idea of deviancy from norms is still pervasive in daily life. Critical scholars have challenged the comparison of African American and other groups to an assumed White norm, and suggested that health disparities are initiated not by racism of institutional practices or prejudiced practitioners (though these may exacerbate disparities), but by reliance on “taken-for-granted background knowledge” (Bowser, 2001, section III, “The Diagnosis,” para. 6) in which “Black difference and

inferiority take on a rule-like status and constitute the unquestioned background knowledge used by researchers studying Black health” (Bowser, 2001, section IIIA, “Racialized Medicine,” para. 5). Bowser refers to the resultant differences in treatment by practitioners as “bedside bias” (Bowser, 2001, section IIIB, “Bedside Bias,” para. 1) that practitioners have developed based on a deficiency paradigm in scholarship and research. The deficiency paradigm subsequently reinforces discriminatory institutional practices in a cyclical manner. Bowser’s critical viewpoint offers both a challenge to the current health care paradigm and an important opportunity for practitioners to be reflective of their own place in systems that embrace the paradigm. It certainly provided that opportunity for me as I embarked on this study.

With these and many other assumptions, biases, experiences, and perceptions I approached the phenomenon of study; but these also generated my interest in it. These assumptions, which may produce bias, may also be a positive reflection of what Strauss and Corbin (1990) called the researcher’s theoretical sensitivity, which comes from familiarity with literature and from meaningful and relevant professional and personal experience: “Theoretical sensitivity refers to a personal quality of the researcher. It indicates an awareness of the subtleties of meaning of data.... [It] refers to the attribute of having insight, the ability to give meaning to data, the capacity to understand, and capability to separate the pertinent from that which isn’t” (Strauss & Corbin, 1990, p. 42).

Tillman (2002) addressed some of these personal and professional concerns as well. She highlighted the need for more sensitive research approaches and frameworks that take into account cultural issues specific to African Americans, and specifically mentions the appropriateness of critical qualitative approaches, like the one I proposed.

She went on to ask, “Can majority scholars engage in research about African Americans that treats race and culture as central to the process of inquiry” (Tillman, 2002, p. 4). My own answer was a resounding ‘yes,’ particularly as I, as a majority race member, have a unique insight into at least one side of the power dynamic. Tillman’s response to her own question was that if the researcher eschews a deficit view of the culture and has cultural knowledge of the minority group (particularly in the form of an established relationship, or “connectedness” in the community); and if the research approach recognizes “the explicit cultural knowledge and norms that exist within a group” (Tillman, 2002, p. 4), then the work fulfills the criteria to qualify as a culturally sensitive approach. She further recommended that the research fulfill specific aims: That the method be qualitative (providing an avenue for participant voice to be heard), that it seek culturally specific knowledge, that it reveal unequal power relations, that the data interpretation be culturally sensitive, and that it lead to the development of culture-specific theory and intervention (Tillman, 2002). I hope that the reader will agree that the body of this proposal demonstrates my commitment to Tillman’s tenets.

As a white, middle class southern woman, and as a member of the American health care system culture, my assumptions, biases, experiences and perceptions are many, and are, perhaps, the reason I have such a great interest in what transpires in health care encounters. Without confronting these biases, I remain domesticated (Thomas, 1993; Madison, 2005), content with life as I know it. Thomas (1993) encouraged researchers to use knowledge in order to act upon the world, rather than be acted upon by the world. Part of knowledge includes an attitudinal approach, or what Madison (2005) called *positionality*, to cultivate a clear view of one’s own culture. A critical component of such

an approach is not to avoid or to try to expunge personal cultural values or the values that may be implicit in questions that are asked, but to identify the values and the distortions they produce in one's thought and to consider them as inherent to the process of ethnography (Thomas, 1993), with the overall aim of providing voice, facilitating understanding of the Other, and creating a relationship of mutuality.

Limitations

There was at least one major limitation associated with the study I proposed, and that was the single data collection source, the interview, I chose from the critical ethnographic method. Critical ethnography usually entails the use of multiple sources including interview, observation, and documentary artifacts like medical records to capture the essence of any given cultural phenomenon. It is also the case, however, that many critical ethnographic studies employ only the use of interviews (Carspecken, 1995). I tried to acknowledge this limitation by referring to my study as an ethnographic interview analysis, as opposed to an ethnography (see Chapter 4). I justified this limitation simply by stating that this study represented a novice effort that I hoped to complete within a limited time frame. I chose to employ a single data source for deep analysis and singular focus, as opposed to a broad superficial analysis or an unreasonably lengthy study. While the addition of observation and medical records review might strengthen and deepen understanding of African American parents' experiences in their children's health care encounters, I was just beginning to establish a program of research which I hoped would expand to include a variety of methodologies and methods used to study African Americans' experiences in health care systems.

A second consideration of the study was its limitation to a sample of low and middle income African American parents, which restricts the transferability of the findings to a similar population. If a certain segment of the population is not represented in a sample, then a study's findings cannot be assumed to apply to them, simply because they share ethnicity with the study's participants. Had wealthy African American parents been represented in the sample, they may have reported vastly different experiences from their low and middle income counterparts. Experiences of African American parents at all income levels are important to consider, however, and in future research I hope to consider the experiences of very high income African Americans, as well. Indeed, Logan and Stults (2011) of the US2010 project cited the issue of residential segregation as a key factor in personal health, regardless of income. Even very wealthy African Americans often still live in minority neighborhoods that limit their access to healthier lifestyle and choices, though they may have plenty of income (Logan & Stults, 2011). Sociologist David Williams stated,

The single example of health inequality that's most dramatic to me is what occurs when we look at racial-ethnic differences and, at the same time, at measures of socioeconomic status. For multiple indicators of health, the most advantaged or the best-off African Americans are doing more poorly than the worst-off whites. (Drexler, 2007, para. 12)

While very high income African Americans were not specifically excluded from my study, I did not anticipate that my sample would yield a large number of high-income participants. The difficulty of identifying a particular margin for "very high income" and

access, in this small south Georgia town, to very wealthy African American parents was limited (as my access to very wealthy White parents would have been).

Research Questions

The questions I hoped to answer with this study were:

- How do African American parents experience their children's health care encounters?
- What factors influence their experiences?
- What are the implications of these experiences on the relationship between provider and patient?
- Does socioeconomic status affect the experiences of African American parents in their children's health care encounters?

However, the qualitative approach required that I remain open to both questions and answers that emerged during the process.

Definition of Terms

There are three terms I used throughout this study which warrant definition. The first of these, *African American*, may be self evident; though there is a great deal of scholarly and popular debate about exactly what the term means and to whom it refers. In deciding whether to use *African American* or *Black*, I consulted the literature about which term is preferred among those it is used to describe. Gallup organization polls in the last decade have shown that for the large majority of African Americans, there is largely no preference, but when there is a preference, there is a slight tilt towards *African American* (Newport, 2007). Most sources simply define an African American as a Black American of African descent (Merriam-Webster, 2011); and some leaders like Jesse

Jackson have encouraged its use to refer specifically to descendants of American slaves (Wilkerson, 1989). I chose to use the following definition of African American: “Those individuals of African descent who have received a significant portion of their socialization in the United States,” which implies that the term “is culturally bound to a group of people within the context of American society” (Sellers et al, 1998, p. 19).

The second two terms I used as defining categories for this study were *low income* and *middle income*. Again, these terms are not without debate in scholarly and research circles, as many may use different measurements to define their parameters. Interestingly, there is no standard for determining income level for national programs; there is simply the establishment of what is considered the poverty level based on income and family size. Various government programs use different standards (i.e., 125%, 150%, or 185%) for determining low income status for eligibility for government assistance, based on the poverty level (United States Department of Health and Human Services, 2011). For the purposes of this study, I used the terms low income and middle income in two different ways. In discussing their families of origin, I asked the study participants whether they considered their families of origin to be low, middle, or high income. In their responses, they self-defined the income level of their families of origin. In establishing the income level of the participants as *low* or *middle*, however, I used the formula provided by the Federal Register (2011) to determine poverty level based on income and number of members in the household. Any participant who fell at or below 133% of the federal poverty level I designated as *low income*. I chose this level based on the 2011 parameters for Medicaid eligibility (Kaiser Family Foundation, 2011). All others I placed in the *middle income* category; as none of the participants could be considered high income.

These definitions are not without pitfalls; as many people may self-report their income or social class in terms other than financial income. However for the purposes of this study, the use of the Federal Register poverty level and Medicaid eligibility created unambiguous and widely accepted categories for evaluation.

There are several other places in this study where definitions of terms are important, particularly in Chapter 3, where the social phenomenology of Alfred Schutz is detailed; and in Chapter 4 where Graneheim's and Lundman's (2004) method of data analysis is discussed. Rather than be redundant at a point in the work where these definitions would be out of context, I refer the reader to those chapters.

Summary

Creswell (2007) stated that “qualitative research begins with assumptions, a worldview, the possible use of a theoretical lens, and the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem” (p. 37). I have particular interest in how African American parents experience their children's health care encounters. It is not only their perceptions of the encounters that are significant, but the conventions, values, and beliefs about health care and institutional professionals that precede and define the encounters. While individual culture, gender, history and experience prohibit objectivity, qualitative research provides an avenue for describing and interpreting shared human meaning and experience, and for individuals to ascribe meaning to their experience. Because I was interested in the cultural context in which encounters between African American parents and clinicians occur, I chose ethnography. Ethnography is used to describe cultures. Because I was interested in the conventions, values, and beliefs that infuse and define these encounters, I chose a critical

ethnographic approach. These philosophical, theoretical, and methodological foundations, and specific method are discussed in Chapters 3 and 4. Next, however, in Chapter 2, I categorize current thought and scholarship into categories of theory and research which have informed my professional and academic interest in and understanding of issues that affect the health of African American children.

CHAPTER TWO: LITERATURE REVIEW

Qualitative inquiry can be inhibited by over-familiarity with popular understandings of a topic and the subsequent imposition of frameworks on the design and interpretation of a study and the data. There are many experts in qualitative inquiry who discourage any review of the literature before undertaking qualitative inquiry, in order to keep the interpretation pure, bracketed, and as value-free as possible. Though there is great debate among qualitative researchers regarding the place and appropriateness of literature review and specific theory in the design of a qualitative study, it seems to me most authentic to acknowledge and recognize research and frameworks that may have informed the way I consider and conceptualize the problems that I perceive to exist or areas of interest that I have developed in my professional and scholarly career.

I believe this acknowledgement to be inherent to reflexivity, which I discuss in greater detail in Chapter 4. Reflexivity helps the researcher identify his or her own biases or preconceptions, and “locates the researcher in the research report” (Holloway & Wheeler, 2010, p. 8). Credibility, authenticity, and theoretical sensitivity may be bolstered when the researcher acknowledges and demonstrates an understanding of theory that may influence his or her interest in and interpretation of the topic of interest. Critical analysis, in particular, assumes multiple influences on interpretation of data. For these reasons, I believe that the significance of this study may be partially established by considering the literature relevant to African American health. I believe that the literature

review speaks to my general interest in the subject, the professional and theoretical foundations for my interest, and the significance of the topic I chose to pursue.

Thus far, Chapter 1 included a significance section which revealed a widely accepted “orienting lens” (Creswell, 2009) specific to African American health through use of concepts like disparity or differences. Chapter 3 details the philosophical and methodological frameworks that grounded my overall approach and study design, but there are several other theoretical concepts which created positionality (Madison, 2005) or orienting lenses (Creswell, 2009), and which influenced the formulation of my research questions. I have categorized these bodies of literature into four main headings. These categories are by no means exclusive, nor do they represent monolithic theories or disciplinary silos; they were simply developed for the purpose of identifying those theoretical/conceptual frameworks that have been influential in my scholarly pursuits, and to extend the argument for the significance of the study. These include theories of ecology, resilience and vulnerability as applied to the African American family; African American parenting; the concepts of cultural competence and trust; and studies which I believe illustrate these theoretical categories. These theories and works did not lend themselves to easy categorization, and the reader will see that the categories are not distinct, but are fluid, comingling, overlapping, interactive and reiterative. Indeed, vulnerability, resilience, culture, and trust could all be categorized as subconstructs of ecology theory.

Ecology Theory

A significant body of literature from a variety of disciplines links culture, socioeconomic status, and race/ethnicity of African Americans with various behaviors,

barriers and outcomes. Though this literature reflects widely varied disciplinary approaches, a plethora of theoretical assumptions that frame the individual studies, and vastly different focuses of interest, the shared theme is African American ethnicity and experience. It is this literature which was also instrumental in my decision to include income level as a comparison factor in the study of the experiences of African American parents. I see ecology theory as the overarching assumption that links this particular body of literature.

In the years following Darwin's "Origins of the Species" there was a blossoming of theory generation in many fields of study. The word "ecology" was coined by Ernest Haeckel, a German zoologist who proposed that a new field of study be established to investigate the inherent relationship between living organisms and their environment; in fact, he suggested that "the individual was a product of cooperation between the environment and organismal heredity" (Buboltz & Sontag, 1993, p. 419). Human ecology theory developed, in part, as a result of the growing problems related to industrialization, immigration, and poverty in both England and the United States; and investigates human interaction and socialization within complex environments (Buboltz & Sontag, 1993). Since its inception, human ecology theory has been widely used in a variety of disciplines. A number of Schools of Human Ecology were instituted in colleges and universities in the United States in the late 19th and early 20th centuries, including one at Cornell University, and also at the University of Minnesota, the University of Michigan, the University of Chicago, and several in Canada.

More recently, beginning in the 1950's there was a renewed interest in human ecology theory, especially in the fields of education, psychology, and sociology. Since

that time, it is also frequently referred to in the literature as social ecology theory, or the social ecological model, terminology coined by Murray Bookchin (1965) in his *Ecology and Revolutionary Thought*. Bookchin's primary concern was the detrimental human effect on the environment, and the negative impact of political systems on humans.

Urie Bronfenbrenner (1979), a researcher in child psychology and education, was the best known of several scholars who interpreted the theory more broadly (as is currently accepted) to apply to human-environment interaction, termed ecological systems theory.

Bronfenbrenner readily acknowledged the use of other theory within the application of ecological systems theory. The theories used include, but are not limited to systems theory, psychological theory, behavioral theory, organization theory, and biological theory. In fact, he stated that ecological systems theory represents "an attempt at theoretical integration" (1979, p. 11). Bronfenbrenner defined social ecology as involving "the scientific study of the progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings, and by the larger contexts in which the settings are embedded" (1979, p. 21). Bronfenbrenner's stated purpose in his ecological systems theory was to "provide a theoretical conception of the environment extending beyond the behavior of individuals to encompass functional systems both within and between settings, systems that can also be modified and expanded" (1979, p. 7).

Today, both the CDC (Centers for Disease Control) and WHO (World Health Organization) use social ecology theory in identifying, proposing, and designing their programs and interventions (Dahlberg & Krug, 2002; Wilkinson & Marmot, 2003).

Many researchers today, including those whose work I use to establish the significance and theoretical foundation for my own study, demonstrate the underlying assumptions of ecology theory in their use of terms like *vulnerability*, *resilience*, *modifiable risk factors*, *barriers to care*, *contextual variables*, *social determinants of health*, and *indicators of health and well-being*. The following body of literature exemplifies the prevalence and importance of ecology theory in considering ethnicity and socioeconomic status when studying African American health and well-being.

In terms of modifiable risk factors, Kendzor et al. (2009) found that measures of socioeconomic status such as neighborhood disadvantage, social support, and perceived stress played mediating roles in manifestation of modifiable risk factors related to weight, physical activity, and alcohol consumption among African American smokers.

Cheatham, Barksdale & Rodgers (2008) conducted a literature review to identify barriers to health care and health seeking behavior among African American men and found that socioeconomic status (lack of employment), masculinity (a need to not appear weak or in need of help), racism (mistrust of the health care system and previous bad experiences), lack of awareness (of disease signs and symptoms and of the need for preventive care), religious belief (fatalism), and peer influence may all act as barriers to health care access. These authors also reported that family members, particularly women, often act as motivators for care seeking among African American men; and that positive provider relationships also facilitate care-seeking among African American men. Specific provider behavior that was perceived as caring included “body language, tone of voice, sitting on the patient’s level, conducting the interview in an unhurried manner, and making eye contact” (Cheatham, Barksdale & Rodgers, 2008, p. 559). African American

men also appreciated being told the truth in an understandable way, discussion about things other than health, being held accountable for behavior, and mutuality in the patient-provider relationship. These authors also reported that having an African American provider eliminated issues of perceived racism and trust (Cheatham, Barksdale & Rodgers, 2008).

Becker and Newsom (2003) reported a gap in the literature in regards to socioeconomic status as it relates to perceptions of health care. They approached their study with the ecological premise that race is both an antecedent and a determinant of socioeconomic status. In their interview with chronically ill African Americans, Becker and Newsome (2003) found that low income respondents expressed greater dissatisfaction with their health care than middle income respondents did. They also identified a history of dissatisfaction with previous care as a key determinant in subsequent care-seeking. Their conclusion was that since socioeconomic status dictates how and where people receive care, it is perhaps the most salient marker for satisfaction with care and quality of care; more salient than ethnic group, site of care, perception of provider competence, trust in providers, or involvement in care decisions (Becker and Newsome, 2003).

Much work has been done that relates various indicators of well-being of African American children and families to socioeconomic status. Leach and Williams (2007) considered the implications of the academic achievement gap on the African American family through the lens of social inequality and ecological theory. Their premise was that socioeconomic status represents the primary indicator of academic success among African Americans, and that academic achievement, in turn, “proves a critical factor in

the overall social and economic well-being of the African American family” (Leach & Williams, 2007, p. 40). They identified ecological influences on the African American family as social inequity, lack of social and economic capital, poorer education, stereotyping by members of the dominant group, discriminatory institutional practices, and degree of parental involvement (Leach & Williams, 2007). Though their focus was on academic achievement, many of these factors would also be relevant for consideration of physical health and well-being, as well. Their findings are similar to those of Hardaway and McLoyd (2009), who drew on theory from a variety of disciplines to investigate individual, family, community, and structural institutional factors as they related to social mobility for African Americans as they transition to adulthood. They found that wealth, racism, stigma, and sociocultural capital (ability to be socially successful) all influence class mobility. Again, though health was not specifically targeted in this study, it is reasonable to consider that similar ecological factors might be influential in the health and well-being of African Americans as they transition to adulthood.

Hughes and Johnson (2001) examined racial socialization among parents of elementary school children. They identified a significant association between parents’ perception of unfair treatment (at school) based on race with increased frequency of parent messages to their children about discrimination. Their findings suggested that parental factors are central in racial socialization messages about discrimination and unfair treatment based on race. One limitation of the study was a sample limited to more affluent African American parents. The authors recommended that future studies investigate differences in patterns across socioeconomic groups. The significance of

research of this type to my topic of interest is that parents choose the messages they give their children about racial stratification and discrimination in order to prepare them for life. Such messages would appear to affect children's health, attitudes about health care, and future disparities within the African American community. Gaps exist in understanding how these messages differ among African Americans of differing economic groups.

After identifying a gap in the public health literature relating parental experiences of racism to children's well-being, Caughey, O'Campo and Muntaner (2004) examined the relationship of racism experienced by African American parents and the mental health of their children. They found that those parents who reported experiencing no racism had children who were more likely to have behavioral and mental health problems; while parents who reported having experienced and actively coped with racism reported fewer behavioral problems in their children. These findings suggest that parental responses to racism are important to their children's mental health.

Buescher et al. (2003) conducted a study of children enrolled in Medicaid in North Carolina and found that Medicaid expenditures on services and use of services was much lower for African American children than White children, despite an overall higher level of health problems. Their findings are consistent with other studies which show racial differences in regards to children's use of health care (Buescher et al, 2003). They suggest that the difference in use patterns may reflect differences in transportation availability, shortages of providers in certain communities, racial discrimination, and other cultural barriers to care. In a similar vein, Ashiabi (2008) examined specific ecological factors to child health status. In comparing data of over 18,000 children from

the 2002 national Survey of American Families, Ashiabi (2008) found that socioeconomic factors influenced perception of quality of care, and that parental depression influence both perception of care and utilization of care for children; though none of these was associated with a difference in actual health status of the children. In his literature review, Ashiabi (2008) discusses a number of theoretical approaches to other studies which have demonstrated an association of a myriad of factors such as trust, perception of quality of care, insurance status, access to care, health seeking behavior, and parenting with both socioeconomic status of African Americans and health care outcomes of African American children.

Several studies have considered contextual factors that affect parenting and family life of African American children. Murry et al. (2008) investigated ethnic differences in parenting in rural African American families. They compared contextual variables such as education, owning a home, family size, neighborhood safety, and neighborhood; and family social variables such as discrimination, and negative life events; as well as religiosity as a cultural variable, to determine their contribution to variations in a parenting measure, parental monitoring. They found that single mothers and parents who were highly religious reported increased parental monitoring. They also found that negative life events compromised parents' expression of warmth toward children. Religiosity was found to be associated with more frequent conversation, and with increased warmth toward children. Parents who reported experiencing racial discrimination were more likely to engage in argumentation with their children. In summary, the authors reported that many contextual factors such as type of neighborhood, negative life events, and racial discrimination were predictors of

variability in parenting processes, and were particularly predictive of less warmth and less monitoring; and that neighborhood support, education, and religiosity were positively associated with specific parental processes.

Hill and Tyson (2008) also investigated ethnicity and context as predictors of parenting behavior. Controlling for socioeconomic status, they found that African American mothers expressed higher levels of self-efficacy and communication of ethnic pride to their children than did White mothers; and that ethnic pride in mothers was positively related to expressions of warmth. Based on their findings, they concluded that differences in parenting practices are due to contextual factors related to ethnicity.

Fouts, Lamb, and Roopnarine (2007) observed African American infants from different socioeconomic backgrounds in naturalistic settings for twelve hours. They found that infants from higher socioeconomic backgrounds engaged in more self-play, vocalized less, fussed less, and had fewer but longer social interactions than did their middle and low income counterparts. Infants from lower socioeconomic backgrounds had more interaction with extended kin. This study showed significant differences in the daily experiences of African American infants from different socioeconomic backgrounds, highlighting the importance that socioeconomic status has a contextual variable for African American children.

It is important to consider ecology theory not only in thinking about socioeconomic and ethnicity factors to African American health and life, but also as these factors affect provider responses to African Americans in health care settings. Houston, Scarinci, Person, and Greene (2005) evaluated the impact of ethnicity and smoking cessation on provider's advice to stop smoking. They found that ethnic minority status,

lower education status, poorer health status, and type of health insurance were significantly associated with lower rates of advice to quit smoking. These data are consistent with findings of other studies, reported earlier, that find differences in medical treatment and intervention for African Americans when compared to Whites. Such findings reinforce the concepts of ecological theory that suggest the interrelatedness of environmental influences and responses to those influences by all who exist within the environment. The concepts of vulnerability and resilience fall under the broad umbrella of ecology theory and are frequently used as theoretical frameworks for researchers interested in the African American family.

Vulnerability and Resilience in the African American Family

Varying definitions suggest that vulnerability is a susceptibility or openness to injury (de Chesnay and Anderson, 2008). De Chesnay and Anderson (2008) referred to vulnerable populations as groups that are “at risk at any given point in time relative to other individuals or groups” (p. 3). The Center for Vulnerable Population Research (CVPR, 2010) identified vulnerable populations as

social groups with increased relative risk (i.e. exposure to risk factors) or susceptibility to health-related problems. This vulnerability is evidenced in higher comparative mortality rates, lower life expectancy, reduced access to care, and diminished quality of life. Vulnerable populations are often discriminated against, marginalized and disenfranchised from mainstream society, contributing to their lower social status and lack of power in personal, social, and political relationships. (CVPR, 2010)

Groups most often are designated as vulnerable based on color/ethnicity, social class or income level, sexual orientation, immigrant status, religion, gender, age, HIV or other chronic illness status (Dorsey & Murd, 2003).

Their status as ethnic minorities, and often their income and social status, along with documented health disparities places African Americans in the vulnerable population category. In researching resilience theory, it seemed clear that one of the greatest factors in resilience is the family structure itself. In discussing vulnerability it is relevant to consider health issues, access to health care, and other health disparities experienced by African American families.

Just as ecology theory and systems theory have applications in both the natural sciences and the human sciences, so does resilience theory (which is widely accepted to be a sub-construct of ecology theory and systems theory). It is interesting and appropriate to consider the parallels. Ecological resilience in the natural sciences was defined, historically, by Gunderson (2000) as “the amount of disturbance that an ecosystem could withstand without changing self-organized processes and structures,” or return to a stable state (p. 425). Gunderson acknowledged more recent definitions that characterize resilience as adaptive capacity of ecosystems to transition among multiple stable states. For reference and comparison it may be useful to point out that an ecosystem, in the natural sciences, is defined as “the complex of interconnected living organisms inhabiting a particular area or unit of space, together with their environment and all their interrelationships and relationships with the environment” (Ostroumov, 2002, p. 141). A simple example is that of a forest or wetlands.

Newman's (2003) definition of human resilience was "the process of adapting well in the face of adversity, trauma, tragedy, or even significant sources of family stress" (p. 42). Keys (2004) stated succinctly why the concept of resilience has been so intriguing to scholars and researchers in the human sciences: "Research has demonstrated that at-risk individuals were more likely to develop undesirable developmental outcomes than individuals without or not exposed to the risk factor. However, not all individuals at risk developed psychopathologies or problems. In fact, enough individuals exposed sometimes to substantial or extreme adversities (e.g., physical trauma) developed normatively and even sometimes developed exceptionally" (Keys, 2004, p. 223).

A current leading researcher and theorist in human resilience theory is Suniya Luthar of Columbia University. She has conducted a great deal of research regarding vulnerability and resilience in children from families in poverty and from families with mental illness. Luthar's work has focused on making distinctions between risk and resilience, and the associated factors that either create vulnerability on the one hand, or act as protectors on the other. She reported that both the risk and the resilience paradigms have their foundations in human ecology theory, and share many commonalities (Luthar & Brown, 2007). She identified the primary difference in the two paradigms as the distinction between negative influences (risks) and positive responses to adversity (resilience), (Luthar & Brown, 2007). De Chesnay, Peil, and Pamp (2008) reiterated this focus on the positives in resilience theory, a contemporary shift from considerations of adversity to a more positive focus on family growth and strength.

The association of the concepts of resilience and vulnerability are well-documented in scholarly literature. Earvolino-Ramirez (2007) identified use of the word

resilience in early psychiatric literature as referring to children who seemed “invulnerable to adverse life situations” (p.73). This “invulnerability” may be reflective of both nature and environment. Perhaps one of the most salient aspects of Luthar’s work has been her consideration of both biological/genetic influences and environmental influences on resilience (Luthar & Brown, 2007). For example, Luthar and Brown (2007) mentioned “national stressors” such as limited insurance, poor access to health care and child care, and high rates of community violence and poverty as influencing lack of stability in interpersonal family relationships; which in turn negatively affect a child’s or family’s resilience. In addition to these social vulnerabilities, there may be biologic or genetic influences that can either enhance or limit a child’s or family’s resilience. Finally, there may be societal and institutional prejudices that affect resilience of entire populations (Luthar & Brown, 2007). Gillespie, Chaboyer, and Wallis (2007) said it succinctly: “The development of resilience is based on the synergy shared between individuals and their environments and experiences” (p. 124). In their concept analysis, Gillespie, Chaboyer, and Wallis (2007) identified three attributes that may be associated with resilience: self-efficacy, hope, and coping. In her concept analysis, Earvolino-Ramirez (2007) identified adversity as the primary antecedent to resilience. The commonly referenced attributes of resilience were identified to be rebounding, high personal expectancy or self-determination, positive relationships and social support, flexibility, sense of humor, and self-esteem (Earvolino-Ramirez, 2007). The consequences of resilience are effective coping, mastery, and positive adaptation (Earvolino-Ramirez, 2007). A similar model was proposed by Gillespie, Chaboyer, and Wallis (2007). Seminal work in resilience theory by Rutter (1987) identified four protective mechanisms of resilience: Reducing the

exposure or impact of risk; reducing negative chain reactions of risk; establishing and maintaining self-esteem and self-efficacy; and creating new opportunities.

The family resilience counseling model developed by McCubbin and McCubbin (1988, 1995) focuses on family strengths and resources as factors that influence adjustment and adaptation in response to transition and crisis. They proposed that families have life cycles in which stressors change from stage to stage, and that successful response to these stressors are facilitated by personal strengths of individuals, family strengths, and community supports along with associated stabilizing factors of ritual, tradition, and routine. They characterized families as falling into typologies of balance, rhythm, and regeneration, all of which affect where a family falls on the spectrum of overall resilience. Their model was applied to resilience in military families with consideration of ethnicity (1988). They found that successful adaptation of African American military families was dependent upon sense of fit in the military, family time together, spouse's commitment to the lifestyle, spouse employment and education level, involvement in the community, neighborhood support, and personal sense of control; these attributes differ from those of their White counterparts. Overall, their recommendations are that clinical interventions and education for families be designed with consideration of both an individual family's strengths and the family's particular stage in the life cycle (1988, 1995); but with the caveat that social class and ethnicity may introduce a complexity that may reduce the generalizable application of interventions based on their model (1988).

Resilience as a concept from ecology theory useful in the context of family therapy is also explored by Unger (2010) in his investigation of the dependence of

resilience on a family's ability to access resources for maintenance of well-being and to participate in discourse about which resources are meaningful, culturally and contextually. Like McCubbin and McCubbin (1988), Unger recommended adaptable, flexible culturally relevant interventions tailored to a family's particular strengths, stressors, and resources rather than those designed toward predefined societal norms. Unger (2010) particularly urged therapists and other practitioners to evaluate their own definitions and interpretations of resilience to avoid projecting their own values into interventional situations that may not be relevant for clients. These recommendations are similar to those made by Maupin, et al. (2010), who discovered that family profiles of resilience were directly related to the family's receipt of public assistance, coping strategies, and perceptions of adequacy of resources. Based on these findings, they recommended designing interventions and support strategies based on individual families' coping skills and strategies, perceptions of available resources, and availability of and attitude toward community resources (2010). These authors reiterated a common refrain in family resilience literature: the ongoing challenge to design large-scale programs that have the flexibility necessary to be tailored to individual family needs.

Keys (2004) summarized resiliency research of the past 30 years:

At the individual level, resilience has been attributed to high IQ, problem-solving competence, high self-efficacy, and personalities that are autonomous, active, outgoing, and warm. At the familial level, researchers have identified high family cohesion, social support, high-quality parenting, stable family units, and higher socioeconomic standing (e.g., higher household income) as enablers of resilience.

Finally, at the level of the community, resilience has been attributed to counseling and support programs and good schools. (Keys, 2004, p. 226)

These three protective contexts are also identified in Werner's landmark work with Hawaiian children from families in poverty (Werner, 1995).

Finally, Luthar and Brown (2007) stated that "it is quite clear that the single most deleterious environmental risk is the sustained presence of neglect and abuse, and conversely, committed, loving relationships have high protective potential" (2007, p. 943); and that "among the various implications studying children... the well being of a child must be examined in the overall well being of the family" (2007, p. 940). It is therefore appropriate to consider the resilience of the African American family, a vulnerable population.

Seminal work by Hill (1972) refuted much previous research that had identified African American family structure as pathological (when compared with White family structure) and instead identified that successful African American families demonstrated strong kinship bonds, strong work orientation, adaptability in family roles, strong achievement orientation, and strong religious orientation.

Carter-Black (2001) conducted a qualitative study of two middle-class African American families in order to compare their experiences with those of families from urban impoverished neighborhoods. They found similar resilience strategies between the two groups: linking their children to successful adults and success-oriented institutions like school and church; close monitoring, supervision, and restrictions on children's socialization and friends; and actively developing childrens' self-esteem and self-efficacy (Carter-Black, 2001)..

While Carter-Black's (2001) qualitative study found church attendance to be a positive factor in resilience, Brodsky (2000) found that church attendance was often seen as a negative factor by single, resilient African American mothers. About half of Brodsky's (2000) study participants were turned off by negative church dynamics and behaviors they perceived as being similar to the negative dynamics and behaviors they tried to distance themselves from in their greater community. This interesting aspect of Brodsky's (2000) work demonstrated that while strong spirituality may be associated with resilience; church attendance itself may not be a manifestation of spirituality. This study is an excellent example of how the concepts of ecology, vulnerability, resilience, and culture are fluid, comingling, interactive and reiterative.

Miller-Cribbs and Farber (2008) evaluated the traditional literature identifying close kinship and extended family structures as evidence of resilience in African American families. In the face of limited and unpredictable availability of resources, the African American community demonstrated adaptive strategies by creating extended kinship care, with shared resources including money, childcare, and housing. They cited evidence that as the African American middle class has grown and as individuals with greater economic choice leave low income communities, those left behind become more isolated and less resilient as the kin network becomes more stretched. The farther kin moved away, the less support they provided to the original kinship network. They reported evidence that as *support needed* increased, *support received* decreased. Ironically, in low income neighborhoods where shared living may ameliorate financial stress, the same shared living has been demonstrated to increase relationship stress due to overcrowding, lack of privacy, and sharing scarce resources. After their review of the

literature of several decades, Miller-Cribbs and Farber (2008) questioned whether it can be assumed that kinship networks remain a source of resilience in African American families today.

In a similar vein, much attention has been given to the high rate of single motherhood in the African American community. Some sociologists and anthropologists have traditionally attributed the high rate of single motherhood to the lasting negative effects of slavery on the African American family structure, while others have cited it as a remnant of wider family structures originating in Africa. Cain and Combs-Orme (2005) found that poverty status is more predictive of poor resilience in single parent African families than is marital status. They reported that multigenerational cohabitation in African American single parent families was associated with poorer parenting; whereas single mother autonomy was associated with better parenting (Chase-Lansdale, Brooks-Gunn, & Lamsky, 1994). The assumption is that in many cases extended kin networks may as often inhibit resilience as foster it. In fact, among autonomous single mother African American families, there was little severe parenting dysfunction. All of these findings result, however, in the “chicken and the egg” conundrum. Is poor resilience a causal or consequential factor of poverty?

Sanders, Lim and Sohn (2008), in their study of African American families with incomes below 250% of the federal poverty level, suggested that though institutional discrimination and poverty may lead to susceptibility to poor social integration, low control, depressive symptoms, and a fatalistic outlook in some African Americans, supportive social networks and church attendance may act as a buffer to these negative effects, thereby enhancing resilience. These authors also piloted a study using tooth loss

as a highly quantitative measure of health resilience. Health resilience was determined by evaluating indicators such as housing quality, social support, familial influence, religiosity, and mental health status. They found that resilient adults in this particular African American community were more than three times more likely to retain 20 or more teeth than less resilient adults. Likewise, children who had resilient caregivers had a lower rate of tooth decay.

Much of the work regarding resilience has been done by sociologists and psychologists and has led to practical implications within those disciplines. There has been a gap for practitioners in the health care arena; Luthar's work, referenced earlier in this paper, highlights this gap admirably. Sanders, Lim, and Sohm (2008) made a critical association between a measurable health indicator and resilience; the very link that has been missing for health care providers thus far.

What is clear in this diverse body of vulnerability and resilience theory is the multitude of ecological factors that influence African Americans. Culture is one such factor evident in all of the resilience-related articles above, and is the factor I am most interested in illuminating in my study of African American parents' experiences in their children's health care encounters. In the context of the proposed study, a discussion of ecology theory and vulnerability/resilience theory is not complete without also considering culture as an influencing factor in the human environment.

Protective resilience seems to be established early in life, and may be rooted in a variety of factors that include temperament, caregiving and attachment, family communication patterns, flexibility in routine, and family belief systems, and other cultural factors. African American culture features a unique combination of values that

should be considered in the discussion of resilience. The National Minority AIDS Education and Training Center (NMAETC) identified these cultural values as spirituality, “an inner strength that comes from trusting in God”; communalism, “a strong history of collective group orientation that incorporates personal relationships, social support systems, and collective resources over individualism”; oral tradition, which “speaks to the communal nature of the people that focuses on face-to-face contact and dialogue”; internal strength; resolve; and respect for elders, (valuing the wisdom and experience of elder family members), (NMAETEC, 2011). Internal strength and resolve are certainly reflective of the concept of resiliency, but I believe that the argument could be made that all of these values independently and in combination may, in fact, foster resilience in the African American family.

Culture

Culture as cultivation of humans relative to external factors (as opposed to genetics), or as patterns of social behavior across populations was first conceptualized in the 19th and 20th centuries by sociologists and anthropologists (Kroeber & Kluckhohn, 1952). Since that time, the concept of culture has been widely used by a variety of disciplines, including nursing. Madeleine Leininger is a nurse anthropologist who began her theory development in the 1960’s in the Western United States in response to the growing diversity of the population and the need for nurses to have relevant practice skills. Leininger’s theory of transcultural nursing (Culture Care, Diversity, and Universality) posits that caring is the essence of nursing. *Care* is a culturally universal phenomenon that refers to a feeling of compassion, interest, and concern for people. Leininger’s theory places caring within a context of culture, and defines culture as “the

lifeways of an individual or a group with reference to values, beliefs, norms, patterns, and practices... that are learned, shared, and handed down” (Leininger, 1985; Leininger, 1997, p. 38). In addition to culture, the environmental context of care also includes physical, ecological, and sociopolitical influences which give meaning to human expressions of care. Transcultural nursing care “is congruent with cultural values, beliefs, and practices” (Dayer-Berenson, 2011, p. 16). Caring assists, supports, and enables behaviors that comfort or heal the patient (Leininger, 1985). Culture care is universal, but its expression, in the form of action, pattern, expression, lifestyle, and meaning may vary (Leininger, 1985). It is assumed that all ethnography, including critical ethnography, is conducted using a theoretical framework of culture. Culture has long been considered to be a factor that is influential to health and health care.

For example, Shrank et al. (2005) found that ethnicity is strongly related to preferences about end-of-life care among African Americans. Culture had an impact specifically on involvement of extended family in decision-making, a preference for practitioners like nurses and social workers who spoke less technically and more compassionately, and inclusion of spiritual leaders and spirituality. African Americans were less concerned with specifics of the illness or disease or about quality of life than with length of life. African Americans also vocalized lack of trust as a factor in their end-of-life decision-making, as well as concern that care would be withheld based on financial status. Spirituality was identified as the strongest overriding theme by these authors: the belief in the power of prayer, the desire for spiritual leaders to be involved in decisions, and the desire that practitioners participate or acknowledge spiritual concerns

as decisions are made. These authors were unable to isolate socioeconomic status as a factor in beliefs about end-of life care.

There is a solid body of literature that provides evidence of the impact of African American culture on access to care and health disparities; of the importance of providing culturally appropriate care to African Americans, and the important role that culturally competent care may play in addressing health disparities (Betancourt, Green, Carrillo & Ananeh-Firempong, 2003; Coleman, 2009; Cooper et al, 2003; Copeland, 2005; Cooper, Beach, Johnson & Inui, 2006; Day-Vines et al., 2007; Johnson et al, 2004; Johnson, Roter, Powe & Cooper, 2004; Napoles et al., 2009; Russell & Jewell, 1992). Cultural factors that may negatively affect access to care for African Americans were identified by the National Minority AIDS Education and Training Center (NMAETC, 2011) as: poor availability of services in certain neighborhoods or communities; economic hardship; stigmatization of certain diseases, like HIV; cultural avoidance of discussing sex and drug or alcohol related behaviors; privacy and honor; distrust; and language or communication difficulty.

Trust could arguably be considered a subcategory of culture, given its roots in the historical/cultural influences on slavery on the African American experience with health care. There is, however, such an abundance of literature specific to trust, that I decided to allow it to stand alone as a category.

Trust

The majority of African Americans in the United States are descended from enslaved Africans brought to North America against their will beginning in the 17th century. Other African Americans are more recent voluntary immigrants from Africa and

the Caribbean. The United States has a long history of institutional racism, social prejudice and discrimination against African Americans. Examples of mistreatment of African Americans by health care professionals and institutions abound, from the classic example of the Tuskegee experiments (Jones, 1993), to more recent examples, like the one cited by Washington (2006). Washington describes a Columbia University study conducted in 1992 in which African American boys were selected to participate in clinical trials of fenfluramine's effect on aggressive behavior. The boys were chosen based on older brothers' encounters with law enforcement, and were identified by the probation department. The purpose of the study was to establish a genetic predisposition towards violence. One parent, Clarisse Johnson, reported that she was asked degrading questions about her parenting, and that researchers induced her to enroll her six-year-old in the study by exploiting her fears about the safety and well being of her older, incarcerated son. The coercive nature of the recruitment, the implied relationship between law enforcement and the health care institution, and the ill effects that Clarisse Johnson's young son Isaac experienced related to the administration of fenfluramine, coalesced into an exemplar of institutional mistrust that some African American parents may have: "To this day my son continues to suffer the severe consequences of the reckless disregard for him as a human being by those experimenters. To them, he was just another guinea pig" (Washington, 2006, p. 278). Dayer-Berenson cited this long history as contributing to "the legacy of mistrust of the healthcare system that persists today" (2011, p. 137). Trust between parent and clinician is critical to creating an environment and positive dynamic in which a child can be healthy and thrive, not only in

childhood, but throughout a lifetime; and in which health disparities can be modified or eliminated.

There has been a great deal of focus on African American mistrust of institutions, racism, and communication within the health care relationship that affect African American satisfaction with care and perception of bias. Kennedy, Mathis and Woods (2007) reported that mistrust of the health care system is a primary factor in poor relationships that exist between poor and minority patients and their physicians, and that African Americans are more likely to report mistrust in their physician than their White counterparts. This mistrust may be due, in part, to continuing inequity and discrimination in treatment (AHRQ, 2004; Coffey, Andrews & Moy, 2005; Schulman et al., 1999). African Americans may feel that they are not treated well by health care providers, and are therefore less satisfied with their care (Coffey, Andres & Moy, 2005; Cooper-Patrick et al., 1999; James, Bourgeois & Shannon, 2005; LaVeist, Nickerson & Bowie, 2000). Qualitative research with 79 African Americans in focus group format identified the prevalence of perceptions of discrimination and racism in participants' experiences in the health care system, and that the expectation of negative interactions inhibited the accessing of care (Jupka et al., 2008).

Citing frequent references relating cultural mistrust with health disparities, Moseley, Freed, Bullard, and Goold (2007) used a Cultural Mistrust Inventory to measure African American parents' cultural mistrust in health care settings. In this study of 69 parents, the findings revealed that African American parents' cultural mistrust was high, and the importance of the protective nature of the parenting role. According to the authors such mistrust may have an effect on the health care decisions parents may make

for their children, thereby impacting child health disparities. For example, it may be the case that high levels of mistrust may lead to avoidance of preventive care, which in children could affect immunization rates; and in adults could affect early diagnosis through screening. In the 2007 study, parents who scored highest on measures of mistrust also reported discomfort with questions about discrimination.

Finally, Rajakumar et al. (2009) compared African American and White parents' attitudes toward their children's participation in research. Their results showed that even when controlled for educational level, race was a significant factor in parents' mistrust of research participation. Mistrust was characterized in the categories of risk of research, fear of inadequate physician disclosure, and belief that participants would receive better medical care than nonparticipants. The significance of their findings was that mistrust may indeed be a deciding factor in whether or not parents allow their children to participate in research. If African American parents have a high level of mistrust in research, their children are likely to be underrepresented in research; which in turn may affect child health disparity by lack of research data regarding certain populations. The authors suggested that future research be directed at additional factors such as income, wealth and socioeconomic status in relationship to trust.

Summary

This literature review of ecology theory and its subconcepts of vulnerability and resilience; and a consideration of the factors of culture and trust issues in African Americans' experiences of health care highlights the interconnectedness of all things. An ecological perspective presents difficulty to the person who desires the placement of ideas, concepts and people into monolithic categories. The review of the literature

demonstrates that many factors influence African American health and experience; and to consider these factors as singular concepts tends to promote superficial understanding. The need for a richer, deeper understanding of African American's health care experiences is what inspired me to approach the topic with a qualitative methodology, using the social phenomenology of Alfred Schutz. Schutz's attention to the intersubjective nature of the social world provides a framework for considering the multifactoral influences on African Americans' health.

CHAPTER 3: PHILOSOPHY, METHODOLOGY AND THEORETICAL FRAMEWORKS

But the order of Nature and of Society is common to all mankind [*sic*]. It furnishes to everyone the setting of the cycle of his individual life, of birth, aging, death, health and sickness, hopes and fears. Each of us participates in the recurrent rhythm of nature; to each of us the movements of the sun and moon and stars, the change between day and night, and the cycle of the seasons are elements of his [*sic*] situation.

(Schutz, 1962, p. 330)

Chapter 3 represents my effort to link the conceptual and theoretical tenets of the philosophy undergirding the qualitative approach, the social phenomenology of Alfred Schutz as an interpretive phenomenological paradigm, and the methodology of critical ethnography to justify my approach to and the design of the proposed study. I demonstrate how they are theoretically related, how they inform one another, and how they ground my inquiry into African American parents' experiences of their children's health care encounters.

The Qualitative Approach

Qualitative inquiry is founded in one primary assumption, that the nature of reality is at least partly subjective and consists of multiple meanings (Creswell, 2007).

Qualitative inquiry generates understanding, rather than answering questions. Qualitative

inquiry provides an avenue through which humans may interact and better understand one another's perspectives. The qualitative researcher is not required to be detached from his or her topic of interest and the participants, and in fact detachment is discouraged. A qualitative approach encourages the researcher to acknowledge his or her values system as significant to the process and the findings. Munhall (2007) refers to the placement of self in the research as *immersion*, reading and thought about a subject and the researcher's relationship to it. Immersion requires not a removal or suspension of self from the inquiry process (as in quantitative inquiry); but an awareness, recognition and acknowledgement of self in relationship to the topic, the process, the understanding, and the participants, in every phase of the inquiry. By recognizing and acknowledging self, or centering, one can recognize, listen to, and hear participant voice more clearly (decentering) (Munhall, 2007).

According to Munhall (2007), all qualitative inquiry, including ethnography, is phenomenological in nature. Phenomenology "is the study of human experience and of the ways things present themselves to us in and through such experience" (Sokolowski, 2000, p. 2). Phenomenological inquiry is rooted in lived experience, or the real, empirical perceptions of persons (van Manen, 1990), and its result is description. Contemporary phenomenology is rooted in the work of Edmund Husserl, who was interested in the relationship between objective reality and human perception. The most important realization about phenomenology, said Munhall (2007), is that "two different perceptions are going to result in two different interpretations of what seemingly looks like one reality" (p. 148). It is this realization that propels qualitative inquiry.

Ethnography, according to van Manen (1990), has phenomenological characteristics in its attention to the commonly shared experiences of a group; however he emphasized that the underlying purpose of ethnography is a description of a group's experience, as opposed to a singular experience in and of itself. Likewise, van Manen characterized phenomenological inquiry as strictly descriptive, as opposed to problem solving, or prescriptive. Van Manen's (1990) narrow characterization of phenomenological methodology as purely descriptive is not unique, nor is it the only interpretation of phenomenology. According to Smith (2009), "the methods and characterization of the discipline were widely debated by Husserl and his successors, and these debates continue to the present day" (What is phenomenology section, para. 3). What follows is an explanation of the philosophy, the methodology, and the theoretical framework; and how they intermesh to establish a cohesive approach to understanding the experiences of African American parents in their children's health care encounters.

Philosophy: Social Phenomenology

Alfred Schutz was a phenomenologist who broadened the scope of individual phenomenology to encompass the social world (Barber, 2011). Schutz was born in Vienna at the turn of the 20th century, and as a young man studied law, social science, and economics. He was strongly influenced by the writing of Max Weber, a sociologist, and Edmund Husserl, who is considered to be the founder of contemporary phenomenology (Barber, 2011). After fleeing to the United States from Nazi Germany, Schutz taught both sociology and philosophy at New York's New School for Social Research, where he was further influenced by American Pragmatism. Schutz placed emphasis on personal action and motive, and understandings of other's actions and

motives, which moves phenomenology beyond perceived experience into the realm of moral action. This emphasis led Schutz to thought in the areas of prejudice and racism, evident in his writings about group typifications (shared characterizations of meaning, knowledge, and experience) which were produced during the time of the American civil rights movement. Some of his final writings converge with political theories of deliberative democracy (Barber, 2011). Deliberative democracy is also a foundational element of critical social theory, which I will discuss more thoroughly in reference to theoretical framework. This convergence of social phenomenology, deliberative democracy, and critical theory was important in my choice of critical ethnography as a methodology for considering African American parents' experiences in their children's health care encounters.

At this point I must make an editorial note about Schutz's use of collective first person in his writings. Schutz assumes that we are intersubjective before we are subjective and therefore always exist as a *we* before we exist as an *I*. My explanation of Schutz's thought and my inclusion of his philosophy in my analysis includes this style of speech, as well. We learn to think, relate, and interpret together, or not at all.

Intersubjectivity and Communication

Alfred Schutz (1962) placed daily human social interaction within a context of "biographically determined situations" (p. 9) which are defined by the individual and dependent on that individual's unique physical space, time, status, role, and ideological position. Some of these elements are imposed, while others are within the realm of individual control. Schutz (1962) referred to our human existence together as "an intersubjective world of culture" in which we are bound by common influence and

mutual understanding manifest in “textures of meaning” (p. 10). Textures of meaning originate in human action in the form of *historicity*, our own and our predecessors’ tools, language, art, and social institutions. Schutz (1962) described historicity (tradition and culture) as the sediment of human activity (p. 10). Intersubjectivity is the capacity of human consciousness to be aware of realities that are not directly available to the self but which are being experienced by others, the awareness of and sharing the experience of others through the medium of human communication (Stoltzfus, 1998). Language and vocabulary are two of the primary mediums through which historicity is transmitted, in what Schutz (1962) referred to as the “vernacular of everyday life” (p. 14); therefore, the media of language and vocabulary are central to my choice of face-to-face interviews as method. According to Schutz, the intersubjectivity of human relationships precludes the ability to “bracket”, in the strict phenomenological sense; instead, Schutz emphasized transcendence.

Transcendence

Transcendence is “the experience of living in a world that extends infinitely beyond the here and now” (Stoltzfus, 2003, p. 184). Our human desire to connect with others requires that we develop the ability to transcend our biographically determined situations. All human encounters reflect some level of transcendence. According to Schutz and Luckmann (1983), there are three levels of transcendence: small, medium, and great. Small transcendences are those of space and time; medium transcendences are those of human uniqueness; and great transcendences are those of nature, art, society, and religion.

Small transcendences are what allow us to move through our daily lives by reaching beyond our temporal and physical world; as in driving a car. Because of past experience and knowledge I am able to transcend space and time by use of memory and motor skills to find my keys, insert them into the ignition and turn, apply the brake, and shift into drive. For example, in some ways, Alzheimer's disease inhibits the ability to engage in small transcendences: The inability to reach into the past and order the future prevents successful use of motor skills and sequential thought necessary for driving a car.

Medium transcendences allow us to respond to and acknowledge the uniqueness of others. Communication through language, music, and art is an example of medium transcendence. Touch, as in nursing care, could be considered a medium transcendence. Using signs and traffic signals to successfully maneuver to a health care facility, which may be marked by a blue hospital sign or a red cross, are examples of medium transcendences. Through medium transcendences, we acknowledge that others, with their own destinations and purposes, use the roads, follow mutually taken for granted rules of driving, and recognize mutually agreed upon signs and symbols.

Small and medium transcendences create situations in which humans engage in activities of daily living, or what Schutz called *practical attitude*, without great concern about the larger questions of shared life (Stoltzfus, 2003). Great transcendences, however, move far beyond the mundane actions of daily life. Great transcendences prompt humans to question the assumptions, meanings, and typifications of everyday life. Great transcendences occur in the mediums of dreams, religious experience, theater, and fantasy. Great transcendences allow the person to contemplate and move beyond the practical attitude or taken-for-granted assumptions of everyday life. Symbolic systems

like religion offer ways for humans to address unknowable questions like, “why do humans suffer” and “what happens after death”. In the realm of great transcendences, for example, a cross is not a sign that points us toward a hospital, but a symbol which represents response to death and human suffering. Great transcendences may be required for work in hospice or critical care.

Symbols

A symbol is something that represents meaning beyond typified understanding. A red cross, for example, is both a sign and a symbol. As a mutually agreed upon, taken for granted sign, it directs us to a hospital or a place that provides health care. As a symbol, it conveys transcendent concepts like mercy, neutrality, protection, and humanitarian aid. A symbol does not, however, have to be an object; it can as easily be a word. Some examples of common societal symbols are *freedom* and *equality*. The terms *health care*, *sick*, *well*, *nurse*, and *doctor* are symbols we use in daily life. Symbolic systems are groups of symbols with associated meanings. Schutz (1962) identified some of these symbolic systems as Art, Literature, and Language.

I argue that *health* is one such symbolic system which is significant in establishing horizons of meaning in relationships between patients and health care providers. Symbols evoke meaning that is shared among individuals. However, symbols and symbolic systems may be understood differently by different groups. Though there is a symbolic system called *health* that encompasses word symbols like *health care*, *sick*, *well*, *nurse*, and *doctor*, these may have different meanings to a member of the health professional in-group, or to African Americans, or to those of low socioeconomic status. One element that creates different meanings and understandings is level of knowledge.

Typification and Knowledge

Given biographical determination and historicity (routine patterns of thought and action), the same phenomenon means something different to one person than it does to another; though there is an understood reciprocity of perspectives in which some meanings or knowledge are taken for granted or mutually agreed upon by more than one individual, a group Schutz (1962) referred to as “the in-group” (p. 13). The in-group varies, and people can be members of more than one. For example, one can be an *American*, an *African American*, a *health care professional*, a *student*, or a *musician* or all of these things. A group’s mutually agreed upon meanings and knowledge, which are understood without reflection, or taken for-granted, are what is meant by typification.

One example of a typification is the experience of *going to the doctor*. Among Americans, there is shared understanding and meaning about what entails *going to the doctor*, to the extent that even if our care is provided by a nurse practitioner, the experience itself is most often referred to as *going to the doctor*. It is also understood that *going to the doctor* often involves a long wait in a waiting area. We therefore are not surprised when we wait in a waiting area to receive health care; and in fact are surprised when we do not. This particular component correlated with *going to the doctor* is part of what we understand when we hear someone else talking about *going to the doctor*. This mutually understood, taken for granted characterization of a component of an experience (or an object), is typification.

Knowledge of the world, ways of life, and typifications are based on a very small amount of personal experience, and are largely derived from the in-group of friends, parents, peers, and predecessors. Knowledge is possessed in varying degrees. An

individual may have expert knowledge in varying areas and varying times, and layperson's knowledge in others. Significantly, Schutz (1962) described the differences in degrees of knowledge using an example from the realm of health: "I know whom and under what circumstances I have to consult as a competent doctor.... In other words, in daily life I construct types of the Other's field of acquaintance and of the scope and texture of his knowledge" (p. 15). Schutz, though an expert in social phenomenology and banking, relied on typifications of doctors to answer questions and address problems which were relevant to him, but for which he had no personal expertise.

According to Schutz (1964), there are three types of personal orientation that represent differing levels of knowledge. We all operate with varying levels of knowledge depending on the situational context. Sometimes, we operate as *the man on the street* (Schutz, 1962). The man on the street operates with *recipe knowledge* which requires only that things be done as they have always been done without questioning why. I have termed this orientation *recipe orientation* and will refer to it thus, from this point forward. Taking a full round of antibiotics "because the doctor said to" is an example of recipe orientation. It is often the level of knowledge to which health care providers appeal in encounters with patients.

The well-informed citizen (Schutz, 1962) is a person who seeks to be as well informed as possible about choices which confront him or her. I have termed this orientation *the well-informed orientation* and will refer to it thus, from this point forward. Information available on the Internet has made consumers in health care much better informed. Many patients enter the health care relationship as well-informed citizens with a great deal of knowledge that they have obtained based on what is relevant to them.

Well-informed patients are interested in having their voices heard and in actively participating in treatment decisions. These patients understand that the purpose of taking an antibiotic is to kill the bacteria that have caused illness and discomfort; and that to neglect taking the entire prescription as directed will result in a return of the illness.

The expert (Schutz, 1962) is a person who has specialized knowledge in a particular area. I have termed this orientation as *expert orientation* and will refer to it thus, from this point forward. The expert knows the exact mechanism by which a particular organism is sensitized to a particular antibiotic, and exactly how the antibiotic should be administered in order to be effective. Interestingly, Schutz (1964) considered expert knowledge and orientation to be confining and restrictive: "The expert starts from the assumption not only that the system of problems established within his field is relevant but that it is the only relevant system. All his knowledge is referred to this frame of reference which has been established once and for all. He who does not accept it as the monopolized system of his intrinsic relevances does not share with the expert a universe of discourse" (p. 242). In other words, the health care provider functioning with expert orientation may know the complex mechanisms associated with antibiotic therapy, but may not be concerned about how the patient will get to the pharmacy or pay for the antibiotic.

When a health care provider interacts with a patient, he or she does so with expert orientation, generally with rigidly defined role expectations. The patient may be seeking a recipe for care, or may be expecting to be an active participant in treatment decisions, or may even enter the relationship as an expert in health care.

Relevance

Individuals and groups form typifications based on what is relevant to their daily lives, in other words, what helps them make sense of their world. The nature of relevances is that they are dynamic, conflicting, and require ongoing prioritization. Both groups and individuals operate within domains of relevances and these may shift, depending on the personal orientation at any given time. In describing relevances of an individual, Schutz (1944) said,

Insofar as he is interested in knowledge of his social world, he organizes this knowledge not in terms of a scientific system but in terms of relevance to his actions. He groups the world around himself (as the center) as a field of domination and is therefore especially interested in that segment which is within his actual or potential reach. He singles out those of its elements which may serve as means or ends for his 'use and enjoyment,' for furthering his purposes, and for overcoming obstacles. His interest in these elements is of different degrees, and for this reason he does not aspire to become acquainted with all of them with equal thoroughness. (Schutz, 1944, p. 500)

The person functioning with recipe orientation generally functions "in the midst of fragmented and inconsistent" domains of relevance (Stoltzfus, 1998, p. 108). Experts, on the other hand, function within highly ordered domains of relevance. What is relevant to me as a school nurse is different from what is relevant to me as an employee, a citizen, or a mother. As a school nurse, I have an interest in keeping students and employees safe and healthy. As an employee I am interested in attending work dependably and regularly, even when I am not feeling well. As a citizen, I am interested in children attending

school, so that they can become well-educated, productive members of society. As a mother, I am interested in the well-being of my own child in his school setting.

Often, the relevances associated with these roles are congruent; but sometimes they are contradictory. For example, I may allow my child to stay home from school due to illness, and I may stay home from work for several days to be with him. In the process of caring for him, I may contract the same illness but return to work as an employee even though, as a school nurse, I know I might be contagious to others. Needless to say, conflicting and competing relevances are complex within the daily life of a single individual. These are even more complex when considered between and among individuals!

Schutz (1964) identified the most desirable personal orientation to understanding relevances to be the well-informed orientation, as described earlier. The knowledge of this personal orientation is characterized by well-founded but flexible opinions gathered in a conscious, reflective manner from a variety of reasonable sources. This personal orientation overcomes fragmentary and disjointed relevances while avoiding narrowness and rigidity and leads to coherence and integration (Stoltzfus, 1998). In this discussion it is important to reiterate that all people function at varying levels of personal orientation at different times, and that the well-informed citizen is not an individual or a personal characteristic, but an attitude, an approach, a dispositional orientation. In encountering a health problem, a person with a well-informed orientation may speak to people he or she knows who have had a similar problem, read some of the literature about the problem, consider the treatment options available, and consider personal lifestyle issues like

convenience and potential side effects of treatment before following the advice of her primary care provider.

Schutz (1964) used the term *ethnocentrism* in reference to the values of good and right that each in-group ascribes to its own shared relevances and typifications. Ethnocentrism and differences in the horizons of knowledge and relevances contribute to dissonance and inequality in social relationships. Health care providers functioning with expert orientation could be considered ethnocentric. One poignant historical example of ethnocentrism in health care is the Tuskegee syphilis study in which African American men were denied antibiotic therapy for syphilis (Jones, 1993). The researchers' understandings and views of the study participants as poor, rural, African Americans were highly typified. Jones (1993) quoted some of the researcher's characterizations of their patients, "syphilitic negro males" (p. 174), "these syphilitics" (p. 126), and "old negro men" (p. 155), as "childlike" (p. 57); "cotton-patch" (p. 107); "cheerful" (p. 186); "filthy" (p. 107); "ignorant" (p. 116); and "easily influenced" (p. 123).

The expertly-oriented researchers and health care professionals involved in the care of these patients thought that denial of therapy was reasonable given the parameters of their study, which was designed to investigate the effects of syphilis on African Americans. Jones (1993) stated, "The men's status did not warrant ethical debate. They were subjects, not patients; clinical material, not people" (p. 179). Had those implementing the study acted with well-informed orientation, their hierarchy of domains of relevance would have shifted from studying the effects of syphilis to curing syphilis; and they would have administered penicillin therapy when it became the standard of treatment for syphilis. Their approach would have considered the relevances of the

participants in the study, rather than their own ethnocentrically located relevances as health care experts. Dissonance and social inequality resulted from an ethnocentric, expert orientation.

Social Relationships, Equality and the Need for Critical Analysis

In everyday social relationships, called mundane we-relationships by Schutz (Stoltzfus, 1998), we base our assumptions and understandings of the “other” on typifications of behavior, and respond and take action (in the forms of habit and routine) based on socially approved behavior patterns. The broader the typifying construct, the more detached it is from individual uniqueness. In typifying “other’s” behaviors we also assume a personal role, or typification. The more we typify and limit others, the more we typify and limit ourselves. These mutual typifications are taken for granted and are expected to stand until, according to Schutz, counterevidence appears (Schutz, 1962, p. 19). Typified constructs may even take the form of objects, like dogs; or institutionalized codes, like laws, which maintain social order: “The more institutionalized or standardized such a behavior pattern is, that is, the more typified it is in a socially approved way by laws, rules, regulations customs, habits, etc., the greater is the chance that my own self-typifying behavior will bring about the state of affairs aimed at” (Schutz, 1962, p. 26). But even the most entrenched typifications founder. For example, it may be that the primary care provider role of nurse practitioners presents a challenge to typifications about nurses. When a patient who has traditionally seen a physician for primary care sees a nurse practitioner instead, a new opportunity arises for nurses to be seen in a different way. As more and more people receive primary care from nurse practitioners, the

typification of *nurse* changes for the individual, for the larger societal group, and for nurses themselves.

When typifications fail or when unfamiliar or unanticipated situations arise, individuals and groups must become actively reflective. The introduction of the Internet and the resultant increase in patient knowledge has led to changes in typical patient behaviors and in the typifications health care professionals assume about patients. Typifications are not static, but are dynamic, characterized as being in a continuous state of individual and collective adaptation. Such adaptive or open nature creates an opportunity for intentional change, or *melioration* (Stoltzfus, 1998, p. 83). Melioration is the engagement of groups and individuals in deliberate evaluation of typifications, institutions, laws, and systems. Schutz emphasized that typifications are not inherently good or bad, and cannot be eliminated, even in the form of prejudice: Problems arise when discrimination is employed to impose roles, mores, or laws at the expense of self-integrity of others.

When discrimination occurs, melioration and social transformation are needed. In the previously mentioned Tuskegee example, the process of melioration began when individual health care professionals began asking questions. Peter Buxton, an investigator for the Public Health Service, heard anecdotal stories about the Tuskegee study and had a hard time believing them (Jones, 1993). He began an investigation and was disturbed by what he found. His complaint to the Centers for Disease Control started a long and difficult process of melioration which was only fully realized in 1972 when he carried the story to the national press (Jones, 1993). The result was a transformation in the way society views research; and in the relationships researchers have with study

participants. The changes regarding research that occurred as a result of the Tuskegee study are an example of large-scale melioration and social transformation, but melioration and social transformation can occur on many levels, large and small.

Transformative Symbolic We-Relationships

When typifications result in discrimination, and when symbols and symbol systems do not offer shared meanings, opportunities arise for the creation of new, shared horizons of meaning, or social transformation. Social transformation occurs when individuals engage in what Schutz called *symbolic we-relationships* (as opposed to the mundane we-relationships of everyday life), which encourage individuals to transcend typifications (Stoltzfus, 1998). Intersubjective participation in we-relationships requires people to move beyond preoccupation with self and into the world of others through thoughtful, intentional activity. The symbolic we-relationship is characterized by greater ambiguity, doubt, and unpredictability, and less typification than the mundane we-relationship. Symbolic we-relationships are creative, mutual relationships in which participants actively work to transcend typifications and create new, shared symbolic meaning. This dynamic is paradoxical, in that we-relationships are generated in the practical attitude of everyday life situations, like an encounter between a patient and a health care provider; but may become reflective and creative through the process of the mutual creation of shared symbolic meaning. This creative possibility provides the foundation for activities like qualitative inquiry, in which researchers and participants are actively engaged in creating shared understanding; and provides hope for transformation in what may be oppressive or discriminatory relationships in health care. Consideration of oppression and discrimination immediately call forth the concept of equality.

Equality

Schutz gave attention to the concept of equality in his later writings. Harris (2006) interpreted Schutz as having posed several propositions about equality: 1) All typification involves equalization in that typification requires us to compare objects, people, and experiences; 2) equality is determined by criteria that are specific to a particular domain of relevance; 3) domains of relevance are ranked hierarchically; and 4) domains of relevance are marked differently by different groups. In fact, Schutz reported Myrdal's findings of an inverse relationship between domains of relevance for Whites and African Americans in terms of economic equality and racial intermarriage (Schutz, 1964). In Myrdal's historical study, White people listed discrimination in the following order of importance: intermarriage, social equality, segregation, political rights, equality before the law, and economic equality. African American people listed these same discriminations inversely in order of importance. Schutz's point was that African Americans had greater concern with rights, legal status, and equality; whereas Whites were more concerned with social values and implications. This is a classic example of how relevances are determined by group membership and what occurs in everyday life; and how these are also related to formal, legalized equality and social equality. Other examples of differing relevances are evident in Nikki Jones' (2010) description of intersectionality, how the lives of African American women are shaped by race, class, and gender in such ways that maintain oppression and permanent inequality. Jones (2010) described the "code of the street" (p. 5) which requires girls in the inner city to command respect, maintain a reputation, and retaliate when either respect or reputation is challenged. They must often choose between societal feminine gender roles that require

them to act “good” (Jones, 2010); and the more masculine street code which may require them to protect themselves by fighting. The constant tension that exists in regards to these gender roles represent conflicting relevances; and is magnified by race and class, and often results in reduced options and opportunity to escape poverty, violent relationships, and oppressive situations. I will discuss the concept of intersectionality later in this chapter.

Interpretations of equality, a cultural symbol, may differ widely between groups based on whether the interpretation is that of the in-group or an outside group. Discrimination occurs when an outside group exerts control over an in-group by imposing its own typifications and relevances. An example of this in the western health care paradigm is the use of height and weight tables for children, which were established based on White middle-class norms (Onis & Yip, 1996). Use of such tables has often led to children of ethnicities, particularly in non-European and developing countries being identified as “outside the norm” which may in turn lead to inappropriate medical treatments and interventions (Janssen et al, 2007). This dynamic has also been an issue for determining definitions of obesity and overweight for both children and adults (Flegal, 1993; Rahman & Berenson, 2010). Further complicating this problem is the clinical assumption that risk factors like a high Body Mass Index (BMI) based on standardized tables is associated with other risk factors, like high blood pressure or higher or lower diabetes risk. These assumptions do not necessarily hold true when ethnic differences are considered (Bell, Adair & Popkin, 2001; Chiu et al, 2011). A study conducted by Sisson et al. (2009) evaluated differences in adiposity of African American and White children, comparing BMI with skin fold thickness and weight circumference.

They found that relying on BMI measurement alone placed African American children at risk for being classified as at risk because of overweight or obesity; when in fact their waist circumferences and skin fold thickness indicated lower risk for obesity-related diseases (Sisson et al., 2009).

In considering discrimination, however, Schutz emphasized the importance of the difference in perspectives of the in-group and outside groups. What an out-group may accept as obviously true may only be a belief of the out-group; and may be considered completely irrelevant by members of the in-group. According to Barber (2004), Schutz said that the evaluation of discrimination, or imposed typification, must be evaluated from the viewpoint of the affected individual. Furthermore, interventions designed by the out-group to meliorate what it perceives to be discrimination or inequality may be irrelevant to the in-group for whom the interventions were designed. This dynamic may be particularly significant when health care providers or health care researchers employ in-group concepts and symbols like health, equality, access, vulnerability, resilience, and disparity in reference to the health of an out-group like African Americans. In his discussion of application of Schutz's social phenomenology as a framework for research design, Harris (2006) stated that if researchers

want to understand the role 'equality' actually plays in people's lives, they must respect and study the various domains of relevance with which people may be concerned; the various ways that different people may rank those domains of relevance; the various kinds of typifications that people may use within diverse domains of relevance.

(Harris, 2006, p. 16)

Barber (2004) described the mystification that may occur for well-meaning individuals like health care professionals, when minority individuals and populations do not “take advantage” of the opportunities available to them, as an example of “the ethical principles that so often block one’s insight into another” (p. 184). Barber (2004) also highlighted Schutz’s caution that since barriers sometimes provide legitimate social purpose and societal support, the removal of barriers to opportunity often has unintended and unforeseen negative consequences, and that in such a context, equality is not easily achieved. The current health care reform agenda in the United States is an example of the complexities of equalizing health care by attempting to remove barriers to access through legislation.

Schutz’s recommendations for establishing solutions to discrimination and to overcoming barriers to equality were that the endeavors be approached with a well-informed orientation in which information is acquired, personal motivations are examined, and the chance is taken to influence others (Barber, 2004); which is strikingly similar to the ethnographic method. Harris (2006) recommended ethnography as a useful tool for investigating concepts relating to equality. Given Schutz’s concepts of intersubjective participation, culture, historicity, and equality it is no surprise that his social phenomenology is widely used by critical ethnographers. Similar philosophical concepts to Schutz’s are reflected in the methodology of critical ethnography and in its foundational theoretical framework, critical social theory.

Methodology and Method: Critical Ethnography

The answer to the question 'what does this social world mean for me the observer?' requires as a prerequisite the answering of the quite other questions

'what does this social world mean for the observed actor within this world and what did he mean by his acting within it?' In putting our questions thus we no longer naively accept the social world and its current idealizations and formalizations as ready-made and meaningful beyond all question, but we undertake to study the process of idealizing and formalizing as such, the genesis of the meaning which social phenomena have for us as well as for the actors, the mechanism of the activity by which human beings understand one another and themselves. We are always free, and sometimes obliged, to do so.

(Schutz, 1964, p. 269)

The nature of ethnography is widely considered and debated. Is it a methodology or a method? Most ethnographers today concur that it can be both (Gobo, 2008; Lillis, 2008). Critical ethnography provides a methodology for the study of how cultural typifications, knowledge, relevances, and symbols affect intersubjective relationships and daily human social interactions; and also provides a method for design, data collection, and analysis. Furthermore, the critical social theory framework undergirding critical ethnographic methodology provides a foundation for creating social transformation. Schutz's (1962) characterization of human interaction as "an intersubjective world of culture" (p. 10) and the tenets of his social phenomenology are particularly appropriate as a foundation for critical ethnographic inquiry.

Ethnographers are "observers of the social world" as described in the quote above (Schutz, 1964, p. 269). Critical ethnographers do not "naively accept the social world", they "undertake to study the process of idealizing and formalizing as such, the genesis of

the meaning which social phenomena have for us as well as for the actors” ; and they are “obliged to do so” (Schutz, 1964, p. 269). Critical ethnography can be considered a kind of formalized melioration.

Critical ethnography originated in the discipline of anthropology and assumes social justice, critical theory and phenomenological perspectives to illuminate social action. Madison describes critical ethnography as “critical theory in action” (2005, p. 13). Thomas (1993, p. 5) described ethnographic emancipation as “the act of cultural liberation, loosens the unrecognized symbolic constraints that restrict our perception, interpretation, discourse, and action” and defines critical ethnography as

a type of reflection that examines culture, knowledge, and action. It expands our horizons for choice and widens our experiential capacity to see, hear, and feel. It deepens and sharpens ethical commitments by forcing us to develop and act upon value commitments in the context of political agendas. Critical ethnographers describe, analyze, and open to scrutiny otherwise hidden agendas, power centers, and assumptions that inhibit, repress, and constrain. (Thomas, 1993, p. 2)

He describes some constraints as unnecessary built-in cultural norms and rituals that serve to create (often unrecognized) social domination, in which some groups or individuals have unfair societal advantage. The framework of critical ethnography assumes that its purpose is modification of consciousness, calling to action, and use of knowledge for cultural change (Thomas, 1993). In specific application to African Americans’ encounters with the health care system, critical theory would assume that there exist passive power arrangements that inhibit the relationship and delivery of health

care, and that magnify the social disadvantages of race and class. Thomas describes critical theory as follows:

Critical researchers begin from the premise that all cultural life is in constant tension between control and resistance. This tension is reflected in behavior, interaction rituals, normative systems, and social structure, all of which are visible in the rules, communication systems, and artifacts that constitute a given culture.

(Thomas, 1993, p. 9)

Critical ethnography has two components, the ethnographic component and the critical component. Ethnography is rooted in cultural anthropology and was used widely in the early 20th century by sociologists, which is why it fits so well with the social phenomenology of Schutz. It is a qualitative design that is used to describe and interpret shared patterns and beliefs of culture sharing groups (Creswell, 2007). The use of ethnography in many disciplines and with varied philosophical foundations has resulted in “pluralistic approaches” and a “lack of orthodoxy” (Creswell, 2007, p. 69). In critical ethnography, methods are varied, and may include observations, surveys, interviews or other methods. Following collection of data, a “cultural portrait” (Creswell, 2007) is formed which provides a rich description of the cultural group that is founded on the observations of the researcher and the views of the participants. Critical ethnography must remain flexible, because the most interesting questions are not usually preconceived by the researcher prior to data collection, but emerge from the data during collection (Thomas, 1993). The final product of the critical ethnography is a thematic analysis, written in narrative format, which includes the application of critical theory. Critical

ethnographies often provide extensive commentary on practical changes that could address needs of the group that is being studied.

Critical ethnography differs from standard ethnography in that it is openly value-laden and its purpose is emancipation: Emancipation of all those within the marginalizing relationship or system (not only the marginalized, but also the unmarginalized, dominant groups). Conventional ethnography assumes the status quo... it seeks to describe in typifications, typified relevances, and symbols for the sole purpose of description, and often serves to reinforce what the audience may already believe about the group. Lynd identifies one of the limitations of standard ethnography as presenting culture as “a self contained universe” (Lynd, 1970, p. 21). Critical ethnography imposes a critical framework to help the researcher translate one set of cultural symbols, those of the participants, into a set that can be understood by the audience (Thomas, 1993); a process that may facilitate transcendence of ethnocentric worldviews. A critical framework is used with ethnographic method to identify systems of power, prestige, privilege and authority that work in concert to marginalize groups of people based on race, class, gender, or any other cultural attribute or category: “Critical theory finds its method in critical ethnography. In this sense, ethnography becomes the ‘doing’ – or, better, the performance – of critical theory” (Madison, 2005, p. 13). Critical ethnography is an appropriate choice for research in which the researcher is hoping to investigate the way that cultural values, beliefs, and behaviors (or typifications) may influence and be influenced by issues related to power and dominance (Creswell, 2007).

Usually a critical ethnographer identifies an overriding theme of interest, for example, the health of African American children, and seeks to analyze how the cultural

group of interest is influenced by power and inequity in the greater cultural milieu. Duffy (2007) stated that qualitative inquiry “functions at the interface of personal and social identity and of the very social world, which is constitutive of such identities” and that personal narratives “reveal, sometimes consciously and often unconsciously, the meanings, conventions, dominant beliefs and values of the time and place in which a person lives and develops an identity” (p. 402). I have particular interest in how African American parents experience their children’s health care encounters. It is not only their perception of the encounters that is significant, but the conventions, values, and beliefs about health care and institutional professionals that precede and define the encounters: what Duffy (2007) called “interface” (p. 402) of the African American parents’ “personal and social identity with the social world” (p. 402) in the context of health care encounters and interaction with health care professionals.

Critical ethnography takes into consideration not only the traditional aim of ethnography to explain or describe a particular group or culture, but also considers power dynamics, social factors, and hidden agendas that may impact the culture or cultural experience under study (Holloway & Wheeler, 2010). Because the history of slavery and racism by the dominant White culture and their impact on African American culture are an integral component of American history and culture, I believed it important to locate this particular ethnography within a critical context. The purpose of my critical ethnography was to investigate the experiences that African American parents have in their children’s health care encounters. My assumption, as a critical ethnographer, was that inequities exist in the health care system and that power imbalances exist within health care relationships. It was through a critical lens that I viewed the data I gathered

from interviews with African American parents. A variety of components such as history, politics, economy, and environment may be considered when identifying characteristics of and influences on the cultural group. Schutz would call these components part of the biological situation and historicity.

In ethnography of any kind, reciprocity is important. Reciprocity is the idea that through the ethnographic process, meanings and values are shared between the researcher and the participants. Reciprocity is a central theme in Schutz's description of the symbolic we-relationship. In critical ethnography, this reciprocity requires that the researcher approach the topic with a well-informed, rather than an expert orientation. With a well-informed approach, the researcher can avoid the strictures and confines of expert relevances and typifications. The well-informed approach is consistent with avoidance of what ethnographers call domestication. Domestication, or the expert orientation, occurs when researchers are inhibited by typifications and domains of relevance associated with their discipline:

There is an outer rim of practices and processes that constrains our research and how we talk about it, and most of us are too concerned with what lies within this narrow universe to examine how its rim is created and what lies beyond it. Our problem is that we are accustomed to our intellectual leash; we have become domesticated. (Thomas, 1993, p.8)

Just as Schutz said that typifications and prejudices cannot be avoided, Thomas (1993) stated that our ideological premises are not the problem... it is our failure to recognize the distortions they produce in our daily lives. The same may be said of health care providers, especially in their relationships with patients.

In “The Stranger,” Schutz (1944) discussed what happens when an outsider encounters a cultural group with an established scheme of typifications and relevances and is required to adjust his own typifications and relevances. Schutz’s description of the stranger was significant for consideration in my study of African American parents’ experiences in their children’s health care encounters in that patients usually enter the health care system as strangers.

Schutz defined the stranger as anyone from outside the in-group who approaches the in-group with the desire to be accepted or tolerated (Schutz, 1944). The cultural patterns of the group are unquestioned by members of the group, but almost every element of the culture is questioned by the stranger. Jones (1993) quoted Nurse Rivers, the primary nurse engaged in the Tuskegee study: “Most had never had a blood test and had no idea what one was. They cooperated, she explained, because ‘it was something new and was some medical attention that they had never had,’ adding that most of them ‘had never been to a doctor – never seen one’” (p. 114). This is an extreme but classic example of the stranger in health care. The stranger does not share the historicity or ascribe to the authority of the in-group’s culture. The cultural pattern of her own group continues to be her domain of reference for participation in the new group. In terms of relevance, participation in the new group becomes highly relevant for the stranger, and the typifications and knowledge the stranger formerly employed with reference to the group no longer work. In addition, the stranger can no longer appeal to members of his or her own group for information about this new group, because he or she realizes that the knowledge the group has is not accurate. It is as though the stranger was provided an inaccurate map of an unfamiliar destination; whereas members of the group do not even

need a map... they have already arrived at the destination. The stranger must proceed carefully and intentionally in order to become successful in the new group. The stranger must both define and interpret typifications, relevances, and symbolic meaning. For example, one of the participants in the Tuskegee study said, "They [the doctors] were young men and that's what made me curious. I said [to myself]: I wonder if they were doing their intern or practicing on us or what? But nobody ever said nothing'" (Jones, 1993, p. 159). The stranger must attempt to distinguish individual traits from typical functions. The stranger's attitude may be characterized as objective and perhaps disloyal.

Because of a need to define and understand, strangers are often critically aware of inconsistencies and incoherence in the group, and take no element of the culture for granted, as do its own members. When the stranger is unable or unwilling to adopt the culture of the group, he may be considered disloyal. Schutz stated that group members may call the stranger

ungrateful, since he refuses to acknowledge that the cultural pattern offered to him grants him shelter and protection. But these people do not understand that the stranger in the state of transition does not consider this pattern as a protecting shelter at all but as a labyrinth in which he has lost all sense of bearings. (Schutz, 1944, p. 507)

This in-group characterization of stranger ingratitude is evident in the words of one of the physicians in the Tuskegee study in regards to participants who refused to be examined. He characterized their refusal as "rank ingratitude for a thorough medical work-up which would cost anyone else a large amount of money if sought at personal expense" (Jones, 1993, p. 158).

Critical ethnography can be used to frame the relationship between patients and practitioners as analogous to the stranger in an unfamiliar culture. Critical social theory provides the theoretical framework by which critical ethnographers may analyze inequities in power relationships that may be exacerbated by cultural differences. For example, western health care, since its inception, has been built on a Eurocentric, positivist paradigm that assumes a single correct approach to disease and illness. Research and treatment have been conceptualized for and aimed at treating disease and infirmity that affect the well-being of affluent White males. The individualized, illness approach of the Western system locates “the individual as the primary site of health” in research and practice and “sets aside wider social structures that serve to maintain and engender these disparities” (Mohammed, 2006, p. 68). Health care professionals operate as members of this cultural group, with an expert orientation. Patients, on the other hand, generally approach health care as strangers.

Another example of framing the health care culture with critical social theory is to consider the fact that minority health care providers are underrepresented in the health care system (Cohen, Gabriel & Terrell, 2002). This underrepresentation may be indicative of educational and institutional racism and classism; and results in African Americans receiving care within a system that may not be as culturally sensitive as it would be with a more representative provider population. It also means that African Americans entering health care encounters as strangers have less opportunity to check their own typifications with members of their in-group who may also be health care providers, and are more likely to be typified by health care professionals who are not members of their group.

It is interesting to consider the concept of the researcher as stranger in critical ethnography. Schutz would not consider a researcher a stranger in the strictest sense of the word, in that the researcher is seeking only transitory and impermanent contact with the participant group; but it must be acknowledged that the researcher, in ethnography, has a relational role that lies somewhere between group member and disinterested observer. This role has been described by various ethnographers as *participant observer*, *marginal native*, and *professional stranger* (Munhall, 2007). While in these various terms there is disagreement about the level of group membership the researcher achieves or should try to achieve, they are consistent that the researcher role should be characterized by honesty, openness, and reciprocity, for the purpose of building trust. Perhaps one difference, then, between the stranger and the professional stranger, is that in taking steps to establish trust by qualifying himself or herself as nonthreatening to cultural integrity, the professional stranger will not be at risk for the group's perception as disloyal.

Theoretical Framework: Critical Social Theory

Critical social theory is the theoretical framework that grounds all critical ethnography and is part of the same postmodern paradigm that supports qualitative inquiry. Critical social theory is a widely used and interpreted theory that originated in the Frankfurt School in Germany (Fulton, 1997). Critical social theory has its foundations in Marxist thought and action, and is considered to be a revision and expansion of Marxist philosophy (Bohman, 2010). The primary philosophers in the Frankfurt School were Horkheimer, Adorno, Marcuse, and Habermas who, in the wake of World Wars I and II, were interested in developing an emancipatory response

(philosophical and practical) to logical positivism, capitalism, and fascism (Bohman, 2010). Critical social theory assumes that life in society is characterized by obvious and hidden agendas and structures that perpetuate inequity at the expense of a marginalized group or groups to the benefit of a dominant or majority group or groups. The purpose of critical social theory is emancipation, “to liberate human beings from the circumstances that enslave them” (Horkheimer 1982, p. 244). Implicit in the theory is that all participants, not just the marginalized, in an unjust society are enslaved by the inequity.

Critical social theory considers rights and equality as overt, explicit, and codified; but also implicit, or hidden. Critical social theory, as it originated in Marxism and as it is espoused contemporarily in the forms of more specific theory like critical race theory, social justice theory, and feminism, defines human emancipation as manifestation of the ideals of freedom and justice; and therefore cannot be separated from the conceptual ideal of democracy. Therefore, democracy may be considered the more practical result of human emancipation; it is important to note, however, that democracy as we define it in the United States today is *not* a manifestation of the practical democratic product of critical social theory as described by Habermas (Bohmer, 2010). Instead, “deliberative democracy” espoused by critical social theory is defined as

Deliberative democracy rests on the core notion of citizens and their representatives deliberating about public problems and solutions under conditions that are conducive to reasoned reflection and refined public judgment; a mutual willingness to understand the values, perspectives, and interests of others; and the possibility of reframing their interests and perspectives in light of a joint search for common interests and mutually acceptable solutions. Deliberative democracy

introduces a different kind of citizen voice into public affairs than that associated with raw public opinion, simple voting, narrow advocacy, or protest from the outside. It promises to cultivate a responsible citizen voice capable of appreciating complexity, recognizing the legitimate interests of other groups (including traditional adversaries), generating a sense of common ownership and action, and appreciating the need for difficult trade-offs. And one of the central arguments of deliberative democratic theory is that the process of deliberation itself is a key source of legitimacy, and hence an important resource for responding to our crisis of governance. (Sirianni & Friedland, 2011, Paras. 1 and 7)

This description of the characteristics of deliberative democracy are highly congruent with Schutz's construct of the well-informed citizen and the process of melioration.

Contemporary, or post-modern, critical social theory considers social and political problems in historical and cultural contexts, which may vary based on situation (Lindlof & Taylor, 2002), or what Schutz would call historicity of biographical situations. Critical social theory is used in a variety of context-specific theory such as feminist theory and critical race theory. Critical social theory is useful for analyzing power structures, institutions, and relationships within a society and within individual relationships, as in health care systems and individual/provider relationships (Sumner & Danielson, 2007). The most important characteristics of critical social theory are that it "must explain what is wrong with current social reality, identify the actors to change it, and provide both clear norms for criticism and achievable practical goals for social transformation" (Horkheimer, 1982; Bohman, 2010). Critical social theory does not result in prescription

for change, but in engagement in personal and societal self-reflection, which may result in deliberative democratic change (Bohmer, 2010).

Critical social theory has been a tool used historically to initiate transformation in the societal position of African Americans. Though the Emancipation Proclamation issued by Abraham Lincoln in 1863 declared that all slaves be freed, this was not an example of critical social theory in action. Following the Civil War and the emancipation of slaves, many years of reconstruction resulted in further alienating the newly freed slaves from participating in free society. Though given the right to vote, receive education, and own land, hostility in the South and industrialization in the North created new problems for African Americans. African Americans made many gains due to their *equal* status in the eyes of the law; but the rule remained *separate but equal* until the late 1940's and early 1950's, which saw the passage of legislation which integrated the United States military and the nation's public schools, and fair employment practices for government agencies. These are all examples of the role government and legislation played in granting overt equality to African Americans. Critical social theory, however, requires that we look beyond codified equality and consider all the societal manifestations of equality. Despite the legal equality of African Americans then, it was clear that great social and economic inequity still existed.

It was during this period that critical social theory was applied by one of the most well-known practitioners in history, Martin Luther King, Junior. King's original plan was to be a practicing academic, not an activist pastor. His bachelor's degree was in sociology, and he was well-schooled in Western philosophy and Marxism (Blakely, 2001). He greatly admired Gandhi, and saw society with a decidedly critical bent:

When we ask Negroes to abide by the law, let us also declare that the white man does not abide by law in the ghettos. Day in and day out he violates welfare laws to deprive the poor of their meager allotments; he flagrantly violates building codes and regulations; his police make a mockery of law; he violates laws on equal employment and education and the provisions of civil services. The slums are the handiwork of a vicious system of the white society; Negroes live in them, but they do not make them, any more than a prisoner makes a prison.... It is not the race per say that we fight but the policies and ideologies that leaders of that race have formulated to perpetuate oppression.” (King, 1967)

King was intrigued early on with Thoreau’s critical essay, *Civil Disobedience* (Blakely, 2001). He came to blend his understanding of critical theory with the tenets of Christianity in an effort to fight oppressive social systems (Blakely, 2001):

From my early teens in Atlanta I was deeply concerned about the problem of racial injustice.... Not until I entered seminary, however, did I begin a serious intellectual quest for a method to eliminate social evil. I was immediately influenced by the social gospel. (King, 1986, p. 37)

He went on in this reference to specifically mention the works of Hegel, Walter Rauschenbusch and Mahatma Gandhi. These thinkers and activists are widely considered to be critical theorists (Klein & Huynh, 2004; Strain, 1978; Bartos & Wehr, 2002).

Without going into great detail, as it is beyond the scope of this paper, I will make the point that critical social theory was used to transform society through the Civil Rights Movement. King’s opinion was that legislated equality was not sufficient; that until the material conditions of people and societal attitudes were changed, true equality did not

exist. In the years immediately preceding his death, King's approach to civil rights had extended beyond race to focus primarily on class, evident in his *Poor People's Campaign* to try to raise wages for sanitation workers. In a classic application of critical social theory, he emphasized the role of militarism and economics in oppressing America's poor:

We have been repeatedly faced with the cruel irony of watching Negro and White boys on TV screens as they kill and die together for a nation that has been unable to seat them together in the same schools. So we watch them in brutal solidarity burning the huts of a poor village, but we realize that they would never live on the same block in Detroit. I could not be silent in the face of such cruel manipulation of the poor. (King, 1992, p. 138)

It is clear that King's general approach to societal transformation was the application of critical social theory. King's seven step process for nonviolent social transformation included: 1) not humiliating any societal participants; 2) identifying unjust systems, not individuals; 3) willingness to accept suffering; 4) requiring both internal and external transformation; 5) grounding in love and respect for all participants (seeing all society members as victims of oppressive systems); 6) unending striving toward justice; and 7) actively resisting injustice without perpetrating violence (change rooted in dialogue, not force) (LaFayette & Jehnsen, 1995). These steps are reflective of classic critical social theory concepts of egalitarianism, dialogue, democratic process, and the requirement for multilevel analysis and transformation. It is a focus on process as both an ends in itself and a means to an end; as described earlier in the definition of

deliberative democracy and in the Schutzian concepts of melioration, transcendence of typifications, and symbolic we-relationships.

Deliberative democracy and melioration, however, are not one-time actions, but ongoing processes. Likewise critical social theory is a flexible tool to be utilized for exploring the ever-changing face of injustice. “Critical researchers begin with the premise that all cultural life is in constant tension between control and resistance. This tension is reflected in behavior, interaction rituals, normative systems, and social structure, all of which are visible in the rules, communication systems, and artifacts that constitute a given culture” (Thomas, 1993, p. 9). My purpose in this study was to use the format of critical ethnography to investigate some of these tensions as experienced by African American parents in their encounters with their children’s health care providers. How were these tensions manifested specifically in the experiences of African Americans in the health care system?

The Malone-Heckler report of 1986 brought to the nation’s attention the frighteningly wide gap in the health status of African Americans (Byrd and Clayton, 2000). Despite the awareness this report brought to those interested in African American health, research shows that the majority of Whites in America were not aware of any racial disparities in health, and believe that any disparities that exist are not related to race or racial discrimination (Byrd and Clayton, 2000). Byrd and Clayton (2000) used a critical approach to identify seven factors that contributed to ongoing racism and classism in American health care. These are: 1) a widespread assumption that health disparities are “normal”; 2) a marginalization of African Americans at all levels of health care (both patient and provider); 3) a lack of acknowledgement that African Americans utilize the

health care system differently than do White Americans; 4) a historical Eurocentric approach to health by Eurocentric providers; 5) inadequate representation of African American health care providers, and lack of impetus in rectifying it; 6) a resurgence of race-based science in research; and 7) contentious racial relationships among health care professions (Byrd & Clayton, 2000). I used their critical analysis to guide my own, and consolidated the factors they identified into three general categories for critical analysis of racism and classism in health care: History, Western health care culture, and root causes of disparities. The categories are not distinct, but are fluid, overlapping, comingling, and interacting.

History

History is perhaps the most salient factor in understanding racism and classism in American health care. The forced migration of Africans to America for the purpose of slavery represents a profound racial and economic power imbalance, which was based on a belief that those with dark skin were, in fact, animals rather than humans. In the years prior to the Emancipation Proclamation, African Americans received plantation-based health care, aimed at keeping them healthy and productive. With the freedom of slaves came enormous increases in morbidity and mortality, due to a complete absence of health care. In the late 19th and early 20th centuries, civic organizations both African American and White began building a system of university education, including medical education, for African Americans. Though the intentions in creating this educational system were considered to be admirable, the functional result was completely separate systems of care and education for African American and White Americans, which are still evident today.

Freeing slaves from bondage did not free them from the pervasive view and treatment of them as subhuman. Washington (2006) described vignettes she found in her research of personal autobiographies and journal articles written by physicians: “The stories physicians told mixed stereotyped comedy with exasperation as they dismissed African Americans as disease-ridden, unintelligent, fearful, distrustful, and, above all, ‘noncompliant’ patients” (p. 16). Though we would like to think that such a view is no longer the norm, it is telling that our culture is willing to accept health disparities as normal. It is also my experience that there remains a cultural tendency of health care providers, in general, both African American and White, to disparage patients and even one another. One study identified negative or disruptive communication as correlated with poorer patient outcomes (due to medical errors, increased mortality, decreased patient safety, quality of care, and patient satisfaction), with disruptive communication defined as raising one’s voice, disrespectful interaction, abusive language, scolding in front of peers, and condescension (Rosenstein & O’Daniel, 2005). Sometimes negative communication may be grounded in providers’ prejudiced and classist beliefs. Even when such communication is not racially intended, it may be perceived by African Americans to be so. This tendency to disparage or engage in negative communication is only one aspect of the Western health care culture that affects the African Americans that encounter and utilize it.

Western Health Care Culture

The culture of Western health care is a major factor in understanding racism and classism in American health care. Western health care, since its inception, has been built on a Eurocentric, positivist paradigm that assumes a single correct approach to disease

and illness. Research and treatment have been conceptualized for and aimed at treating disease and infirmities that affect the well-being of affluent and middle class White males. The individualized, illness approach of our Western system locates “the individual as the primary site of health” in research and practice and “sets aside wider social structures that serve to maintain and engender these disparities” (Mohammed, 2006, p. 68).

Minority health care providers are underrepresented in the health care system. This underrepresentation may be indicative of educational and institutional racism and classism; and results in African Americans receiving care within a system that may not be as culturally sensitive as it would be with a more representative provider population.

Root Causes of Disparities

Resistance to acknowledging the foundational, multi-systemic causes of health disparities is the third major factor in understanding racism and classism in American health care. Outside the health care system, there are several factors that influence the care that poor African Americans receive. One of these is lack of access. Inner city, poor, minority areas are notoriously underserved. Providers generally choose to locate their practices where they can live comfortably and make a profit. This dynamic serves to limit the availability of primary care and create a dependence on emergency care. Likewise, simply finding transportation necessary to access care may create a problem for those from low-income families, African American or White. Once care is obtained, there may be inequity in treatment provided, as discussed earlier in this paper. African Americans receive care later and receive less intervention than do their White counterparts (Dubois, 2010). Part of the discrepancy in treatment may reflect a hesitancy

on the part of African Americans to access care that they perceive to be unequal (Dubois, 2010), and a mistrust of providers. This hesitancy and distrust cannot be separated from the historical factors and the Western health care cultural factors mentioned before.

There are also the greater economic and political issues associated with privatization of health care. The market approach to health care has created competition in the industry to gear service to the most affluent and most healthy. Those who are unable to afford insurance and who suffer the most health disparities are not considered to be desirable consumers. A culture of individualism has created a health care environment that blames the individual for his or her health status and inability to pay for health care. It is apparent that in the United States, racism and classism are intertwined and often indistinct. It may be difficult in many cases to determine whether racism or classism is at the root of inequity in health care. Some African American scholars argue that distinguishing between the two is irrelevant (Robinson, 2010), since the resultant disparities for poor African Americans are the same.

Beyond the causes and evidence of racism and classism that are obviously related to health care provision and access, there are the broader race- and class-related societal factors that affect the health of African Americans and serve to contribute to health disparities. These include geographical segregation of neighborhoods by race and class; community violence and neighborhood safety; proximity of grocery stores; community design and planning; disability and welfare policy; employment and hiring practices; and educational systems. Openly identifying and acknowledging the racism and classism perpetuated within and among these systems and practices is a key component of critical

social theory and the first step to creating a milieu in which democratic processes and dialogues occur.

Nursing's primary purpose is to improve the health and well-being of individuals and populations. Probably the greatest advantage of using critical social theory in nursing is in its ability to move beyond the standard Western bounds of interpretations of normal and to promote "study of the environment as a place that not only promotes but impedes human health and fulfillment" (Boutain, 1999, p. 38), whether that environment be nursing education, practice, or research. Critical social theory provides not a standardized framework, but rather a way to respond to the assumptions of standardized frameworks already used, in order to promote new ways of thinking about processes and problems. In a broader application, practitioners are encouraged to see beyond stereotypical negatives that they believe have negative influence on African American health, to consider strengths like spirituality, resilience, and family cohesiveness which positively affect health and well-being. Furthermore, critical social theory makes possible the identification of system-related obstacles to health, such as low health literacy. Rather than dwell on the individual's low literacy level, critical social theory prompts the practitioner and the system to alter practice and process by developing creative ways to communicate with clients of all literacy levels. Critical social theory prompts the practitioner to change practice and process in collaboration with the client, rather than responding to a health problem with a one-size-fits-all solution or blaming the individual client for health problems or lack of compliance. Changing the speech, understanding and acts or processes (Habermas, 1984) changes the practitioner and the client, and results in the emancipation of both.

Critical social theory encourages researchers to acknowledge the complexity, fluidity, and dimensionality of social identity. In researching African American health, research aimed at deconstructing oppressive stereotypes can challenge traditional models of addressing health and wellness by resisting comparisons to white “norms” and establishing interventions that move beyond race and class. Culturally specific designs may be employed not to compare African Americans with Whites but to create population appropriate interventions for community identified problems, as in the community based participatory research model. For example, Mohammed (2006) utilized critical social theory to analyze the multi-factoral nature of diabetes. Critical social theory enabled her to move beyond the individual-oriented dimensions of nutrition, physical activity, and compliance to examine how oppressive arrangements in society, such as poverty, food scarcity, and housing hindered the individual’s nutrition, physical activity, and treatment.

A further subcategory of critical social theory which addresses the complexity of the interactions of factors like these is *intersectionality*. Though the concept of intersectionality was not integral to the justification of my approach to this study, it was a concept which had the potential to be pertinent in evaluating themes that emerge during the data analysis. Intersectionality is also a concept which could be considered to be encompassed within Alfred Schutz’s interpretation of the intersubjective nature of the social world. For these reasons, I included a brief overview of intersectionality.

Intersectionality

Intersectionality is a subconstruct of critical theory that frames the consideration of inequality as the result of complex interactions between categories of difference, such

as race, class, gender, and sexuality (Kelly, 2009). It has been defined as “the oppression that arises out of the combination of various forms of discrimination, which together produce something unique and distinct from any one form of discrimination standing alone” (Reynoso, 2004, p. 64). Though age is not commonly mentioned in the literature about intersectionality, I would argue that age is a major intersecting factor in health care, considering the health disparities of the very young and the very old; and one that could be an important framework for questions about children’s health. The concept of intersectionality was introduced in the 1980’s by Patricia Hill Collins (1986), an influential scholar in African American feminist thought. In subsequent years it was further developed by scholars like Kimberle Crenshaw (1989, 1991) and Nikki Jones (2010) in application to complex interactions of race, class, and gender in the shaping of African American and immigrant women’s lives in the inner city.

For example, Nikki Jones (2010) told the story of young African American women in the inner city who, because of the complex factors of gender roles, exposure to violence, and lack of access to education and employment, remain trapped in poverty and the inner city, often in violent and abusive relationships. It is not enough to consider the singular factors of race, gender, or class in order to create interventions that will effectively change the status of individuals or the population as a whole. Jones (2010) and Crenshaw (1991) both specifically reference the failure of programs that have a singular focus, such as job training, that fail to take into account the complexity of factors at work.

More recently, intersectionality has been considered and applied by scholars whose primary interest is in health care and who consider it a critical step in addressing

social determinants of health (Iyer, Sen & Ostlin, 2008). Iyer, Sen, & Ostlin (2008) discuss how intersectionality affects thought about health disparity: “Risk factors do determine health outcomes... but as both gender and class exert an influence, the pathways leading to social inequalities in health can be complex, and cannot be predicated along a single dimension of social inequality” (p. 11). Intersectionality is a framework that can be used to consider a variety of individual, institutional, and societal factors related to health, including access, utilization, discrimination, perception, and others as they are influenced by a confluence of social determinants. Western health care has traditionally considered disparities within singular categorical dimensions such as race, gender or income, as opposed to a multidimensional approach (Kelly, 2009). This singular consideration reflects a positivist approach. Critical scholars encourage the use of qualitative and mixed methods to capture the multidimensional nature of the social determinants of health by using a framework of intersectionality (Kelly, 2009). Kelly (2009) specifically mentions nursing as a discipline that could be at the forefront of application of intersectionality. It is also a concept, however, that is widely considered to be difficult to apply in terms of method and measurement of outcomes (McCall, 2005; Mens-Verhulst & Radtke, 2006).

Airhihenbuwa and Liburd (2006) discussed the interface of culture, gender and power in relationship to the elimination of health disparities of African Americans. These authors used the term *interface*, which is another way of referencing the concept of intersectionality. In their response to the Heckler Report (USDHHS, 1986), they emphasized that the key to elimination of health disparities is the examination of the interface of culture, gender, and power in the social conditions that create an environment

in which chronic health problems exist and persist. They include consideration of not only the more obvious factors like neighborhood segregation on creating these conditions, but also the White structural framework that is used to define deviance from societal norms. They referenced the ethnocentrism of health care practice and research which blames the failure of programs on “unhealthy” cultural practices of African Americans, and the dynamic in which “many researchers unwittingly hide the cultural lenses that are normalized in the institutional structures within which their analyses have been framed” (p. 491). They offered the challenge that the way a health problem is defined does not necessarily offer a framework for the solution. What we, as health care professionals and scholars view as *racial disparities* and *health problems*, may not be viewed as such by the communities who experience them. In the discussion of the study I conducted, I address some aspects of intersectionality that became evident in the interpretation of the data provided by my participants.

The concept of intersectionality as it relates to the study as it was originally conceived is introduced with a caveat: I did not know whether or not intersectionality would be relevant to the concepts and themes that emerged from my data collection. I did, however, believe that the concept was very important to consider, and I believed the larger questions addressed in the study related to issues of intersectionality. Mentioning it as a theoretical framework that is influential in my own interest was important, too, in helping me to identify personal assumptions and avoid imposing a framework that does not fit. Whether or not intersectionality should be a primary theoretical point of discussion in relationship to African American parents’ experiences in their children’s

health care encounters was something I could only determine following data analysis, in the discussion section of the dissertation.

Qualitative inquiry honors the subjective nature of reality, and the many meanings that may be inherent in a particular phenomenon or experience. The social phenomenology of Alfred Schutz, with its focus on the intersubjectivity of the social world provides an interpretive framework for considering the experiences of African American parents in their children's health care encounters. Critical ethnography, with dual components of both ethnographic and critical analysis is a useful methodological tool for analyzing these experiences within the Schutzian framework.

CHAPTER 4: METHOD AND DATA COLLECTION

Critical ethnography is considered both a methodology and a method. The methodology as a foundation for concrete method was explained in Chapter 3. My interest in this topic and the overall development of its design began in the Fall semester of 2010 when I took a class in qualitative inquiry. Students were asked to conceptualize a qualitative study and formulate a proposal based on a question of interest. That proposal, in a more rudimentary form, provided a foundation for the further development of an interview guide and a pilot study to test the guide of a research practicum in Spring semester, 2011. Institutional Review Board approval was granted from Kennesaw State University for both the pilot study (Study # 11-182) and related documents, and for the dissertation research (Study #12-007) and related documents (see Appendices A, B, C and D).

Method

Because this study was centered around data collected through interviews (which, according to Wilson [2001] may be considered participant observation), and did not include the broader ethnography components of researcher observation and records (artifact) review, I elected to refer to my method as an ethnographic interview analysis (EIA), as a complementary equivalent of what Altheide (1987) called ethnographic content analysis (ECA), or the “reflexive analysis of documents” (Altheide, 1987, p. 65). I defined ethnographic interview analysis as *the reflexive analysis of interviews*. Like ethnographic content analysis (ECA), ethnographic interview analysis (EIA) is

characterized by reflexivity and fluidity among data, concepts, analysis, participants, and researcher. I also acknowledged that while Altheide (1987) referred to ethnographic content analysis (ECA) as it relates to artifactual data like television and newspaper reports, others have referred to qualitative content analysis (QCA) as referring to documents including transcribed interviews (Graneheim & Lundman, 2004). Altheide (1987) relied heavily on the concept of reflexivity, as conceptualized by Glaser and Strauss (1967), in defining ECA as a method. Reflexivity is discussed in depth in the section entitled *Frameworks for Trustworthiness and Rigor*.

Aim

The overall aim of this study was to gain understanding of the personal, familial, and sociocultural forces that shape African American parents' encounters with health care providers and the health care system. The understanding gained in this study may facilitate the creation of culturally sensitive approaches that health care providers and institutions can implement in relationships with parents of African American pediatric patients that may ultimately improve the health and health care of African American children. In the final chapter, I have made specific recommendations for providers based on my findings.

Data Collection and Instrument

The primary data collection method I employed was face-to-face, open-ended semi-structured interviews with African American parents, which were digitally recorded and transcribed verbatim. There were several background and demographic questions, which included questions about age, family description, income level and employment. The interview guide was based on an instrument I developed and piloted in Spring, 2011.

The focus of the pilot study was to develop and refine an interview guide to use to gather information from African American parents about their experiences in their children's health care encounters. The preliminary guide consisted of a series of about 20 questions I developed from reading Madison's (2005) text on Critical Ethnography in which she evaluates several models for interviewing. The Spradley model categorized questions, in part, as "tour questions", which address concrete situational descriptions of phenomena; "example questions", which ask the participant to recount an experience that best exemplifies the experience of a phenomenon; "experience questions", which ask the participant to detail the experience of a particular phenomenon (Madison, 2005, p. 28). These characterizations of questions helped me develop the questions that loosely guided each interview.

Pilot studies in qualitative research are employed for a variety of reasons. One of these is to develop and test research instruments; another is to improve the internal validity of a questionnaire by refining technique and identifying ambiguities and inconsistencies in questions. Piloting can also help clarify a study's focus (NC3Rs, 2006; Teijlingen, Rennie, Hundley & Graham, 2001). The pilot study was critical to the development of a usable instrument and for the purpose of developing my comfort and skill as a novice interviewer. My personal objectives of the pilot study were to insure personal comfort with interview skills and techniques; to check authenticity of interview questions; to check understandability of the questions; and to triangulate with mentor faculty. I employed purposive sampling for the pilot study. Because I wanted honest and straightforward feedback about the guide and the relevance and appropriateness of the questions, I garnered participants from among coworkers and contacts I had through my

work as a school nurse. Some were staff and faculty within the school system, others were parents of students in the school system.

During the process of piloting the guide with seven participants, I refined and changed the original questions twice based on participants' responses and recommendations, and on changes suggested by guiding faculty. My goal was to refine not only the interview guide, but my own interview technique. It is widely accepted in the qualitative paradigm that the interviewer is an instrument (Lincoln & Guba, 1985) as well, and that a pilot study is one way to test that instrument (Teijlingen, Rennie, Hundley, & Graham, 2001). Finally, the pilot study gave me the opportunity to develop comfort with use of the digital audio recording device and to assess the quality of the recordings. The result of the pilot study was the refinement of the interview guide into its final format (see Appendix E) and refinement of myself, the primary research instruments for this study.

As I became more comfortable with the interviewing process, I used the instrument less and less; remembering the questions and content without having to refer to a hard copy. I also felt more comfortable with allowing participants to direct the conversation. It became clear that there were things they felt were important, that were not specifically mentioned on the instrument. Rather than redesign the instrument over and over, I came to accept the agendas of the participants as uncontrollable and highly individual, and just listened to what they had to say. In this give and take, I was able to glean the information necessary to answer the specific questions I had; but also allowed them to answer important questions I had not thought of, but that were important to them. This flexibility in the semi-structured interview is what I had been hoping to gain during

the pilot process. In the qualitative interview, over-adherence to a guide can inhibit the process and preclude the possibility of discovering “how the interviewee frames and understands issues and events—that is, what the interviewee views as important in explaining and understanding events, patterns, and forms of behavior” (Bryman, 2004, pg. 314).

Setting

The study took place in a small metropolitan community in south Georgia. Interviews were conducted in places of the participant’s choosing, with attention to ensure enough privacy to guarantee confidentiality. Interview locations on most occasions were participants’ homes; but I also interviewed them in my home; in a secluded booth in a fast-food restaurant; at a local park with playground equipment to occupy a participant’s energetic children; in the school clinic where I work and see children (after hours); and at a school library at the school where a participant worked. Greater detail about the setting is provided in Chapter 5, for the purpose of contextualizing the data that immediately follows.

Population and Sample

Various methods of purposive sampling were employed. As I had originally planned in my proposal, the sample was drawn from African American parents ages 18 to 60 from a variety of backgrounds and occupations throughout south Georgia. It did not include guardian grandparents or foster parents, though many of the participants I interviewed had children of other family members living with them, as well as their own. As planned, participants were identified through professional and personal contacts through a school system. The first seven participants were those who participated in the

pilot study. They were contacts and acquaintances I had from my work as a school nurse. Four additional participants were recruited through letters sent home to students of one small elementary school (with permission from the superintendant and board of education). School nurses in the local city school system, with permission of the superintendent, asked parents with whom they had contact by telephone or face to face contact over a period of one week if they would like to participate in a voluntary research project. If they indicated interest, they were given my phone number; thus, five more participants were recruited. Chain referral (snowballing) by participants resulted in identifying two additional eligible participants during the research process, who were given my contact information by other participants. Inclusion criteria included voluntary participation in the research. In the pilot study, though I did not specify that participants be female; all participants were mothers. At that time, most of my participants indicated that they, as women, were the primary managers of health care access and communication in their families. This dynamic held true, and all the participants of the study were women, though men were not excluded. I anticipated that all participants would be either low or middle income; and though high income participants were not excluded, it turned out to be the case that as anticipated, all participants were low or middle income. Demographic characteristics of the sample are detailed in Table 1. Greater detail about the participants is provided in Chapter 5, for the purpose of contextualizing the data that immediately follows.

Sampling continued until data saturation was achieved (Lincoln and Guba, 1985). I had anticipated that twenty participants would be necessary for illumination of the study phenomena; but after eighteen interviews, it seemed as though no new themes were

evident or emergent, and in fact I began to feel as though I might be oversaturated with data! In the next chapter, I will discuss in greater detail how my original plan to consider emergent themes by income category was altered, based on the data I collected.

Table 1

Participant Characteristics

Demographic Category	n	Percent (%)
Gender		
Male	0	0
Female	18	100
Age Groups		
20-29	2	11
30-39	9	50
40-49	6	33
50-59	1	6
Educational level		
< 12 years	0	0
High school diploma	4	22
Some college or technical degree	7	39
Bachelor's degree or higher	7	39
Economic Status		
At or below 133% of the poverty level	11	61
Above 133% of the poverty level	7	39

Human Subjects Considerations

Munhall (2007, p. 419) described several ethical standards for human subjects qualitative research that are applicable to this particular proposal: Relational responsibility, which includes respect, sensitivity, and availability of the researcher to the participants; mindfulness of the effect that participation may have on the participant; comfort with intimacy; attention to procedural standards such as informed consent, confidentiality, and IRB approval; and care in balancing integrity of the content and confidentiality of participants in the final report. As described earlier, I had IRB approval for this study; and conducted the interviews with careful attention to issues of consent, confidentiality, and sensitivity. All names of participants and their children were changed, and identifying information was altered to ensure privacy.

Another ethical consideration of critical ethnography, in particular, is providing voice to participants' justice issues that emerge from the data. Providing voice is foundational to promoting rigor and avoiding bias in that the researcher be acutely aware of her own positionality in relationship to elements of the study. In relating to human participants this awareness encourages what Lugones (1994) called "world traveling" (p. 631), comfort in moving between worlds from familiar worlds in which one is comfortable, into unfamiliar, uncomfortable ones. In critical ethnography, this ability and willingness to engage in world traveling is not just important to rigor and accuracy in reporting data, it is a foundational component of ethical relationships with participants. In general, providing voice in the interviews was not difficult. All participants were open and willing to share their ideas, some more colorfully than others. In the next chapter, I hope that "providing voice" is demonstrated by my consideration of issues that emerged

as important to them, while still addressing the questions that were of particular interest to me.

Frameworks for Trustworthiness and Rigor

According to Munhall (2007), many ethnographers use Lincoln and Guba's (1985) criteria to establish rigor, or trustworthiness. Lincoln and Guba (1985) made specific recommendations for establishing credibility. These include "a prolonged period of engagement" in the environment, "evidence of persistent observation", and utilization of methods of triangulation (Lincoln & Guba, p. 307). The prolonged period of engagement was described by Lincoln and Guba as a period of time during which the participants develop trust and confidence in the researcher. I argue that my extended presence in the community for seven years as a school nurse has established trust and confidence through a long period of engagement. Indeed, I believe my ability to easily recruit participants for the study reflected the existence of a long-established confidence and trust with community members.

Likewise, I consider my professional presence in the lives of participants and their children as adding the element of persistent observation. My interest and questions were generated by over 20 years of observing and participating in interactions between African Americans and health care professionals in both acute care settings and community health settings. Though my closeness to the subject matter may introduce bias, I believe the alternate side of bias is identification of salience, or being able to determine what is important. In fact, Lincoln and Guba (1985) recommend triangulation, a third technique that may help mitigate bias.

In qualitative inquiry, triangulation may involve using different methods, different sources, or different investigators to verify research design and findings. In designing the interview guide, I relied heavily on recommendations by my committee member who is African American, the mother of small children, and a social work professor, to critique the content of both the questions and the structure of the guide. In addition, the pilot study enabled me to solicit information from participants about the appropriateness and understandability of the questions. Finally, including the viewpoints of multiple participants (different sources) to the point of data saturation created a kind of participant triangulation. Member checking, verifying meanings and understandings during the interview process itself, may also be considered a form of triangulation. Member checking occurred throughout the process of conducting the study.

Lincoln and Guba (1985) also discussed both peer-debriefing and more formal member checking as techniques to bolster credibility. To this end, I secured the commitment of two African American colleagues, one of whom was a participant in the study, another who was not, to evaluate a sample of interviews and my subsequent analysis. One of these colleagues is master's prepared, another doctorally prepared, in counseling. Both of these colleagues are from south Georgia and have strong community connections, both personal and professional, in south Georgia. They are also familiar with research and considerations associated with it. They are both also mothers of young children. I believe they were reliable sources for peer-debriefing. Not only did they read snippets of interview and the relevant analysis, they served as sounding boards even as I was deciding what parts of interviews were relevant to my questions, and which could legitimately be set aside. For example, in an instance where I had to choose between two

fairly long accounts of which best illustrated discord in a parent/provider we-relationship, my peer-debriefers were able to identify for me that which seemed to best illustrate the dynamic.

Lincoln and Guba's (1985) final criteria for trustworthiness are the establishment of transferability, dependability, and confirmability. Transferability refers to the ability of the reader to apply his or her understanding of the phenomena to other settings and contexts. This is achieved through purposive sampling and through thick, relevant description. In considering Lincoln and Guba's (1985) recommendations for dependability I would say that it is difficult, due to the solitary nature of dissertation work, to have a second "inquiry team" (p. 317) to verify the process of the research. Another recommendation for establishing dependability, then, is to employ a person or persons in the role of "auditor" (Lincoln & Guba, 1985, p. 318). I argue that my dissertation committee has served in the auditor capacity for the purpose of this study.

Finally, Lincoln and Guba (1985) discuss confirmability as "dovetailing" (p. 319) from dependability as part of the auditing process. Establishing an audit trail includes the researcher's maintenance of a reflexive journal, detailed field notes, transcribed interviews, and other documents that establish ongoing reflection and attention to detail; characterized by transparency and explicitness. I started this process during my research practicum in Spring of 2011, and maintained it throughout dissertation planning and the writing of the dissertation, though perhaps less diligently once I finally began writing the data analysis and findings chapter. Once I began writing that chapter, I tried to include evidence of my thought and analysis process in the body of the data analysis section. I got this idea from an article by Dickie (2003), in which she recommended moving

beyond the strictures of codes and labels to tell the story not only of the data, but of the analysis process. I hope this is evident as the reader becomes engaged with Chapters 5 and 6. I also considered the ongoing interaction with my committee chair and committee as part of a semi-formal auditing and confirmation process.

Besides trustworthiness, Munhall (2007) described reflexivity, which is the researcher's own awareness of his or her relationship to the topic, the participants, and the interpretation of the data. Researcher awareness is related to the ideas of domestication in critical ethnography (Madison, 2005; Thomas, 1993) and bias, in general. Thomas (1993) referenced Schutz in defining domestication as living within a 'taken for granted' reality that does not require looking beyond superficial experience or analysis of different meanings or understandings beyond accepted norms or biases. Reflexivity is the ability to move beyond domestication and bias by relating the researcher's own positionality (Madison, 2005) to the interpretation of data and to the well-being of and significance to the participants.

Reflexivity is an integral component of rigor in ethnographic analysis, as described earlier in my discussion of Altheide's (1987) use of Glaser and Strauss' (1967) concepts in describing ethnographic content analysis. Reflexivity is not just part of the process of the researcher's identifying his or her own bias and preconceptions; it is also the idea that the very questions asked in the research design can limit the information one hopes to gain. While it is important that the researcher employ reflexivity in designing and conducting the study, it becomes most significant in the data analysis and writing of the findings. Finlay (2002) detailed several types of reflexivity: introspection, an exploration of the researcher's own bias and point of view; intersubjective reflection, the

awareness of how the relationship with participants influences the research; mutual collaboration, the involvement of the participants in the process of the research; social critique, the acknowledgement of power differential in the research relationship; and discursive deconstruction, acknowledging multiple meanings in findings. Though Finlay (2002) did not reference the work of Schutz, these concepts are reflective of a Schutzian approach.

In the end, it is the reader who can best determine whether I successfully established trustworthiness and demonstrated reflexivity in the conduct of the study and its subsequent analysis. I have tried to be authentic and transparent throughout the process, and I hope the final product reflects an authenticity, transparency, and relevance of process. I refer again to Dickie (2003), who referenced Wolcott (1994) in saying that qualitative researchers should strive to “not get it all wrong” (p. 55) by doing the following: “Talk a little, listen a lot; record accurately; begin writing early; let readers see for themselves; report fully; be candid; try to achieve balance; and write accurately” (p. 55).

Data Analysis

I chose to use Graneheim and Lundman’s (2004) qualitative content analysis method to analyze my data and to meet Lincoln and Guba’s (1985) trustworthiness criteria. Graneheim and Lundman (2004) specifically used the trustworthiness criteria in the development of their analytic method. They adhered to the basic premise that qualitative data collection requires mutuality between researcher and participant, and that any content, whether interviews, observations or records review, contains many meanings; and relied heavily on application of communication theory to justify their

approach. Graneheim and Lundman (2004) defined ten key concepts related to qualitative analysis. *Manifest content* is the visible, obvious content of the text. *Latent content* is the deeper, relational meaning that lies underneath or alongside the manifest content. The *unit of analysis* refers to the object of the study and can refer to people, situations, encounters, or records, among others. For my purpose, the unit of analysis was each interview conducted. A *meaning unit* is defined as “words, sentences, or paragraphs containing aspects related to each other through their content and context” (Graneheim & Lundman, 2004, p. 106). A *code* is the label given or assigned to a meaning unit. *Condensation* refers to the physical shortening of phrases and thoughts while preserving the meaning and highlighting the essential core of the text. *Abstraction* refers to grouping and aggregating under higher level abstracted codes, categories, and themes. *Content area* refers to parts of a text that fall within a specific domain or easily identified area, which may be identified through topics in an interview guide, or specific theoretical assumptions. The *category* is considered to be the core of qualitative analysis. The category is “a group of content that shares a commonality” (Graneheim & Lundman, 2004, p. 107) and was also referred to as “a thread throughout the codes” (p. 107), that answers the question “what?” A category is created to include all meaningful data, and may be divided into subcategories. Graneheim and Lundman (2004) used the concept of *theme* as a way to link underlying meanings within categories, or a way to assign meanings to categories; and define it specifically as “a thread of an underlying meaning through, condensed meaning units, codes or categories, on an interpretive level. A theme can be seen as an expression of the latent content of the text” (Graneheim & Lundman, 2004, p. 107), may be broken down into subthemes, and are not mutually exclusive.

Graneheim and Lundman (2004) offered several quite different examples of how their system can be applied. They argued that using their system will specifically address credibility, dependability, and transferability; thereby establishing trustworthiness as defined by Lincoln and Guba (1985). The beauty of the method is that it is quite flexible and can be used in many different ways. Once I decided that it would be most relevant to analyze and interpret the data through a Schutzian lens, Graneheim and Lundmans' (2004) method was quite useful to me in organizing and defining broader content areas, categories and codes at the beginning of data analysis, and more as a processual reference and support as I wrestled with the more abstract themes.

I began data analysis by listening to each recorded unit of analysis, or interview, within a week of its occurrence, and making casual notes in my research journal about topics or comments that seemed to reflect manifest content and latent content directly related to the research questions. After each interview was completed and I had made initial notes, it was transcribed into hard copy. As I read each hard copy, I highlighted what I felt were relevant meaning units; and created a subset of interview documents that included only those words, sentences, or paragraphs containing meaning relevant to the content and context of the study's purpose and the overarching theoretical frameworks of race, ethnicity, culture, social justice, and critical theory. After reading through the interview subsets several times, I established two major content areas based on the subsets: 1) relevant precursors to health care encounters, and 2) encounters with health care professionals; and assigned codes to these content areas that would be consistent with Alfred Schutz's social phenomenology. I then read through the data subsets again and, using condensation and abstraction, established codes for specific categorical threads

that ran throughout the data in each of the two major content areas. At this point, it was necessary to return to each fully transcribed interview to see if I had missed relevant data when I created the subsets. There were several additional meaning units I identified and added into the growing group of Schutzian codes and categories I had established within the content areas. These data were then analyzed and thematically interpreted within the framework of Alfred Schutz's social phenomenology. That the meaning units were so easily categorized was evidence that social phenomenology established a solid and appropriate foundation for finding meaning in this particular inquiry. When they were not easily categorized, I knew there was a processual problem: there were several instances during the analysis process in which my attempt to over-categorize either obscured important meaning or assigned meaning that did not exist. Recognition of this led me to create broader categories and subcategories and to be satisfied with allowing the data to speak. More detail about specific codes, categories, subcategories, and themes introduce the *Data Analysis and Findings* section in the next chapter. I use them to introduce that section, rather than here, so they make sense to the reader in that immediate context.

Analysis of the coded data consisted of interpreting Schutzian themes that emerged from the coding process in light of the overarching theoretical frameworks of race, ethnicity, culture, social justice, and critical theory through what Munhall (2007) called discovery through writing. Indeed, van Manen (1990) stated that "creating a phenomenological text is the object of the research process" (p. 111), that writing is, in fact, the method; and enables the writer to objectify thought and experience into an understanding of the world. Madison (2005) discussed the relational nature of writing,

which considers the obligation to and care for not only the participants of the study, but also the obligation to and care for the readers. I hope I have both honored my obligations and demonstrated care in my method.

Summary

Ethnographic interview analysis was the method I employed to conduct a qualitative analysis of African American parents' experiences in their children's health care encounters. Through this analysis, I hoped to gain understanding of the personal, familial, and sociocultural forces that shape African American parents' relationship with health care providers and the health care system; with the hope that better understanding might facilitate the creation of culturally sensitive approaches that health care providers and institutions could implement in relationships with parents of African American pediatric patients. My method included ongoing attention to investigator reflexivity and other ethical considerations, and careful data analysis using Graneheim and Lundman's (2004) data analysis guidelines, in order to fulfill the criteria of trustworthiness and rigor recommended by Lincoln & Guba (1985). In doing so, I hope I have communicated the new understandings I gained in the process by telling the stories of the participants in an engaging way (in the data analysis and findings chapter); and by making salient recommendations for application of the gained understanding (in the final chapter).

CHAPTER 5: CONTEXT

As I began writing my data analysis, I felt some unrest. At first, I thought that perhaps this was just the novice's apprehension and lack of confidence about a process not yet mastered. But as I proceeded, I felt more and more as though something was missing, and eventually came to realize that it was two things: 1) the essence of the town in which the participants live, beyond the mere description "setting" in the *Methods* chapter; and 2) the identities of participants, beyond the superficial demographics of age, gender, and ethnicity, as the central speakers about their experiences. Schutz (1962) referred to such settings and identities as components of biographically determined situations. I know the town and I know the participants, but does the reader know them? I believe that it is imperative that location and identity establish a context for voice, and so this section was designed to precede the data analysis and findings in order to provide geographical and biographical context for details and specific excerpts from the interviews with the participants. And so, I welcome you to town and invite you to meet the parents!

Geographical Context: The Place

This small town in south Georgia is home to a regional state university, an air force base, a state prison and several large manufacturing plants. The town is home to about 55,000 residents (in a larger county of about 100,000), 43% of whom are White, 51% African American, 4% Latino or Hispanic, and about 1% other; with an overall poverty rate that averaged about 30% between 2005 and 2009 (about double that of the

state) (United States Census Bureau, 2011). The unemployment rate hovers around 9%; and county statistics reveal higher rates of low birthweight, infant mortality, teen births, youth STDs, child abuse, child neglect, and poorer overall health status of adults and children in comparison with state averages (Georgia Family Connection Partnership, 2011).

Beyond the quantitative data available from a variety of sources, this town has some unique characteristics that can only be described from a historical perspective and personal experience. The original inhabitants of this area on the edge of Georgia swampland were the Creek and Seminole Indians, of whom there is little evidence today. The region was settled in the early 1800s as a farming community (first cotton, then tobacco, pecans, soy and peaches), and the town incorporated in 1860 when the railroad was built (City of Valdosta, 2011). This town has several claims to fame: Over one hundred African American citizens from the town and surrounding area emigrated as original settlers to Liberia in the wake of the Civil War (Jackson, 2003); another being the rampage of a circus elephant in 1902 in which the elephant, Gypsy, killed her trainer, terrorized the town and was eventually lynched (yes, *lynched*) by angry citizens (New York Times, 1902); and is now home to the “winningest” high school football team in the nation’s history. A perusal of the city website indicates that this town is also associated with several persons of note (City of Valdosta, 2011). John Henry Holiday lived here, and later became famous as Doc Holiday, a wild-west gunslinger. It was also the home of James Lord Pierpont, the writer and composer of “Jingle Bells”. It was the location of a high school oratory contest in which Martin Luther King, Junior took second place; where former president George W. Bush received flight training; and was home to the

famous lead singer of The Doors, Jim Morrison, during his teen years. The small, typical southern town's rich and interesting history set the stage for the current diversity stimulated by the presence of both the university and the air force base, which are also significant influences on the town's economy. In addition, many families who live here today, both African American and White, have deep historical ties to this area, with relationships and connections established over generations. There exists an interesting mix of members of good ol' boy networks (both African American and White) and transplants who successfully challenge those networks on a regular basis. As is the case in many small towns in the rural south, it doesn't matter what color you are as long as you love football and go to church regularly. New transplants are often asked before anything else, "Have you found a church home", and "What team do you root for"? Ironically, people do not really care what faith you might practice – there are Christian churches here of many denominations, a Muslim faith community, a Jewish temple, and even a Hindu Ashram – as long as you practice something. In fact, the two biggest religious fundraisers are highly symbolic of the town's religious diversity and its religious (and familial and gustatory) priorities: the annual Father-Daughter Dance sponsored by a local Presbyterian church, a two-night event with attendance in the thousands; and the annual Kosher Corned Beef Sandwich Sale sponsored by the local Jewish temple, with sales topping 5,000 sandwiches. Alas, atheists and agnostics often voice their frustration with the community's religiosity; and academics with its dedication to athletics. If you are here for any length of time, you either grow to embrace it all, or you leave (if you have the means)!

Walking down the street will garner honks and waves, even from people you may not know. A trip to the grocery store almost always guarantees running into a friend or neighbor; and even if you do not see somebody you know, it is the rule rather than the exception that you will have several friendly conversations with complete strangers about the weather, the most recent football scores, the local headlines, or an upcoming event. Children of all ethnicities who misbehave at school know their parents will have heard about the misbehavior before they ride the bus home; and they still precede any adult given name with “Miss” or “Mister” and follow the answer to any adult query with “ma’am” or “sir”. People come together over births, weddings, and deaths; and dividing lines tend to be over the favored football team and where you went to high school, rather than race, ethnicity or religion.

There is strong African American leadership here, with the city council reflecting the racial composition of the city, and the interim mayor being African American, having replaced a White mayor. Despite the generally positive and respectful relationships and deep friendships among African Americans and Whites, there are still profound racial divisions and discord. Neighborhoods here, as they continue to be across much of the country, are highly segregated geographically, with African Americans living mostly on the south and east sides, and Whites being concentrated in the north and west. Churches and other social organizations tend to be racially homogeneous here, with some notable exceptions like nondenominational congregations and the ministerial association. This is one of only nine communities in Georgia that still has two school systems... a county system and a city system. The county system is about 85% White, serving mostly the middle class and rural poor, while the city is about 85% African American, serving

mostly the impoverished urban poor. A recent and highly controversial attempt by wealthy local businessmen and the Chamber of Commerce to force school system consolidation resulted in a landslide victory by opponents of consolidation, led by African American community leaders and including a small but dedicated minority of White upper middle class liberals and long-time city school system alumni and supporters. The mostly White proponents of consolidation raised over \$300,000 to mount a highly racialized campaign designed to sway the African American vote by using references to Martin Luther King Junior's "I have a Dream" speech, and radio ads voiced by an impersonator of African American actor Morgan Freeman. Local news coverage and public forums made it clear that the African American community feared the loss of school ownership and the special programs provided by the city school system that target and are tailored to a high-need demographic. This event captures the complex nature of racial dynamics in the town, not readily evident to those not from here.

The town boasts a good primary care network and two reputable hospitals, a large health department, and two clinics that operate on sliding scale fees. Specialty care is limited, with residents having to travel either across state lines to Gainesville or Tallahassee, each about two hours away, for specialty care; or north to Augusta or Atlanta, both about four hour's drive. The air force base has its own primary care, dental, and immunization clinic, and there is a primary care Veteran's Affairs clinic in town. There are seven pediatric practices and several family practices that serve children. In addition, both hospitals offer after-hours pediatric clinics in an effort to reduce emergency room use. Many of the primary care practitioners have ties to the town or region, and are well known by their patients both professionally and socially. Word of

mouth is a strong and powerful tool in a small town, and health care providers are generally well aware of and attentive to their professional and personal reputations. There remains, however, a dated perception of physicians, in particular, as almost god-like. For someone moving from a major metropolitan area, it can be frustrating indeed to call their practitioner's office and never get to speak to the practitioner. Physicians are highly protected by their office staff and rarely communicate with patients beyond the examining room. This dynamic, however, seems fairly widely accepted by those accustomed to small town living.

Small towns are as different from one another as families are. My goal for this section was to give the reader the overall flavor of one town by providing some particularly interesting tidbits. In the section that follows, I hope to accomplish the same goal in regards to the fascinating individuals who participated in the study. It is the strength of a qualitative design that rather than generalizing findings for application to a homogenous group of people who share a specific label, the researcher can instead give the reader a highly detailed glimpse into the unique lives and experiences of real people, people who may be very much like the patients that other providers encounter every day in their own practices.

Biographical Context: The Parents

Adele

My first interview was with Adele, age 42, who works as a paraprofessional at a local middle school in this small south Georgia town. Adele is a plump woman with skin so beautiful and smooth she seems too young to have two grown children with kids of their own. She and her husband, who works at a local factory, live with and raise her son

from a previous relationship and the grandchildren of her husband's adult daughter (who is incarcerated). Adele grew up in a middle income family in which both parents were employed full time. Adele described a lot of frustration with raising her husband's grandchildren, ages 3, 7 and 8. She also cares for her daughter's baby in the evenings and on weekends while her daughter works and goes to school in addition to being the primary caregiver and support for her disabled mother, who is confined to a wheelchair and homebound because of complications of cancer and poorly controlled diabetes.

Adele is a good example of some parents I interviewed who may appear at first glance to be middle income, but who may transition between low and middle income depending on circumstances that change frequently. She is employed full time and her husband has a secure job in manufacturing that provides medical benefits. But at the time I interviewed Adele, their financial responsibility for parents, children, and grandchildren actually placed her family in the low-income category, though they were not receiving any public assistance or welfare benefits.

Benita

Benita is a 29-year-old guidance counselor in the local school system who is also studying full-time in pursuit of a doctoral degree. Benita is the consummate professional, attentive to detail and dependable. She is always well-coiffed and on the day I interviewed her after school in her office, she was strikingly turned out in a stylish pantsuit, perfectly accessorized. She has a great sense of humor, an easy rapport with the children she counsels, and is greatly respected by both parents and co-workers. She has the enviable personal and professional gift of seeming comfortable in any environment, with many different kinds of people. She is also the mother of an energetic young fellow

named Caleb, aged 5. Caleb's father currently is incarcerated and Benita no longer maintains contact with him or his extended family. Benita was the only child of parents who died when she was young, so she relies on an extensive network of friends to help her raise her son. Her conversation with me revealed an unflagging dedication to this network of friends and to her church, where she performs with a traveling gospel choir. The experiences Benita described gave me insight into her apparent ability to move effortlessly in and among so many circles: Until she was a young teenager, she grew up in a middle class, two parent family; her dad in the military and her mom a registered nurse. After her parents died unexpectedly within a year of each other when she was an adolescent, Benita was passed among friends and relatives who lived in circumstances quite different from those to which she was accustomed. She described her teenaged self as a nerd who consoled herself with books, but who also developed the skills and independence necessary for survival under pressure. Interestingly and perhaps another indicator of her social flexibility in a geographically segregated community, she is one of just two parents I interviewed who live in a predominantly White neighborhood on the north end of town.

Chantel

Chantel, aged 43, is the single mother of an adult daughter and two teenaged sons. She lives in a small home on the south side, just off a busy highway that connects the busier metropolitan area with a more rural farming community ten miles south. Chantel works as a paraprofessional at a local elementary school (though she has almost completed a bachelor's degree), but her youngest son, aged 14, is facing so many health and emotional problems that she feels as though she may have to give up her job. Doing

so will put her, at least temporarily, in an insurance coverage no-man's-land as her family transitions between the private insurance provided by her employment with the school system, and the public insurance on which her two children at home will be dependent when she leaves her job. Chantel grew up one of several children of a low income single mother. At age 78, Chantel's mom is still living, and struggles with the challenges of the effects of poorly controlled diabetes and the financial imperative to work on her feet all day as a greeter at a local large-scale chain retailer. My interview with Chantel made clear the agony of parents who have limited education and limited resources with which to enter the health care arena on behalf of their children; and the feelings of guilt and anger they may feel as their children's problems spiral out of control.

Diane

Diane came to my house one Saturday morning and we sat across the table from one another drinking coffee while our 13 year old sons played video games together in the next room. They had not known each other prior to that morning, but like most teenage boys, found a mutual interest and harmony in killing and maiming aliens and foreign invaders in virtual reality. Diane is a 33-year-old petite rounded lady with a deep, melodious voice, and tight, tidy braids and wire-framed glasses that give her a distinctly no-nonsense air. She was born in a small cotton farming community about fifteen miles west of here, but spent most of her childhood here with her mother and five brothers and sisters; and still lives with her mother on the south side of town. Diane is very active in all of her children's schools, volunteering for a variety of school events and activities. She also occasionally takes classes at the local technical college and has completed an associate's degree. Diane is a single parent but the father of her children owns a local

trucking service, and she sometimes does part time administrative work for him. Though he does not pay regular child support, he is active in his children's lives and he and Diane have an amicable relationship. Diane receives disability payments because of arthritis and has Medicaid coverage for her four teenage children, three boys and a girl, all of whom have problems with joint disease and autoimmune disorders. Her family's history of poorly diagnosed autoimmune disease has made Diane a savvy and cynical consumer of health care.

Evette

Evette is a 41-year-old woman with arresting green eyes, soft-spoken, intelligent, and deeply religious. Her employment story is interesting, unique to manufacturing towns, and may be a relic of the past since the national economy has declined and large corporations no longer feel obligated to provide severance benefits for laid-off employees. Evette had her first child at 15, and like her mother before her, got a job at an international clothing manufacturing plant here in town that was a major employer in the region until it closed in 1999. This factory employed low-skilled workers, mostly women, at a good solid wage, and provided excellent medical benefits. Many of the women with whom I spoke had either worked at this plant themselves, or their parents had worked there. In 1999, the plant closed several of its factories nationwide, offering workers eight months pay; and to the company's credit, offered extensive job counseling, placement and retraining programs for its former employees. They offered each employee an additional \$6000 toward tuition, training, or small business start-up (Melkers, Rushing & Sjoquist, 2006). Evette was one of those workers who took advantage of the program, went back to college, and became a teacher, eventually

completing a master's degree. The child she had at 15 is now grown and independent, but Yvette has two other children of school age whom she raises alone. During that time she returned to school, Evette was on Medicaid when she was pregnant. Like others whose stories I recount in this chapter, Evette has transitioned between low and middle income for much of her life, depending on her employment status and other factors. She has encountered health care under various conditions; her status in the health care system, she believes, dependent on her changing economic status.

Felicia

Felicia, aged 34, is a tiny, energetic, assertive lady who works as a middle school custodian. She and her partner, who does not live with them, raise two children, a boy, age six, and a girl, age twelve. Felicia grew up one of several children of a single mother who, like Evette's mother, worked at the same clothing manufacturing plant that so many women in this town depended on for employment and benefits. Felicia reported that it was her mother's employment status that enabled her to get regular medical care for Felicia and her siblings: "My momma pretty much kept us up under the doctor." Felicia, like many other parents I interviewed who grew up in the same small town they live in now, reported strong, positive relationships with providers in which they feel empowered to speak up about their children's needs: I found this to be the case with parents whose own childhood pediatrician currently provided care for their children; or in Felicia's case, when her own childhood pediatrician was the father of the pediatrician who takes care of her kids today. This may be a unique feature of relationships between providers and patients in small towns, where there may be long-standing shared personal and professional histories.

Gwen

I went one evening to Gwen's house to talk to her about her vast experience encountering the health care system and health care professionals. Gwen is 34 years old, a self-described "voluptuous" woman, colorful in her style of dress and makeup, and always loud (she says her sisters and children call her "ghetto"). It would be easy for a White person who does not know Gwen well to misjudge her based on a stereotype with which even her own African American sisters label her. But Gwen is a walking dichotomy. Interestingly enough, Gwen was the only participant other than Benita who lives on the mostly White north end of town, along with her two school-age daughters and disabled mother. The irony of her conscious choice to live in a White neighborhood is evident when she explains that she does not want her daughters to grow up around "all that ghetto trash." Gwen laughs all the time, and is one of those people who sees humor in even the darkest circumstances, which is fortunate, given her health care history. She has faced enormous health challenges in her 32 years, as both a patient herself and as the parent of a child with Prader-Willi syndrome and its associated complications. Gwen's story is so fascinating that it probably could stand on its own as a dissertation topic or a foundation for a work of biographical fiction (I say fiction, because nobody would ever believe it is all true, unless they know Gwen). Gwen grew up in this small south Georgia town, her Texan father an air force transplant and her mother a hometown girl who also served in the military. By the time Gwen and her sisters came along, their parents had retired from military life and her father worked as a full-time pastor and civil rights activist. She described the family in which she grew up as "middle-middle income." Her parents' approach to life was influenced not only by their college-level educations but by

their military travels and exposure: “We kind of grew up in the know. Good and bad.” Gwen and her sisters followed their parent’s lead in education, all obtaining graduate degrees in their chosen fields of study, Gwen’s being in Human Resource Management. Though she does not work, she is middle income due to her own and her daughter’s income from disability payments, and because of private health insurance and social security payments she receives from her deceased husband’s survivor benefits.

Honey

Honey is a full time student at the local state university, studying religion. She and her husband are both unemployed and live with their five children (who range from ages 1 to 10) and her disabled mother in a well-kept brown and brick split-level house in a mostly African American neighborhood on the west side near the center of town. Honey’s neighborhood is reflective of many neighborhoods on the west side, made up mostly of rental houses, some maintained meticulously by residents who have lived there for many years, while others appear seedy and overgrown, reflective of the traffic of a series of hard-luck tenants and long-term neglect by absent, disinterested landlords. When I arrived, her youngest child was asleep in a playpen in a sunny spot near the front door. Her husband was in the kitchen, and the children moved between their father in the kitchen and their mother in the living room, where a large screen television played cartoons. Honey grew up the oldest of several brothers and sisters, children of a divorced mother who moved frequently and lived in many places including Miami, New Orleans, Houston, New Jersey, and Virginia. Of her transient childhood she said, “We’re just the kind of family that if, you know, things aren’t working, then, we’re going – there’s just no point in hanging onto something that’s not working for you.” Their frequent moves

also affected their financial security. Honey described the family she grew up in as sometimes low income and sometimes middle income, “just depended on who had what job... where we were, and what job was going on.”

Iris

Iris lives with her three children, a girl aged 6 and two boys ages 8 months and 5 years, in a sparsely furnished old wooden frame house with a dusty dirt yard and an enormous pecan tree, that sits at the junction of two busy roads that lead from downtown to the mostly poor, African American south side. She grew up ten miles south of here in a small rural community where her parents were employed in factory work, providing what Iris describes as a middle-income lifestyle. Iris works part-time as a nurse’s aid and goes to school part-time. Iris was one of the first respondents I had when I recruited study participants at her child’s school. She called me the very afternoon she heard about the study and told me that she is always anxious to help out in any way she can. She was positive and forthcoming during our interview, and eager to please. Iris lives within a few hundred yards of the neighborhood elementary school, two housing projects, and a convenience store. Her proximity to school, friends, and a store is important, because her car is not reliable and her partner is currently incarcerated. When I entered her living room, where she sat vigorously patting her plump baby to sleep, I noticed a calendar placed prominently on the wall near the front door. She later referenced that calendar when talking about her partner’s incarceration for a probation violation. She and her oldest child were counting down the twenty days until his release. Usually, her partner works as a construction laborer when work is available; but since the economic downturn, construction jobs have been few and far between for him. Since his

incarceration ten days before, she had not been able to work because she had no one to watch her baby. Her partner was incarcerated because he failed to attend a mandatory class one day, because Iris had the car, was working and had no one else to watch the children.

Janice

Prior to our interview, Janice and I had forged a sometimes harmonious and sometimes contentious relationship over the three years I had cared for her child, Alphonse, a boy with severe asthma, at the middle school where I work. My visit to Janice's small home, (a tiny, crowded frame house with peeling paint and a sagging roof, housing at least seven people) took place one Saturday morning. Along with another relative, she and I sat together on her front porch. As the children of the house came and went from inside to outside, she started her story by describing her life growing up in a low-income, single-parent home with her eight siblings. A television inside blared *Wheel of Fortune*, and the street in front of us was busy with cars, bicycles, and pedestrians, all of whom Janice (wearing a housedress, slippers, and bandanna) called to and waved to as they slowed or stopped at the stop sign at the busy intersection in front of her house. Our conversation that day drastically changed my understanding and feelings about Janice and her children. I will interject here that my role as a school nurse creates complicated dynamics, at times, with parents. My relationship with Janice is one that exemplifies this complexity. We always had pleasant and respectful telephone conversations about Alphonse's asthma, in which she concurred that his symptoms were terrible and assured me that she would get him to the doctor; but I would become perplexed and frustrated about her seemingly laissez-faire approach to some serious symptoms when Alphonse

would show up at school the next day, just as sick or often sicker, not having seen the doctor and out of medication at home. On more than one occasion I had to strong-arm Janice into retrieving Alphonse from school for an immediate visit to the doctor for symptoms approaching the status of life-threatening, by telling her that if he did not bring a doctor's note the next day, I would report her to social services. This is a tactic that almost never fails with parents, but one that I detest and use only as a last resort. In August, several months before I interviewed Janice, a new school year had started with Alphonse as an eighth grader, his third year with me. He is a tall, smiling, gentle soul and loved to visit me in the clinic. I must say I was happy to see him, too: I had come to love Alphonse's sweet, polite demeanor, such a rarity in middle-schoolers! He dropped by the clinic on the first day of school to say "hi", and I asked about his summer. He replied "Nurse Green, it was great! I stayed with my grandma in Alabama all summer long. She cooked lots of good food for me and I played with my cousins outside all day. I just got back Sunday." When I asked how his asthma symptoms had been, Alphonse replied that he had not been symptomatic at all over the summer, not requiring a single breathing treatment. I was thrilled, thinking that perhaps he had grown so much over the summer, the surface area of his lungs increasing just enough, to perhaps put him over the worst hump of his chronic asthma. Alas, within two weeks of returning home, Alphonse's asthma symptoms had returned, worse than ever; along with the all too familiar, tell-tale scent of cigarette smoke and unwashed clothes. My transient bad attitude about Janice returned with a vengeance, and I was back on the phone with my usual tactics and professional demeanor. It would be several months before Janice and I came to a better understanding of one another that Saturday morning on her front porch,

as we talked together about experiences with health care and health care professionals. The reader may question, at this point, whether it was appropriate for me to ask Janice to participate in the study, given the inequity that may exist in our relationship. I will simply reply that I felt that there existed enough mutual respect, and certainly no fear of me on Janice's part, that I felt comfortable enough to at least ask her; and she didn't hesitate to say "yes"... in fact, she seemed quite enthusiastic about the idea of having a chat with a visitor. I believe Janice's and my relationship is profoundly representative of the complicated dynamics that exist between patients and providers; but also that our conversation represents the transformative power of the mutual understanding gained through qualitative inquiry and all the possibilities such understanding entails.

Kay

I interviewed Kay one afternoon after school in a public park, while her children played nearby. She is a reserved young woman with four happy children. She kept a watchful eye on them as we talked, vigilant and quick to intervene in sibling squabbles or when someone strayed too far. Kay, age 32, grew up the youngest of four children, with three older brothers. In a house full of older rough-and-tumble boys, she learned quickly to fend for herself. Though she grew up in a small city in central Florida, she described her family as "rooted here" in this small south Georgia town. Her parents were solidly middle-class, her dad working as an electrical cable worker and her mom doing full-time assembly work in a factory. Today she is a full-time student and single mother, raising three boys and a girl in somewhat different circumstances from those in which she was raised. Until her mother died of lupus several years ago at age 60, Kay was able to both work full-time and go to school; but today she relies on part-time work as a medical

assistant and on welfare programs and public assistance so that she can both go to school and care for her children. They are currently without medical insurance.

Latrice

Latrice, age 33, is raising four boys with her partner of several years. She grew up in a two parent family in south Florida. She described the family in which she grew up as low to middle income, her father a laborer for a small local business and her mother an administrative assistant in a public school. She was the only biological child, but her parents also raised a cousin whom Latrice considered a sibling. Latrice works in a local seasonal industry as a mid-level manager; and her partner, James, is unemployed. The seasonal nature of Latrice's employment places her family in the low income category, reliant on public insurance programs for her children and other assistance in the off-season, and with no insurance coverage for herself or her partner. Latrice and I talked one evening in the living room of her spacious, well-maintained home in a solidly African-American neighborhood on the south side of town. When I arrived, she had not yet gotten home from work, and James, a quiet, lanky, dreadlocked young man in a white t-shirt, was in the kitchen getting supper ready and managing the four high-energy boys who range in age from three to fourteen years old. Latrice's home is immaculate and her children are always perfectly groomed and dressed and are charming and polite. But her oldest two have trouble academically and have been diagnosed as having Attention Deficit Hyperactivity Disorder (ADHD). After the kids were fed, James joined us for a portion for the conversation that went far beyond discussion about health care. It became clear that Latrice's family has faced many health and other personal challenges. James' ongoing conflicts with law enforcement in this small town have made the family feel

targeted every time they leave their home. Latrice and James firmly believe that these conflicts are a result of racial profiling. In this community just north of the Florida state line off Interstate 75 (widely considered to be one of the primary drug trafficking corridors in the nation), and heralded nationwide as the gold standard of drug crime enforcement and drug-related property seizure, James' experience is not uncommon and is certainly no surprise. I confess, however, to having wondered about the attention James receives from local law enforcement, and curiosity as to how Latrice and James afford such a large, beautifully furnished home and how her children could wear designer clothes on a low-income budget. My suspicions are reflective of dynamics that may exist when health care providers label and stereotype their patients.

Marilyn

Marilyn, a 37-year old woman with a tired smile, sad eyes, and smattering of freckles across her nose and cheeks, lives with her four sons in an African American neighborhood of very small, older homes on tiny lots located on the south side of town. As I drove through Marilyn's neighborhood on a hot Spring afternoon, I noticed a lot of vacant and unkempt houses, and many homes with young adults in front yards and on front porches just hanging out. Marilyn called for me to come in when I knocked on her open screen door. When I entered, she was sitting in a chair watching television in a small crowded central living area, with a kitchenette at the rear. There were several small children present, engaged in a variety of activities from playing with toys to watching music videos on a small laptop computer. Marilyn described these children as neighborhood kids whom she "watches" while their parents work, though she is not formally employed. Marilyn grew up as a child who was one of three children of a single

mother in this small town. Her mom worked at a factory of an internationally recognized clothing manufacturing company that was located here. The factory was originally built in 1966 and was the largest manufacturing employer and the sixth largest overall employer in this region until its closure in 1999, when almost 900 workers were laid off (Associated Press, 1999). When asked whether she considered the family she grew up in as low or middle income, she said “Well, [my mom] had a boyfriend at the time, so that’s who raised us. But she wasn’t married, so I say she was single, but she had a spouse. So, middle, ‘cause he took care of everything.” Marilyn comes from a family with a variety of health problems related to hypertension; in fact, her mother died of kidney disease eleven years ago at the age of 50. As we talked, it became clear that Marilyn has had a lot of experience in the health care system.

Neva

One sunny afternoon after work I drove to a nearby elementary school where I interviewed Neva, a petite, 43-year-old master’s prepared teacher with beautiful silver hair pulled back in a bun, and silver-framed glasses. We sat across from one another in child-sized chairs at a child-sized table, surrounded by tidy shelves of books and colorful posters and artwork in the bright and airy school library. She is a married mother of Jayla, a 10 year old daughter, her pride and joy. Her husband is a college-educated professional, as well. Neva grew up here in town with her three siblings and her mother, with lots of extended family around to help out. Her mom worked until Neva was in first grade, but then developed an intestinal blockage which permanently disabled her. Like Marilyn, Neva has had many interesting experiences with health care professionals from the time of her mother’s illness when Neva was a small child, to her own reproductive

health problems beginning when she was a young adult, to her husband's recent cancer diagnosis, and her daughter's ongoing problems with asthma.

Oneida

Oneida is a single mom and full-time student, aged 33, raising a son and three daughters. Like others of the low-income women I interviewed, her eligibility for welfare assistance is tied to her status as a student. Oneida has studied for a variety of health care related jobs at the local technical college, often dropping out due to ongoing health problems. She lives in a small rental house downtown on a fenced corner lot. She has moved frequently during the past two years because of concerns about neighborhood safety. Her mother, a retired nurse and single mother herself, lives with her and helps as much as she can with the children, but has a multitude of health problems herself; so the caregiving and support is mutual. Oneida works hard to shelter her children and keep them safe, not allowing them outside in this marginal, poorly-lit neighborhood. She keeps them very active in church-related and after-school activities, and is very involved as a school volunteer. When I meet her at her home one evening, they had just returned from a trip to the neighborhood grocery store. As we talked, the children unloaded soda and juice boxes, chips, bread, lunchmeat, sweet snacks, fruit cups and boxed pasta dinners. Brianna (the oldest at age 12) took charge as her mom bragged on her ability to prepare a meal for the family. It is clear that Oneida has great pride in her children and their abilities. The children are quick to recount for me stories of their academic and other achievements in school. When they finished unloading groceries, the children gathered around us at the kitchen table where their mom had provided a variety of coloring and reading activities for them to keep them busy as we talked. The children

were alert and talkative, and very interested in our conversation. Oneida described the circumstances in which she grew up as “secure.” Her mother was a nurse who worked a week on and a week off, and they lived with Oneida’s grandmother, whom she described as “like my second mom.” Oneida has three half brothers, but she did not grow up with them or having a father active in her life. Having grown up with a mother who was a health care professional, having studied for a career in health care herself, and having a multitude of health problems, Oneida had a lot of interesting experiences with health care and health care professionals.

Paulette

Paulette is a forthcoming, assertive 43-year-old teacher at a local elementary school. Her husband is employed as a long-distance truck driver, and they have a nine year old son. Paulette’s connection to this small town is similar to many others who live here, in that her family settled here due to her father’s military status. The air force base established in 1941 is part of what makes this small town unusually diverse. Almost 5000 people, military and civilian, serve at the facility, and it is one of the major employers and financial contributors to the region (New Georgia Encyclopedia, 2008). Paulette’s father was a pilot who died in a helicopter crash when she was an infant. She was an only child of her widowed mother until she was in elementary school, when her mother remarried and had a second child. Paulette’s grandparents also lived in Valdosta, and were important supports following the death of her father and after her mother’s divorce. Paulette described the family in which she grew up as middle class. Her own mom was a stay-at-home mother until she remarried, and retained her deceased husband’s military benefits, including health coverage. Paulette, like so many of the

parents with whom I talked, has an intimate relationship with the health care system because of her own serious health problems, including lupus which resulted in a kidney transplant many years ago. She considers motherhood a miracle, as her pregnancy occurred following her transplant. She never thought she would be able to have a child; and amazingly, she had no problems with the donated kidney during her pregnancy. Paulette's accounts of her interactions with health care professionals left no doubt that she is a well-informed health advocate for herself and her family.

Quinn

Quinn is a smiling, beautifully dressed 30-year-old single mother of two girls aged 9 and 10, and two boys aged 4 and 5, who works as a nurses' aid in a small skilled nursing facility. She lives near the middle school where I work as a school nurse, and met me one afternoon after school in the school clinic. She grew up in a two-parent family in this small town, her dad working as a self-employed laborer and her mom as a house cleaner. She describes her childhood as "pleasant, but it was like not enough money, financially". The family had no health insurance until she was in her early teens, when she and her brother qualified for Medicaid. She and her children are surrounded by lots of extended family and friends who share their lives and provide emotional support. Like so many of the parents I interviewed, her family has been plagued with chronic illnesses like diabetes and early-onset arthritis that have shaped her perceptions of health and health care.

Renee

Renee and I talked together one Saturday morning in a quiet corner booth in a McDonald's halfway between our two houses. Interestingly, we do not live far apart...

about a mile separates our homes; she living on the edge of the mostly African American east side, I on the edge of the Whiter west side. Like so many large-scale fast-food restaurants in the United States, our local McDonald's sits squarely in the middle, with equal access for everybody. Renee is a middle class, 45-year old college educated married mother with one son, an eighth grader. She works for a local agency that provides social services to foster children. Her husband is a delivery driver for a large international delivery company. Renee is tough and world-wise, raised mostly by her grandmother in Florida because of her own mother's transience and drug use. When Renee was 10, her grandmother died and she was taken in by a very strict aunt for three years, until her mother married and "wanted to start a family, so to speak," moving Renee to the housing projects of New York City. She excelled in school and other activities and had an after-school job because she hated her step-father and didn't like to go home, so she kept herself involved and out of the house. Her goal was to leave home as soon as possible; which she did at age 18, and she "never looked back." She then moved to this small town to live with a great-grandmother. She described living here as "really too slow for me" after New York City, but she met her husband, "an old country guy, he's real good people... you know, Christian man," and she has been here ever since.

Renee, too, worked at the international clothing manufacturing plant, until it closed in 1999. She went to college when the company closed and offered severance benefits that included payment of tuition. Some of her comments heralded issues that would emerge in the data analysis, in her description of how the closing of that plant affected so many women in this small community:

And it was a big tragedy for a lot of people because [the company] came here in sixty-six. That's the year I was born. A lot of those people started working [at the plant]. They don't know anything but a needle and machine, so if they didn't try, if they didn't get their education [after the plant closed], all they know is fifth or sixth grade or whatever. They don't know anything different. And they're stuck. I can see some of them now working Wal-Mart, some of them working fast food. I say, "What you doing up here, oh my God." Like, yeah, I got that degree. So, if they took advantage of [the severance benefits offered by the company], great; if they didn't, that's too bad. But we all missed out health care [benefits].

I hope my introduction to the place and the parents provides fertile ground, in the form of geographical and biographical context, for the imagination of the reader. A garden would not be complete, however, without some seeds (the data); sunlight (the social phenomenology of Alfred Schutz and the work of all the researchers whose work is represented in the literature review); some water (the support of my professors, committee, and family); perhaps some organic material (my own contribution); and a great deal of hard labor (the reader's)!

CHAPTER 6: DATA ANALYSIS AND FINDINGS

Using Lundman and Graneheim's (2004) flexible content analysis strategy, data gleaned from units of analysis (in the form of interviews with eighteen participants) revealed several Schutzian themes that were grouped within two major content areas: 1) relevant precursors to health care encounters, and 2) encounters with health care providers. *Relevant precursors to encounters* was coded in Schutzian terms as *precursory parental relevances* and were categorized as: a) the symbolism of illness and wellness in the participants' life worlds; b) participants' typifications of health care providers; and c) participants' in-group/out-group membership status. *Encounters with health care providers* was coded in Schutzian terms as *we-relationships*. The content area that addresses the participants' encounters with their children's health care providers is first introduced with a section about events which initiate encounters; and is subsequently divided into the three following subcategories: a) the taken-for-granted, routine we-relationship; b) the problematic we-relationship; and c) the transformative we-relationship. For the purpose of helping the reader visualize the categories, subcategories, and relationships within the content areas, a table is included (see Table 2).

Table 2

Outline of Data Analysis Content

<p>Precursory parental relevances (relevant precursors to encounters)</p> <ul style="list-style-type: none"> Symbolism of illness/wellness Typifications of health care providers <ul style="list-style-type: none"> Ideal motivation Ideal disposition Ideal communication Ideal professionalism In-group/out-group membership <ul style="list-style-type: none"> Race/ethnicity Health care background Insurance status <ul style="list-style-type: none"> Complexity Expense Access and choice Treatment <p>We-relationships (encounters with childrens' providers)</p> <ul style="list-style-type: none"> Entry into we-relationships <ul style="list-style-type: none"> Routinized daily parental health care of children Initiating event and level of knowledge Taken-for-granted we-relationships Problematic we-relationships Transformative we-relationships
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Precursory Parental Relevances

Alfred Schutz (1962) placed daily social interaction within a context of “biographically determined situations” in which people function based on what is relevant to them (p. 9). These relevances influence how people make sense of their world and how they react in day to day interactions and communication, and what is relevant to them in any given situation. Upon embarking on this study, I made the broad assumption that entry into health care represents a change in domains of relevance for a parent; and that the nature of relevances is that they are dynamic, always shifting. What

I discovered was that for the participants in my study, day-to-day recipe orientation did not require that they think about health or health care for their children. When a child showed symptoms of illness, a parent's domains of relevance and her personal orientation shifted. In particular, when a child's symptoms became severe enough that the parent no longer felt confident in providing routine illness care, the child's illness and all the meanings associated with it became the parent's primary domains of relevance, and the parent entered into a health care relationship in order to seek professional expertise. But it was not a matter of parents simply availing themselves of professional advice. There were precursory relevances that influenced a parent's interaction with a health care provider (and which may represent relevances different from those of the provider). These relevances began with a parent's general understanding of and beliefs about illness and wellness, their typifications about health care providers, and their in-group/out-group status.

Symbolism of Illness and Wellness

A symbol is something that represents meaning beyond typified understanding. I argued in Chapter 3 that *health* is a symbolic system that is significant in establishing horizons of meaning in relationships between patients and providers. Symbols and symbol systems, however, may be understood differently by different groups. The data from this study revealed valuable information about the participants' symbolic systems of illness and wellness.

Many participants discussed wellness or health as a normal state of being characterized by a lack of severe symptoms: In regards to her child, one stated that “[he does not go] for ache and pain because, he is, you know, normally a healthy child. He

doesn't require to go a lot." Another stated that her family seeks health care when "only, like, deathly ill." Janice, whose son has severe, persistent asthma, also said of her children that "they don't normally be sick." Renee articulated what she perceived as overuse of primary care: "If they sneeze, alright take them to the doctor. Now, come on now, you're a hypochondriac. Just go too much. I just think you need to know when it's time to go."

Another common descriptor was that health was characterized by an ability to go about normal daily life, such as going to work or going to school: "I know we went every day to school. I don't think we were sick. We didn't never screw up attendance, perfect attendance. So, I don't think we were sick-like." Another participant stated: "If you up, and you breathin', and blood flowin', ah, go to school."

Illness, therefore, was characterized by how much the symptoms affected normal, daily functioning like going to school or work, or whether the symptoms prompted the seeking of health care: "I remember her going to the hospital three times, but other than that, it wasn't a lot of constantly illness." Adele described her son's symptoms: "and he had to go to the doctor, and he had perfect attendance, too. And that was one time he said, 'Mom, I got to miss school.'" Another said that "you got to be dead or nearly near death in order to miss school."

Renee could count on the fingers of one hand the number of times she went to see health care providers in her own childhood and youth, one of which was an emergency situation. Hers is a telling example of the types of conditions that warranted entry into health care:

I remember at thirteen, I had a tooth pulled. I do remember that. But I never was in and out of the doctor's office or the clinic. I went there to get a tooth pulled. I took myself to the clinic to get on [birth control] pills. Other than that... I only remember one other time. I hated my step-father so much I took a whole thing of aspirin. I tried to kill myself once, but that didn't work. I just got sick on my stomach. He didn't believe me though, and I remember I was real sick on the stomach, and I wanted to throw up. And my mom saying we need to take her to the emergency room. He didn't want to take me. He was like "She's just playing. She's just playing." It just made me hate him more. But I ended up going anyways.

Gwen stated,

We try not to stop and slow down because of it. Because we feel like if we do we'll just stop and won't ever be able to get our momentum back as a household.... This whole household just basically fall to shambles within itself if we just give in and stop because somebody sick.

Honey told her children with "a little sneezing": "'You know what? Go take a nap, some rest. You'll be fine.' I'm not going to the doctor." Quinn said, "If I'm sick, I'm just going to take whatever and keep going." Another participant stated that in her family, they didn't seek care "unless there was really something wrong.... There were no hypochondriac people in our family." Interestingly, she also said "We don't go unless there's something wrong or something tragic has happened. But we just don't go."

Paulette discussed the repercussions of her own family's history of associating illness with persistent and severe symptoms: Her grandfather "didn't go to the doctor regularly,

so by the time [severe symptoms set in] it was too late. With most of them, by the time they get sick, boom.” Some associated accessing health care with bad news: “It’s like we always waiting for bad news, whether we want to hear it or not. And it look like we just... we just waiting for it.”

Illness often represented impairment of a parent’s ability to work: “...that’s the worst part about it, then I have to take off work. ‘Cause he home today with my mama caring [for him].... That’s the hardest thing... to have to take off work.” Another described dealing with minor symptoms herself “instead of taking the day off, and then the next day they’re fine.” Neva said, “I can’t lose no time off from work. You know, but just think about how much time you’re going to take off.” Renee said of her husband that, “He never misses work ever. He has to be on his deathbed, and still, he’ll go to work—he just does not miss work.”

It was not uncommon for participants to reference illness as having divine purpose: “You know, I kept saying nothing wrong with my child. I was in denial, but you know, God gave him to me for a reason, and I love him.” Some described wellness as a divine blessing and illness as divine punishment for life not lived correctly: Evette stated that “it’s a blessing that nothing has happened that they need to go to the hospital”; and another participant that “if you do right by your household, God won’t punish you with being sick. So, just really, do what you supposed to do.” Beliefs about God also often affected a parent’s response to illness. In some cases, it was a fatalistic acceptance. For example, the participant whose son is mildly mentally retarded and has Attention Deficit Hyperactivity Disorder (ADHD) stated of her son’s condition: “I cried so much the other day, I think it was Wednesday, I just cried. Just, what else can I do Lord? ...all

I could do was cry, cause all I can do is accept it.” Janice, in giving advice to another mother of a sick child, said to her “‘He done took you this far,’ I said, ‘whatever His will’s going to be regardless.’ I said, ‘But you keep the faith.’” Others verbalized depending on God for appropriate response:

... praying, that there’s nothing actually wrong... but at the same time, if something needs to be taken care of or needs to be done, then, you know, pray that I have enough money and enough strength to take care of it like I need to.

Some parents described illness and wellness as something separate from the person, coming from some other source, or having a life of its own. About her son’s ADHD, one parent said, “and that’s why I try to explain to them... that it’s really not James that’s acting like that; it’s something that having him.” In regards to her daughter’s asthma, Gwen stated that “instead of letting it handle us, we dealt with it.”

Virtually every parent expressed knowledge and understanding of lifestyle and genetic issues particular to chronic illness among African Americans, often in an interesting dichotomy of having conditions both within their control, due to lifestyle, and outside their control, due to genetics.

Most of us in the south, basically, we are raised on a lot of foods that are not good for us. Like my granddaddy says, “the piggy-wiggy.” He bring up that piggy-wiggy all the time. We eat the pork, and it’s not good for us. And now, the Bible says everything that God made is good, and it is. But everything is not good for you. And I think it has a lot to do with the way we eat. We eat a lot of fried foods. We eat a lot of foods that’s pork. A lot of greasy things. I think it has a lot to do with the way we eat that causes our blood pressure and our diabetes and all that

type of stuff. And a lot of people say it's an African American disease, which it's everybody, you know. But, to me, it's also the way we eat in the south. We eat a lot of foods that's not good for us, which causes our health to fail. If we think back to the way we supposed to eat, we think about these things, then we might do a little bit better.

Another said,

I think we've put so much in our body just growing up, and you know, how they say southern cooking, or you know, just in general, the way Black people eat or whatever, we pack so much into our body that we really don't know what we're putting in our system. And it's causing everything, especially diabetes 'cause every time you turn around everybody has diabetes. And, well, this person has diabetes or—my aunt has diabetes. Everyone to me, and our high blood pressure. Maybe it's all those collard greens with all that salt that you put in there. Or those hog jowls or all that stuff with all that sodium in it. We could probably be a lot healthier if we didn't put all that extra stuff in our bodies.

Gwen referenced both diet and genetics:

Well, my mom and my dad were always on top of making sure that they did not let us eat anything because they didn't want us to be obese child. They didn't want us to have [whispers] hypertension, even though all the boys do have that. It's hereditary. Because both of my parents have it, and it ran in their family very strong. And they did everything they could to proactively keep it from occurring, but, you know, hey, genetics [laughing].

Another emphasized the role of health care providers when referencing genetics: “If you’re not healthy, and you have those inheritable genes going through your body, then you need somebody who’s willing to help you be healthy.”

Wellness and illness were part of a symbol system that participants used to establish daily relevances. For participants in this study, wellness was equated with normal daily life and characterized by an ability to engage in activities like working or going to school. Even minor symptoms were of little concern as long as they did not interfere with daily life. Only when symptoms were of a nature or severity that they interfered with daily living did a person consider them significant illness. In fact, presence at work or at school was often implied to be of primary relevance. When illness was discussed it was often done in terms of how it might jeopardize school or work attendance, not necessarily as a concern in and of itself. Health care was something that became relevant only in the case of severe illness symptoms, and was often associated with severe illness and death. Illness was often referred to as an entity separate and apart from the person, sometimes as a blessing, a judgment, or something with an agenda of its own. An illness that was described as being either divine in origin or having its own agenda also implied some level of lack of control over it. Indeed, participants also often mentioned lifestyle changes meant to control risk factors as diametrically opposed to what they perceive to be uncontrollable genetic predisposition. Other than immunizations, health maintenance activities were not something associated with seeking health care; health care was really seen as sick care. Specific to children’s health care encounters, illness symptoms were usually what initiated health care encounters. In the

we-relationships section, I argue that a child's symptoms also fell within the larger symbol system of wellness and illness.

Symbols of wellness and illness were important precursors to how African American parents experienced their children's health care encounters. Another component of this symbol system of wellness and illness, and the second precursory parental relevance to children's health care encounters, was parents' typifications of health care providers.

Typifications of Health Care Providers

The very act of identifying someone as a health care professional requires typification. Typification is a mutually understood, taken-for-granted characterization. Members of American society share a generalized understanding of highly typified titles like those of doctor and nurse and the role expectations and characteristics associated with them. Typifications are broad characterizations that are based on personal experience, routinized cultural and historical understanding, and on knowledge derived from others. In seeking health care expertise, the person seeking care already assumes and expects a certain kind of interaction with a provider, and is already situated as separate and apart from providers. This dynamic of seeking care, then, establishes the primary cultural in-group/out-group divide which is that of provider/patient. The patient's typifications of professionals, and the encounter as a whole, could be considered *patient-centric*; since health care providers' typifications of their own roles would probably be different from those of patients, and their daily routines as health care providers includes typifications of patients that patients themselves do not necessarily share (these could be considered *provider-centric*).

Typifications of health care providers can be identified by broad assumptions and characterizations of them as a group. Parents' statements, beliefs, and understandings about health care providers as a group and about their own, family members', and acquaintances' personal interactions with them were of precursory relevance to their children's health care encounters, in that they established the typified understanding that existed even before the encounter occurred. Participants in this study were clear about how health care providers ought to be. I placed these typifications of health care providers among four categories: Ideal motivation, ideal disposition, ideal communication, and ideal professionalism. Personal experiences with providers were often described in terms of whether or not these ideals were fulfilled. The first typification was based on provider motivation.

Ideal motivation. Motivation is “emotion, desire, physiological need, or similar impulse that acts as an incitement to choose a certain action” (American Heritage Dictionary, 2009). Participants had definite ideas about what should motivate professionals (which was sometimes discussed in terms of priorities): According to Janice,

Well, I say he have to have a lot of God in him. And that's what make you a good doctor. It's when you got the Lord in you, and you love – there's a difference in just doin' a job for a paycheck, comparison to doin' out of love and because you know you're helping that next person.

A similar sentiment was echoed by Kay: “It's a difference in a person that it's just a job to... and to this is what they love to do. It's two different things.” Gwen said:

“they’re doing it ‘cause, hey, they love doing it. They love taking care of people, making them better.”

Financial motivation was most frequently mentioned as contrary to this ideal: “It’s a way to make money.” Felicia said it bluntly: “I mean, you got your good doctors; you got your bad doctors. Basically, it’s a money thing to me.” Gwen captured this common perception when she said,

It’s become a money-making machine. I don’t think there’s too many genuine health care providers. I’d say out of the health care providers in America, maybe thirty-five percent of them may genuinely, genuinely be in it for the Hippocratic Oath. I don’t think the majority of them take that oath seriously anymore. And that sad to say – as in doctors.... I think a lot of people going into the field of practicing medicine, a lot of them are doing it ‘cause “I’ll make a lot of money doing this.”

Paulette mentioned financial gain as affecting even prescriptive practices; “They make sure that the medicine they’re pushing for you is some that kind of benefit them also.” Another said,

It’s all about the mighty dollar. They getting’ paid, what do you think they care about us? They went to school all those years so they can get paid. It doesn’t matter how sweet you are and all that. “Can you pay my bills” is the bottom dollar.

Evette asked the question, “Can these doctors get by with making maybe a little less money, instead of being a billionaire, or millionaire at the expense of sick people?”

Honey’s personal experience was troubling:

And I remember this last guy, during my surgery, he's in there talking about how much money he has, you know... I mean, he was literally in there, you know, sticking, you know, laughing and joking in there with the nurses and everything, and I feel him, you know, he's in my body doing this, that, and the other, and he's talking about the money: "Oh, I got so much money!"

Financial gain was not the only skewed priority that participants perceived among health care providers. Janice believed that "they got their heads screwed around wrong on a whole lot of issues...where you think you helpin' in one hand, and you hurtin' in another." Renee and others talked about time as being prioritized over the patient: "You can't fit an hour's worth of my questions into fifteen minutes. Not even fifteen minutes sometime. Ten minutes, or eight minutes, or seven minutes. So time, a person that's willing to take less clients to take more time."

Diane mentioned time, too, lamenting that if providers took time to get to know their patients, instead of making a quick buck, they can actually understand where the patient coming from with this pain or this problem. And why they keep coming back for the same reason. Or why more problems are added on to them 'cause you didn't take care of the first one.

Some participants described some providers as failing to honor God:

Here you is cuttin' off necks and body parts and all trying to make the test-tube babies and all this mess. God didn't put it like that. He didn't mean for it to be like that. They done crossed a whole lot of lines.

Paulette echoed: “You know, the doctor says one thing, God has a whole different plan.” Kay recounted an example in which she and her family were praying for recovery of an aunt, and the provider’s response was,

“Well, if God going to heal her, He would have done it a long time ago”... and that sets back in my mind like did you really, really do everything you possibly could or did you give up just because, you know, you feel like she’s not important enough.

Parents had specific ideas about what should motivate health care professionals. They also had specific thoughts about how health care providers should “be,” what I coded as *disposition*.

Ideal disposition. Disposition is one’s “usual mood, inclination, or tendency”, or how something is situated (American Heritage Dictionary, 2009). Participants often discussed what I coded *disposition* in terms like caring, passion, kindness, and patience. Diane’s thoughts summed up well what many participants had to say about passion or compassion of health care providers: “I think that the health care provider could be more passionate towards their patient.”

Gwen linked compassion with motivation when she described how health care providers should have “passion for the best interest of the patient. The passion. ‘Cause if they don’t have passion and they’re in it for a dollar... I don’t want to be bothered with that health care provider.” Nurses were frequently cited as fulfilling these provider ideals. Chantel said of nurses that “they really been patient and work with me....” Paulette described her ideal of health care providers as “someone who is genuinely concerned about your health and about you, and they making sure that you’re well taken care of in

the right way that you're supposed to be." Renee made an interesting comment about the ideal caring quality: "Even if you don't care, act like you care. You know, you can act like it."

Participants described encounters from their own personal histories that fulfilled these ideals of care. "I thought the nurses were so nice," said Evette,

I can remember them bringing a doll to the room. And the doll had the head bandaged like it was me, so I thought it was me! As a little child, I'm like "oh this is so cute, this is me," and I got attached to the little doll and I think they said, "Oh you are going to do better, cause that doll is well, and that doll is better, and that doll is going to get out of the hospital." And I thought that it was me, so I felt like, "Okay, I got to get better"; but I remember that doll that one of the nurses gave to me as a gift. And I took it home and showed my sisters, "this is me."

Gwen talked about a childhood experience as well, in which "they were so sweet to me even though I'd clawed and scratched, fought and bite.... They were really, really patient." Janice described a doctor who treated her when she had severe burns that required frequent debriding:

It touched him for him to hurt you, and still he know what he was doing was making you better and all. And he just cry with you. I never seen no doctor that had such concern feelings.... I never met another doctor like that before. And I just give his glory and praises.

All participants told personal stories of violation of this ideal. Benita remembered doctors from her hospitalization:

But the doctors were just rude. I remember that. 'Cause they would just come in and sign the little... sometimes they wouldn't say anything; just read stuff, and look, and rip my dressings off and look at it. Oh yeah, the doctors were horrible. Honey said, "They had very terrible bedside manner. 'It's what I say. I'm right. You're wrong. You do what I say. I'm the doctor.'" Janice told of her own experience:

He asked me what was my problem and everything. And I told him, I said, "I've got a knot and an infection down here on my groin and all." He say, "Well, how you know it's a knot?" It was like being smart. And I'm like, "this is why I'm here to see you. I know what I felt."

Participants also mentioned the importance of familiarity in health care providers' disposition: One described it as, "Knew the doctor by name, knew his family, and felt easier about going, felt like it wasn't a big pressure." Evette described her grandmother's relationship with her health care provider:

She was really, really fond of him. And whatever he said, she believed it. She would do what he would tell her to do. She would always come back and say different things that he had said, I guess he would ask her stuff about us, what's going on in our lives, and she would talk to him about it.

Benita also mentioned situations in which providers talked about things other than health, taking "time out and talk to me, you know, outside of taking my blood pressure, outside of normal health care things." She described one nurse in particular who would just ask me about school... And I remember she bought me, when I got ready to leave [the hospital], a notebook. And it was during a time when the gel

pens were really hot, and it was like black paper, and she bought me the gel pens so it looked really neat on the paper. I, I remember that.

Many participants verbalized a sort of “in my shoes” quality that was a desirable disposition in providers: “Just as long as you treat me the way you want to be treated if you were in the hospital,” said one. Diane said, “And I just don’t think they should look down on patients. I think if they took a step in their patient’s atmosphere and their life to find out what’s going on with them.” Janice voiced a similar idea, “But when you got someone who care for you and feel at least some of the things you’re going through and can relate with you... then you got a bond. Something that everybody don’t have.”

Evette said,

You know, even people who may not be on your same level, might not make the same kind of money, may not live in the same neighborhood; but these are the people that are supporting you. And so you have to find a way to connect to those people, more so on a personal level. Where it’s not so businesslike. On a human level. No matter what their race, no matter what kind of money they have, no matter how they look or how they smell or any of that. You just need to find a way to connect.

Quinn included the quality of not judging to the ideal disposition: “Not somebody who’s just going to chastise you.” Another mentioned a specific provider, “something about her – bedside manner, I guess – that was just very relaxing, very calming. I didn’t feel like I was being judged or criticized.... So, she was just a really nice lady and had a really friendly office environment.”

Diane characterized some health care providers who violate the ideal disposition:

I think some of the arrogance can come off the shoulder 'cause they have that degree that don't make them more subordinate or superior than the next person or patient. And it took somebody to guide them or to help them, see about them, to get them to the status where they are.

Neva had a poignant personal description of this, and described her reaction, and what followed in the relationship:

I went to the dentist, and it was so funny because someone had told me that—he's dead now—they were telling me about his personality, about how we would talk to you or whatever. So, he did. He was like "how do you let your teeth get in this shape" or whatever. So, he had this thing in my mouth, going through, and I pulled his hand out and said, "Let me talk to you for a minute." I said, "I grew up in a house with four children in the house, and my mother was a single parent.

Going to the dentist was not a top priority. But I promised myself when I got a job that I would go to the dentist, and I would see about my teeth. And I'm here today. So, don't tell me 'why I hadn't been here early.'” And ever since then I had that conversation with him, he was always pleasant with me. He took care of what I needed to have done. I had the procedures done or whatever, as a matter of fact, but it was that tone to me. "You don't know what I've been through. Let me tell you, I'm here now 'cause I made it here. But before, this was not a necessity for us. We had to eat. The light bill had to be paid. The water bill had to be paid. And dental thing was the last thing to be paid. My momma worked a fulltime job, but you didn't have no extra to go to the doctor 'cause every week you was trying to see if this water bill is going to be paid or if I needs new shoes or sister needs new

shoes or whatever. So, this wasn't—we brushed every night and make sure we went to bed. We didn't eat a whole lot of candy because there was no extra money. So, we did the best we could.” And after saying that to him, it was different.

Provider disposition was a common theme in participant interviews. Disposition was referenced in terms of how providers seemed to participants, what their attitudes were like, and how they approached and comported themselves with participants. Closely related to typifications of provider disposition were their typifications of provider communication, which was the actual speaking and verbal exchange that occurred between participants and providers.

Ideal communication. Communication is “the exchange of thoughts, messages, or information, as by speech, signals, writing, or behavior” or “interpersonal rapport” (American Heritage Dictionary, 2009). It includes concepts mentioned by the participants as talking, listening, and general manner. Evette said, “How you talk to people is so important.” She went on to describe her midwife:

She would talk to me on my level. She didn't try to use big words, she didn't try to make me feel bad if something was wrong, that I was doing something wrong. Let's say if I was overweight, I'm pregnant but I'm overweight, the doctor could have said “you gonna lay off those potato chips”, being real rude. But now she would have said “okay now, you're just getting a little, the scale is getting a little heavy. But we're gonna work on that, right?” And I'd say yeah, I'm gonna do what I need to do. “Cause we don't want that baby to be so big he can't come out!” You know, something like that.

Neva referenced the quality of communication when she said,

I want somebody to be able tell me, you know, and be nice mannered, you know, about you know you be overweight. “OK, now you know you got to get some weight off.” It’s a certain way to say it [laughing]. I look for the correct way for you to say it. You can tell me as many times as you want, just don’t say it in the wrong tone.

Iris said, “Like, some people criticize people about their weight. You know, say it in a nice way. Don’t ‘You need to lose weight’, I don’t like that.” And Quinn, “I hate when doctors say ‘Well, you know you’re not supposed to be doing this.’ Okay! I know I’m not supposed to be doing that!”

Quinn described discomfort in that sometimes occurs in communication with providers:

’Cause the doctor just come in and use these words where you lookin’ at them like “what does that mean?” And you feel kind of uncomfortable to ask them because you don’t want to feel like you’re incompetent or anything like that. Just like well, I don’t want to ask this question he look at me like “you don’t know what that mean?”

Gwen also mentioned the critical nature of mutual communication in describing a personal experience when she accompanied an acquaintance to an appointment:

The reason why [the provider was] not able to treat the child when the parent’s telling them [what is wrong] is because the parent is not able to communicate the point for the doctor to understand. I had to go to the doctor with one lady [who said], “I keep tellin’ the doctor he runnin’ all over, he dukeyin’. And [the doctor]

won't hardly do nothin'!" So I go with her, and I said, "Well doctor, the baby is not able to hold anything down. He is regurgitating and defecating frequently, like every 20 minutes. I mean, he's going through, in an hour, three or four Pampers being soiled." And immediately, the doctor writes a prescription and in three or four hours, the baby's better.

Participants often mentioned honesty and straightforwardness in communication as desirable traits for health care providers: They want "somebody who's gonna be straight forward with me. Going to answer all my questions I need to know. Somebody who's not rude; gonna treat my kids good – that's basically what I look for.

Communication. That's very important." Paulette said,

be honest with me about things. Don't just tell me something to pacify me....

Whatever you getting ready to do, especially if you know I'm afraid of needles or whatever, but don't tell me something to pacify me. Just tell me it's going to hurt. Something that simple.

Quinn echoed: "I'm going to ask you this question and I want you to answer it.

Don't just kind of brush me off and give me whatever you think I want to hear."

Latrice said,

Don't try to sugarcoat something. You know, "this is how it's going to be. This is what you need to do...." I just like it raw. Know what I'm looking at, know what I'm facing. What the possibility of a cure or antidote or how do we fix the problem, bottom line.

Marilyn also appreciated this quality in her nurse practitioner: “She’ll tell you... ‘You fixin’ to lose your foot! You better get this medicine!’ You know she don’t cut nothin’ short. I like her.”

Participants commonly mentioned listening skills as an important component of ideal communication. One participant stated that a health care provider should demonstrate “good bedside manner and listening”. Diane described an interaction she had with a provider: “She listen to everything, not matter if she got another patient waiting, she listen to everything.”

Honey described,

There been situations where I’m not being listened to. You don’t know me. I know me, you know? I’m not an idiot. I don’t need you to tell me how to breathe, okay? So I tell you I’m either this way or not that way, listen to me....

And I have pulled my kids out of situations where I’m like, you know what, the doctor didn’t listen to what I said. The money an’ all that, you know, we can work that out later, but we’re never going to get to that point if you don’t listen to me.

Motivation, disposition, and communication were all common themes in participants’ typifications. Other typifications fell within a thematic category that I coded *professionalism*.

Ideal professionalism. Professionalism is “professional status, methods, character, or standards” (American Heritage Dictionary, 2009). Participants mentioned several of these components of professionalism. Diane and others mentioned choosing a provider based on their reputation among people they know: “They go by eye or word of

mouth.” Janice chose a provider based on what her coworkers said about him: “All the young ladies worked in the office with me, they had this particular doctor, and they was talkin’ about how good the doctor was and all this, and so [I went to him].”

Another said, “I listen for the good, bad, and ugly. Because my life in your hand, so I want to know.... I even think back, friends of him say, ‘Oh, child. They party up something.’” Iris said, “I ask around first, and if I hear negative things from more than one person, I won’t go to them.” Neva “listen at people talk about their doctor... kind of just listen at conversations ‘cause I know what I want.”

Several participants made comments about providers that they perceived as personally violating their own practice standards:

I hate to see anyone in a health care situation where they’re supposed to be an example. I hate to go, you know, to the doctor’s office and nurses are outside smoking... or, your CNA is fat. Or a dentist with bad teeth, bad breath. I had a dentist with bad breath. It’s like a blind eye doctor. Something’s not right.

Chantel mentioned violation of confidentiality as a concern:

Some nurses keep the confidentiality, you know. But some of them talk.

Whenever people come in there, they’ll talk about it. That’s the only thing I have a problem with. I don’t care if I do know you and you know me, my business is nobody else’s business. What I come into the doctor’s office or hospital for. And some nurses have been seen to talk about that stuff, and I don’t think that’s everybody’s business.

Every participant mentioned expertise and knowledge as important in providers.

Oneida described a provider’s knowledge as the most important thing to her: “If you’re

good and you know your stuff, I'm not picky." Quinn specifically mentioned "a variety of experience... you've seen different things. Gone through different experiences." The ideal provider was able to offer usable information: "Say, 'Okay, this is what you might want to do to stay on that right track', give me options."

Neva mentioned thoroughness:

A lot of times I end up seeing the nurse lady. The last time I saw the nurse lady, she was real thorough. And I kind of loved her. I was like, "Are you a nurse or a doctor?" 'Cause I had been constantly having this, you know, the sinus stuff and the headache. And finally when I went to her, she just performed a miracle, 'cause she just said, "You going to need this and this." And within a week's time, I felt like a new woman.

Participants often mentioned situations in which they felt that health care providers were wrong, or had no answers, or made a mistake. Benita described her family's response to her mother's illness and subsequent death: "My family felt like the doctor didn't diagnose it, or he gave her the wrong medicine." Janice asked me to "imagine how many probably have passed away and deceased because of a mistake the doctor made." Diane had undiagnosed rheumatoid arthritis as a young adult, and said

I remember having a lot of pain in my joints, and the doctors never knowing what was wrong. I hated going 'cause they would tell me the same thing, "growing pains"... all the symptoms could probably be related, but they not sure.

Of her grandmother's death, Marilyn stated "She had never gotten sick, but they put her in a nursing home because she stopped walkin'... they couldn't figure out what was wrong with her."

Quinn expressed frustration when her health care provider could not give her answers:

“I’ve got good news and bad news. Your thyroids are fine, but I don’t know what’s wrong with you.” She told me straight out like that, and I just looked at her like “you don’t know what’s wrong with me? You tell me it’s good and bad news. Good news my thyroids are fine, but you don’t know what’s wrong with me?” So, that’s it. She left it like that. After that and you tell me you just don’t know what’s wrong with me, that’s the last thing you want to hear from your doctor.

Participants typified health care providers in terms of motivation, disposition, communication, and professionalism. In the *We-relationships* section, the reader will see these typifications rise to the surface over and over as parents describe both problematic we-relationships and transformative we-relationships with their children’s providers.

Symbols of illness and wellness and typifications of providers were not the only relevant precursors to how participants experienced their children’s health care encounters. The third precursory parental relevance was their in-group/out-group membership status.

In-group/Out-group Membership

In-group/out-group membership is at the heart of Schutz’s social phenomenology. Consideration of in-group/out-group status is also at the heart of this study, because understanding in-group/out-group typifications is central to a Schutzian understanding of equality and inequality. One of the primary premises of this inquiry is that the patient/provider dynamic assumed in all clinical relationships creates the most obvious cultural in-group/out-group. But as discussed in Chapter 3, people may be members of

more than one group at a time, which can result in differing and conflicting domains of relevance. One of the precursory parental relevances to children's health care encounters was in-group/out-group membership in a variety of groups. In my interviews with participants, there emerged three primary in-group/out-group distinctions that affected participants' perceptions of encounters with health care professionals. These in-group/out-group memberships were based on race/ethnicity, professional background in health care, and insurance status. The first of these in-groups/out-groups was race/ethnicity.

Race/ethnicity. In designing this study, I had imagined that race or ethnicity might be of great importance to the participants in discussing health and health care. And indeed, it was evident that some participants felt that race is sometimes a factor in health care encounters. Some mentioned feeling highly typified by providers because they were African American, or that the quality of care delivered by white providers might sometimes be based on patients' race.

Evette stated, "I believe, for the most part, white people, they're really gonna take care of their own. More so than Black people. And I just believe maybe some of those doctors they may have a bad perception about Black people." Another said, "some White people, not all, if their parents were sick they'd do anything they can to get help for them... but when it comes to us... heaven and earth don't be movin' like that."

Janice described feeling as though providers sometimes withheld information based on race:

You know, they don't tell African American folks everything about what's out there and what's there for us.... That's what really get you. I'm not prejudice or

nothing. It gets me what you got to look at my color and then say if I'm going to help you or not. I did not have a choice, just like that next person. Tell me one person, just like Bible say, those who sin, haven't sinned, throw that stone. OK, tell me one person here in the world, not [this town], the whole wide world, that had a choice of who they momma and daddy.

Gwen thought social class was more important:

I think then your socioeconomic status overrides your race when you get to the middle-middle class African American... And it kind of hard to break it all down... 'cause it's so complicated. And I just feel like the biggest thing is socioeconomics—the culture that comes with socioeconomical class. And I even see it done even, umm, Caucasian people who were in a lower socioeconomic class. And the doctors don't understand them, and they don't get the proper treatment. So, it may be more of a communication issue that's brought on due to socioeconomical status and academia, academic limitations.

Diane echoed this when she said,

I do know some White people that's on the same level as far as me. I stayed in a shelter, and they don't get the same treatment either. Especially if they know you're from the shelter. And you can be in the shelter for various reasons. And they won't give you the same type of care.

Another participant referenced a personal experience with a provider in which she mentioned the perceived prejudice of one provider in contrast with a second:

But he would say something like, something I just couldn't receive, or I'm thinking, he's just saying this to me because I'm Black. And I could remember

the other lady who was going to the same doctor, saying “Oh he’s so sweet, and I love him, and he does this and he does that”; and I was about to say “I was about to change doctors, but his midwife was so nice, that’s the only reason why I didn’t change”. I don’t think [the midwife] was all White, she could have been mixed with something like Italian, or something. But she was nice, she was really nice. Because I felt like he really wasn’t in tune with me as far as me as a person. Now someone that’s about to deliver a baby, maybe, well then yes; but as a person, I didn’t feel it.

It is of interest that most did not mention race or ethnicity at all, or when they did mention race or ethnicity, it was to iterate a belief that race is not a factor in health care encounters or of concern to them in choosing providers: Oneida said of her choice of provider,

It’s not necessarily race. But if you’re a butt, they can be in any form, shape, or size, so no, not race. Like I said, Dr. A, he’s Indian, White, whatever. Whatever he is, he is what he is, but I love him.

Some even had the perception that they, as African Americans, were treated more poorly by African American providers. Diane said, “I know there’re Black physicians... maybe because of the way they had to fight through school and the position they had to get there, they got that big chip on they shoulder. And it’s toward the Black community.”

That most participants did not mention race may be due, in part, to limited choice of providers. Because several participants did mention the dearth of African American health care providers, in general. Benita said she had noticed “a lot of techs were African

American – more the nurses and doctors of course were White – so I noticed almost all the techs were African American... and female.”

Renee said,

I don't see a lot of Black people in the health care profession. I really, really don't, so I don't know what that reasoning is, but I never had to really deal with any. I only dealt with Caucasians or White people, but I've never gotten a bad sense from them. But it would be nice to see more Black people in the profession to see how that would go.

Gwen had specific ideas about this problem:

I feel if there were more African American doctors that came from these backgrounds and treat these families they would be more in-tune and more on-top of health care because then they would feel more comfortable with somebody. And walk in and say, “Hi, I'm Dr. Jones. And what's been going on?” [I said] “Well, he been runnin' off, and he dukeyin'.” [The doctor said] “So, really? You say he's been dukeyin'; what color that dukey been?” So, like, they can understand, and they can relate and talk like that because even—You know, I think maybe that would make a difference. So, that's one thing I would like to see more African American doctors that come from these backgrounds that can truly understand. Not some African American doctor from a family of doctors who doesn't know anything about these people. You know. We need Pookey who grew up at 807 South Fry Street [local housing project address] to grow up and go to medical school and become a doctor. Well, he's just as capable, but he's got one up. He's bilingual because he can speak Ebonics English and English English.

That participants may not mention the race of providers as important in their health care encounters because of the dearth of African American providers, may be particularly true in this small town, in which only three of the primary care pediatric providers are African American, a number reflective of the national average. But that low percentage is even more significant in a metropolitan area in which almost half the population is African American. In other words, the ethnicity of the provider may be less important in choosing a provider if the choice is limited anyway.

While race was mentioned as a parental relevance in terms of biography and historicity, it was only mentioned twice in discussions about children's health care encounters, and that was as third hand stories about relatives' experiences. No parent mentioned race as influential in their own child's health care encounter, except as it related to insurance status and class. Only one person mentioned race as a decisive factor in choosing a provider for her child, and this was in the case of finding a dermatologist:

The only time I would prefer African American doctor is because of Jada's skin and her scalp. I just felt like—and I could be prejudice—but I just felt like he would know about black hair. What would work, that's the only reason. But, I mean, preference wise, I just don't pick them. It doesn't matter.

American society is highly racialized, and health care, in general reflects the racialized nature of the broader society. Because this is a critical analysis involving experiences of African Americans, I felt it important to consider race as a factor and to elaborate on it as a precursory relevance; however it will not be a major point of discussion in the *We-relationships* section, since the participants did not highlight it as important in their children's health care encounters. When the topic of race did come up,

it was most often immediately re-evaluated in the context of income and insurance status. I found this association to be critical, both in terms of importance and in terms of theoretical framework. It is the complex relationships between and among gender, race/ethnicity, employment, income, and insurance status that demonstrates the intersectionality existing in health care encounters. I will discuss intersectionality more in the concluding chapter.

Race was the first of three in-group/out-group memberships that appeared to be important in participants' experiences of their children's health care encounters. The second category of in-group/out-group membership was associated with a participant's background in health care.

Health care background. When I designed the study, I had thought that educational level might be important in how a participant experienced health care. I created demographic categories that included educational level, thinking that themes that emerged as important to the more highly educated might differ somehow from those important to those with less formal education. What I found, however, is that participants with any background in health care sometimes made reference to that background when they discussed health care encounters, and that those parents most likely to report fear and distress in encounters were those with no background in health care.

Of eighteen participants, nine had either worked in health care (most as Medical Assistants or Certified Nursing Assistants) or grown up with a parent who was a college-educated health care professional. Oneida said that when a physician asked about her mother's health (her mother having worked for this provider's father), the nurse asked her who her mother was. Oneida responded: "My mama trained your mama"; and she further

referenced how her mother's background affected her: "So my mama, her nursing style, she don't take no crap from nobody. It took me a while to tap into it...took me having children."

Gwen referred to her own father's background, too:

My dad, being when he was in the military, he was like the head rescue person like for the paramedics and flight line. So, he knew a lot of medical terminology. So, him communicating with doctors, he pretty much understood everything they were talking about. So, there never was a breakdown in layman's terms. So, I guess that's why I'm kind of, when I'm talking to my kids' doctor, I'm already there.

Status as a member of the health care background in-group clearly affected the way parents experienced health care encounters in ways that level of education did not. This phenomenon will be discussed in more detail in the *We-relationships* section.

In-group/out-group membership based on race and health care background were important precursors to how participants experienced their children's health care encounters. The third, and perhaps most important group membership that affected these experiences was in-group/out-group membership based on insurance status.

Insurance status. When this study was conceptualized, my review of the literature indicated that there remained a gap in terms of understanding the relationship between social class and children's health indicators. This gap was the primary reason I felt it important to include class or income as part of my study. As discussed in the introduction, though it is clear that children in poverty have poorer health than their non-poor counterparts; and while some of this disparity is explained in terms of

environmental factors like air quality (as related to asthma) or access to fresh produce (in the case of obesity); there are still disparities that cannot be completely explained by quantitative measures. Even when controlling for income, for example, on many quantitative measures African American children are less healthy than White children. By the same measures, even when controlling for race and ethnicity, low income children are less healthy than their higher income counterparts. As discussed in both Chapters 1 (significance) and 2 (literature review), the factors that contribute to child health disparities are complex, multifactorial, and poorly understood. One contributing problem, referenced in Chapter 1, is the historical reporting of morbidity and mortality in the United States by ethnicity, but not by social class or income level. A reason for this gap (also discussed earlier), is a cultural resistance, in the United States, to place people in class groups. When it becomes necessary to consider class, therefore, income level is often substituted. This was certainly the case when I designed this study.

After a great deal of thought and research about how I would consider “social class” in the context of a critical framework, I was eventually reduced to using income criteria, as so many others have done. As I actually began to interview participants, however, an interesting and unexpected phenomenon came to light, one that I had not anticipated, and perhaps the most significant finding of this study: That in the context of their children’s health care encounters (and indeed in all of their health care encounters) and relationships with providers, insurance status appears to eclipse many relational factors that may exist, and becomes a sort of categorical substitute that transcends either class or income.

While I thought that insurance might come up, I had imagined that other factors (particularly race, educational level and income) might be more important in specific encounters. While my intent was to discuss details of specific encounters, every participant, without exception, spoke about insurance status throughout the interviews; often responding to questions designed to elicit responses about their children's health with comments about their insurance status. I realized that it would be very important to consider this finding in my analysis and discussion. Insurance status is a phenomenon that lends itself well to Schutzian analysis in terms of in-group/out-group membership status. For participants, simply having health insurance or not having health insurance was not the only problem; instead, it became clear that all participants perceived themselves to be part of a sort of insurance out-group, and *having it* or *not having it* was just one facet of being part of that out-group. This phenomenon will be discussed at length in this section, in order to establish how participants described the phenomenon of being an insurance out-group member; in the *We-relationships* section that follows, in which participants described how being a member of that out-group sometimes affected their children's health care encounters; and in the following chapter, particularly in terms of how insurance status fits within a framework of intersectionality.

Participants discussed insurance more than any other single topic during interviews. One reason why the participants had so much to say about insurance, and so often seemed expert in the ins and outs of insurance coverage, was because all of them, without exception, had transitioned among no coverage, public insurance, and private insurance; often frequently throughout their lives. I will discuss the implications of this phenomenon in terms of intersectionality, in the final chapter. Participants most often

referred to insurance in terms of complexity, expense, access to care and choice, and personal treatment by providers.

Complexity. A frequent theme in the insurance discussion was the complexity of getting it, keeping it, and managing it: “As long as you keep up the information and renew... so I try to keep it current so it won’t lapse”. Oneida told the story of her mother:

The whole insurance thing, it’s terrible. Like, when my mom got sick, she was always—she was a nurse by profession. So, we were never on any kind of, you know, welfare, food stamps, nor Medicaid. She footed it for all of it. I guess it was just me and her, so we never really had any financial problems at all. We were—I wouldn’t say rich—we had what we needed. But when she got sick and when she stopped working, just having to deal with going to apply for Medicaid for her, it was like “Do you have a job?” I was like “Well, technically, yeah. She’s on temporary disability leave, so yeah, she does have a job.” “Well, we can’t help her because she has a job.” But it was really, really frustrating not being able to get any kind of medical assistance just because she has a job. She has a job, but she’s not working; how do y’all—and it was like “Can you just explain how that makes sense?”

Kay, among others, discussed the complicated nature of maintaining coverage for her children:

So, it’s like, now, I’m trying to get Medicaid for them, and that’s, like, a hassle... and it’s just too much. You know, it’s crazy. Right now, we don’t have any insurance ‘cause I’m trying to get Medicaid and all of that for them, and well, I thank God and knock on wood, I haven’t had any problems... in between or

nothing. If push come to shove, I'd take them to the emergency room or something like that.

Latrice referred to the complexity of shifting coverage, too. When she was laid off from her manufacturing job, she extended her insurance coverage through COBRA (Consolidated Omnibus Budget Reconciliation Act). But in trying to schedule a routine procedure with her provider, she was told:

“We just went to put the insurance through, and they said it was canceled.” And I called, and they're like, “Yeah, actually, what happened,” they said, “we received your payment one day late.” I mailed it off—I thought I had until the first because the, how do you call it, the lapse date, the cancelation date, it would either be on the last day of the month or the first day of the month. But it differed different months. And I was always paying it late, and I was just got in the habit of paying it, always making sure it was dated and mailed off on that last day. And I thought it was the first. And it was actually the thirty-first. And because it was one day late, they canceled my insurance. And they would not reinstate it. Would not reinstate it. I'm like, “It's one day late!” It was like [they were probably saying], “We got her! Yay! We can't. Sorry. [Clapping sound] Yay!”

These examples are just a few of those mentioned by participants that illuminate the complexity of having or not having insurance coverage. Besides being complicated, insurance is expensive; but it is also expensive not to have insurance. Whatever the insurance coverage status of participants, expense was also a problem.

Expense. Expense associated with insurance and health care was of major concern to all participants. Those who were uninsured did not get care because it was too

expensive: But even those with insurance still had to come up with money for premiums, co-pays, and medications. The result was that participants in every situation perceived insurance issues as expense-related barriers to care: “Even though there are those of us that have jobs, the health care plans is just no good.”

Renee’s husband had what she considered “good” insurance benefits, but he was thinking of retiring from his job working as a driver for an international packaging and delivery service. Renee’s son will no longer have coverage if her husband retires, so she was thinking of changing jobs in order to get health insurance. She said,

It’s pressing on me now. I think about it probably every day, give it some serious thought... ‘cause you know how the job market is right now. But I need to start thinking of something. Even if I have to purchase individual insurance... me and my husband talk about it. [My son] going to have insurance some kind of way. We’ll just have to pay an arm and a leg.

Chantel talked about the challenges of low-paid employment and Medicaid:

Medicaid ain’t gonna cover everything. And I’m just a parapro [school paraprofessional] so my income ain’t gonna cover it. Even if his dad finally get some insurance on him, I got to pay a deductible... James’ medicine run me \$250 a month.

Felicia voiced similar ideas when she said,

Everybody can’t afford it. That’s like with me, I had a family plan. Especially, you know, with what we [school custodians] make, it’s not done right. That’s twenty something dollars I got to pay out for my kids to have insurance... It’s sad, though. Real sad, ‘cause a lot of people need insurance and can’t... it’s not

that they don't want it; they can't afford it. Sad, 'cause you got a lot of kids don't go to the doctor just because parents don't have insurance. It's like some people gotta make a decision: "I'm either gonna have insurance or have somewhere to stay."

Neva, who has good coverage, stated a dilemma similar to the one Felicia described: "But the cost of it so high you be like "'Whoa, do I do without this or without that.'" Quinn mentioned this, too:

My co-pay is thirty dollars, too. And I have not—and sometimes, it's just gas. I need that money for gas. And that's another reason why I'm not seeing my doctor yet. I haven't even looked in to going to find another doctor because the co-pay is so high. And then still have to worry about pharmaceuticals, get your prescription filled, and how much that's going to cost.

Evette, a college-educated professional, referred to how much was taken from her paycheck to cover health insurance:

Whereas here I am paying all this money, I'm praying every day that nothing happens, that I stay healthy, that my kids stay healthy, so I don't have to use money. In fact I'm already using money, 'cause I have a high premium for my family.

Evette also referenced expense of care as directly related to health among African Americans:

Your life is worth more, but they don't look at it like that. They look at it like, "this fixin' to be another bill." Like, "if I go, then there's going to be a problem. So I don't have a problem."

Quinn reported a time when she had to utilize the ER, because she couldn't afford the thirty dollar co-pay required for an office visit:

I went to the ER one time, and it's horrible, but I didn't have the thirty dollar co-pay to go to my doctor, and I went to the emergency room 'cause I know I wouldn't have to pay nothing right now. Even though it cost two-fifty [two hundred and fifty dollars], it's not right now.

She went on to describe the subsequent difficulty of filling the prescription:

And the Z-pack cost so much, and my insurance itself doesn't cover as much as it should. It should cover all of it, but it doesn't. It was just, well, more money out of my pocket. So I still got that prescription for the Z-pack in my purse. If I get a little bit more money, I'll go fill it.

Expenses related to being insured or not being insured were problems everyone mentioned. They also mentioned access and choice based on whether they had private insurance, public insurance, or no insurance.

Access and choice. Of access to care, one participant said, "I see it. I read about it. I hear about it. I have a friend who has a little shop over here called HairWorks. They work for themselves. They don't have insurance and it's a daily struggle for them." Another said,

'Cause that's the first thing they check: what kind of insurance you got. Which it shouldn't matter.... And then you know you got a lot of people, doctors, "Well, we're not accepting new Medicaid patients right now." But call and say, "Oh, I got United Healthcare," [and they say], "Okay, we can schedule you to come in." It play a big, big role. I don't care what nobody say; it play a big role.

Chantel said, “I feel like with us, they try to send us, ‘cause we’re on Medicaid, to see certain doctors. So I can only go to certain places.”

Diane discussed the challenge of finding Medicaid providers for specialty care: My insurance is Medicaid, and certain things, like two of my kids get braces—I have to go to Columbus, Georgia. I have to go two hours out of the way. To get braces because none of the orthodontists here won’t do braces by Medicaid.

Umm, Tyler, he has to go to Macon, Georgia for a rheumatologist because the rheumatologist here don’t do kids under eighteen. And it’s only one. And I wish there was more physicians that could... that’s open up to more than just one, I guess, status or specialty, so they can invite more people.

Latrice put it succinctly:

If you got insurance, you’re good. I mean, if you got insurance, you’ve got a POS [Point of Service plan], hey, you’re top of the line. Got an HMO [Health Maintenance Organization plan], you still get health care. But if you don’t have insurance, you just... You are SOL. I mean, that’s basically how it goes.

Many, many parent participants were without coverage themselves, which inhibited their ability to get proper treatment of any kind. One participant described indigent care she received in the local ER:

I’ve been going to the emergency room because I have the indigent care with [the local hospital]. It’s not the best. I mean, it’s not great. It’s not like when you have insurance and you can go to a doctor. It sucks actually [laughing]. It’s free care, so have to deal with it. It’s all I got right now. My blood pressure would be high, and I would go to the emergency room, and they would check it, and say, “Yeah.

It's high. You need to see your primary care physician. What you need to do is go home and rest. Relax, and go see your primary care physician." [And I said], "I don't have a primary care physician! That's why I'm coming to you! Hello!"

Complexity, expense, and access/choice were described as part of the insurance out-group phenomenon. A fourth component was how participants perceived they were treated by providers based on insurance status.

Treatment. Participants rarely distinguished whether the difference in treatment they experienced was based on the actual services provided or a perceived prejudice on the part of the provider. There was just a general description of "differentness". One participant said,

I have been in the equation for every aspect, from being on public health care to Cadillac private health care to mediocrit [sic] private health care. And every aspect of health care, I realized there is a difference in the way that you are treated. Unless you demand respect, you will not get respect if you on public health care. When you on private health care, you always have to beat them off of you 'cause they're trying to over-care for you.

Another participant said,

As a parent, I feel that services are provided based on your insurance, which I think is wrong. I think that's my biggest gripe, that, you know, services are based on your insurance and—or lack of or whatever—and it shouldn't be that way.

Honey described feeling forced into certain procedures based on her status as a Medicaid patient, whereas private coverage had afforded her more choice and control:

And when I refused to go to the diabetes doctor, I was told, “Oh, well, we’ll drop you from our practice.” I was, you know, seven months pregnant. You know, again, because of my insurance... They varied extremely when I had private insurance, you know, I opted to not do the whole diabetes thing, and she says, “OK. Just sign this form, and you’re done.” OK, fine. Well, when I had private insurance, it was “Do you want this procedure or not? You don’t? OK. Just sign this form, and you’re fine.” But with Medicaid, it was “You have to get this procedure. You have to go to this appointment. You have to take this test.”

Felicia said,

When you got Medicaid they treat you totally different than some of them. And when you got that good insurance, you fine. You know what I’m saying? Because I guess I feel they look down on people, I guess you got to be poor or whatever to get Medicaid. But it’s not so much of the fact, you know? When my kids was on Medicaid, little did a lot of people know it was based on my income. I wasn’t one of the mamas wasn’t workin’; it was based on my income.

When Benita was pregnant and in graduate school, she qualified for Medicaid. She had to go to the emergency room late one night because of contractions, and she said of the emergency room provider: “And he just assumed that I was like on Medicaid, that this was probably my sixth child. He just treated me so bad, and I’m thinking to myself, ‘Dude!’”

Iris mentioned social status as it relates to insurance type:

Some [providers] may think it’s a bad thing to be on welfare or trying to get Medicaid, but if it helps, it helps. It’s high. I know that much just for a doctor’s

visit. It helps with my children. If they didn't have health care [insurance], they would not be going.

Insurance status was characterized by participants as being complex, expensive, affecting access and choice in health care, and resulting in unequal treatment based on coverage. No participant referred to insurance providers in terms of individual people. "Insurance" is instead referenced with a highly typified "they" or "it": "When you get big corporations and insurances, they're going to do what they're going to do regardless, so what's the point in asking me?"; "they're saying they never heard of it, and they're saying they don't want to pay for it"; "it makes no sense how they figure out the tables of who needs help and who gets medical coverage"; "I wish it was cheaper in some sense. They should change some issues about that, they should have lower standards so that everybody that ask for it, get it"; "they try to send us, because we're on Medicaid, to see certain doctors"; "It's just crazy how they do the prices like they do." It is my interpretation of the participants' descriptions that they all feel like members of an insurance out-group.

In summary, I will simply restate the points I made when introducing precursory parental relevances: Entry into health care represented a change in domains of relevance for a parent. The nature of relevances is that they are dynamic, always shifting. Day-to-day recipe orientation did not require that most parents think about health or health care for their children. When a child showed symptoms of illness, a parent's domains of relevance and their personal orientation shifted. In particular, when a child's symptoms became severe enough that the parent no longer felt confident in providing routine illness care, the child's illness and all the meanings associated with it became the parent's

primary domain of relevance, and the parent entered into a health care relationship in order to seek professional expertise. But it was not a matter of a parent simply availing themselves of professional advice. The precursory relevances that influenced the participant's we-relationships with their children's providers were: the symbolism of illness and wellness in their life worlds; their typifications of health care providers; and their in-group/out-group membership status.

We-relationships with Children's Health Care Providers

We-relationships are generated in the practical attitude of everyday life situations, like an encounter between a patient and a health care provider; but may become reflective and creative through the process of the mutual creation of shared symbolic meaning.

Entry into We-relationships

As demonstrated in the previous sections, parents entered their children's health care encounters with a variety of precursory relevances. In making the decision to initiate a specific encounter with a particular health care provider, however, other relevant factors came into play for participants.

Routinized daily parental health care of children. Participants described daily, routinized activities that they employed to maintain the health of their children. Parents perceived these activities as being preventive of illness, enabling them to maintain their activities of daily life. These activities could also be part of the greater symbol system of wellness and illness (discussed earlier as precursory parental relevances), in that engaging in them was representative of routine parenting and health maintenance. When asked what sort of things parents did to maintain their children's health or teach their children about being sick or being well, participants' responses generally focused around hygiene,

apparel, and diet. Adele said “I do it, like, wear your hat, put on your scarf, put on a coat, put on shoes, wear your socks. I’m always just about their appearance, especially with the weather, different kinds of weather.” About the importance of what one parent called a “balanced diet” for children, she said

You need meat, some kind of fruit, some kind of vegetables, ‘cause I complain with Deshon about he say he don’t, “I don’t like vegetables”; “Well, yes you do. You just don’t want to eat them, so.” He needs some green vegetables in his diet, instead of chicken and bread all the time. So, I think that could play a good part in how we, you know... we sick, well, and functioning every day.

Diane told her children,

“Just wrap up. Stay warm.... do what you supposed to do. You know you’re supposed to wash your hands. You know you’re not supposed to eat off the floor. You know you’re, umm, not supposed to do certain things, so don’t make problems worse than what it could be.”

Paulette taught her son about “not eating and drinking behind people that he doesn’t know... Just things like that. You know, just the basics.” Another participant referenced safe food handling. She taught her children about “not putting this back into the refrigerator or not drinking out of the milk jug and putting it back.” Benita also taught her son about germs:

I teach him to, you know, about germs. He knows about germs, and don’t put things in your mouth, and he’ll say, “Why, because there are germs on it?” I think he gets a lot from TV, too. And we have some books and stuff about, umm, health and the body, so... I mean I try to teach him the right thing.

Another described:

I tell him to wash his hands. Make sure he bathe real good... And if he starts sneezing and coughing, I tell him, “you coming down with a cold, I’m gonna go on and get that now, and go on a take care of that, give you something now, get rid of that bacteria” or whatever. And I don’t have to worry about that ‘cause everywhere he go he wash his hands.... But as soon as they go to coughing that’s why I tell them they gotta keep their rooms clean and disinfected, the bathrooms clean ‘cause the germs come in any way. That’s why I tell Jay when he go to school to wash his hands real good.

These activities represented the routine, recipe knowledge with which parents approached their children’s health on a daily level. When minor symptoms appeared, parents still approached them with recipe orientation, in a highly routinized manner: “Go take a nap, some rest”; “[if he’s not feeling well] I check on him at night, I still peep on him and make sure he makin’ sounds”; “”If she gets a cold or fever, sneezin’, coughin, whatever... I give her some Tylenol, maybe I can back it up with some Dimetapp, and then we’ll watch and see what happens”; “An’ I went just for a while medicatin’. I went and got some mucous release pills. When I say I was on a budget, I didn’t even go to Wal-mart. I went to Dollar Tree. They has this stuff, *Mucous Release*. One Dollar”; ““Cause you know how children always come in ‘Oh, I feel bad. I feel bad,’ you know, ‘I don’t feel good’ or whatever. Just, ‘OK. Well, go lay down’ or something like that... I would give them a little Robitussin”; “Sometimes when he’s not feeling well, I will allow him to sleep in my bed. Not that I want him sleep in my bed, but I would just rather keep a watch on him”; “[When my daughter has bronchitis] I tell her to ‘get up! Move around!

Walk up and down the hall! Come on, move!’ Then I be doing some percussion therapy on her back”; “[When my daughter has a cold, her nose bleeds, and she’ll say]’Mom, my nose is bleeding!’ [And I’ll say], ‘Oh, did you wipe it? You okay. Are you hot? You’re gonna live. You’re fine, you’re fine’”; “Sometimes if I hear wheezing, I’ll go give them the asthma machine... the only time they really get asthma attacks is if they have a cold.”

These parental responses to minor symptoms represented part of a routinized, recipe orientation to the care of sick children. But sometimes, symptoms presented or developed to a point in which a parent determined the need to consult an expert. In this way, I believe that symptoms were signs that directed parents to seek expert care and symbols that carried deeper meanings.

Initiating event (symptom symbols) and level of knowledge. Just as Alfred Schutz (1962) knew “when and under what circumstances” (p. 15) he needed to consult a health care expert, the parents I interviewed knew when they needed to consult a health care expert. There were two occurrences that happened which prompted a parent to change daily, routinized approaches to the care of their children and enter the health care culture. The first of these occurrences was the emergence of signs of illness in the form of more severe symptoms; the second was a change in knowledge and orientation.

Schutz refers to both signs and symbols in his social phenomenology. In Chapter 3, I gave the example of a red cross as both a sign and a symbol. As a mutually agreed upon sign, it directs us to a hospital or a place that provides health care. As a symbol it conveys transcendent concepts like mercy, neutrality, protection, and humanitarian aid. I also argued that *health care*, *sick*, *well*, *nurse*, and *doctor* are symbols that are part of a greater symbol system that establishes typified meanings for patients and providers

within the health care relationship; but which also may have different meanings for different groups.

In the interviews with participants, it was clear that they had unique understandings of illness as part of a greater health symbol system. It also emerged that symptoms of illness in their children served as both signs and symbols for participants. It is interesting to note that the origins of the words *symbol* and *symptom* are similar. *Symbol* comes from the Greek roots *syn*, which means *together*, and *bole*, which is *a throwing or a casting* (Online Etymology Dictionary, 2011). The word's origins suggest a throwing of two things together in order to compare or associate them. *Symptom* comes from the Greek roots *syn*, which means *together*, and *piptein*, which means *to fall* (Online Etymology Dictionary, 2011). The word origins suggest a falling together of two things that are related, more of a natural association (falling together); whereas symbol suggests an intentional association (throwing together). The point is that the meanings share common origins, and today share similarities in meaning, in that a symbol, in Schutzian terms, is anything that is representative of underlying meaning; and a symptom is representative of an underlying illness.

For participants, symptoms of illness served as both *signs* that suggested to parents the need to seek health care for their children, and *symbols* of illness that represented a whole host of meanings, as discussed earlier in this chapter. As symbols of illness, symptoms for these participants represented meaning beyond a sore throat or wheezing: They represented a threat to health, interference with activities of normal daily life, and a loss of control. But as more concrete signs, they were indicators that parents needed to seek outside expertise from a health care professional.

The second occurrence which prompted a parent to change their daily, routinized approach to the care of their children and seek expert care was a change in the parents' knowledge level and orientation. The word *expert* is pivotal in understanding the second occurrence in Schutzian terms. As described in Chapter 3, Schutz suggested that there are three knowledge orientations with which people approach situations. The first of these is recipe orientation, in which people do things as they have always done them, without asking why. The well-informed orientation, then, is when a person has been proactive in acquiring information as possible and approach a situation with a moderate level of understanding. An expert orientation is that in which a person has highly specialized knowledge in a particular area.

In routinized everyday life, parents, in general, have expert orientation in terms of their own children. They have raised their children and know them best in just about every way. They know their habits and quirks, their likes and dislikes, and every detail about what is normal and not normal for their own children. Most parents also function with recipe orientation in terms of illness prevention in their households as did the participants in this study. The parents in this study also exhibited recipe orientation with minor sick care of children, as in the case of allergies and colds. But when a child's health status, whether it was an emergent situation like an accident, or an escalation of already existent symptoms or emergence of unfamiliar symptoms, then a parent's routine was upset, and recipe orientation was no longer sufficient. While the parent was expert enough in knowledge of her child to recognize that something was wrong, she was operating with recipe orientation in terms of addressing the child's symptoms. Parents described situations in which they recognized the signs that indicated a need to seek care.

Typified understandings of health care, providers, and situations that require care prompted parents to enter encounters with providers.

Adele told of one time when her child's normal sinus problems developed into more serious symptoms: "He always have a problem when he go into the water, 'cause he has bad allergies, sinuses, so... [one time after swimming] he was saying he couldn't breathe, and I took him to the emergency room."

Another parent attributed her child's complexion to what providers had attributed to high bilirubin at birth: "And he was born. And he was fine. Actually he was born with yellow jaundice, and they had to put him under the light. It's so bright and colorful. He's the brightest child I got." But when this child's normally "bright" complexion changed, the parent knew something was wrong, and sought care: "My baby's sick. You can tell he sick because he be pale. [I said], "Dang, you lost color!"

Another parent sought professional care for her daughters because "they constantly were having constipation... they had chronic abdominal pain 'til my one daughter was in tears... and I didn't know if it was a bowel obstruction". Another described,

I don't know what made me notice, but alls I know is my baby wasn't eating like he suppose to. I would give him milk, milk too thick. Water, he was gagging.

Then, you know, soft food, bananas, he wasn't eating that either. So I took him to Dr. L.

One parent described the initiating event:

I came home, and his eye, like, big. So, that's like the only thing that really, really I remember that's pretty much bad. And I was like, well, "Mom, what's

wrong with my baby's eye?" And she was like, "I don't know. It just swelled up." Like, Mike Tyson had been punching him all day long in his eye. So, that's why I took him to the doctor.

Another described symptoms she later found out to be eczema, which prompted her to seek provider advice:

So, he has it [on] one [of] his cheeks, around his arms, under his armpits. I mean, I didn't know what it was at first. It was like big bumps, and then, suddenly, they turned into he was complaining about them burning. And I didn't understand. I was like why is it burning? And then in the genital areas. And he would complain taking a bath. He said that when the water hits it, it would burn. And I didn't understand that 'cause he—I'm bathing him, he's like "Mommy, the water burns." I'm like "Are you sure?" And then I would put like different kind of A and B ointment under there. But then it started looking like—you ever had a burn and look like it's healing over? Look like he was burnt underneath there. I started looking it up. I said, "Okay, what is it?"

Parents with backgrounds in health care sometimes referenced this in relationship to recognizing symptoms that needed professional attention: "One time... I think my baby's fever was one hundred and four... and being that I'm in nursing, I know that fever is not supposed to be that high. I need to get them there as soon as possible."

Other parents described symptoms over time that had not improved:

He was at school, and it was Valentine's Day. And I'm thinking, you know, the teacher calls and said that he was sick, and he had threw up. And I'm thinkin' maybe it was because of the Valentine party... or eating candy and all this or that.

No. It wasn't that. I had to go and pick him up. Pick him up and brought him home. He laid down and went to sleep. He was fine. The next day he got up, [and I said], "You feel like going to school? You alright?" [And he said] "Yes, ma'am. I feel fine." He goes back to school that Thursday. That Friday, he got sick again, throwing up. So, I kept him the Thursday evening when he got out of school he was feeling bad. So, that Friday morning I called the doctor, and he, Dr. H, and he told me to bring him in.

Another described a similar situation:

[I know] when he's not himself, and I feel like I can't handle it. Umm, for example, he was throwing up real bad, and I know they're probably not going to anything but "make sure he had fluids" and whatever. And, so, I would get the Pedialyte and whatever, and until he was so dehydrated—Okay, it's time to go to the doctor 'cause this is really wrong with him; it's not getting better.

Often, it was an emergent event or accident that prompted a parent to seek care: "But what had happened, he was running and playing, and his head hit the edge of the wall, and that's how he busted his head. So I got him to the emergency room."

Another parent had the horrific experience of a child's near drowning.

Fortunately, she and a bystander both knew CPR:

My one-year-old drowned in the pool, and I had to administer CPR on him. I had to administer CPR on him, and he came back through. And I kept yelling "Bring him to me! I know CPR!" 'Cause the longer the water stays in his lungs, the worse his chances get. And together we started CPR. I gave the breaths; she gave the compressions. And every time I gave him a breath you could just hear the

water gurgling in his lungs. And she turned him upside down, and the water started coming out. And he started coughing.

Sometimes parents whose children had chronic illness realized that the symptoms had become too severe to handle at home. One mom described the symptoms of her child, who has Prader-Willi syndrome: “Her lung function was down very low. She could hardly breathe on her own. We were having to turn the oxygen levels up for her.”

Other parents noticed the significance of their children’s failure to meet developmental milestones, and consulted a professional: Honey said, “My daughter is two, and we are feeling that her speech is not where it should be.” Another stated, “He couldn’t do none of the stuff that four-year-old kids was supposed to do.”

Other parents mentioned more subtle behavioral signs that their child needed attention, recognizing “the difference from when he’s faking and when he’s not because, umm, him, it’s easy to see ‘cause he’s such an active child. And when he’s sick, anybody knows... he won’t say anything, and he talks all the time, so it’s easy to see....”

Another described it:

I know he came home from school not feeling well, was in daycare at the time—he wasn’t feeling well. And I knew because he was just wanting to go to sleep, and he wasn’t talking. He didn’t want to play; he just wanted to lay down and go to sleep. And I tried to get him to eat, and he didn’t want to do anything; he just wanted to go to sleep. And, so, I gave him some children’s Tylenol or something, and he went to bed. And I went to check on him later on, and he was shaking really bad, and I got so scared.

It was precisely at this point and with this orientation that a parent entered the we-relationship with her child's provider. I reiterate that these entries into care were characterized by a heralding sign or event that professional advice was needed; and a change in parent knowledge and orientation.

Taken-for-Granted, Routine We-Relationships

It is important to discuss taken-for-granted, routine we-relationships that exist between parents and providers; these are best exemplified by what *usually* occurs in the context of well child care or within the context of sick care when care provided meets parents' routine expectations or typifications. I italicize *usually* in order to emphasize a point that is critical to Schutzian analysis: That transformation and change is not likely to occur unless relationships transcend the typical. Transcendence occurs when typical responses and orientations no longer suffice or when situations themselves move beyond the typical. Parents described many instances of taken-for-granted, routine relationships in health care. Their descriptions reflect encounters that meet routine expectations. Often these occurred in the context of well-child care (like immunizations); or sick child care in which the parent with a well-informed orientation knew what was wrong with a child and entered a relationship simply in order to get a prescription for a particular medication the parent knew would help their child. These encounters were described in perfunctory terms. One parent described it like this:

I call him; I tell him what's wrong, and they call the medicines in. We have that understanding now. When I go in, he sees them. He does this, and, "OK, this, this, this, this. We need to get him back in to check on this."

Another parent described a typical provider response to her child's stomach ache related to stress:

He just said his stomach was hurting, but I knew [it might be stress] 'cause he had already told me. But the doctor was like "He'll get over it." He gave him some Zantacs, but he kind of like talked to him and was kind of like telling him that things happen sometimes. You just have to be strong and everything, kind of like counseled him more. He didn't do anything to Deshon, but he did prescribe some Zantacs, 'cause he said his stomach was hurting.

Benita said:

We'll wait—it's usually not a long wait in that particular office, but—and the nurse will ask, "Are there any questions or concerns?" Or sometimes, sometimes, she'll say, "Well, we're going to give you this shot" or "This is what's going to happen today," which I like when they do that, but sometimes they don't; they just say, "The doctor'll be in." And, umm, soon after—usually I don't have any concerns or sometimes I'll think of it while the doctor's in there—then soon after the doctor comes, and just does his thing [laughing], whatever that is. A little knocking in the... wherever.

I will not dwell on these, I simply describe them for the purpose of providing a point of comparison with we-relationships that are not typical. Atypical we-relationships were the encounters which prompted detailed stories and descriptions. The reader should keep in mind the patient-centric ideal typifications of health care providers that were established in the previous section: Ideal motivation, ideal disposition, ideal communication, and ideal professionalism; as well as the precursory parent relevances

also previously established; and the Schutzian categories of knowledge-based orientation discussed in Chapter 3. I will make reference to these in the context of problematic we-relationships and transformative we-relationships.

Before I go further, it is necessary to comment on the nature of the analysis of problematic and transformative we-relationships that follows. Thus far, the descriptions and interpretations I have provided have been relatively straightforward and easily categorized. But searching for meaning in qualitative inquiry is by nature, messy (Lather, 2010). Efforts to neatly categorize and define phenomena result in superficiality, as opposed to fruitfulness. While the “mess” can be approached in a disciplined manner, there must be an acceptance by both the researcher and the reader that there is no right way to categorize data; and indeed, that rich data defy categorization. Acceptance of this inherent messiness was difficult for me, a lover of well-defined, organized categories. Until this point in my data analysis, I felt confident in having provided a consistent and logical presentation of Schutzian themes and categories for the data that I was analyzing, and in having given relevant examples of each.

But when it came to actually analyzing the specific, one-on-one encounters with their children’s providers that participants had described, the many relevances, knowledge levels, and orientations of the participants and providers defied any neat categorization. It was not possible for me to present a participant’s description as fitting within a neat category, as an exemplar of a particular phenomenon. At first I thought I simply had my categories wrong, and needed to create new ones. Then I realized that the descriptions defied categorization because of the multiple provinces of meaning that were evident in them. And so, to borrow the words of Alvesson (2002), I will “take the side of

the messy,” which means accepting multiple meanings (as opposed to reaching consensus about what the meanings are) and illuminating rich, complex, reality (rather than assigning snippets of data to superficial categories).

Schutz himself noted that we-relationships are characterized by multiple provinces of meaning (Schutz, 1962). From a Schutzian perspective, the greater clarity health care providers achieve by reducing the patient's subjective experience to a set of abstract types (race, gender, temperature, symptoms, standard prescriptive treatments) the more anonymous the patient becomes. The same is true when patients typify providers.

The more individuals (like doctors and nurses) express themselves through pre-constituted typifications, the more they suppress their own unique creativity, and the unique creativity of others, in favor of anonymous roles, types, motivations, relevances and conventions (this level interaction may work for routine health care encounters, as described above, but not when problems arise or unexpected events transpire). That which is being suppressed in the most profound sense is the potential for mutual collaboration which is the foundation of a transformative we-relationship. While the meaning of a mundane (unproblematic) we-relationship can be represented in reflective (past) typifications, the meaning of a symbolic we-relationship must be presented (present), not represented, through immediate and simultaneous participatory experience. This type of relating will be messy, complicated, and beyond simplistic categories.

Individuals in we-relationships have to create ways of communicating across multiple provinces of meaning and relevance in the immediacy of the relational encounter in order for transformation to occur; because a typical solution to a typical problem is not

yet established. Being available to another in the immediacy of a transformative we-relationship requires the participants to render pre-constituted typifications ambiguous in order to open the possibility of creative, collaborative understanding and communication. Ambiguity, uncertainty, even anger or confusion are conditions for the possibility of creative collaboration between individuals across and within multiple provinces of meaning. In transformative we-relationships, expression and interpretation do not fall within typified schema but are created in an ongoing state of spontaneous construction. This construction involves a level of trust in the creative intelligence of the other. Ambiguity and uncertainty are requirements for the manifestation of novelty and new perspective. If one individual is not open to trusting the other as described, then the relationship is likely to fall back into typical patterns. Trust, faith and making oneself available to new insight are critical to the process.

Typification involves a pre-constituted, abstract, monolithic appraisal, while transformation involves an immediate availability to the feelings, thoughts, relevances, and meanings of another. Transformative relationships involve knowledge of people not in their typical roles of nurse, doctor, patient, parent, but as complicated and dynamic individuals with a multiplicity of perspectives, motivations, relevances, agendas, and knowledge.

Since it is only when there is conflict or a challenge to typification that transformation occurs, I decided it appropriate that the participants' encounters could only be presented as they were told, against the backdrop of the Schutzian themes of typification, relevance, orientation, and knowledge previously provided. Rather than force consideration of these encounters into pre-defined, typified categories, I have

simply divided the accounts in to two broad categories for comparison, and these are *problematic we-relationships* and *transformative we-relationships*; so that the reader can construct meaning for himself or herself. Along with each account or after a series of accounts, I highlight what I believe are the multiple provinces of meaning evident in the descriptions; but my meanings are not the only ones that may be gleaned from the stories. There is not necessarily any good way to tease apart the interactions of all possible meanings, and in fact, teasing apart would simply create artificial and superficial isolated categories of phenomena. The meanings cannot be teased apart from one another and still retain richness, depth, and potentiality. What these complex meanings, as I see them, might suggest for providers in practice will be discussed in the final chapter.

Problematic We-Relationships

Problems in we-relationships often occurred when providers failed to exhibit parent-centric ideal role typifications, when orientations of parent and provider were disparate, or when parents perceived that what was relevant to them, as parents, was not of relevance to providers. Sometimes parents perceived that providers appeared to rely only on professional expertise in children's health care encounters. Many parents mentioned the frustration of being told that their child did not fit within an established health care norm. The parents often referenced individual differences among children, and feeling as though their child's individuality was not being acknowledged.

Quinn said,

He doesn't take enough time to look at the child. He kind of look, look, look, and OK, this is what it is. And writes a prescription. Doesn't go into why or what might of happened or even asking me any kind of questions on, well, "When did

you see this start,” or, you know, he’s not in-depth for me. And then not every child has the same thing ‘cause he’s made a comment before “Well, this is going around ‘cause we’ve already had some kids that have come in that have this” or “this is going around.” Just because other children have that, doesn’t mean my child has that. So, don’t just kind of put everybody in a little ball and feel like this is what everyone has ‘cause every child, every person is different. Everybody’s immune system is different. And I don’t care for that.

Another participant said:

And I get frustrated. I’m little. I’m a petite person, so I go to my kids’ [provider], though, and they’re like, “Oh, they’re on the twentieth percentile or they’re....” [But] they’re not going to be big. They’re going to be little. And, you know, they’re, you know, “Got a ways to go. They need to be up here. They’re down here.” [But I know] they’re never going to be there. I tell them, “Those round babies aren’t necessarily healthier. ‘Cause they can’t move. That’s why they’re so round.” And all of my kids are very active. They’re all very healthy. So, that’s been my only gripe about that whole chart thing. And what gives them the right to say what’s average? We’re not going to be average. I’m petite. My husband’s not that tall, you know. And, so, why would they think we’re going to have these humongous children? I toss that out, and I tell [myself], “You’re fine. I mean, you eat good, you play good, you sleep well. I don’t care about the rest of that.”

Evette said:

And so some of the things she would say on the little paper we had to fill out, I would not even answer it, because I felt like you know, if I want my five year old

to climb in the bed with me and go to sleep, then she gonna come in and go to sleep with me. Even though she has her own bed. I mean, I don't see the connection with that, and I don't see how a doctor could tell you, "don't do that", "don't let them sleep with you" and stuff like that. That's the only big problem I had with her. And then I know they had the dietician, you know, what they supposed to eat, and what they supposed to drink, and you know, how many this they had, how many of that they had. You know my little daughter is petite, she's tiny, real little, and she could eat, she could put it away. So when they asked those different things, they ask how many juices they had a day, I don't know. I mean if she wanted five juices, she's not overweight, as a mother I don't feel like she's overweight or that's nothing wrong with her health, she's healthy. I mean, why would you tell everybody the same thing? That's what I'm saying.

Everything don't fit every parent, that's all I was saying. And to me that's what they try to do, put us all together. 'Cause different things how they talk to you and tell you things, and so she was like that, that doctor was, she'd say "don't do this and don't do that, and you giving her too much." But then when she read the little chart, she say she still on target. Height, weight, she's there. And so there's not a one-fit-all child. And you're there to help us if we're having problems or concerns, but not just to impose and say don't do this. And then she had a pamphlet that say something about spanking, like, I have to give you this pamphlet so you know about not spanking your child. "Do punishments and not spankings." And I read through it and I'm like, I don't know what this is right here, but how can you tell? It's not a one-fit-all child.

Another described her problematic encounter with her child's provider like this:

My four-year-old, they claimed he was going to be a large baby, which he came out a little over nine pounds. Which, you know, okay. But his pediatrician, you know, she was an obese lady. And she's asking me our feeding schedule and what was he eating or whatever [and suggesting he was obese]. I'm like, he doesn't need to be [called] obese, and I'm [thinking], "How can you counsel us on obesity when you sat here and look like, 'Oh, I eat at night and go straight to bed,' and you're obese." I mean, and I understand big-boned people, but she was, she was obese. And, I mean, out of her own mouth... she was telling me about not having an obese child, and she was obese. To me, that's kind of like a doctor telling me don't smoke while he's lighting his cigarette in my face. I can't grasp my mind about somebody trying to tell me something when they're not... doing so. Especially when it comes to things like health. And then, it's not like [my baby] went from nine pounds to twenty pounds in two months. It wasn't like that. He was, you know, steady. He wasn't making these huge leaps. And I'm getting a lecture about obesity from you? But she was, like, actually the best doctor in town. I mean [being on Medicaid], it's not like I had a lot of choices.

The previous accounts illuminated parents' perceptions of differing relevances of parents and providers. Parents' primary relevance appeared to be the health status of their children as normal. These were well child visits in which children were being given standard well child care. As discussed in the precursory parent relevances section, the parents in this study were entering what would normally be a highly routinized care situation, in which they were expecting that their children would be pronounced healthy,

as there were no signs of illness obvious to the parents. When providers referred to a highly typified standard of norms in the form of weight and size tables, or provided a standardized plan of care for what are considered common parenting issues; parents perceived that they or their children were being typified by the provider, rather than being acknowledged as individuals with unique characteristics and needs. Providers were perceived as practicing within highly typified parameters, performing in a routine way; with parents believing that standardized tables and measurements seemed more relevant to the provider than were individual circumstances.

The last example in the series, in which the parent reacted to what she perceived as a violation of professional ideal (in the form of an obese provider), also showed that the parent was operating with highly typified provider role expectations. She perceived the provider's obesity to be related to lifestyle, and thought that the provider's lifestyle should be consistent with the advice she gave to patients. In reality, while she may have been correct, the parent knew very little about the provider's health, habits, and lifestyle; but made a judgment based on superficial appearance. This last parent also made reference to her status as an insurance out-group member, having little choice about who provided her care. Mutual typifications and/or perceived out-group status precluded the possibility of transformative we-relationships in these examples.

In some encounters, parents experienced the providers as being insensitive or dismissive, which was indicative of a disparity in parent and provider relevances. In the following example, the provider was perceived to value ease and smoothness of a routine encounter; while the parent's greatest relevance was the comfort of the child and the inclusion of a valued family member. Power was also at issue in the following

encounter, when the provider attempted to dictate whether or not a family member would be allowed to be a part of future encounters. Evette described an encounter in which a provider was intolerant of a family member who had accompanied them to a well-child visit:

[Aliyah's] godmother went with me one time cause she was gonna take her home [after the visit], 'cause she keeps her a lot. So she was there, too, and it was funny, but I don't think the doctor thought it was funny. We went in there and her godmother was in there and I was in there. And Aliyah's godmother [told my daughter], "Honey, you gonna get your shots and they're gonna hurt but Grammy's gonna be right here." And I said to myself, "Oh my God, she's about to get on this doctor's last nerve." So when the doctor came in, she's like "Hi", everything's fine, she's asking her questions, and so then it's time to get the shots. So the godmother was up over the baby, like holding her, and her legs were like hanging out, because they were going to give the shots in the thigh, and [she was saying to Aliyah] "It's okay, it's okay, I'm right here." And the doctor was like, "What in the world?" And the baby of course screaming and crying so hard and so the godmother was crying too and [when it was over, she said], "let's put your clothes on, let's put everything on, okay Evette, we're gonna go, we're gonna go, do you need her for anything else?" And the doctor's looking at her like she crazy.... So of course they left and after they left, the doctor asked "Who is that, her grandmother?" And I said, "No, her godmother." And [she said], "Her Godmother? She does not need to come back!" That's what she said, "She does not need to come back." I'm like "Why?" She just said, "You do not need to

bring her back.” And so I asked if we were done, could I leave and go pay; and she said we were done. But she had a lady in there with her, like an intern, and the intern didn’t say anything. And I noticed too, about that doctor’s staff, she has a high turn-around of people staying with her. You know and it just could be the type of person the doctor is.

Gwen, a participant whose daughter has Prader-Willi syndrome, described an encounter with a provider in which an inability to engage in mutual, well-informed collaboration resulted in an untenable relationship:

[My daughter] was like six years old when she stopped seeing Dr. R in Tallahassee ‘cause [Dr. R] wanted to continue the Genotropin treatment. And I had her do blood work ‘cause there was so many kids dying as a result of the Genotropin side effects with Prader-Willi ‘cause I’m a researcher on stuff I want to know about. And I just wasn’t going to let somebody tell me what’s best for my child and use her as a guinea pig. And I felt at that point, with so much not being known and so much trial and error there, it was a guinea pig-type situation, and I wasn’t going to risk. So, I said, “Okay. You do blood work, and tell me what her hormone levels are and what the dosage is based upon in comparison to her deficiency. And when she did the blood work and stuff, the deficiency was so, so minute to there wasn’t no point in endangering her to take the Genotropin. I said, “Well, there’s no reason for her to take this Genotropin if it’s such a minute difference, and increase the chances of my child dying in her sleep.” And, so, she was like, “Well, I just don’t see if you’re not giving her Gentropin is not going to be good for her.” Her letting me give it to her is not going to be good for her. I

said, “Is there any other way you can treat it.” [But she said], “Well, I can’t continue to treat her if she not going on Gentropin.” I said, “Well, I understand that, but I didn’t think a doctor had the right to do that.” I said, “She just won’t see you anymore.” And that what that happened. So, I had health care providers that I have not agreed with. And that was a referral I just had to stop using her. And I was like, “Fine. I’ll sit here with my child while she’s alive. You go ahead and kill the rest of the little kids, but you won’t kill this one.” And I don’t think the doctor meant to be so brazen. I think she was trying to scare me into complying.

Gwen’s example reflected a disparity in orientation and relevance between parent and provider. Gwen felt herself to be knowledgeable about her child’s needs and condition, and had gone to great effort to gain relevant information about the child’s treatment. Gwen thought that the provider demonstrated inflexibility in modifying a treatment protocol that the provider valued over her daughter’s well-being. To Gwen, it appeared that the provider was relying solely on standard expert knowledge without considering Gwen’s knowledge when designing a treatment plan. Gwen also referred to the provider’s attempt to employ expertise and fear as control tactics.

Another parent described an encounter in terms of conflict:

That time that doctor was trying to say there wasn’t nothing wrong with her and didn’t even really look at her because she was on Medicaid only at the time... but he treated us as though we’re just riffraff. And I’m like I don’t care if I was riffraff—even I wasn’t—but the case is even if I was, this child deserves to be treated just as well you’d treat the next child. I don’t care if it was the president’s

child, you give my child the same treatment because their lives are just as important.... [The provider] was telling me, "Ma'am, I am not going to admit this child in the hospital because she has the sniffles." I said, "Well, you have not x-rayed to find out what's wrong with..." [And he said], "There's no need for me to do x-rays because I am the physician." I said, "Let me tell you something. ... she's running a fever. She's not been herself. I'm very concerned. I don't want my child to go home and die in her sleep. She already has breathing problems. And she's not sounding right. I would be more satisfied if you ran all appropriate adequate tests." He was like, "I don't have to do anything." And I was like, "You don't? Okay." And then I called hospital administration. By the time I finished it had turned into a three-ring circus. She was admitted into the hospital. She ended up having to stay a week and a day. I want to say it wasn't because of race, I think it was more he socially classed us, and you don't social class anyone 'cause that should not matter when it comes to somebody's life. And that really made me upset.

This encounter, as described by the parent, also showed that the parent perceived that her expert knowledge as a parent was being discounted by the provider in favor of the provider's expert knowledge and the parent's out-group status in terms insurance and possibly race. It is clear that this parent perceived an extreme disparity in power, which resulted in her own action to equalize the disparity through other channels of authority.

The previous series of encounters illustrate that conflicting relevances, knowledge levels, and orientations were not likely to result in a transformative we-relationship, and may have resulted in attempts by the involved individuals to exert control over one

another. I believe that attempts to control health care encounters reflected in-group/out-group conflict between parents and providers.

Sometimes parents described encounters as problematic because, as laypeople, they lacked understanding of what was occurring in the encounter. These encounters were often described using terms that indicated fear and distress, and seldom included specific details about individuals.

For example, Renee described her son's emergency:

So, I park in the emergency room thing, and they got the chair out. And took him on in, and I parked. So, I walk in, and I tell you, by the time I walked in from the parking to the emergency, they had already took him in the back, and people were swarming over him. I don't even know what's wrong. I'm just crying. So, [the nurse] asked me questions, [and I said] "I know this sounds crazy, but I don't even know." [It seemed like] they don't know what was going on. You can't ask me, hysterically, what's going on. His heart's beating fast. Something's wrong. And I guess they were trying to ask me his history. And I didn't know... but I just didn't think they knew what they were doing. Because there were so many people over him. And maybe that's how it is. I don't know. I'm not in health care. ... What's wrong—I mean, it was the on-call doctor, nurses, everybody was just over him, and I'm thinking well, okay.

This same participant described the way she experienced the encounter in another facility, after her child was transferred for the same condition:

Now, in [the other facility], they were good. They were coming to tell me what they were doing. [They explained]... He's having some—[SVTs, supraventricular

tachycardia]. So, it was really good. I felt like I knew what was going on. Over there [at the first facility], I don't know anything. You know, I stayed there and watched them. No one came to talk to me about what was going on, maybe because I didn't know the initials parts, so they were like if you don't know, we're not going to tell you. So, I wasn't really happy.

Another described how her fear and lack of knowledge resulted in not even hearing the provider's diagnosis:

And I went to check on him later on, and he was shaking really bad, and I got so scared. And, so, I could not even drive; I was glad my boyfriend at the time was over there. And, so, he had to drive us to the emergency room. Like, I just started shaking myself. I was like, "Oh my God! Oh my God! I don't know what's wrong with him." And, he, his fever was like really high—I forgot what it is—but it was like really high, and I was just, "Something's wrong," you know, "I don't know what... Something is the matter," but I remember we went to the—I was just so scared—went to the ER.... And, umm, so that was weird, but... I was just—I remember being scared, and I don't even really remember what the doctor said.

Another parent was quite afraid during an emergent situation, and there was added distress due to the threat she perceived of possible DFACS involvement:

But what had happened was he was running and playing, and his head hit the edge of the wall, and that's how he busted his head. So, I got him to the emergency room. Well, the first this is, I wasn't working in this field then, but I was working in probation, so I dealt with probation and DFACS. So, the first thing is they're thinking "what has happened to this child?" And I knew that's what they were

thinking. And because, so the nurse came in “When did this happen and how, and be real specific.” And I wanted to say, “No, I did not strike my child.” And they tried to talk to him, they said, “What happened?” And he kept saying “I was playing,” so I think they got enough to understand he was playing. But that was traumatic for me. Talking to him was fine, but when they got ready to staple his head, I lost it. I wasn’t like screaming or hollering, but I was like “Oh, oh, oh.” He was fighting. He was like six people holding him. I wasn’t holding him, but I was standing off to the side, and it was like click, click, click. That was traumatic for me. And after it was over, it was OK. I went home, and the next day—and I still get goose bumps about it. I took pictures of it because I want him to see it later on in life. That was traumatic for me. And I know they can’t—maybe sedate them a little bit or something. I know ‘cause that’s not necessary, but if they could give them something like calm them so you wouldn’t have to do all that, that’d be good. But I know they can’t just medicate them. I understand that. But just to be holding them down, and they’re screaming. It’s like, oh my gosh. Find a little pill or something.

Another parent described her appeal as a first time parent needing professional advice, and the provider’s unwillingness to share professional knowledge:

I remember one time I asked him—and this had to be, let’s see, Christmas maybe, like two or three [years ago]—and, I mean, all kids do this, but I just still, this is my only child, my first child. I felt the need to ask. And it may be a stupid question to him, but look, I don’t know. It’s... This is my first time being a parent, I don’t know. And so I asked him, I said, “He’s not eating vegetables. You

know. He doesn't like vegetables....” And no kid like—I don't even like eating vegetables really, but I was asking him, “You know, is it okay, should I... You know, he takes vitamins, but what, what can I do to make it more appealing to him.” Just... I don't even know if I really needed an answer; I just kind of wanted that support. But he was just... he basically said, “If that's all you feed him that all he's gone eat.” Like, hmm, okay, so, you're saying that... I don't need to feed him anything but vegetables so that he'll eat it. Right! And that's like... okay, never mind, I see what I am dealing with now. And I mean... I understood where he was coming from. Yeah, okay, I understand if I present it to him, he's going to eat it if he gets hungry enough. Yeah, I know that. But that's not what I am looking for, and he didn't kind of take the time, you know, even if, even if I didn't get the answer, I still would have felt better if he had taken the time, “Well, tell me what's going on,” or, “You can try this,” or something. You could have said, “Well, as long as he is taking his vitamins, he'll be okay,” or anything. But, just me wanting that professional opinion, and I did not get it in the way I thought that I should [laughing] disappointed me.

Chantel attributed some of her son's problems to her own lack of knowledge and the provider's lack of intervention and lack of knowledge sharing:

I feel like I got them [answers] too late. I don't think it's really... I'll probably continue to take him on through with the doctors and whatever. I can't stop and go back and start over. I should have went on from the beginning.... I wish I had found out back in the early days so I could take him to *Babies Can't Wait*, these different programs that try to work with him. I used to bring it to Dr. A's

attention, and Dr. A he told, said, oh, he's gonna be alright, he's fine; he gonna do so-and-so. He used to encourage me instead of telling me the truth. And that's what I kinda hate about Dr. A. I wish if he woulda did the tests and all that that he should have done when I was asking him about James, telling him about James, you know, maybe I coulda found out. ... I didn't have nobody really to tell me. Cause my mom couldn't tell me cause she didn't come up in, she didn't know, what to think of my child. Because she couldn't tell me how to say, well, I think something wrong with him. But she did used to tell me something about him ain't right. Dr. N [just recently] told me he act the way he act because he slightly mentally retarded. So when he told me that all I could do was cry cause all I can do is accept it. I hate I had to find out so late like this, you know that it come to this point where I had to find out.

The previous examples highlight the problems associated with differing knowledge levels of parent and providers. These are probably the best illustrations of the overall patient/provider in-group/out-group dynamic, as none of these parents had the expert knowledge that would have helped them understand what was happening with their children. Renee's experiences in two different facilities, in particular, shows how transformation can occur when providers demonstrate parent well-being (in addition to child well-being) as a primary relevance and are willing to share knowledge so that parents without health care backgrounds are better informed. This example demonstrates how, in a health care setting, a shared relevance (the child's well-being) can be transformative if providers communicate even basic information or individual expressions of care or support to parents.

Sometimes parents had problematic we-relationships when they perceived that a provider was violating standards of the profession. Felicia's son had suffered from asthma his whole life. She had a great deal of knowledge about managing his asthma, and had experienced many hospitalizations associated with it. She described a particular hospital encounter:

You know as they come in to give him his medicine, I always see and watch and ask what you give him. This particular time, the nurse came in—they had already gave him medication, so they was going to overdose him. And I was sitting there, and I'm like, "No! No! You've already gave him his medication." It was the worst thing ever. I told them.... The head nurse came in—you know how they do "I'm so sorry; I'm so sorry," trying to make everything right. And I was like, "I'm ready to check out. I'm ready to go home 'cause y'all 'bout to kill my child." Well, I had to actually just raise hell for a moment, okay? Then that's when they sent the head nurse in there 'cause, you know, look, you guys done made a mistake, and now you trying to get me calmed down, but it was on your time, your clock. And I was just one of them parents sitting there, know what Jay go through when he get sick, so I know what you're supposed to be doing and what you're not supposed to be doing. But that's one I will never forget. That right there. That was the worst—and I will never use that hospital again. So, I... nuh-uh. That was the worst experience.

Marilyn described a trip to the ER in which a provider discounted her assertion that her child had had an asthma attack:

I had took Christopher to the hospital. I know he had an asthma attack, but they say he didn't. But Christopher, I took him to the doctor [the next morning], and they had to call EMS for Christopher at the doctor's office. And [when we got back to the ER] I seen the same doctor that sent him home the day before. He looked at me. I said, "Yeah. I'm back." Somebody that don't know their job and don't know what going on and stuff. Get a right diagnosis.

Neva described a particular provider who she believed did not use enough professional knowledge in treating her daughter:

Dr. K, I don't like his bedside manners and look like every time she's gone, she's gotten sicker. And I explained it to him. He's letting you talk, and he's, rather than asking you questions about this, "what about this"—it's more so, "whatever you say, momma, I'm going to do." But that's wrong. I'm not a doctor—I can tell you anything about phonics, okay. And I'm not a doctor, by no means. But I know the questions to ask if your child is struggling. So, as a doctor, I feel like you should be asking me some questions to see what's going on, rather than me just saying, "Oh, she's got a cough." But, you know, "When did this cough start?" or something detailed. 'Cause when I walk back through those doors and I see which direction they're taking me, "Where we going?" "We're going to Dr. K," I said, "No. I'm sorry." And [the nurse] was like "Well, then you're going to have to wait a long time." I said to him, "I don't care if I have to wait until y'all closed, but [my daughter] will not see [Dr. K]." I've gotten to that point now 'cause every time—I know it's been three times—we've gone, and she's gotten sicker afterwards. So, and then after a conversation in the doctor's office one day, I

heard a parent say, “Oh, I love [Dr. K].” And her reason for loving him was because, “Honey, I tell him what I want for my baby. And I know it’s going to knock him out,” you know. And that’s my thing. Oh, I know I don’t want him for sure now. No. I’m saying to myself, “I want my baby to be better, not sleeping.” You know, because he sleeping, I don’t know what’s going on. ‘Cause [Dr. K will] say, “What do you need?” That proved to me what I had said about him ‘cause he’ll say, “What do you think he needs?” That’s why the lady was like “Oh, I love him.” Then another lady [asked me], “Who you waiting on.” I said, “Dr. A.” And they said, “Oh, no. I don’t see nobody but Dr. K, he’ll hear me out. Give me what I need, and I just want [my baby] to go to sleep.” Okay. So, that proved the point to me.

Iris, a CNA, described her recognition of what she perceived to be violation of ideal provider disposition, professionalism, and communication. She also mentioned that she and the provider were members of the same racial in-group:

[When I got to the local hospital, the admitting nurse] was my own race. You know, I don’t know if his job getting to his head or what, but I know how you’re supposed to talk to patients. I know there’s some who just don’t [know how]. The way he talked to me, you know, he ruled everything. I’m concerned about my child. I mean, if I want to ask questions, that’s what you’re here for. I don’t know if [his behavior was] to boast up his rating at the hospital or what. And [now] if he’s there, I won’t let him see my babies. I’ll go somewhere else. I will. Ever since that experience, if he’s there in that window, I will not let him see my babies or me.

Oneida described her knowledge and background in health care as affecting her we-relationship with a child's provider:

I look for somebody who listens, who's thorough, who knows their stuff because being raised by a nurse, [and] going to [CNA] school, some stuff I do know, some stuff I don't know. But you can tell, like her doctor now. Oh, God. Nuh-uh. Well, her old doctor, (we're getting a new one), I asked him, "Well, what are you going to do about it?" [And he said], "I don't know. We'll just watch it." That's not been working out for us. That's why we're here. It's time to do something. "Well, next time she comes next month..." And it's like, no. Come up with a plan that's, you know, if we need the money for, you know, but we got to come up with a plan to do it. Let's not wait and see if it gets worse. No. Don't tell me that. That's not a plan. That's my job; that's what I do. And then it got worse, that's why I'm here. That's why you go, because it got worse.

Latrice, who had CNA training, described her lack of confidence in a local facility and its staff when her child suffered a near-drowning:

And we got to the hospital there, and he was just crying, crying, crying. It seemed like to me that [the local hospital] was just not equipped to handle his situation. Well, when he was at [the local hospital], and they were trying to sustain him, I guess you could say, it was a little frustrating that they could not stabilize him. And it was like they were—I don't know. I don't know. I don't know. If something bad happen to me, do not take me to [the local hospital]. Don't take me to [the local hospital]. It was like they just weren't well-equipped. They didn't have the knowledge, I guess. I mean, they got plenty of equipment. But I guess

they just didn't know what to do in that situation. And they could not get him stable. And it took like five or six hours for them to actually get him stable enough to transport him. And I just think that was a ridiculous amount of time to try to get a baby stabilized from near drowning and to take him to another hospital that could actually help him. That your hospital is not equipped to handle that you've got to send him to another state, you know, let alone another city to be taken care of.

Another parent described feeling upset when making a special trip to specialists resulted in what the parent perceived less-than satisfactory attention and inadequate professional knowledge:

He came in there, and he just, you know—he asked them some questions, and he pushed on their stomach a little bit. “Well, I don't see anything wrong with them.” And that was it. And I looked at him like you serious? And I was like “You're not going to take anymore x-rays or do anything else?” “Well, no, you know, just keep giving them...” Oh, what is the powder stuff? I can't think of what it is, but “Keep giving them that, and hopefully it will probably clean them out.” Ugh, are you serious? I just drove an hour and a half, two hours for this? Really? I said no. He said, “Well, come back and see us in a month.” I'm not coming back. Not for you to do nothing else but ask them a couple of questions, and then you push on their stomach—just, I mean, he did like this. That was it, and he was sending us out the door. Yeah. No, he didn't write us a prescription. He told us to get some prune juice. That's what he told me 'cause I was really upset. I was walking to the car [saying], “like really, prune juice?”

These examples all demonstrate parent's perceptions that a professional ideal has been violated. Parents typified professionals' roles in terms of disposition, motivation, communication, and professionalism; and these experiences all found providers lacking. Their typifications were due in part to their own knowledge of the child's condition or a personal background in health care. This knowledge afforded the parents well-informed orientation. When well-informed parents entered a health care encounter and perceived that inappropriate professional care or advice was being rendered, problems arose. I believe they also sometimes recognized differing relevances at play: Parents perceived that providers had inappropriately prioritized professional time, status, or control over the well-being of the child.

There were other instances in which what parents perceived to be differing relevances seemed to contribute to problematic we-relationships: In some cases, parents perceived that insurance coverage, money, or convenience was more important to the provider than anything else. For example, Diane described:

It was my son, had a real bad asthma attack, and my Medicaid or something didn't come in or we didn't have it at the time, and we didn't have any money. But [the provider] was like, "Come on in the office so I can take care of him, and anytime he need anything, don't hesitate to come back to the office. Whether you have the money or not, just come on back." And my other children had insurance—and I went to go see her about one of my other kids' problem, and they turned me around because my older son's insurance, his bill [from the asthma treatment] wasn't paid, so they won't see none of my children. And I thought that was wrong because I understand if you're not seeing the one for that

bill or try to work something out. But you turned down the whole family. And that right there put a sour taste in my mouth with her. I had got a letter from Dr. L one time after that, and saying, “Sorry you felt like you had to leave and go somewhere else. I wish we could have worked things out,” and stuff like that, but I was like, this you telling me, I’m getting two different feelings here, you know. We could have did this instead of me going somewhere else, but you turned around, turned away my whole entire family, you know, all my kids from that office because of one bill. And at that time my husband—I wasn’t working—but my husband had just lost his job. And my son needed his asthma treatment, he was having a real bad asthma attack. So, that’s the reason why we had gotten behind off of paying a bill. But I thought that was just wrong.

Another said “The first thing they do is ask for my co-pay, which is like, “Really?” Which is, but [laughing]... And, so, that’s disheartening. First thing, they think I’m going to skip out.”

Sometimes parents described interactions with other office staff, like receptionists, which affected the parent’s relationship with the provider:

When Trevion was, I think, five I told them I was going to move him. But I never did...[it was because of] the secretary that be up there. ‘Cause Trevion—he had got sick, but it was late. After four thirty, so, you know, I ain’t going to go to the ER. So, I took him—‘cause they don’t suppose to close until five thirty—and [the secretary] act like she didn’t want to see him. I’m like, “What, y’all not going to see my child ‘cause it’s after four thirty?” You know, we got into a little argument or whatever, but that’s the end. ‘Cause, you know, this a doctor.... So, after that, I

didn't like Ms. L, but she alright now. She alright now. I think we got into it twice, but the second time, she got alright after that. They just been going since they were little babies. Like I say, I was going to change from the incident, but I like the other people and the nurses and stuff over there. I like them. I like they personality. So, they good. They work fast. There ain't nothing I don't like about them. Just that little incident and stuff, but we got it straight. She know who I am. She know. She ain't have that attitude in her voice no more. You know, the kindness is coming out. She know [laughing].

In these examples, providers (who are ideally typified as caring first about patients) were perceived as caring more about a patient's insurance status, the parent's ability to pay, or even convenience, in terms of office hours. It was not likely that a transformative encounter would occur, or a transformative relationship would be built if a parent perceived that a provider did not prioritize a child's well-being.

I continue to posit that the primary issue at play in problematic we-relationships is group membership, with providers being in-group members and patients being out-group members in the health care culture. In summary, problematic we-relationships seemed to occur when this in-group/out-group status was exaggerated by disparities in knowledge between parents and providers; by parent perceptions of differences between their own relevances and provider relevances; by parents feeling as though they or their children were being typified by providers; when parent's ideal role provider expectations/typifications were violated; and when power differentials between patients and providers were exploited.

Transformative We-Relationships

Transformative we-relationships often occurred when providers were able to acknowledge parent expertise in planning treatment or were able to transcend group memberships; and were thus able to engage in a sort of mutual well-informed collaboration.

Parents appreciated when a provider personally recognized the parent or the child as individuals, seeing them as people rather than just as patients. One parent made reference to a provider's good reputation and her subsequent experience with that provider:

I had always heard good things about Dr. A. So, when my daughter was born, I, ever since then, I've had them beside my children. They know me personally, by voice, by name, 'cause I've seen them with all my children.

Another described her daughters' provider in terms of a shared relationship, mutual group membership in the human race that transcended the group division of patient/provider:

He was absolutely in love with Amber and Tenisha when they were babies growing up. And he kept—'cause you know he got twin boys—he kept trying for the longest to get my girls to [be friends with his sons]. He had a birthday party for them when they turned six. He was like “We're having a slumber party for the boys. I want your girls to come.”

Another parent described a dispositional quality that made her choose an unfamiliar provider as her child's pediatrician, when he was the on-call provider who attended the birth: “But when he bundled my little baby up, you know, I never met the

man before, he just took so much care in wrapping him up and how he held him and just how he cared for my son.”

Another described a provider’s willingness to set aside typical office protocol when she had to take off a day from work to bring one child in; this provider was perceived as acknowledging parent relevances in terms of the time, effort, and money implications of a day taken off from work. He also demonstrated care and concern for the parent’s health:

And when he sees [one child], he’s like “Oh! Ms. M!” You know. I had to take off [a day from work], and he’s like “Just spread them all out on the bed.” A lot of them just do it one at the time. “Nope, come on, just get up, okay, what’s wrong with you?” And it is so funny ‘cause he always does it. Then, he’ll take me in, and [he’ll say] “Okay, come on, you next.” [And I say], “Oh, I didn’t come to see you today.”

Another referred to her transformative relationship with her daughter’s surgeon in terms a shared relevance in honoring God:

And he came, and he [said] “Okay, we’re going into surgery right now. Can we pray?” I [said] “Thank you.” You know, my pastor was already there, we had already prayed. We prayed again. But that was just wonderful, to have the surgeon put the surgery in God’s hands. That was it. We were hooked. That was love at first sight.

Neva, who had not background in health care, gave an account that reflected a perception of shared relevances with her provider, and also feelings that her own parental

concerns were of primary relevance to the provider, who then tailored her response to Neva's concern:

I'm comfortable that she want me to ask questions, you know, what about this, and what do you think about this. 'Cause I remember when Jayla was young and with Dr. R, I was afraid—after she got weaned from the bottle, she wouldn't drink whole milk. She wouldn't drink it out of a cup or whatever. So, I just thought she was going to have a deficiency, so that was my thing. I asked the question. My baby never drinks milk. Put strawberry Quik in it, chocolate, none of that works. She just like “nuh-uh.” I was worried about that, and [Dr. R] said, “Let me tell you, she's fine. Does she eat pizza? Does she like cheese or whatever? Let me tell you, she's safe. Doesn't just have to be milk.”

Another described her provider's disposition, communication, and willingness to spend time, which demonstrated to the parent a shared relevance, her child's health and well-being:

“He'll sit there and cross his legs and talk to me and, well, ‘How are you doing? Well it seems like he is doing well.’ And he'll just spend all day and answer any kind of question.”

Another parent referenced her children's provider's disposition and communication:

But he's an open and true and honest doctor. That's what I interpret him to be. 'Cause, like I say, he sit there and talk to you, then he cut the fool with the kids. Ask them boys questions, “Well, you got big feets” or “You're tall. Real tall, you going to play ball?” or whatever. Something like that. And he, you know, just

make the time more comfortable, and not afraid of a doctor because you at a doctor's office.

Oneida described her child's provider in a similar manner:

But the lady came in, that was the first thing I liked 'cause she actually came in and sat down, and she crossed her legs. And she was like "Well, alright, tell my about your little girl." I mean, [my baby] was only a couple weeks old. It was like, oh, okay, cool. I like that. I was new at everything. We made it up as we went. She was really, really cool.

Still another:

He had some kind of staph infection, and it was a follow-up appointment. [The provider] just sat down in there chair. She didn't even blink an eye about—as opposed to standing up "Yeah, uh-huh. Yeah." She sat down. She pulled her thing out and just sat there. Somebody had told me when we got there—this is like the first time we went—"Now, you're probably going to be here awhile because she really listens." And she did.

The previous encounters demonstrate that parents equate a provider's willingness to spend time with a prioritization of the child's well-being... a relevance the parent shares. The descriptions also imply that the parents perceive equity in power: that the provider is willing to spend as much time as the parent requires.

Providers sometimes appealed to parent's expertise and acknowledged that expertise in designing treatment interventions. Honey described a transformative encounter in which her knowledge and relevances were acknowledged and shared by the provider, who then prescribed treatment specific to the needs of that parent and child:

My daughter's two, and we are feeling that her speech is not where it should be. And it was Dr. B's office that recommended the referral to Babies Can't Wait. And she just actually had her evaluation today. You know, she's going to get the therapy that she needs. And I realize it wasn't something they had to do. But, you know, they asked me if I had any concerns when she gets her health check. I voiced them, and she said, "Okay. We'll take care of it." Yeah. In addition, they will stay in contact with doctor B's office so there's going to be that communication amongst all parties to make sure she gets where she needs to be. It wasn't all this, "Well, let's wait and see what..." It was, it was not that at all. I mean, like I said, right after her two-year birthday, she had her appointment. I said it, and within a week, I got my referral.

Honey went on to describe that the therapists would perform all treatments and evaluations in her home, elated that she would not have to come up with gas money or child care for the other children for those appointments, and easing the burden of getting appropriate care for her child; and showing how the care rendered showed attention to issues of relevance to that parent.

Another parent described a situation in which her child's provider deferred to her parental expertise, the acknowledgement of parent concern resulting in the diagnosis of a potentially life-threatening condition. I believe the parent's description of this encounter exemplifies perceived equity and balance of power:

She was like, well, she listened to his chest, she said that he's sounding fine. His airway not obstructed; it sounds fine. I said, "Something's wrong 'cause my baby keep throwing up." She was like, well, send him home, and—take him home—

and if it continues bring him back. I was like, “I’m still not satisfied with that,” ‘cause I said, “I gave him milk. He’s not drinking his milk. He’s not eating his banana—the baby food bananas, and he’s not drinking water.” I said, “Something is wrong.” She was like, “If you—if it’s just to ease your pain, we’ll send you to outpatient, and get him checked.” And just as sure, he had a penny that was sort of bent that was lodged in his throat, and it was starting to corrode. Right there, in his throat.

Gwen described a transformative relationship with her child’s provider in which the provider’s motivation, disposition, communication, and professionalism and the parent’s well-informed orientation were all factors in the establishment of a mutually respectful, collaborative relationship, when the outcome could have been anything other than transformative:

Of course, Dr. G, which is her primary pediatrician—been all her life, diagnosed her and everything. He’s my foundation with everything. You can never understand what he’s saying, but we, I guess, have a mutual understanding, but he’s good. And... it goes deeper than language. It’s just this bond. I know that he knows what he’s doing. And with—Dr. G is referred to Uncle G by [my daughter]. That’s just how close we are [laughing].... He’s thorough. He’s thorough, and he listens. And his main priority is the child’s best interest, more or less what the parent feels, because what made me respect and really like him as a doctor—and this may sound crazy to most people— is when she was three months old, she developed a respiratory virus from the daycare center, and they have to put her in the hospital. And did x-rays and stuff. And all they were doing

all x-rays and stuff and found that she had cracked ribs. Three cracked ribs on each side. And, so, he called DFACS [Department of Family and Children's Services] in 'cause he was really concerned about how does this baby have cracked ribs. And I couldn't take her home until the investigation was finished. And found out that it happened during birth 'cause she popped out of me when I was only dilated six centimeters... she got squeezed. Almost got squeezed death [laughing]. And so, you know, he [said], "Well, mom, I just want to make sure the baby fine and nothing wrong." [And I said to him], "No, Dr. G, you know what, in all due respect, I can respect a doctor more that's more concerned about the best interest of the child than a dollar from the parent." Because that's what I want, a doctor that cares about my child, so that what really built my rapport with him that I know I can trust him. He explained. And, and I think that was very admirable of him to do that, and he had the upmost [sic] respect for me, and I had the upmost [sic] respect for him, and we've just been buddies ever since. We may not understand everything, but we can nod our heads and smile [laughing].

Not only did this provider meet parent role expectations, he demonstrated that he shared the parent's primary relevance for the child's well-being. The parent acknowledged what she knew to be a professional relevance for the provider. The situation, in the absence of transformative properties, could have resulted in a power differential, but did not; because of transcendence on the parts of both the provider and the parent. Her description of their relationship demonstrated shared group membership in the human community, as opposed to an in-group/out-group dynamic. It is a stark

contrast to the earlier description of an encounter that resulted in an untenable relationship, when a parent refused Genotropin therapy.

Another parent described:

One really good experience I had—the all knowing, omnipotent [sic], brainiac, think-I-know-it-all parent—took Jada to the ER and told them that I think her appendix is rupturing ‘cause she was just in chronic pain. And they did all the x-rays. They didn’t just take my word for it. They were so genuinely concerned about the child that they did all their part. And come to find out, she has pneumonia, and it was a deadly form of pneumonia, but it was down in here... it was lungs, but she was feeling it down here. Because they were willing to go above and beyond and look and see what is wrong with this child. We want to make sure we get it right. We’re going to make sure we treat her correctly. We don’t want to assume, and the mom is genuinely concerned, and she want this child to be okay, but she’s not a doctor, and we not going to let her kill the child she going to love to death. Like, “Look! My child is having an appendix rupture at this time. You all need to hurry up and find out what’s going on, and get her in surgery. Do whatever you need to do. Get her fixed!” And they were like, “Calm down, Ms. W. We’re going to go ahead and start taking x-rays.” And they went to work immediately, doing blood work and x-rays and all that. And sonograms. They did sonograms, too. Found out that child had pneumonia. But I was relieved to know that they did all that, and it happened within an hour—all the tests—I mean, it was moving so fast. At that time we were still on Cadillac insurance. Check for a hangnail [laughing]! But it was so hilarious because as much as I

thought I was right, that it was appendicitis... but it was something just as deadly. It made me realize just go in and tell what the symptoms are and shut-up [laughing]. It was awful, but very humbling for me. Just very unusual: I'm, I'm actually humbled [laughing].

The previous encounter reflects transcendences on the parts of both the providers and the parent. The parent described feeling that the providers acknowledged and accommodated her fear and lack of knowledge with grace; and the parent was actively reflective about her own actions and behavior during the incident. It is, however, interesting to note that the parent perceived that the positive encounter was at least partially due to her "Cadillac" insurance.

Another parent told of choosing her child's provider, and the transformative relationship that was created:

I never heard anything bad about Dr. G. And I think I had a chance to go and actually talk to him before he ever saw my baby—oh, I know what it was; I talked to my midwife, and I told her the ones I had come down to, and she recommended Dr. G. And I had a chance to talk to him, and once we had a chance to talk, and I really felt his—he was real personable, you know, to me. He showed he really cared. And that was good for me, you know, to show that you were really concerned about especially when he found out about my health care background. So, he was really concerned and all those types of things. That just kind of leaned me towards him. I just like the way he broke things down, explained to me things he would do and all that type of stuff. So, I just felt like he really genuinely concerned, especially when it come to my child. You know, tell me what you're

doing, why you're doing it, how you're doing it, and all those type of things, and that's something that Dr.G does, for me, he does 'cause he knows I'm going to ask him. He talk fast. And we probably got along well with that 'cause I talk fast too. Especially if I am upset or excited, I'm just rambling off. We probably just going back and forth, him and I both, and both of us knew what we were saying. And I love him, and I love him dearly. He's really good, good bedside manner. He treats me and my son very well, but he knows if my insurance doesn't pay for it, I'm not getting it. So, he prescribes things he know that I can get.

When Quinn had reached a point of frustration in a provider in one practice, she asked to switch providers:

The next time I took them in there—took my children in there—I said, “Well, can I please see somebody else?” And they gave me Dr. S. First thing he said is, “How many times have you been up here?” He say, “We going to get some x-rays on them to see what's in their system.” He put that out there. And I said, “Oh my goodness. Thank you so much. You know, at least you were trying to do something else 'cause you've seen we've been up here six, seven times.” And then we did the x-rays, and he said he doesn't see anything, but he wants them to go to a specialist. So, he sent us to [large regional facility] to a gastrointestinal specialist. And, you know, it's just like—I appreciated that so much that he took the extra necessary steps instead of just giving us another medication or something else. I mean, it's awful that you have to give your child an enema. And my daughter, just looking at her face when she's laying the bed, and she's like “Mommy, how am I supposed to be laying here?” And I'm just like “Just a few

more minutes,” you know. And you know something? I don’t know if he gave me anything for—I think he did give me one more prescription, but he was just telling me “Well, what is that you guys been eating?” ‘Cause I told him it didn’t happen until we moved down here. And he was telling me “Well, that could be a factor. You changed environment, changing your diet. That could be what definitely you guys been eating.” And I told him, and he said just give them the medicine, and cut-off all that stuff. And see how that works with their system. If something’s actually in there, then it will still be there. And it was the environment. We started eating differently, and that’s how it started packing in there and hurting them. I haven’t had any more issues. But it was taking my children to him that made a big difference.

The previous accounts are examples of encounters in which parents felt that there were shared relevances with providers and that providers prioritized the concerns of the parent.

In some situations, providers shared their knowledge with parents, transforming the relationship. When the provider both acknowledged a parents’ ability and shared with the parent their expert knowledge, the parent became well-informed. These types of encounters seemed to minimize in-group/out-group status differences, rather than exaggerate them, and demonstrated a sort of professional power sharing through knowledge sharing.

Janice described this:

Because with [my daughter] I learned for six weeks straight, one day out of the week, she always went into, I mean, she was running a temperature. I mean, head

to toe, she was red as she want to be, and her eyes'd go back in the back of her head. I mean, really some scary times. And I was, like—Dr. A was her doctor at that time. [I asked], “Is there anything you can give me, or where I can stop it before it starts, or catch it, or do something?” So, that’s where the training and all started, and then the helping on using the machines. Stuff like that.

Another participant described the transformative power of providers sharing expert knowledge:

It’s because they made sure you was aware of what was going on at each and—every time you went there, they would tell you the procedure. And, then, if they couldn’t explain or bring it down to your terminology where you understand, then they had videos. They got a library there. They make sure that they give you information concerning that. And if you got any questions, you may have a question later on and can’t remember, they want you to write it down. I mean, it’s just openhearted and open—I mean, just honest.

When providers were perceived as prioritizing the patient and family over issues of money, the relationship was transformative. Providers were perceived as transcending typification of parents based on insurance status.

And for some reason, [the insurance provider] didn’t get the paperwork out to me, and all my stuff got cancelled with their Medicaid. I mean, but [the nurse practitioner] still see my child. I just, whenever I got it back on, I had to take my card back up there to them.

Likewise, when a provider took pains to ease the burden of financial cares, even in small ways, participants were appreciative that providers were attuned to their

relevances. Quinn described an ER provider who was sensitive to the price of prescriptions when her child was seen in the ER.

The ER doctor, he said, “Well,” he was looking at the prescription, “well, this is not on the four dollar. Let me write you something else.” And then he was like “Amoxicillin, you can get from Publix.” I said, “Yeah, I know about that.” He was actually able to go down the list and whatever he’s getting me, alter it where I’m still getting the same thing, but I won’t have to pay so much. Makes a very big difference. Very big difference.

Marilyn mentioned this, too:

Well, sometime Dr. G will, ‘cause he know we’re on Peach Care, we’ll have to pay more money or whatever. He’ll try to give me the generic brand or whatever, so I don’t have to pay that much money for it.

Neva described an experience with a nurse and a receptionist:

Seven hundred dollars. That’s what they said I had to pay up front. I was like “Well, I guess somebody’s going to have to die because I don’t have seven hundred dollars to give y’all right now.” That’s what I told—the nurse said, “Wait! Wait!” The receptionist said, “No. At least we can set you up on a payment plan.” She said, “Can you pay a hundred dollars when you come?” I said, “Oh, I can do that.” And they’ll set you up on a payment plan, and they did. They were really nice and set my payment plan for fifty dollars a month.

Just as some problematic relationships resulted from problems with staff other than direct care providers, sometimes parents described a transformative atmosphere of an entire office or staff:

I think it's the atmosphere. They're very respectful. They come in, they don't come like they're trying to, like they know everything or they don't come in like they got this big chip. Make you feel at home, for one. And they ask you the problem is, you know, ask you questions as well as asking the kids, you know, so they can open up. My kids have no problem with opening up to them. And then the RNs, the nurse that gives the shots, they real sweet. So, I think it's the atmosphere and the type of staff they have, so... They care.

Sometimes providers and their office staff fulfilled parents' role expectations by their ability and willingness to facilitate quick and easy access to other types of care.

One participant described:

They are wonderful. They are handled extremely well. They are so on top of things that I can just call Dr. G's office—anything going on with her, they'll be like, if I need something, call in, and I'll call in, or if something's going on where she need to see the doctor immediately, I can just take her to Dr. G's office. And he'll see her right away, and if he thinks she needs to go to [large regional facility], he'll call and get her an appointment. I can take her up there right away. If he sees the need to be put her in the hospital, he does it right away. It's never any hesitating or hiccupping on their end. They're very on top of it with her.

This same participant described the staff at a large regional medical facility as advocates, particularly in terms of insurance status:

And, then, the people at [large regional facility]—the children's medical hospital—they're just really adamant about advocating for everything she needs. There's never a problem when she needs something. Whenever Peach State

denies her medicine saying prior approval, they'll send it right in and get it, so I don't have a problem with that.

Another parent described a transformative relationship on an individual and an institutional level. This account demonstrates the transformative possibilities in health care relationships at the institutional level. This woman's child was quite ill, and eventually died from Acute Lymphocytic Leukemia. This is her description of the staff and large facility several hours from here where he received treatment, and how the providers were able to assuage her feeling of guilt, even in a terrifying situation:

And when they flew up to Atlanta, they, I mean, all the doctors and nurses, once they got him in there, they just swarmed in on him. Talking about several different people asking me what was the sign and symptoms, what had happened. And I'm talking from one doctor to the other doctor, I mean, constantly. And here he is, other doctors just working on him 'cause they had to have Red Cross there where they filtered his blood out. I actually seen where they did all the needles and tubes and everything. And then have his blood running out, filtering, and then it runs back into him and left it up all night long. It was red, and then the next morning it was snow white, you know. It's a story to tell. It's something I never went through and never would possibly thought I had to go through. Then that's when [I asked], "Well, what could I have done? Why wasn't it a symptom that"—I mean, the guilt in other words. Why couldn't it be seen sooner? Why couldn't something show up sooner? But it was just out of our hands, and then the doctor took forever to try to convince me "Well you did everything you supposed—but it's just things that happen. We don't know why it happen."

She went on to describe the months of treatment that followed, made easier by the attention given to the family's relevant needs:

I mean, they did everything they could do for you as far as giving you phone cards to call back at home to check on the other kids and the family members back at home. They roll out the red carpet for us, making sure you was well taken care of, you was fed. They gave you a little allotment card so you can go and get groceries, or the hospital had food, food bank. Other people had—companies had gave to them to give—they had like a kitchen built on to the hospital for just the cancer patient and everything. I mean, it was like home away from home, really. It was just really nice how they really roll out the red carpet and made me feel—made you feel more at ease. And, like, if you didn't have your bills—you was worried about your bills 'cause you had to be there, too, so they had companies that donated money for them to pay your bills at home so all that could still be going the same while you trying to take care of him.

This same parent described how the transformative relationship continues, even now:

And, you know, right today, every Christmas and ever time his birthday come around, July the thirteenth, I get a card from them. Every Christmas. "We miss Jeffrey because he was so outgoing and brave young man, you know, with the chemo and radiation and stuff that he went through."

In summary, transformative we-relationships seemed to flourish when providers met or exceeded parents' ideal role expectations; when providers transcended group membership status; when they acknowledged parent expertise; when they demonstrated shared relevances with parents; when they prioritized parent relevances; and when they

shared their professional knowledge with parents. These dynamics resulted in transformative collaboration in the context of balanced power.

Summary

Parents were experts about their children, and had varying levels of knowledge that allowed them to perform routine sick care for their children. However, there was usually an initiating event which served as both a sign that they needed to seek professional health care advice, and a symbol of the many meanings associated with illness. When specific health care encounters were described, they were described in terms of routine, taken-for-granted we relationships, problematic we-relationships, or transformative we-relationships. Each of these types of we-relationships was characterized by parents in terms of how patient-centric provider role expectations, relevances, group memberships, and knowledge affected the relationship. These characterizations and the findings of this study have implications for health care practice and research. The next chapter describes these implications, and the associated recommendations.

CHAPTER 7: IMPLICATIONS AND RECOMMENDATIONS

The stated aim and purpose of this study was to gain understanding of the personal, familial, and sociocultural forces that shape African American parents' encounters with health care providers and the health care system; with the supposition that greater understanding of African American parents' experiences may facilitate the creation of culturally sensitive approaches and interventions that health care providers and institutions can implement in relationships with parents of African American pediatric patients. Better understanding and culturally sensitive approaches and interventions create the potential to measurably improve health outcomes for African American children. In order to address this stated aim and purpose, the study was centered around four questions, posed in the following order.

- How do African American parents experience their children's health care encounters?
- What factors influence their experiences?
- What are the implications of these experiences on the relationship between provider and patient?
- Does socioeconomic status affect the experiences of African American parents in their children's health care encounters?

This concluding chapter provides consideration of the analysis and findings of the previous chapter in the context of these research questions. It includes an interpretation of the cultural and social implications of the findings (a reflection of critical ethnographic

method); and suggestions for practical applications related to these findings. This chapter also addresses whether or not the findings related to these questions fill any of the stated gaps in research, and includes recommendations for future research with consideration of some of the other theoretical concepts that informed the study. For better flow and consistency with the Schutzian analysis, to reflect the new understanding gained through inquiry, and to draw conclusions in a logical format, the original order of the questions was altered.

Factors that Influenced African American Parents' Experience of their Children's Health Care Encounters

Parents' experiences of their children's health care encounters began long before specific encounters took place. There were precursory relevances that influenced a parent's interaction with a health care provider. These relevances began with a parent's general understanding of and beliefs about illness and wellness, their typifications about health care providers, and their in-group/out-group status.

Health and illness were part of a symbol system that participants used to establish daily relevances. For participants in this study, health was equated with normal daily life and characterized by an ability to engage in activities like working or going to school. Even minor symptoms were of little concern as long as they did not interfere with daily life. Only when symptoms were of a nature or severity that they interfered with daily living did a person consider them significant illness. Parents often mentioned the financial implications associated with illness such as missed days of work, or a smaller paycheck, or potential loss of a job.

Parents had patient-centric understandings and expectations of health care providers. Their statements, beliefs, and understandings about health care providers as a group and about their own, family members', and acquaintances' personal interactions with them were of precursory relevance to their children's health care encounters, in that they established the typified understanding that existed even before the encounter occurred. Participants in this study were clear about how health care providers ought to be in terms of motivation, disposition, communication, and professionalism. Personal experiences with providers were often described in terms of whether or not these ideals were fulfilled.

Finally, in-group/out-group membership in a variety of groups affected participants' perceptions of encounters with health care professionals. These in-group/out-group memberships were based on race/ethnicity, professional background in health care, and insurance status. Race was sometimes a factor in parents' descriptions of encounters. This varied from feeling typified by White providers based on race to perceiving poorer treatment by providers of their own ethnicity. Race/ethnicity in-group/out-group membership was less a factor than were other group memberships

In-group/out-group membership as health care professionals, and the related disparities in professional knowledge were often at the root of encounters that parents described as problematic. Parents with backgrounds in health care were members of an in-group who had special professional knowledge that enabled them to understand what was occurring in health care encounters. Sometimes they recognized problems because of their knowledge; and sometimes their knowledge contributed to transformational relationships with providers. Those without a background in health care described

feeling fear and distress when they did not understand what was happening, and when providers failed to share knowledge about what was happening.

Insurance in-group/out-group status as the most influential group membership factor that affected how parents experienced their children's health care encounters is discussed in greater detail in a subsequent section, which addresses the research question, "Does socioeconomic status affect the experiences of African American parents in their children's health care encounters?"

Entry into health care represented a change in domains of relevance for a parent. The nature of relevances is that they are dynamic, always shifting. Day-to-day recipe orientation did not require that most parents think about health or health care for their children. When a child showed symptoms of illness, a parent's domains of relevance and their personal orientation shifted. In particular, when a child's symptoms became severe enough that the parent no longer felt confident in providing routine illness care, the child's illness and all the meanings associated with it became the parent's primary domain of relevance, and the parent entered into a health care relationship in order to seek professional expertise. There were precursory parental relevances that influenced African American parents' relationships with their children's providers. In this study, those relevances were most often related to a parent's general understanding of and beliefs about illness and wellness, their typifications about health care providers, and their in-group/out-group status.

This understanding of what is relevant to African American parents, especially as those relevances impact relational encounters with providers represents one small step toward filling the gap identified by Copeland (2005) in regards to personal and

nonstructural barriers to care; and to that gap referenced by Cooper et al. (2005), in terms of new knowledge about “less visible” demographic characteristics. This study provides a deeper, richer understanding of precursory factors that influence relationships between African American patients and their providers. It also addresses gaps mentioned by Fongwa (2001) in regards to providers’ lack of familiarity with issues that are relevant in the lives of African Americans. Later in this chapter, recommendations specific to patient relevances in clinical practice and recommendations for potential future inquiry are made.

How African American Parents Experienced their Children’s Health Care Encounters

African American parents in this study experienced encounters with their children’s providers in three ways: As taken-for-granted, routine we-relationships; as problematic we-relationships; and as transformative we-relationships. Taken-for-granted, routine we-relationships that existed between parents and providers were best exemplified by what *usually* occurred in the context of well child care or within the context of sick care when care provided meets parents’ routine expectations or typifications.

Problematic we-relationships often occurred when providers failed to exhibit parent-centric ideal role typifications, when orientations of parent and provider were disparate, or when parents perceived that what was relevant to them, as parents, was not of relevance to providers. Many parents described encounters in which they perceived that they or their children were being typified by the provider, rather than being acknowledged as individuals with unique characteristics and needs. Others felt as though

their own knowledge of their child was dismissed in favor of a standard treatment protocol. Others described encounters in which a lack of personal professional knowledge resulted in fear and anxiety. Parents with health care knowledge had problematic we-relationships with providers when they perceived that the providers were violating professional ideals. Problematic we-relationships seemed to occur when in-group/out-group status was exaggerated by disparities in knowledge between parents and providers; by parent perceptions of differences between their own relevances and provider relevances; by parents feeling as though they or their children were being typified by providers; when parent's patient-centric ideal provider role typifications and expectations were violated; and when power differentials between patients and providers were exploited. In these problematic we-relationships, parents often reported that their child's needs were not met.

Transformative we-relationships often occurred when providers were perceived as acknowledging parent expertise in planning treatment or were able to transcend group memberships; and were thus able to engage in a sort of mutual well-informed collaboration.

Parents reported transformative situations in which they felt that their individuality was honored; when their own expert knowledge of their child was honored by the provider; when providers shared relevances or acknowledged parent relevances; when providers were perceived as transcending group memberships; and when providers shared professional knowledge. Providers' success in meeting or exceeding patient-centric ideal provider role typifications and expectations also contributed to parents' perceptions of relationships as transformative. All of these situations and conditions

contributed to transformative collaboration between parent and provider in which the relationship was reflective of human equity and power balance.

This study resulted in new knowledge and unique understanding about how African American parents experienced their children's health care encounters. Chapter 1 highlighted some gaps in the literature cited by Cooper (2005) and Johnson, et al. (2006). Cooper recommended the use of "relationship-centered" (p. 521) frameworks for developing new knowledge about health disparities. Johnson, et al. (2004) identified a gap in the literature in regards to patients' perceptions of cultural competence, and recommended further investigation into mechanisms through which either cultural competence or experiences of bias affect health and health care that incorporate the patient perspective. Schutz's social phenomenology provided the relationship-centered framework through which new understanding was gained about African American's perceptions of health care encounters, from the perspective of the parent. The importance of relationship-centered interventions is in their potential to improve children's health and reduce health disparities. This study produced new insight into relational dynamics that exist between African American parents and their children's providers. While these findings cannot be generalized, they can inform clinicians in similar settings and with similar clients. This new understanding resulted in concrete recommendations for clinical practice, which are detailed later in this chapter, in the section entitled "What are the implications of these experiences on the relationship between provider and patient?"

How Socioeconomic Status Affected the Experiences of African American Parents in their Children's Health Care Encounters

When this study was conceptualized, a review of the literature indicated that there remained a gap in terms of understanding the relationship between social class and children's health indicators. This gap was the primary reason that class or income was included as part of this study. As described earlier, income was used as a proxy for social class.

The discussion of critical theory in Chapter 3 highlighted the implications of marketized health care, particularly in terms of how difficult it is to determine whether race or social class is at the root of health disparity. The market approach to health care has created competition in the industry to gear service to the most affluent and most healthy. Those who are unable to afford insurance and who suffer the greatest health disparities are not considered to be desirable consumers. A culture of individualism has created a health care environment that blames the individual for his or her health status and inability to pay for health care. This culture of individualism is also one intersecting factor that exacerbates health disparities.

Chapter 3 also emphasized the broader race- and class-related societal factors that affect the health of African Americans and serve to contribute to health disparities, beyond the immediate causes/evidence of racism and classism that are obviously related to health care provision and access. These included geographical segregation of neighborhoods by race and class; community violence and neighborhood safety; proximity of grocery stores; community design and planning; disability and welfare policy; employment and hiring practices; and educational systems. One theoretical

concept that described the way these race- and class-related factors work together to create even deeper inequity than any one factor alone was intersectionality.

Intersectionality was described and defined as a subconstruct of critical theory that frames the consideration of inequality as the result of complex interactions between categories of difference, such as race, class, gender, and sexuality (Kelly, 2009); and as “the oppression that arises out of the combination of various forms of discrimination, which together produce something unique and distinct from any one form of discrimination standing alone” (Reynoso, 2004, p. 64). The data in this study were replete with evidence of intersectionality. Participants’ descriptions provided evidence that intersectional factors like race, gender, and heredity; and social determinants of health such as geographic location, income, and education were influential to precursory parental relevances and also in parents’ decisions to initiate encounters with health care providers.

Alfred Schutz (1962) placed daily social interaction within a context of “biographically determined situations” in which people function based on what is relevant to them (p. 9). I described precursory parental relevances as components of parents’ biographically determined situations. Intersecting factors were apparent in parents’ beliefs about illness and wellness, their typifications about health care providers, and their in-group/out-group status.

As described in the data analysis section, a common theme in parents’ beliefs about illness and wellness and in their decisions to initiate health care encounters was that an absence of symptoms was indicative of absence of illness, and that wellness was defined mainly by an ability to go about normal daily activities. Participants described

accessing care only in situations of severe illness or emergency. For many of the participants in this study, these beliefs about illness and wellness were reflective of family histories that included culture–related factors like religious belief and dietary choices; gender-related factors like living in a single-parent home; socioeconomic factors like limited money to pay for care, limited access to care, limited health benefits, a necessity to be present at work; ethnicity-related factors like genetics; and even simple access-related factors like transportation and proximity of care. These same intersecting factors were evident in the manner that parental relevances shifted when children became sick.

Considering each of these factors independently of the others results in a superficial picture of parents' beliefs about illness and wellness, and the subsequent understanding of precursory parental relevances. It is in concert that their significance is apparent. The picture becomes even more complex when beliefs about illness and wellness within Western health care culture are added as further intersectional factors.

Likewise, intersectionality was at play in parents' typifications of health care providers. Members of American society share a generalized understanding of highly typified titles like those of doctor and nurse and the role expectations and characteristics associated with them. But for participants in this study, intersecting factors were likely to result in greater typifications of providers and a greater divide between the participant and the health care provider in-group. For example, factors such as the disparity in minority representation in health care professions created the likelihood that there would be educational and cultural differences between parents and providers. Parents also perceived their own relevances to be different from those of providers. Providers often

were perceived as being financially motivated, rather than motivated by concern, a finding that reflects the socioeconomic gap that exists between low income patients and providers. Having a health care background was a mitigating factor in parents' typification of providers; a finding that highlights education as an intersecting factor in precursory parental relevances. Perhaps the most important consideration of intersectionality evident in parents' typifications of providers was in parents' repeated references to the transformative potential of ideal practice, when through ideal motivation, communication, disposition, and professionalism, a provider was able to step into patient's shoes and see the work from the patient's perspective. This finding has enormous implications for incorporating understandings of intersectionality into professional practice and health professions education, and will be discussed in the *Recommendations for Health Professions Education* section.

It was, however, the use of intersectionality as a framework for considering group membership status that generated a unique understanding of insurance status, and that best summarizes the dynamics of insurance in-group/out-group membership. As the interviews ensued, an interesting and unexpected phenomenon came to light, one that was not anticipated, and perhaps the most significant finding of this study: That in the context of their children's health care encounters (and indeed in all of their health care encounters) and relationships with providers, insurance status appeared to eclipse many relational factors that existed, and became a sort of categorical substitute for either class or income.

While insurance was anticipated to be an important factor, other factors (particularly race, educational level and income) were expected to be more important in

specific encounters. These are often cited in health literature as intersecting factors in health disparities (Jackson & Williams, 2006). While the intent of interviewing was to discuss details of specific encounters, every participant, without exception, spoke about insurance status throughout the interviews; often responding to questions designed to elicit responses about their children's health with comments about their insurance status. It became evident that consideration of this finding in my analysis and discussion would be very important.

For participants in this study, simply having health insurance or not having health insurance was not the only problem; instead, it became clear that all participants perceived themselves to be part of a sort of insurance out-group, and *having it or not having it* was just one facet of being part of that out-group. Participants discussed insurance more than any other single topic during interviews. Insurance status was characterized by participants as being complex, expensive, affecting access and choice in health care, and resulting in unequal treatment based on coverage. Intersectionality is a nebulous, complex phenomenon. Many of the accounts in the data analysis section reflect intersectionality at work. But perhaps the use of a final poignant example from a participant's life experience is the best way to summarize how intersectionality creates insurance out-group membership, which represents a precursory relevance that influences patients' we-relationships with providers in preventing basic access to relationships. In other words, transformative relationships between patients and providers cannot occur if patients cannot access care. Hear the story of Janice's sister, Nelda:

Alphonse's auntee, with her stomach being so big, everybody thinks she's pregnant. But she has a tumor. I have try to find out how I can get her help if you

done been seen by doctors and all. And due to the fact that it not cancer, then she cannot get help or get a doctor to do surgery to remove it. She used to work, but it get bigger and heavier where it up [in her way], she can't [move around as well]. And they don't want to do nothing for her because she don't have insurance, and she can't go back to her job because they say they want her to get that taken care of before she come back. And she's, like, out now, and just sitting. And I went through the social security, and they wouldn't do anything. She's fifty-six. The only thing she want to do is to have the surgery. And then once she has the surgery, she wants to go back to work and be working for herself to get her own paycheck. It ain't like she wants to be on disability and don't want to work no more and all. And they don't want to do nothing for her. They claiming, okay, when you talking to social security, and then she done worked and got social security in. Okay, now, they saying, well, what is Medicaid going to do? Medicaid said it's 'cause you don't have a child in the household, or she's not pregnant, they can't do anything. So, who you to go to? You're going to sit there and wait 'til this tumor get so big and burst her stomach wide open or before it become cancerous. Then, okay, we'll do something? Now, that's the part that is really sickening to me. Even if the doctors could do it and have some kind of little thing where, this a tax write off. You're putting something back into the community. Because God knows, it ain't like they charge one person a arm, leg, and the foots, toes, they ears and all. And like I say, there is a God. There is a God. And He gone make sure she goes through with that from somebody. Somebody going to have the heart to do it. And I told her just hang on in there.

That's all you can do right now. But if I even had two dollars left in my little check, I need to use that for the kids. Where justice?

Janice's sister, Nelda, is an African American woman without a high school diploma, daughter of a poor, welfare-dependent single mother who was born in a small south Georgia town in 1955 and has spent her entire life there. History will inform the reader that biography and history started Nelda off in life with profound disadvantage. Like so many women in this small community, she worked most of her adult years at the clothing manufacturing plant that closed in 1999. Subsequent to the closure of that plant, Nelda worked at a series of part-time jobs, often more than one at a time, in order to earn a subsistence living. Employers do not have to provide benefits to part-time workers. When she developed an abdominal mass, she was simply unable to afford to get care. She had no option but to continue to work as a part-time housekeeper in a local motel. When her mass got so large as to be obvious, her employer felt she was a liability, and told her not to come back to work until she was well. So she went to the Emergency Room, where they ran diagnostic blood work and performed a biopsy. The diagnosis? A benign tumor. Nelda is not old enough to qualify for social security based on age. The benign nature of the tumor had rendered a verdict of "not disabled." No one will hire her full-time because there is little enough full-time employment available in this small town even for those with college degrees; much less for a far-side-of-middle-aged African American woman with no diploma and an enormous visible abdominal tumor. Nelda's story exemplifies the complex intersections of race, gender, age, history, personal biography, employment and health status that contribute to insurance out-group status. Evidence of how intersectionality and insurance out-group status affect children is

evident in what Alphonse's mother concluded might be the only solution to Nelda's predicament... turning over guardianship of Alphonse to her sister, Nelda, and sending him to live with her: "I tell her I need to do I guess is just let Alphonse move in with you since I got him in the system. That the only way you going to get any help." Alphonse is both a dependent minor and classified as disabled due to chronic asthma and learning impairments. As his guardian, Nelda would qualify for both Medicaid and Alphonse's social security disability benefits. This example speaks for itself.

Nelda's story is an extreme example of intersectional dynamics at work in the stories of all the African American mothers I interviewed. Concerns about how insurance affected access to care and daily life choices were common to every African American mother I interviewed, regardless of education, income, marriage status, or health status. Illuminating the many-faceted implications of insurance coverage status using an interpretive framework of intersectionality provides a critical piece of the health disparities puzzle. This study's findings in regards to insurance out-group membership status generate more questions than answers, but I do feel as though they contribute to knowledge that may eventually result in filling some gaps in the literature. A review of intersectionality literature shows evidence of the difficulty of using income as a measure of socioeconomic status, and little mention of how the complexity of both public and private plans may contribute to health disparities (Schulz & Mullings, 2006; Baynes-Smith, 1996). One study used intersectionality as a framework for explaining how private insurance coverage benefitted White women more than African American women in terms of reproductive care (Bengiemen, Capitman & Ruwe, 2010); and legal scholars have discussed intersectionality at work in the denial of public assistance benefits

(including insurance) to drug offenders, many of whom are poor, African American women (Brown, 2010). Others have discussed insurance issues of transgendered and gay/lesbian persons within a framework of intersectionality (Diskin, 2008). The scant literature that uses insurance coverage and status to investigate disparities within a framework of intersectionality is evidence of great opportunity to pursue knowledge development in this area.

Kawachi, Daniels, and Robinson (2005) identified the lack of reporting of health statistics on the axes of both ethnicity and class as an issue that has led to a gap in understanding of the multidimensionality of health disparities. They suggested that race and ethnicity have been used in the discussion of health disparity in order to “suppress class-based discourse” (p. 343). Becker and Newsom (2003), reiterated that gap in understanding of African Americans’ perceptions of care related to socioeconomic status, particularly in the understanding of socioeconomic status as “not just a confounder of racial differences in health but part of the causal pathway by which race affects health” (p. 742). Lillie-Blanton, Martinez, and Salgonicoff (2001) stated that though the documentation of health disparities is great, the underlying factors that cause them are poorly understood. Their recommendation was to improve knowledge “of the extent to which racial/ethnic differences persist in the site of medical care will inform future investigations of the causes of health disparities” (p. 15), and specifically mention differences in the sites of care, content of care and the patient-provider relationship, financial barriers, or any combination of these as contributors to health disparities. Similarly, Smedley, Stith and Nelson (2003) in their Institutes of Medicine report found that stereotyping, bias, and uncertainty in the health care relationship can contribute to

unequal treatment. Their summary stated that there are specific gaps in understanding how disparities emerge in the structure and process of care.

The identification of insurance out-group membership as a factor that represents intersectionality serves to fill a tiny part of the gaps identified by these authors as cited in Chapter 1. Intersectionality as a conceptual factor in insurance out-group membership did turn out to be one of the most significant theoretical findings of this study. The findings of this study suggested that income and ethnicity were just two of many intersecting factors in health care relationships; and that for the participants, insurance out-group status was more relevant to access and to patient/provider relationships than were income or ethnicity alone. This sort of understanding and discourse is imperative to addressing disparities of race and class at a systemic and policy level.

Though it was anticipated that intersectionality would have bearing on the findings of this study, the overall purpose of this study was not to explain issues of intersectionality in health care. Because of its emergence as a relevant concept however, further consideration of intersectionality is included in recommendations for health professions education and future research, later in this chapter.

Practical Implications of these Experiences on the Relationship between Provider and Patient

African American parents entered encounters with their children's health care professionals with unique biographic historicity, and with unique, dynamic relevances; all of which influenced their relationships with providers. As a result, parents experienced these encounters as either routine and taken-for-granted, problematic, or transformative. It is important to acknowledge that each provider entered the relationships with his or her

own unique historicity and relevances, as well; but consideration of provider experiences is, perhaps, a topic for another study. A major premise of this ethnographic study was that the health care system represented a culture, complete with signs, symbols, codes, mores, and language; and that providers were in-group members of this culture. I found that when a child became ill, parents' relevances shifted from ordinary concerns of day-to-day living, and required a journey into another culture. In some cases, parents had problems with providers, characterized by typification, knowledge disparity, inequity, disappointed expectations, and exaggerated in-group/out-group membership status. In others, the relationship between parent and provider was transformative, characterized by appreciation of individuality, sharing of or acknowledgment of relevances, transcendence of group membership, knowledge sharing, equity and balance of power. In these encounters, patients and providers were able to engage in mutual, well-informed collaboration with the well-being of the child as the primary shared relevance.

These findings are replete with implications for practice in terms of the patient/provider relationship. While providers cannot control or even completely know the biography, history, or relevances of each patient, they can engage in *transformative practice* by actively practicing melioration. Melioration is the engagement of groups and individuals in deliberate evaluation of typifications, institutions, laws, and systems. Schutz (1962) emphasized that typifications are not inherently good or bad, and cannot be eliminated, even in the form of prejudice: Problems arise when discrimination is employed to impose roles, mores, or laws at the expense of self-integrity of others. Melioration represents the intentional efforts to address inequity in relationships. Practitioners can actively meliorate inequity in patient relationships by integrating the

findings of this study into their practice, using several specific practical applications; all of which require an attitude of intentional self-reflection and a commitment to melioration and transformative practice. The findings of this study suggest that melioration may be best addressed within the framework of relevances. In this study, there were three precursory parental relevances that affected the health care encounter: general understanding of and beliefs about illness and wellness, their typifications about health care providers, and their in-group/out-group status.

Beliefs about Illness and Wellness

Parents in this study entered we-relationships with providers because symptoms of illness were affecting routine, everyday life. Parents most often characterized illness in terms of how it affected their ability to engage in normal activities like working and going to school. Based on these findings, I recommend that providers ask questions about how patients characterize illness, and how illness affects their day-to-day lives. In a mutual collaboration, it is important for providers to share their own understandings of illness, particularly in terms of the less visible, non-symptomatic processes of disease that may impair normal, daily life in the future, if this is a primary concern of the patient. Incorporating those aspects of illness that most affect patient's day-to-day lives and creating plans that consider these are more likely to make treatments practical for patients. In some cases, this may mean simply asking questions about a patient's transportation, work schedule, home environment, geographic location, and family responsibilities. This type of melioration was evident when a parent described how one institution gave attention to parental relevances like bills, transportation, and concerns back home when her child was receiving treatment for cancer. But understandings and

beliefs about illness and wellness and the signs and symbol systems associated with them vary greatly from group to group and from patient to patient. Therefore, the only way a provider can incorporate a patient's understandings and beliefs is to ask patients about them, and be flexible enough to include them and even prioritize them when they conflict with the provider's own understandings and beliefs. Providers must approach encounters with patients prepared to prioritize the patient's understandings and beliefs about wellness and illness, rather than imposing their own. Achieving equity in patient/provider relationships requires the acknowledgement that the approach and beliefs of one culture, the health care culture, are no better or worse than those of the culture of the patient.

Typifications

Providers should be aware of patient-centric typifications and have certain role expectations. Parents' experiences of problematic or transformative we-relationships with their children's providers was, in part, based on providers' fulfillment of an ideal provider typification, based on the provider's motivation, disposition, communication, and professionalism. It is ironic to consider Schutz's assertion that a high degree of typification in a relationship creates barriers to transformation, in light of the expectations parents had of providers. But just as Schutz (1962) knew "whom and under what circumstances I have to consult as a competent doctor" (p. 15), parents expected providers to first meet expert minimum role expectations within a highly typified setting. Like Schutz, parents entered encounters expecting to receive expert knowledge.

When providers remained within highly typified roles, relationships remained taken-for-granted and routine; which was fine for non-problematic encounters. When problems arose in the encounters and the providers failed to meet ideal role expectations

or failed to transcend them, parents perceived the encounters as problematic. Likewise, even when problems arose in encounters, and a provider met typified expectations, then transcended them by engaging in a mutual collaborative relationship with the parent, transformation was actualized. It therefore becomes important for providers to recognize and honor the typified expectations patients have of them. Patients in this study perceived that providers met their expectations in simple ways through typifications related to ideal provider motivation, disposition, communication, and professionalism. Some of these included sitting down when they talked to parents, taking time to listen to and answer specific questions, being honest and straightforward, explaining unfamiliar terms and ideas, and by providing new options for treatment when necessary.

It is also important that providers acknowledge their typifications of patients they encounter every day. Typifications are not intrinsically good or bad and cannot be avoided. It is through typifications that people make sense of the world. In this study, in order for transformation to occur in a relationship, providers had to engage with parents beyond typifications. This was most often evident when parents described providers as asking about their lives outside the health care setting, and by considering and including parental relevances in the care rendered, by sharing knowledge, and by transcending group memberships.

Knowledge

In this study patients who had expert knowledge about health care shared in-group membership with their children's providers. This level of knowledge was a factor in both problematic we-relationships and transformative we-relationships. All parents had expert knowledge about their own children. Transformation was most likely to occur when

providers acknowledged parental expertise or shared professional knowledge with parents. Problems arose when parents felt as though their expertise was not acknowledged, or when providers did not share expert knowledge with them. I recommend that providers enter encounters with parents and patients with a meliorative attitude, prepared to share knowledge rather than to deliver or impose expert knowledge. Again, this is best achieved by asking patients what they believe is happening, and by listening to patients concerns and questions; as did the provider who referred a child for an x-ray because of the parent's concern, when a potentially life-threatening problem was identified and treated. Providers may also share professional information, as one parent described when a provider arranged for her to learn to deliver nebulizer treatments to her daughter at home. When patients and providers share their own expert knowledge, the well-informed collaboration results in a treatment plan that is more viable and useful for the individual patient, and that reflects equity. Rectification of the power imbalance inherent in patient/provider dynamics requires the acknowledgement that the expert knowledge base of one person, the health care provider, is no more valuable or less valuable than that of the individual patient.

Group Membership

In this study group membership status was often at the heart of both problematic and transformative encounters. When providers were perceived by parents as unable to transcend expert orientation as members of the health care culture, or when parents felt typified by providers, problematic we-relationships occurred. Parents spoke of group memberships in terms of race/ethnicity, background in health care, and insurance status. As a precursory relevance, some participants mentioned race as a factor they believed

sometimes affected the way patients experience health care. They were also likely to refer to their knowledge or lack of knowledge about health care as affecting their experiences of encounters with their children's providers. Every participant reported insurance status as affecting either their access to providers or their relationship with providers in health care encounters. In fact, insurance was mentioned more often than either race or health care background by participants.

When parents perceived that a provider was in some way able to transcend group membership status, either their own or the patient's, the encounter was transformative. For example, when a provider invited a participant's child to his own children's birthday party, I believe he was transcending group membership and appealing to mutual group membership as parents, or as humans. There were many examples of this kind of transcendence in transformative encounters, and I believe it is the most easily practiced meliorative intervention for providers. When entering encounters with patients, providers can easily appeal to mutual group memberships if they know even a little of a patient's biography and history. In the case of children's providers, shared membership in the parenthood in-group is the most obvious one. Members of the parenthood in-group in American culture share signs, symbols systems, and relevances. For patients who have backgrounds in health care, there is an opportunity for using shared professional knowledge and group membership as a foundation for well-informed collaboration and potential transformation. For those patients who do not share membership with providers as having health care backgrounds, establishing shared group membership is even more important.

Providers and parents may share any variety of group memberships, for example they may be employees, religious believers, women, sports fans, cooks, gardeners, or school system alumni. Appealing to shared group membership first and foremost establishes fertile ground for transformation and a mutually collaborative relationship. It introduces human equity in what is an inherently unequal relationship. Shared group membership also provides another context in which to share health-related information, perhaps through the use of metaphors, signs, and symbols from that shared culture.

In this study, sometimes it was not shared group membership that resulted in transformation, but provider recognition and acknowledgement of the relevances of the patient's group membership, and attempts to meliorate problems associated with that membership. I have posited that all participants were members of an insurance out-group. Sometimes they perceived providers to be members of the insurance in-group. One example of this was the parent's description of her family being turned away by a provider because of the unpaid bill of a single uninsured child. There were many similar examples in which participants grouped providers with the insurance entity; with themselves as out-group members. But there were examples in which providers showed concern about whether or not insurance coverage allowed a certain prescription or directed patients to low cost alternatives for filling prescriptions. There were other examples in which providers were described as delivering care regardless of coverage, or waiving co-pays. Others described accessing care provided by grant-funded clinics which they perceived as existing outside the realm of insurance influence. These descriptions are evidence that some practitioners may have an understanding of intersectional factors at play in the lives of their patients.

Given the marketized system of health care delivery in the United States, the insurance in-group is a difficult group membership for providers to transcend. It represents that group membership that is greatly responsible for the power differential and resultant inequity in relationships between patients and providers in the United States. Individual providers may meliorate by considering patient relevances within the context of that group membership; by being well informed about various insurance plans that exist or alternative options for patients, by facilitating re-enrollment when insurance status changes, or by providing bridge care for patients during periods of insurance coverage lapse. Rectification of the power imbalance inherent in patient/provider dynamics requires the acknowledgement that membership in one group is no more valuable or less valuable than membership in another group.

Summary of Recommendations for Health Care Providers

The previous section included several general recommendations for health care providers based on the study's findings. These recommendations are summarized in the following paragraph and specific practical applications for a variety of providers in different settings are suggested. I recommend that practitioners:

1. Ask questions about how patients characterize illness, and how illness affects their day-to-day lives. This is particularly important in primary care settings when the relationship between the patient and provider is long-term and ongoing. For example, physicians and nurse practitioners should note and address activities of daily living or functional outcomes that are important to the patient, and discuss the success or failure of the treatment plan in terms of these patient identified activities and outcomes.

2. Develop plans of care and treatment that incorporate and prioritize those aspects of illness that most affect patient's day-to-day lives. For example, in discharge from an acute care setting, the discharge nurse should ask questions and provide information specific to a person's physical environment, family support, access to follow-up care, and return to work. This may require creativity and flexibility when priorities of the patient may fall outside the expectations of the provider. For example, if a daily 20 minute walk is considered a necessary component of healing, the nurse must collaborate with the patient in determining an alternative if the patient does not feel safe walking outside in his or her neighborhood.
3. Share their own understandings of illness with the patient, particularly in terms of the less visible, non-symptomatic processes of disease that may impair the patient's normal, daily life in the future. For example, in the pediatric setting it is important that providers explain to parents the importance of adherence to therapy in the context of daily life. A provider might explain that finishing a course of antibiotics will not only prevent the return of symptoms but also will prevent subsequent absences from work or school. In primary care settings, explaining the control of diabetes and high blood pressure as related to prevention of specific future impairments is likely to resonate with patients who have seen a friend or family member suffer from consequences of the same disease.
4. Acknowledge and honor patient individuality. Clinicians of all types can note children's individual traits in a complementary way and refer to them by name. Primary care providers should refer to clinical standards and norms in the context of individual differences; differentiate quantitative results of laboratory tests and

measurements from hierarchical measurements of adequacy, like school test scores; and explain how specific tests and measurements are relevant to that individual. The use of tools like height and weight tables can be explained to patients as ways to interpret wide variations of human difference and to identify the unique characteristics and needs of individuals.

5. Recognize and honor the typified expectations patients have of them by personal attention to motivation, disposition, communication, and professionalism. Providers should sit down when they talk to patients, take time to listen to and answer specific questions, be honest and straightforward, explain unfamiliar terms and ideas, and demonstrate professional knowledge of options for treatment.
6. Engage with patients beyond typifications. For example, providers should ask about patient's lives outside the health care setting. This may simply mean remembering or noting a spouse's profession in the patient chart and commenting on it, or asking about a recent holiday; or knowing what school a pediatric patient attends and asking about it.
7. Acknowledge parental expertise. Primary care providers should listen closely for a parent's descriptions of changes from normal for that particular child. Parent observations should be considered important data in evaluation of a problem.
8. Share knowledge rather than deliver or impose expert knowledge. Knowledge of both the parent and the provider should be included in the plan of care and treatment. Referencing the parent's input and observations in the written plan of care creates mutual ownership of the plan. For example, a provider may recommend that a dehydrated child be given only clear fluids for 24 hours. The

provider might explain why other fluids should be avoided; but could also ask the parent what types of clear fluid he or she knows the child will best tolerate. These specific parent suggestions should be included in the plan of care and written in the discharge instructions.

9. Appeal to mutual group memberships. Providers and patients may share any variety of group memberships, for example they may be employees, religious believers, women, sports fans, cooks, gardeners, or school system alumni. Appealing to shared group membership first and foremost establishes fertile ground for transformation and a mutually collaborative relationship.
10. Transcend group membership status. In an Emergency Department setting, transcending group membership status might mean that someone on the health care team temporarily step out of the role of patient caregiver and instead respond to and be available for a parent or family member who may be afraid for the well-being of the patient and who may not understand what is happening in a complex health care setting. A nurse can “step into the shoes” of a family member because he or she knows or suspects what that person may be experiencing as a parent. By transcending his or her status as a patient care provider, the nurse can relieve distress by giving frequent updates, explaining what is happening, and creating a comfortable and safe space to wait. In an institutional setting, this role may even be assigned, but it is most often spontaneous.
11. Meliorate problems associated with group membership. Patients may experience problems because of group membership. In this study, membership in the insurance out-group created problems in accessing care. Providers’ understanding

and attention to details of insurance coverage made a big difference to parents of pediatric patients. Simply knowing which prescriptions were available for four dollars at the Publix pharmacy created potential for a transformative relationship with patients. It is important that providers acknowledge many possible group memberships and be aware of and sensitive to potential barriers related to them, and act to reduce or remove these barriers.

Recommendations for Health Professions Education

The study's findings have important implications for health professions education, as well. In the last decade, cultural competence in the education of health care professionals has emerged as a key component in addressing health disparities (Betancourt, Green, Carillo & Park, 2005), because of increasing diversity of patient populations; the link between patient satisfaction, adherence of health instructions, and health outcomes; and the relationship between patient-centered care and improved quality of care. These authors highlighted the need for cultural competence training at multiple levels; for system-wide and institutional buy-in, not just individual buy-in. System-wide buy-in requires that changes be made not only in training provided to employees and students, but that operating systems and management systems be evaluated as potential barriers to the delivery of culturally competent care. These authors also refer to the need for increasing diversity in the health care workforce, which requires consideration by academic institutions of methods by which they recruit minority students.

It is important, therefore, to consider the findings of this study in the context of both individual provider education and institutional systems. Much of the cultural competence curriculum available today is focused on individuals becoming competent in

communicating and relating with people from diverse cultures. This is a worthy and important focus; and the findings of this study confirm the importance of this focus and enhance knowledge about cultural factors that influence the health care relationship. The findings of this study also illuminate, however, the importance of developing a curriculum that includes understanding of health care as a culture, as well; in a way that moves beyond the consideration of ethnic culture, but that is also fundamentally different from consideration of organizational culture through the lens of the business model. Critical analysis requires that those associated with health care focus inward to seek out and illuminate obvious and hidden agendas and structures that perpetuate inequity at the expense of a marginalized group or groups to the benefit of a dominant or majority group or groups.

Specifically, the findings of this study suggest that a viable avenue for expansion of cultural competence education would be the development of a cultural competence curriculum with a greater emphasis on understanding the culture of health care, and how its language, mores, customs, values, codes and practices serve to alienate those persons it purports to serve. Students and practitioners in all health care disciplines could benefit from being taught to view the health care relationship as the intersection not only of individuals' ethnic, racial, or historical cultures; but professional and nonprofessional cultures, as well. Creating student and health care professional awareness of how different professional cultures (such as medicine and nursing) interact and how these interactions affect interdisciplinary collaboration and patient care should also be an important component of health professions curriculum; perhaps best delivered in an interdisciplinary classroom format. This type of critical self reflection and engagement in

the educational setting is one avenue through which social transformation may occur; transformation which may include reduction and perhaps elimination of health disparities.

A second recommendation for health professions education that was generated by findings from this study is for the incorporation of intersectionality as a framework for consideration of environmental macrofactors that contribute to health disparities. Ethnocentrism in the health professions creates a dynamic in which health professionals imagine their knowledge, understanding, and interventions to be the most important factors in individual and population health. The reality, however, is that medical care is not the major determinant of health: In fact, medical care explains no more than ten to twenty percent of variation in health status (Drexler, 2007). It is critical that those entering the health professions understand that: 1) Medical care itself is far less an actual determinant in health status than are factors like education, socioeconomic status, housing, and geographic location; and that 2) Deficits in these policy-related and societal macrofactors are responsible for group vulnerability and disparities in health; and create the milieu in which medical care becomes an important factor in addressing health problems resulting from vulnerability. Incorporating intersectionality into health professions curriculum would encourage students to think beyond health care interventions as the most important factors in individual and population health. Students who have an understanding of intersectionality and who incorporate that understanding into the way they practice and conduct research may become advocates for patients and leaders toward policy changes that recognize that health equity cannot be achieved without attending to the intersecting factors of race/ethnicity, class, gender, disability,

sexuality, age, culture, and the social determinants of health. Creating a new generation of students who embrace intersectionality as a concept is critical to the future of health disparities research. Collins (2011) stated that the greatest significance of intersectionality is not necessarily in its implications for current scholars and researchers, but in “building a base of undergraduate and graduate students” (p. 95) who will shape patterns of emphasis and thinking in intersectional research in the future.

The recommendations made thus far, in response to the practical implications of this study’s findings, have been confined to potential changes made by the individual provider in the properties of a specific practice setting, and for health professions educators in institutional or academic educational settings. Larger context implications will be considered in the final section, following recommendations for future research.

Implications of these Experiences on the Relationship between Provider and Patient: Recommendations for Future Research and Action

This study’s findings in regards to precursory parental relevances and parent typifications of providers provide enormous potential for future inquiry. Chapter 3 included a reference to Myrdal’s comparison of discrimination between African Americans and Whites. It was this reference that stimulated thought about the future implications of this study’s findings in regards to relevances. Schutz reported Myrdal’s findings of an inverse relationship between domains of relevance for Whites and African Americans in terms of economic equality and racial intermarriage (Schutz, 1964). In Myrdal’s historical study, White people listed discrimination in the following order of social importance: intermarriage, social equality, segregation, political rights, equality before the law, and economic equality. African American people listed these same

discriminations inversely in order of importance. Schutz's point was that African Americans had greater concern with rights, legal status, and equality; whereas Whites were more concerned with social values and implications. Myrdal's was a classic example of how relevances are determined by group membership and what occurs in everyday life; and how these are also related to formal, legalized equality and social equality. I recommend further qualitative inquiry specific to expanding the depth and richness of knowledge about domains of relevance to parents, not only those entering health care relationships. Expanded understanding of relevances could result in the development of an instrument or group of instruments designed to evaluate hierarchies of relevances of parents in a variety of situations. Such instruments could be widely applied in a variety of disciplines to develop interventions and treatment plans that prioritize patient relevances.

Likewise, further qualitative inquiry in regards to domains of relevances of providers from a variety of disciplines could generate knowledge that could be used to develop similar instruments. It would also be interesting to pursue a line of inquiry into providers' typifications of their own roles; and their typifications of patients. The ability to compare domains of relevances and typifications between and among disciplines and between and among patients and providers could result in more individualized treatment plans, in which patient relevances are prioritized and in which relevances that are divergent or disparate could be revealed and meliorated. Provider, disciplinary, and patient unity in development of an equitable treatment plan or intervention has the potential to result in better outcomes and improved health.

The findings of this study can be used as a foundation to generate new relationship-centered methods for clinical practice. The deeper, rich understanding produced in this study would be useful for further qualitative inquiry into the many facets of problematic and transformative we-relationships. In addition, developing and testing the efficacy of specific interventions designed to meliorate patient/provider relationships in the areas of relevances, knowledge, typifications, and group memberships could result in development of a concrete, measurable theory of transformative practice that could be used in a variety of disciplinary settings. A theory of transformative practice with measurable components could be then applied and evaluated in terms of its ability to improve health outcomes and meliorate health disparities.

Some of the richest potential for future research comes from considering the frameworks that informed my interest in the study, as they were outlined in the literature review. While these frameworks were not intended to be vehicles for analysis of the data, secondary analysis of the data might reveal interesting new understandings of existing theoretical frameworks of vulnerability, resilience, cultural competence and trust.

Seeking evidence of self-efficacy, hope, and coping (Gillespie, Chaboyer, and Wallis, 2007) in parent's reports of their encounters could illuminate theoretical links between resilience and transformative collaboration. Likewise, problematic we-relationships could be considered adverse events that might be linked to either positive or negative adaptation. Relating theoretic concepts like precursory parental relevances to vulnerability and resilience theory-related concepts like adaptability, risk, and protective factors could also fuel new qualitative and quantitative inquiry. McCubbin and McCubbin's (1988; 1992) counseling model could be used as a framework to consider

how family relevances change during transitional family life cycles, or even how differing relevances among family members may serve as triggers for transition.

Similarly, Schutz's concepts of signs and symbols systems (1962; 1964) could be used to consider theoretical concepts related to cultural competence; and to investigate how signs and symbols are interpreted differently by patients and providers, resulting in potential for either cultural mismatch or cultural congruence. If instruments are developed that can evaluate and order patient's and provider's individual relevances in a particular encounter, these could be administered in conjunction with an instrument like Moseley, Freed, Bullard, and Goold's (2007) Cultural Mistrust Inventory; to determine whether or not shared or inverse patient/provider relevances are related to measures of cultural mistrust.

The recommendations made thus far, in response to the implications of this study's findings, have been confined to potential practical changes made by individual providers in the context of specific practice settings, for changes in health professions educational curriculum, and for future research directed towards designing interventions for individual providers in specific practice settings. There are, however, larger context implications of this study's findings.

Conclusion

This study's identification of insurance out-group status as one factor related to intersectionality holds perhaps the most promise in terms of generating deeper and richer understanding of intersectionality in health care, and the most potential for generating new thought and perspective that might result in systemic change. The findings of this study resulted in the development of this one small dimensional factor that may

contribute to addressing inequities in health care access by providing more theoretical detail for developing method and measurement. Intersectionality is also a concept, however, that is widely considered to be difficult to apply in terms of method and measurement of outcomes (McCall, 2005; Mens-Verhulst & Radtke, 2006). And perhaps intersectionality is not primarily something to be measured, but something to be recognized, something to spur on those who recognize it, to acknowledge it and allow it to inform us and transform us as providers in practice and as members of a culture we share with patients, the human culture. As mentioned earlier in this chapter, it certainly could serve in both health care practice and health professions education as a practical tool for more robust social analysis and critique of health care relationships and health care systems. The concept of intersectionality is an obvious fit with ecology theory's focus on the multifactoral, multicontextual nature of health.

Ecology theory is one of the frameworks that informed this study and which influences the way it was conceptualized and interpreted. The summary to Chapter 2 related the foundational tenets of ecology theory to those of Schutz's social phenomenology. Schutz's attention to the intersubjective nature of the social world provided a framework for considering the multifactoral influences on African Americans' health. Bronfenbrenner's (1979) definition of social ecology, cited in Chapter 2, makes reference to influential factors in immediate settings of individual's lives and the larger context "in which the settings are imbedded"; and defined social ecology as involving "the scientific study of the progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings,

and by the larger contexts in which the settings are embedded” (p. 21).

Bronfenbrenner’s stated purpose in his ecological systems theory was to “provide a theoretical conception of the environment extending beyond the behavior of individuals to encompass functional systems both within and between settings, systems that can also be modified and expanded” (1979, p. 7).

There are, therefore, relational implications for the study in terms of the “larger context” in which health care settings and relationships exist. These implications are most evident in the findings related to intersectionality; and perhaps in the broad, generalized perceptions voiced by the participants that something is fundamentally wrong with the way health care is delivered in this “larger context.” Their statements also serve to honor true critical method and the mutuality of qualitative inquiry, by allowing me to voice not only my own conclusions about my topic of interest and the answers to questions specific to the topic of study, but to provide an avenue for the voices of participants. The participants have topics of interest, too, and thoughts about and recommendations for providers and society as a whole. Because this is their work, too, this final chapter must include the participants themselves. Their statements represent the answers to many unasked questions, answers of import that go far beyond the narrow focus of the study, answers that do not fit neatly into a concluding category for this particular study, but which speak volumes to health care providers and to our society as a whole.

One participant explained problems in the current system of delivery as exemplified by her own brother’s experience:

It's so many people that don't have that type of money or so far in-between that they can't afford this or they... they're pinching by a dollar, and I wish there were clinics that can do more pro bono for those that are less fortunate because they the one that get left out of everything. Like, how can the community help with the health care of inmates, especially inmates just coming out. And I speak of, for one, my brother. It's hard for them to get any kind of insurance, whether they were wrong accused for something or whether they did something... or whether they were reborn in the system, you know, whether they have a change in heart. And those people, they do deserve equal health care, and it's hard for them to get it. When my brother been locked up, and because he's been locked up, 'cause of whatever, it's hard for him to get a job. And it's hard for him to get health care. And they should be able to get some kind of Medicaid, some kind of food stamp or whatever. But it's not so for certain ones. Because I have seen where my brother cannot get Medicaid. They told him, "You supposed to be working. You supposed to be knowing better. If you didn't do what you did...." And he [tells them], "I was wrongfully accused...." But it stays with him 'cause he can't afford to fight the system with it. So, you know, I just wish it was equally and people look at everybody equally. But I know sometimes it's not going to happen.

Another believed that people of all ethnicities in the United States are equally affected by inequity in health care: "Because, I mean, I see Caucasian people in the same boat that I'm in. I mean, I see Mexican people. I see Hispanic people. I see Haitian people. It's just American in general."

Evette described how even middle class working people are marginalized by the current health care delivery system:

I see where the country needs to be where even working people, so that they don't have to worry so much, even when different things may happen. Not just for wellness, even when something may happen, a child may break their leg or something, then they should work with them, you know. And then my mom when she was sick, I think she told me, and this is a blessing, she told me, her bill was eighty-some thousand, cause she was in the hospital so long. And I was like "What!? Eighty or ninety thousand! And she didn't have to pay anything because she had the assistance. I thought, good gosh, if I would get a bill like that, I would just... I don't know. I would have to take out a loan. I wouldn't want to worry about my health and then on top of that, worry about the bill. I just think that somehow they need to look at the cost of everything that they are doing, if it's really necessary.... And health, I mean, if there's gonna be none of us left in this world. If everybody's sick, can't nobody help nobody. What would happen? Those people who on assistance, if they didn't get these cards where they can go get care, then what would happen? And you think, when you go into the hospital, just the cost, it's unbelievable. And I can remember having my kids, with both of them I was able to get the assistance, Medicaid paid. And that was because their dads was not making enough money and I qualified, based upon the income level. Had I not had that, I would have been spending so much money. So what happens when you got a married couple that barely are making it? You gotta come up with that kind of money, and after that you gotta come up with more

money. You gotta keep taking the baby to the doctor, you gotta pay for day care, you got to get their formula. If they're sick you gotta get the medicine, and then if they get too sick you gotta miss work. If you don't got days, they're gonna start docking your money; and if you miss too many days, they're gonna want to replace you. It's a lose/lose situation. Nobody wins. And if we can't find a way that everybody can win, especially with health care, cause if you got bad health you can't do nothing, can't work. If you can't even go to the doctor cause they won't see you 'cause you can't pay for it!" But you got to pay for that. Nothing is free. They charge you all the way to your last breath. And beyond.

Charlotte characterized the problem as a national concern related to government spending priorities:

You know what, I've been trying to follow what they're doing with the health care, with Obama and the Democrats and the Republicans, and my husband has been trying to explain it to me, and I'm trying to figure out what is the big deal. My thing is we all need health care. I understand that, but some people just cannot afford it.... So, if we can find a way to help those that don't have it, then why not? And I know it's a big expense to the country, but we use money towards everything else, for things we don't need. I'm still all confused with what exactly they want to do. I'm just going to be honest with you, and my husband, he's always trying to explain it to me, but I'm still saying if we can help those that really need it, why not? 'Cause that's what we supposed to do as Americans. If they can find a way to help the jobs have better insurance policy where they won't be a big expense to America, then do that. When those that go to the doctors now

and the hospitals and they don't have that stuff, it's going to fall back on somebody. And most of the time it's us tax payers. So, if you could get a health care policy that's going to help but not hurt America, then do that. Just come together 'cause those who are saying no to it or those that are saying yeah—I think it's the ones saying no to it—but think about what if that was you. I'm not all that sure about what they're trying to do or how they're trying to do it, but I'm saying if it's going to help, help. That's what we supposed to do as Americans anyway, as people. That's what God wants us to do. If you can help somebody else, help them. That's the only way I see it. But I'm not really sure about how he's doing it. You know, I love Obama as my president or whatever. When it comes to politics, I'm confused. And I listen when he has his speeches, and I listen even when Bush was in office, I listened, and whoever was in there before Bush. I always listened. But I'm trying to figure out what's the big deal. I understand that it all boils down to money. Everything does. It all boils down to money. But y'all think about all this money that's going to places it just doesn't need to be going, then don't put it there. Put it where it's needed, and health care is a place where it's needed. Take that money, put that in the health care system and let that help them.

Janice characterized government spending priorities most succinctly: “Like I say, then they stop sending all the darn money up to the moon. The moon ain't coming down here and bothering us.” But most participants did not place responsibility only with the government or the health care delivery system.

Renee mentioned the responsibility of citizens in prioritizing health, too: “I think our priorities are just jacked-up. I really feel like we put our money on more frivolous things than our health care. And I say that every day.” When asked what types of things she meant, Renee mentioned designer clothing, shoes, jewelry, and vacations.

Another referenced the vicious cycle of negative individual health behaviors and lack of systemic resources to address these, when she said,

I don't understand why other countries can have nationwide health care, and we don't. I think it is absolutely crazy that you tell people, “you're obese, go fix the problem,” but they can't afford insurance, you know. And we ask for help from the government, and they're like, “No. You don't qualify for our insurance.”

Another also believed that other countries may have better systems of delivering care and also acknowledged that in such systems citizens have mutual responsibilities:

I know some other countries, they have free health care. And I think a lot more people are healthy that way. Then you see over here in the United States everything costs so much. All that much, people don't want to go to the doctor because it costs so much, and they don't have the funds to do so. So, they just kind of lay there and wallow in their own sickness, and then get worse and worse. Compared to if we had free health care, then it could be taken care of, looked at. We probably wouldn't have so many obese people, you know. And because of obesity, you have high blood pressure and heart disease and everything else that comes along with it. You know, it wouldn't be so much because in Japan they have free health care. But also in order to get the free health care you can only limit your family size, so it's two children per family, and then they work pretty

much for the government. The government takes care of everything. But we probably would have too many children around. I love all four of my children, but, when you have all that extra stuff going along with it, you have to limit yourself just like with anything. You have to limit yourself, but I feel like a lot more people would be healthy if they considered something like that. It doesn't even have to be free. If you're low income or no income, it should be a little less.

Benita thought that there must be some solution that involves all stakeholders:

I'm just saying that I think there's a way we should be able to come together as a parent, [providers], and the health care [insurance] peoples. We all should be able to work together. I wish we could all just become of one accord. One page, you know. Even with the health care, you know, be able to apply something that ought to pay for the kids. It pay for some of the stuff but not all of it. 'Cause that's why most parents are on Medicaid and PeachCare, 'cause they can't afford to buy the medicine, they can't afford to put their child in the hospital and pay the hospital bill. And all of them need to come into an agreement to try to get a plan that work out for the people that low income, for the folks that can't afford it.... I just want to know if one day it will ever change. To be better than what it is now.

And so, the single larger context implication of this study's findings is a recommendation for transformation of the current health care delivery model in the United States. What I believe and what the participants believe is that unless the system of care delivery changes so that the primary domain of relevance for providers and for the system as a whole is people rather than profit, disparate group membership and the conflicting relevances of insurance in-group and out-group members will remain the

primary barrier to transformative relationships between patients and providers, as it was in this study. The current system of health care in the United States represents a cultural dynamic which is rife with discord and is characterized by problems, and which may seem insurmountable. But the very nature of discord is that it creates instability that provides potential for transformation. It is my belief that health care relations and dynamics currently exist within an environment similar to that in which race relations and dynamics existed fifty years ago. Just as the untenable cultural system of segregation and discrimination resulted in systemic change in the form of civil rights, I believe the untenable inequity and disparity that result from our cultural system of health care will eventually result in systemic change, and in fact has already begun. The current health care system, along with its mores, laws, language, and symbol system, is so culturally ingrained in all of us, that most of us (least of all those of us who are providers) do not even recognize the gross inequity and disparity it represents and perpetuates; but perhaps in fifty years, our children's attitudes will have changed so much that they will wonder how we could not see it.

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Appendix A

IRB Approval Letter for Study #11-182: Pilot Study: African American Parents'
Experiences in their Children's Health Care Encounters

1/8/2011

Rebecca Green, Student
WellStar School of Nursing
1000 Chastain Road, #1601
Kennesaw, GA 30144-5591

RE: Your application dated 1/7/2011, Study #11-182: Pilot Study: African American Parents' Experiences in their Children's Health Care Encounters

Dear Ms. Green:

I have reviewed your application for the new study listed above. This study qualifies as exempt from continuing review under DHHS (OHRP) Title 45 CFR Part 46.101(b)(2) - educational tests, surveys, interviews, public observations. You are free to conduct your study as approved without further reporting to the IRB.

NOTE: Should you choose to revise the study, please notify the IRB prior to implementation of any changes. The board must review all revisions to ensure that the study continues to fall within an exempted category of research.

Thank you for keeping the board informed of your activities. Contact the IRB at irb@kennesaw.edu or at (678) 797-2268 if you have any questions or require further information.

Sincerely,

Christine Ziegler, Ph.D.
Institutional Review Board Chair

cc: tnelms1@kennesaw.edu

Appendix B

Cover Letter for Participation in a Pilot Study

COVER LETTER FOR PARTICIPATION IN A PILOT STUDY

Research project title:

Pilot Study: African American Parents' Experiences in their Children's Health Care Encounters

Investigator's name, address and telephone number:

Rebecca Green, 701 Pineridge Drive, Valdosta, GA 31602, 229-245-7197

Faculty Advisor's name, address and telephone number:

Dr. Tommie Nelms, WellStar School of Nursing, Kennesaw State University
1000 Chastain Rd. #4102, Bldg 14, Rm 3033, Kennesaw, Georgia 30144-5591
678-797-2088 (o)

Brief description of the research:

I am interested in the health care experiences of African American parents and the relationships between African American parents and health care providers and how those experiences and relationships impact the health of the child. The purpose of this project is for the investigator and the participants to gain insight into these experiences and relationships.

You are being asked to participate in a 1-2 hour interview in the setting of your choosing. Your interview will be recorded with a digital audio recorder. The interview will later be written down in a word-for-word format and parts may be used in a published document. Any personal identifying information such as your name will be protected and kept completely confidential. The initial interview will be conducted at a time of your choosing between February 1, 2011 and June 1, 2011; however, I may contact you at a time beyond the study dates to clarify answers you have provided. You are free to decline to participate in this study, to stop participation at any time, and to decline to be contacted by me (the investigator) or to answer questions that may arise after the initial interview.

In order to be included in this study, participants must be African American parents aged 18 - 60, with infants or school-aged children. Minors will not be allowed to participate.

The purpose of this research has been explained and my participation is voluntary. I have the right to stop participation at any time without penalty. I understand that the research has no known risks, and I will not be identified. By completing this survey, I am agreeing to participate in this research project.

THIS PAGE MAY BE REMOVED AND KEPT BY EACH PARTICIPANT

Research at Kennesaw State University that involves human participants is carried out under the oversight of an Institutional Review Board. Questions or problems regarding these activities should be addressed to the Institutional Review Board, Kennesaw State University, 1000 Chastain Road, #0112, Kennesaw, GA 30144-5591, (678) 797-2268.

Appendix C

IRB Approval Letter for Study #12-007: African American Parents' Experiences in their
Children's Health Care Encounters

7/19/2011

Rebecca Green, Student
WellStar School of Nursing
1000 Chastain Road, #1601
Kennesaw, GA 30144-5591

Re: Your application dated 7/11/2011, Study #12-007: African American Parents' Experience in their Children's Health Care Encounters

Dear Ms. Green:

Your application has been reviewed by IRB members. Your study is eligible for expedited review under the FDA and DHHS (OHRP) designation of category 7 - Individual or group characteristics or behavior.

This is to confirm that your application has been approved. The protocol approved is participation in audio-recorded interview. The consent procedure described is in effect.

You are granted permission to conduct your study as described in your application effective immediately. The study is subject to continuing review on or before 7/19/2012, unless closed before that date. At that time, go to <http://www.kennesaw.edu/irb/forms.html> and follow the instructions for closing/continuing a study.

All records relating to conducted research must be retained for at least 3 years following completion of the research. For additional information, see [http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm#46.115\(b\)](http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm#46.115(b)).

Unanticipated problems or adverse events relating to the research must be reported promptly to the IRB. Select the Reporting of Unanticipated Problems in Research tab at <http://www.kennesaw.edu/irb/> for definitions and reporting guidance.

Any changes to the study as approved must be promptly reported and approved. Contact the IRB at irb@kennesaw.edu or at (678) 797-2268 if you have any questions or require further information.

Sincerely,

Christine Ziegler, Ph.D.
Institutional Review Board Chair

cc: tnelms1@kennesaw.edu

Appendix D

Cover Letter for Participation in a Study

COVER LETTER FOR PARTICIPATION IN A STUDY

Research project title:

African American Parents' Experiences in their Children's Health Care Encounters

Investigator's name, address and telephone number:

Rebecca Green, 701 Pineridge Drive, Valdosta, GA 31602, 229-245-7197

Faculty Advisor's name, address and telephone number:

Dr. Tommie Nelms, WellStar School of Nursing, Kennesaw State University
1000 Chastain Rd. #4102, Bldg 14, Rm 3033, Kennesaw, Georgia 30144-5591
678-797-2088 (o)

Brief description of the research:

I am interested in the health care experiences of African American parents and the relationships between African American parents and health care providers and how those experiences and relationships impact the health of the child. The purpose of this project is for the investigator and the participants to gain insight into these experiences and relationships.

You are being asked to participate in a 1-2 hour interview in the setting of your choosing. Your interview will be recorded with a digital audio recorder. The interview will later be written down in a word-for-word format and parts may be used in a published document. Any personal identifying information such as your name will be protected and kept completely confidential. The initial interview will be conducted at a time of your choosing between September 1, 2011 and June 1, 2012; however, I may contact you at a time beyond the study dates to clarify answers you have provided. You are free to decline to participate in this study, to stop participation at any time, and to decline to be contacted by me (the investigator) or to answer questions that may arise after the initial interview.

In order to be included in this study, participants must be African American parents aged 18 - 60, with infants or school-aged children. Minors will not be allowed to participate.

The purpose of this research has been explained and my participation is voluntary. I have the right to stop participation at any time without penalty. I understand that the research has no known risks, and I will not be identified. By completing this survey, I am agreeing to participate in this research project.

THIS PAGE MAY BE REMOVED AND KEPT BY EACH PARTICIPANT

Research at Kennesaw State University that involves human participants is carried out under the oversight of an Institutional Review Board. Questions or problems regarding these activities should be addressed to the Institutional Review Board, Kennesaw State University, 1000 Chastain Road, #0112, Kennesaw, GA 30144-5591, (678) 797-2268.

Appendix E
Interview Guide

**Qualitative Interview Guide: African American Parents' Experience in their
Children's Health Care Encounters**

DEMOGRAPHICS

Participant Number:

Age:

Number of participant's infants and school aged children:

Gender and ages of participant's children:

Total number in household:

Participant's marital status:

Participant's employment status:

Occupation:

Participant's highest completed educational level:

Family annual income: _____ Would you describe your family today as low, middle, or high income?

INTERVIEW

A. Participating in research

1. How do you feel about research? Have you ever participated in any research, or known anyone else who has? What was that experience like? Why did you agree to participate in this interview?

B. Participant as Child

1. Tell me about the family you grew up in. Would you describe the family's income as low, middle, or high income? What do you remember your parents saying about health or illness, health care, and health care providers? Where do you think your parents got most of their information about health? What did your

parents teach you or tell you about being well or being sick? Tell me about any significant health problems in your family when you were a child. How were these problems treated or handled by your family? How were these problems treated or handled by the health care provider?

2. What was your health like, when you were a child? What kinds of health care facilities did your parents take you to? For what reasons would they take you? Describe the health care providers you saw as a child. In taking you to see a health care provider, your parents probably had ideas about what would happen as a result of your visit: What do you think your parents needed or expected when they took you to get health care? How did your parents interact or communicate with the health care provider?
3. Tell me about a particularly good health care experience you had as a child. What happened exactly and how did you feel about it? What role did health care providers play in that experience? Describe any interaction or communication that occurred. What made the experience good? What happened after this experience? How did it affect you or your feelings about health or health care?
4. Tell me about a particularly bad health care experience you had as a child. What happened exactly and how did you feel about it? What role did health care providers play in that experience? Describe any interaction or communication that occurred. What made the experience bad? What happened after this experience? How did it affect you or your feelings about health or health care?

C. Participant as Patient and Parent

1. What are your general thoughts and feelings about health, health care, and health care providers? Describe your health care resources, in other words, who do you consider to be part of your family's personal health care system? Tell me about any significant health problems in your family. How are these problems treated or handled by your family? Describe your own health level. Describe any health concerns that you deal with every day. Tell me about health care you have received. What is important to you in a health care provider? What is your provider's race and gender? How did you choose this provider? How would you describe your relationship with that provider? How has that provider handled your health problems? Tell me about your interactions with your health care providers.
2. Where do you get most of your information about your child's health? What do you teach your children about being well or being sick? How is your children's health? Tell me about health care your child receives. For what reasons do you take your child to health care facilities? Tell me the process of what happens when you take your child to get health care. Describe your child's health care provider(s). What made you choose this particular provider? What is the race, gender of your child's provider(s)? How would you describe your relationship with that provider? What do you need from your HC provider when you take your child? Describe how your child's health care provider meets or does not meet your needs? What do you think your child's provider expects you to do? Tell me about your interactions with your child's health care providers. How do you feel

your child's health care provider understands you, your life, and your concerns?

Tell me about how your child's health care provider does or does not take into account things like insurance coverage, convenience, or transportation when prescribing medication, treatment, or follow-up care when giving your child care.

3. Tell me about a particularly good experience you have had with your child's health care provider, or health care. What did you do exactly and how did you feel about it? What role did health care providers play in that experience? Describe the interaction or communication that occurred. What made the experience good? What happened after this experience? How did it affect you or your feelings about health or health care?
4. Tell me about a particularly bad experience you have had with your child's health care provider, or health care. What did you do exactly and how did you feel about it? What role did health care providers play in that experience? Describe the interaction or communication that occurred. What made the experience bad? What happened after this experience? How did it affect you? Or your feelings about health or health care?
5. What other things related to health are important, that we have not discussed? Do you have any other thoughts, feelings, or ideas about your child or your experience with your child's health care or health care professional?
6. What are your opinions in general about health care in America?
7. What are your thoughts about African American health?