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RACISM, RESISTANCE, RESILIENCE: CHRONICALLY ILL AFRICAN AMERICAN WOMEN’S EXPERIENCES NAVIGATING A CHANGING HEALTHCARE SYSTEM

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RACISM, RESISTANCE, RESILIENCE: CHRONICALLY ILL AFRICAN AMERICAN WOMEN’S EXPERIENCES NAVIGATING A CHANGING HEALTHCARE SYSTEM

DISSertation

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the College of Arts and Sciences at the University of Kentucky

By
Elizabeth New

Lexington, Kentucky

Director: Dr. Mary Anglin, Professor of Anthropology

Lexington, Kentucky

2018

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This medical anthropology dissertation is an intersectional study of the illness experiences of African-American women living with the chronic autoimmune syndrome systemic lupus erythematosus (SLE), commonly known as lupus. Research was conducted in Memphis, Tennessee from 2013 to 2015, with the aim of examining the healthcare resources available to working poor and working class women using public sector healthcare programs to meet their primary care needs. This project focuses on resources available through Tennessee’s privatized public sector healthcare system, TennCare, during the first phases of the Patient Protection and Affordable Care Act (ACA). A critical medical anthropological analysis is used to examine chronically ill women’s survival strategies regarding their daily health and well-being. The objectives of this research were to: 1) understand what factors contribute to poor women’s ability to access healthcare resources, 2) explore how shared illness experiences act as a form of community building, and 3) document how communities of color use illness narratives as a way to address institutionalized racism in the United States. The research areas included: the limits of biomedical objectivity; diagnostic timeline in relation to self-reported medical history; effects of the relationship between socio-economic circumstance and access to consistent healthcare resources, including primary and acute care, as well as access to pharmaceutical interventions; and the role of non-medical support networks, including personal support networks, illness specific support groups, and faith based organizations. Qualitative methods were used to collect data. Methods included: participant observation in support groups, personal homes, and faith based organizations, semi-structured group interviews, and open-ended individual interviews. Fifty-one women living with clinically diagnosed lupus or undiagnosed lupus-like symptoms participated in individual interviews. Additionally twenty-one healthcare workers, including social workers, Medicaid caseworkers, and clinic support staff were interviewed in order to contextualize current state and local health programs and proposed changes to federal and state healthcare policy.
KEYWORDS: Intersectionality, Healthcare Reform, Health Inequalities, Lupus, TennCare, Race and Racism

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March 12, 2018
RACISM, RESISTANCE, RESILIENCE: CHRONICALLY ILL AFRICAN AMERICAN WOMEN’S EXPERIENCES Navigating A CHANGING HEALTHCARE SYSTEM

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Lupus is defined as a chronic autoimmune syndrome that causes chronic pain and tissue inflammation in multiple organ systems (Wallace 2007). However the experience of living with an autoimmune syndrome is more complicated than identifying and managing symptoms. Lupus symptoms are known as flares. Flares are frequently unpredictable. Flares can involve one or multiple bodily systems simultaneously. They may include widespread chronic pain, persistent skin rashes and blisters, headaches, and loss of memory and coordination. The severity and frequency of flares, as well as the bodily systems affected by lupus are specific to an individual. These unpredictable, and oftentimes debilitating symptoms, are further intensified for those living in poverty or those without access to consistent, reliable healthcare. The experience of living with lupus can be as chaotic and unpredictable as the symptoms that define the illness. This volume seeks to highlight how women living with lupus create strategies and interpersonal networks in order to navigate the uncertainty of their chronic illness.

The women I interviewed for this project shared their frustrations with uncontrollable pain, chronic exhaustion, and medications that created additional unexpected symptoms. While clinically lupus is defined as a collection of observable and measurable symptoms, these women also defined lupus in terms of the negotiations they made with their own bodies, their support networks, and their environments. For these women, living with lupus meant learning to live in a world where the familiar could become foreign without warning. Gay Becker (1999) uses the term *disruption* to describe the emotional and intellectual process individuals experience when chronic health problems change the narrative they have written for their bodies. Becker argues that
people are taught to think about their bodies in a linear fashion and connect health with age and aging. Chronic health problems, or prolonged illness, disrupts the linear relationship constructed between body and health and forces the individual living with the illness to renegotiate their understanding of a healthy body (Becker 1999). It was common for the women who participated in this study to describe how they had to “relearn” their bodies after they began experiencing lupus symptoms. Yolanda, a forty-two year old office manager described her experiences learning to live with lupus as a second adolescence.

“I feel it was kind of like a second puberty…When you’re a teenager and you get a few pimples, at first you don’t really notice it because you’re a kid and you don’t think about your body like that…your body is just there to get you places and do things…but then the breakouts get worse and they’re painful and it’s not just an irritation…and it hurts so you know there’s something wrong, but is some of it in your head too?…You start buying stuff they advertise on television and it [acne] gets worse, and you don’t know if it’s worse because there’s something physically wrong with your body that needs treating…or the something that’s wrong is your own self-esteem…or if you’re making the problem worse because you keep irritating your skin…I feel like with lupus I had to learn my body again in my thirties…all the things I learned about my body when I was younger…about what my skin should look like, what I should feel like when I get out of bed in the morning…Those things were different…but lupus doesn’t fit with the stories we’re told about aging either, so I didn’t really have a road map or a measurement for what normal should look like…”

The lupus support groups I attended frequently focused on the disconnect that occurred between the lupus sufferer and society. Attendees felt that personal and professional support networks were willing to accommodate their physical needs, but were less compassionate to their emotional needs. They described the process of learning to live with lupus as “ongoing,” “changing,” “frustrating,” and “disheartening.” Chapter Five provides more detailed examples of how women learn to navigate the affects of
chronic illness in their daily lives through the stories of the women who attended the Morningside Baptist Church lupus support group. The support group provided a space for women to physically express their bodily pain, as well as a space to debate and share their experiences with lupus. The support group also provided a caring space for women with lupus to support one another.

Many women I interviewed also challenged the public discourse that living with lupus could be documented and defined by periods of pain and periods of remission. While all the women I interviewed did report periods of time they categorized as “symptom free,” they also questioned whether they were ever truly without symptoms. Many women questioned whether their own perceptions of pain had changed over time and whether their changes in pain tolerance altered their ability to feel pain. Others made a clear distinction between the terms “pain free” and “symptom free.” Although widespread, chronic pain is considered one of the most common symptomatic manifestations of lupus, the women who participated in this project were quick to remark that living with lupus was not always directly connected to physical pain. Chapter Six features the stories of women who built knowledge sharing networks in order to discuss how living with lupus changed their relationships with their bodies and shaped their political ideologies. Lala, a thirty-six year old bank employee argued that even without pain, she still felt lupus affected her physical daily life.

“I think it’s a real misconception that you’re in pain all the time if you have lupus…I mean I do have pain a lot, and maybe it’s possible I’ve just had it for so long that I’ve kind of forgotten that there are people who actually live life pain free…But there are a lot of days when it’s not so much pain I feel, as much as it is a slowness…like my body is working in slow motion…Like I’m in one of the action scenes from those Matrix movies…The [scenes] where there were all those cameras positioned to take pictures at just the right moment so the characters appear to be frozen
in impossible poses before everything speeds up again…Sometimes that’s what lupus is like for me…It’s like everything is stopped and I’m outside my body…I’m not in pain…I’m not mentally blocking out pain…I’m just in suspended animation…Like my brain is the person with the camera taking the perfectly timed slow motion pictures, and my body is just stuck in some sort of impossible pose that I can’t get out of…”

Women’s daily struggles with lupus extended far beyond each individual woman’s experiences with symptoms or support networks. Forty-five of the fifty-one women with lupus interviewed for this project were African American. In support groups and individual interviews, African American women regularly cited racism and sexism as both triggers for lupus flares and factors that impeded their access to the medical care needed to treat their illness. Lower income women faced additional barriers since they were not employed at jobs that provided health benefits and sick leave. These women were also more likely to have less time and resources to care for their own health since they frequently took on care giving or care sharing roles with other low-income family members and neighbors.

Since I met a large number of study participants through formal and informal support groups, it is not surprising that many of the women I interviewed framed their frustrations with lupus within the context of self-care. National online and brick and mortar lupus advocacy and support organizations promote self-care strategies for individuals, families, and support group leaders. These self-care strategies frequently recommend prioritizing personal needs first. They also focus on thoughtful meal preparation and balanced diets, incorporating periods of rest into daily routines, activities to monitor energy levels, time management, and guides to setting boundaries with loved ones. Women who had little or no control over their work schedules, worked in jobs that were physically demanding, served as primary care givers, lived in homes with high
levels of environmental irritants, or experienced long periods of economic insecurity did not feel they would ever be able to incorporate these types of self-care strategies into their daily lives. Venus, a thirty-one year old single mother employed by a local non-profit, described the added pressures of experiencing racism while living with a debilitating chronic illness.

“Do you know what I mean by ‘Spoon Theory?’...It’s this super bougie coping strategy people with chronic pain are supposed to do to keep track of their energy levels... Everyday you begin with twelve imaginary spoons...it takes you a certain number of spoons to do certain activities throughout your day...I think getting out of bed is one spoon, going to work is three spoons...At the end of the day you’re supposed to have one spoon left so you can relax and go to bed. When I first saw ‘Spoon Theory’ I thought: What if it’s ten in the morning and you’re already out of spoons? Do you call it a day and go to bed?...Where’s the black woman’s spoon test? It would need at least twenty-four spoons...Like one spoon for that look the rich white lady gives you when your kids misbehave in the check out line. Two spoons for casual racism in the workplace, three spoons for I can’t even today, and four spoons for something’s gotta give soon cause we can’t keep living this way...”

For Venus, and most of the other women interviewed for this project, the experience of living with lupus was not separate from the experiences of living with racism and sexism. This project used an intersectional approach to explore how social categories such as race, gender, age, and class affected healthcare options for African American women living with lupus. Early intersectionality scholars were interested in creating a conversation that brought attention how individual lives could be affected by multiple, overlapping forms of oppression (Crenshaw 1991, Collins 1998). The early intersectionality theory of the 1980s provided a framework to identify and discuss power and oppression. Twenty-first century intersectionality focuses on action and collaboration. This reframing of intersectionality as a methodological tool creates a space for action outside the academy (Cho et al. 2013, MacKinnon 2013, Carbado et al. 2013).
Intersectionality can be used to build relationships and coalitions between groups of people who have experienced different forms of marginalization and oppression but share goals of social change (Davis 2016, Carastathis 2013).

Race, gender, and class are three social categories regularly used to document the intersections of power and oppression. The women interviewed for this project overwhelmingly reported using shared experiences with racism and sexism as pathways to build strength and support between individuals and groups. Sharing illness experiences with each other was a way the women shared information about their illness and strategized self-care methods. They used their personal experiences with racism and sexism as a way to resist the illness narratives created by biomedicine, the healthcare system, and high profile lupus advocacy networks. Exclusion from the healthcare system and negative personal exchanges with individual healthcare workers were commonly cited as forms of racism. Specifically women believed they encountered racism when they were accused of drug seeking behavior during emergency room visits, tested for STIs, HIV, or given pregnancy tests before being tested for common chronic illnesses, and dismissed when they tried to share the notes they kept on their own symptom histories. Many were also frustrated they rarely had access to African American physicians, even though more than sixty percent of the city’s population was African American.

The women also shared similar experiences in regards to the ways in which their gender affected their diagnostic experiences, their treatment options, and the impact lupus had on their interpersonal relationships. Roughly half the women I interviewed received a lupus diagnosis as the result of enrollment in state-run maternal health programs. Most
women lost their individual coverage once their children were old enough to be placed in children’s wellness programs, thus they also lost access to physicians who could help treat lupus. Conversations in support groups often focused on gender specific issues related to health including wage gaps and employer based benefits, loss of healthcare access due to divorce, and the reality of living with lupus versus societal expectations of beauty. Overwhelmingly women reported feeling that physicians and loved ones initially linked their concerns about their health to motherhood. Women who experienced infertility or chose not to have children were told their pain was the result of the guilt or jealousy they felt as the result of their childlessness. Women who did have children were told their pain was connected to overprotectiveness or fear of their children’s independence.

The intersections of age and class played the most significant role in the relationships between the women with lupus interviewed for this project. Women over fifty had lived with lupus symptoms for years, if not decades. These women viewed lupus as a continuous thread in their personal histories since lupus affected their professional aspirations, their ability to have families, and intimacy in their interpersonal relationships. They claimed to have released much of their anxiety and fear and were eager to discuss their comprehensive self-care plans. Older women also viewed their experiences with lupus as a way to create intimacy and share knowledge with other women living with similar pain conditions. Older women controlled lupus support group spaces so their perspectives on the diagnostic process and self-care strategies frequently dominated group discussions.
Younger women were not eager to identify as lupus sufferers. Many did not believe lupus would keep them from achieving their goals or have a lasting impact on their lives. Younger women joined lupus support groups because they had been encouraged to join by members of their support networks, they were affiliated with an organization or church that encouraged them to attend, or they were struggling to access healthcare and were seeking advice. The younger women who agreed with the older women’s dominant discourse in support groups were given small advantages in the form of personal support or gifts. Younger women who questioned or confronted older women were frequently labeled “troublemakers” or subtly ostracized by the group. Despite the age related tensions, women of all generations were adamant that showing support for one another as African American women was more important than interpersonal tensions within support groups.

The way women loosely defined class was also closely related to age. Socio-economics was only one way the women appeared to define class. While markers of socio-economic status, such as home and car ownership or education were central to how women understood class within their own age cohort, those definitions were not the same across generations. Age itself became a marker of class between age cohorts. The class differences between age cohorts were also reflective of larger changes in labor, education access, and cost of living in the United States in the latter half of the twentieth century. Older women who had been able to find stable employment, accrue savings, and acquire material markers of middle class status despite their low levels of education defined themselves as middle class. Younger women were more likely to have higher levels of education, but fewer long-term, living wage, employment opportunities. They were also
more likely to have large amounts of personal, medical, and student loan debt. Younger women were more comfortable identifying themselves and others as working poor. Only women who had personal histories with families or spouses who worked in unionized industries identified as working class.

This project began as an exploration of two forces that were in constant states of change, the illness lupus and the United States healthcare system. Specifically, I was interested in investigating how people facing multiple social and political barriers, including racism, sexism, and economic insecurity faced uncertainty and navigated change. Lupus is an autoimmune syndrome that can affect any organ system in the body. The manifestation of the illness is unique to each individual and the symptomatic criteria used to diagnosis the illness are broad (Benedek 2007, Bertias et al. 2013). Chronic widespread pain, severe headaches, skin irritation and rashes, and chronic kidney infections are all common manifestations of lupus. The onset of symptoms, known as flares, may manifest in clusters or as individual symptoms. The types of symptoms and severity of flares can change over the course of a person’s life, thus making it challenging to design long-term treatment plans (Wallace 2009, Mendelson 2006). Although lupus more widely affects women than men, and is more commonly observed in women in their late teens through early thirties, lupus symptoms can manifest at any age (Petri et al. 2012, Yu et al. 2014).

Access to consistent, comprehensive, healthcare is essential to maintaining a good quality of life for individuals living with lupus (Zell Gillis et al. 2007, Yazdany et al. 2012). Individuals and families living in the United States who have limited access to private health insurance frequently find themselves interacting with an unstable
healthcare system (Becker 2007). Private health insurance has served as the primary healthcare delivery system in the United States since the middle of the twentieth century (Murray 2007). Since profitably is the goal of private health insurance companies, the types of services offered to clients is influenced by the cost of care incurred by the provider. When policies fail to produce economic returns for the company, benefits can be restricted or terminated (Quadagno 2006, Sered and Fernandopulle 2005). Poverty compounds chronic health problems for unemployed and underemployed residents who are unable to access or afford the same employer based health insurance options offered to their middle class colleagues (Murray 2007, Fletcher 2014). The combination of poor chronic health, economic insecurity, and restricted access to health insurance results in the use of higher cost emergency services as primary care facilities, less access to diagnostic tools and medications used to treat chronic illness, the rapid progression of illness, and poor prognoses for long-term health (Geronimus 2004, Baily et al. 2017).

Individuals and families who are unable to access or afford private health insurance are then placed in public sector programs that are frequently under funded and under staffed. The two-tiered healthcare system that exists between private and public healthcare services grants the wealthy and privileged access a wide variety of services, while the poor are offered inconstant care and fewer provider options (Becker 2007). Tennessee serves as a unique space to study the relationship between healthcare access and chronic illness because private insurers are responsible for providing services to the state’s public sector clients (Braverman et al. 2008). Unlike states that rely exclusively on state and federal taxpayer dollars to fund public sector programs, the services in Tennessee, known collectively as TennCare, are in a constant state of flux resulting from
ongoing negotiations between private health insurance companies and the state (Chang
2007). The TennCare system was introduced in 1994 as a way to address coverage issues
for the state’s large uninsured population as well as combat the state’s rising cost of
healthcare (Mirvis et al. 1995). Since participation in the TennCare system has rarely
been profitable for insurance companies, TennCare has experienced several large-scale
restructurings over the past twenty years (Chang and Steinberg 2014).

The system’s largest restructurings in 1999, 2002, and 2005 curtailed benefits or
ended services for tens of thousands of TennCare clients (Aizer et al. 2000, Farrer et al.
2007, Chang and Steinberg 2014). Since consistent access to healthcare is imperative to maintaining good health for lupus sufferers, participation in healthcare programs that do not provide comprehensive services vastly increases the frequency and severity of lupus flares (Yazdany et al. 2012, Katz et al. 2017). The introduction of the Patient Protection and Affordable Care Act (ACA) also changed the healthcare landscape at both the state and federal levels. While the ACA promised to provide insurance and services for the country’s under- and uninsured population, states had the ability to opt out of many of the services offered through federal programs. Tennessee’s elected officials used the presence of the TennCare system and existing relationships with private insurers as justification to forgo federally funded Medicaid expansion under the ACA (Harrtigan 2013, Goodnough 2014). The decision to decline federal assistance had significant ramifications for Tennessee residents who were unable to access health insurance through employers, did not meet TennCare’s economic enrollment requirements, or were unable to find affordable comprehensive care through the federal healthcare marketplace (Chang and Steinberg 2014, Garfield and Damico 2017).
In addition to studying women with lupus’ strategies for accessing healthcare through the changing TennCare system, I was also interested in the power dynamics that exist between low-status healthcare workers and TennCare clients. Critical anthropological studies of the United States in the last decade of the twentieth century examined how discourses on personal responsibility shaped social policy regarding welfare reform (Morgen 2001, Morgen et al. 2010, Collins and Mayer 2010). Research found that caseworkers’ perceptions of their clients deservedness to services played an important role in the types of assistance they were given when attempting to access services, and the information they were given in order to navigate bureaucracy (Morgen et al. 2010, Collins and Mayer 2010). Clients who were perceived as non-compliant were given less information regarding their options for social services (Collins 2008). African American women were frequently given the least number of options and perceived to be the most confrontational (Roberts 2008, Deeb-Sosa 2007). Since the language of personal responsibility that is present in debates surrounding welfare reform is also present in discussions of healthcare reform, I was interested in whether or not the power dynamic that existed between welfare caseworkers and clients also existed between healthcare workers and TennCare clients.

While I initially started with two distinct research samples, healthcare workers and TennCare clients, interactions between the two groups changed depending on setting (personal or clinical) and the type of coverage the client was receiving. Getrich and associates (2017) argue that while the focus on personal responsibility in both welfare and healthcare reform debates attempt to create an ahistorical landscape free from structural barriers, the circumstances surrounding each type of reform are different.
Welfare caseworkers have more direct, prolonged, contact with clients and far more power in the decision making process regarding the client’s access to services. The power relationship between caseworker and client is linear in the sense that the caseworker’s perception of their clients plays a role in their desire to provide information and access to resources (Morgen et al. 2010, Collins and Mayer 2010). The power dynamics that shape relationships between clients and healthcare workers is more diffuse. Clients navigating the healthcare system must contend with a variety of interrelated, but separate, institutional entities in order to access care (Lamphere 2005, Willging 2005). While a social worker or caseworker may hold power in the context that they help clients enroll in programs or control certain avenues of communication, they do not have power in clinical spaces. Clinicians have power in determining the cause of illness and the course of treatment, however their decision making process is not necessarily influenced by their clients ability to pay for treatment or access medication (Werner and Malerud 2003).

Since one of the primary goals of this project was to explore the social factors that created opportunities or barriers for women living with lupus, I reduced my time in clinical spaces and state offices in order to spend more time in community spaces that served as networks of support for women with lupus.

The narratives of healthcare workers are not featured in this dissertation, however my daily interactions with healthcare professionals played a vital role in my ability to navigate spaces affected by poverty, racism, and segregation. Feminist and critical race scholars call for a reimagining of intersectionality that extends beyond an intellectual academic framework. They argue that intersectionality can be used as coalition building framework used to foster communication between groups of people who can offer
different perspectives while also supporting one another as a catalyst for social change (Mullings 2013, Carastatis 2013). In this sense the pragmatic application of intersectionality calls for the methodological framework of research to be shaped by the experiences of participants rather than relying exclusively on intellectual frameworks tied to the academy (Cho et al. 2013). During the twenty months I spent collecting data for this project, the first year focused largely on learning from the women I interacted with on a daily basis and building rapport with residents in low-income and working class neighborhoods. The second year focused on reframing research objectives and conducting formal interviews.

Of the healthcare workers I interviewed, social workers made the largest contribution to this project. Two social workers in particular played a significant role over the course of my time in the field. Within weeks of arriving in Memphis I was introduced to Anita¹, a supervisor and informal matriarch to a group of predominantly African American, politically engaged, social workers. Anita had spent her college years at Fisk University engaged in activities connected to the Civil Rights Movement. She enjoyed subtly disrupting racialized and gendered power dynamics in staff meetings and viewed her position as a supervisor as a way to support younger African American professionals. Anita introduced me to Michelle, who quickly became a close confident and mentor as I interacted with women living at the margins of their communities. Michelle was raised by a single father in a government subsidized, North Memphis, housing community. Her childhood relationships with social workers shaped her belief that social workers could serve as a voice for political and social change. Anita, Michelle,

¹ All names have been replaced with pseudonyms.
and a small group of their colleagues played pivotal roles in shaping my understanding of Memphis’ social and political landscape. By shadowing the social workers I learned how to enter communities, how to engage with residents, and how to discretely document emotionally painful or traumatic events. The social workers also trained me how and when to speak (or not speak), what to wear, and how to be humble and compassionate with challenging interviews.

Shadowing the social workers involved a wide variety of activities. While I did not attend home visits with clients, I did accompany them to meetings, spent time in clinical spaces where they met with clients, and attended events where they networked with members of the communities they serviced. The social workers eventually began inviting me to their bi-weekly breakfasts. Initially my role was to listen and take notes. I served as the informal secretary during many of our social interactions and Anita or Michelle would ask me to reference my field notes in order to back up their arguments during staff meetings. Eventually I was included in group texts and asked for sources that might be helpful during their own grant writing processes. Although I built relationships with Anita and Michelle quickly, the other women in the group only started sharing their personal opinions with me after I had been part of their network for close to a year.

Similarly, I spent up to a year interacting with working poor, working class, and middle class women living with lupus before they began to include me in their discussions and activities. Over the course of my fieldwork, I regularly attended three support groups. Of these groups I had the most intimate and sustained contact with the women of Morningside Baptist Church. The seventeen months I spent attending meetings and church events helped shape the final direction of this project. Building rapport with
women living with lupus progressed slowly. I was in regular contact with the women at Morningside Baptist Church for roughly a year before I was able to interview support group members. In the year leading up to my involvement with the group, I volunteered at the church, spent time in the church’s offices, and attended affiliated support groups. Morningside Baptist Church has a long history of civil rights engagement and extensive experience with researchers. Church staff created a comprehensive set of volunteer requirements interested parties needed to fulfill in order to conduct research with church members. Volunteer opportunities not only allowed church staff to vet and train potential researchers, it also provided free labor for a facility that offered a broad range of social, spiritual, and legal services for the surrounding community.

Three major intellectual themes emerged from this project: racism, resistance, and resilience. Fifty-one women living with lupus were interviewed for this project. Forty-five women directly tied their chronic poor health and frustrations with the healthcare system to structural forms of racism. Their descriptions of chronic poor health extended beyond their ability to access clinical resources. They frequently connected social and environmental issues to racism that included chronic under- or unemployment, prolonged periods of psychosocial stress, and limited availability to specialists and medications needed to treat lupus. The limited availability of reliable, permanent healthcare resources in poor communities have been widely documented as contributors to poor chronic health issues for African American women (Mullings 2002, Becker et al. 2004, Geronimus 1992). Social science and public health scholars have also connected these patterns of

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2 A more extensive discussion of these requirements is outlined in Chapter Five.

Social issues, including local reactions to the events that unfolded in Ferguson, Missouri in the summer of 2014, also shaped the final direction of this project. While many of the women I interviewed either renewed their interest in public protest or engaged in political activism for the first time, not all resistance came in the form of direct action. Charles Briggs and Clara Martini-Briggs (2016) use the term biomediation to describe a coproduction of knowledge between medical professionals, lay media depictions of health, and the personal narratives of communities affected by health crises. Communities experiencing health crises resulting from social exclusion, including racism, create their own health narratives to draw attention to inequities (Briggs and Martini-Briggs 2016). Lupus support groups served as a space where participants could construct, circulate, and record knowledge based on their individual illness experiences rather than relying exclusively on the authority of medical professionals.

The women who attended the lupus support groups created illness narratives that called into question the relationship between biomedicine and whiteness. They connected issues of access to care and advancement of lupus symptoms to historical and current forms of racism. Since they believed they would not receive recognition as full citizens by current institutional standards, they were interested in changing the structures and systems that perpetuated inequality rather than conforming to existing healthcare models. For example, they understood health insurance created a pathway to much needed medication or access to specialists that might improve their quality of life. However, working class and working poor women felt a system relying on care through private
insurers was a “white” system of care. They actively sought to find other care options that allowed them to use the resources that met their individual needs but did not require full or sustained participation. They sought care from physicians and facilities that provided samples of prescription medication, shared medication, and compared strategies to circumvent predatory billing practices.

Catherine Panter-Brick (2014) writes that qualitative research using a multisystems approach is vital to discussing resilience. While the concept of resilience has been used to critique the victim blaming risk model in intellectual literature, Patner-Brick argues that without collaboration from a multitude of participants, resilience as an intellectual framework runs the risk of becoming two-dimensional. With collaboration between researchers and participants, resilience can be conceptualized as an agency based series of survival strategies identified by the individuals sharing their experiences (Mullings and Wali 2000, Panter-Brick 2014). Over the course of this project it became apparent the living with lupus is an experience shared between family members and within communities. Caring for women with lupus was viewed as a community activity and passing on knowledge from one generation to another was vital to maintaining personal and community well-being. Knowledge of autoimmune syndromes and how to treat lupus symptoms circulated within family units where the illness affected multiple generations. Ultimately, discussions of lupus initiated both by women living with the illness and their support systems were discussions of health inequalities, historical forms of social exclusion, and community building exercises. The ethnographic work presented in the following chapters is the result of a collaboration between the researcher and a diverse group of women who gave their time and stories in order to illuminate the
complicated relationship between health inequalities, chronic health conditions, and a changing healthcare system.

Chapter Two provides an overview of my fieldsite, data collection techniques, and analytical framework. Memphis is Tennessee’s largest and most racially diverse city. The city has a long history of racialized oppression and injustice dating back to slavery and plantation agriculture, continuing through Jim Crow segregation, and reinforced in late capitalism. Memphis also has a public and well documented history of resistance during the Civil Rights Movement. In addition to discussing why the city of Memphis provides a unique backdrop for the shared experiences of research participants, Chapter Two also provides a discussion of the research samples and in depth examination of how research objectives evolved between the fall of 2013 and the summer of 2014.

Chapter Three provides an overview of the bodies of literature used to inform the research objectives and ground research findings. The field of anthropology has a long and complicated relationship with the social construction of race. Since the early twentieth century, U.S. based anthropologists have drawn attention to social inequality and critiqued arguments that present race as a biological phenomenon. Ethnography has played an important role in intellectual and legal discussions of racism and civil rights. U.S. anthropology has also made significant contributions to the study of inequality in urban spaces and the social origins of health inequalities. This chapter also provides an overview of intersectionality, the analytical framework used for this project.

Chapters Four through Six use ethnography to detail the complicated relationship women with lupus have with their health, the system that is supposed to provide care, and their communities. Chapter Four explores how structural racism and classism contribute
to health inequalities in the United States. This chapter focuses on the specific histories of two African American women, Patrice and Rosemary. Each woman was in her mid-sixties in 2014 and had been living with lupus symptoms for more than three decades. While both women had struggled with lupus for most of their adult lives, their class backgrounds influenced their access to healthcare. Patrice, a middle class woman, participated in one of the nation’s first lupus studies. Her story explores the shifting boundaries used to identify and diagnose lupus, as well as the racist history of medical research in the United States. Rosemary, a working poor woman, had moved in and out of the TennCare system since 1995. Her story illustrates how shifts in healthcare access affect economic stability for the working poor and compound chronic health problems.

Through the narratives of women attending support groups at Morningside Baptist Church, Chapter Five explores issues of building and circulating knowledge about lupus. Morningside is an economically and politically diverse, historically African American neighborhood in North Memphis. The neighborhood and the church have a long history of caring for the poor and building community through direct action projects. The women attending Morningside’s chronic pain and lupus support groups connect their illness to racialized violence aimed at African American communities. Although their personal struggles differ, they attempt to write a community narrative that addresses poor health as a form of racism. This chapter investigates the tensions that exist between middle class and working poor women living with chronic pain and follows the transition the closed lupus support group experiences in the wake of interpersonal issues between members.

Chapter Six focuses on intergenerational support networks. Although U.S. medical establishments view lupus as a relatively new illness, African American women
regularly reported knowing of others who had been living lupus or lupus-like symptoms for generations. Media made for and by African Americans also share a narrative of lupus that focuses on caring and empowerment. This alternative narrative contradicts the dominant white media illness narrative that presents lupus as mysterious and frightening. Passing down knowledge from one generation to the next and sharing self-care strategies was an important part of the experience of living with lupus for African American women who participated in this project. Lorraine and Kendra are a mother and daughter both living with lupus. Their story exemplifies the ways in which knowledge is shared between generations and how chronic illness creates barriers for economic stability and class mobility.

Chapter Six also features stories of Tanisha and Leia, two young women who left the Morningside Baptist Church lupus support group. Their stories are used to illustrate the evolution of relationships formed around a common illness into a relationship based in a shared desire for political change. In 2014 and 2015 Tanisha and Leia became increasingly involved with political activities tied to Black Lives Matter. Each young woman’s experiences with racism related to her illness resulted in her involvement in anti-racist justice movements. Each of these ethnographic chapters feature examples of not only how lupus affects women’s daily lives, but also shapes the forms of resistance they employ in their daily interactions and activities.
Located on a bluff above the Mississippi River, the city of Memphis was once one of the wealthiest cities in the southeastern United States. As the largest city in the Mid-South region, Memphis was a hub for trade during the nineteenth century. Cotton, livestock, and produce destined for markets across the United States traveled through Memphis on a daily basis. The slave trade was also an important part of the Mid-South’s plantation agriculture economy, and the city facilitated transactions for human lives and labor. After the Civil War, the city’s wealth began to decline. Following Emancipation, mass migration of newly freed blacks created a flood of new residents the city was not equipped to feed or house. Many of these new residents were temporary, as promises of social and economic opportunities encouraged further migration to the north and west. In the years following the Civil War, as city’s regional power began to wane, affluent black residents moved to Memphis in hopes of increasing their wealth through agriculture, shipping, and real estate (Sanford 2017).

Poverty continued to replace prosperity as the nineteenth century grew to a close. As a port city, bars, juke joints, and brothels had always been important avenues of entertainment in the downtown area. As trade wealth began to diminish in the city, Memphis gained a reputation for violence and corruption (Lauterbach 2016a, Wedell 1991). Infectious disease also had a dramatic impact on the city in the late nineteenth century. Memphis encountered a number of widespread infectious disease crises, ranging from malaria to influenza. The city experienced six major yellow fever epidemics over the course of the nineteenth century. The most devastating of these epidemics occurred in 1878, claiming the lives of more than five thousand residents (Wailoo 2001). In the
wake of the yellow fever epidemic, the city enacted new public health measures that changed the physical landscape of the city. New roads and sewer systems were built. Closely spaced, low-income housing was demolished. These new measures pushed poor residents to the periphery of the city, and created physical, segregated, boundaries that are still visible more than one hundred years later (Rushing 2009, Wailoo 2001).

From the late nineteenth century until the middle of the twentieth century, Jim Crow laws dominated the southeast. Jim Crow laws were state and local policies and ordinances that legally enforced racial segregation. Examples of Jim Crow laws in Tennessee included segregated schools, hotels, railcars, streetcars, and healthcare facilities. Marriages between blacks and whites were deemed a felony, and poll taxes and literacy tests were used to determine whether or not citizens had the right to vote (Strub 2007, Sanford 2017). E.H. Crump, one of the city’s most polarizing public figures came into power in the early twentieth century. Known locally as “Boss” Crump, E.H. Crump began his political career as the mayor of Memphis from 1910 until 1915. He was then elected to a position within the state legislature and eventually earned a position in the U.S. House of Representatives. Although Crump was only mayor of Memphis for a short period of time, the political machine he created gave him the power and influence to shape the outcomes of Memphis mayoral races from the late 1910s until his death in 1954 (Dowdy 2006).

Crump was able to maintain power over the decades by soliciting black voters. Crump, a Democrat, ran as a progressive who was invested in creating a dialog across racial divides and including the city’s black elite in local decision making. Memphis was unique amongst Southern cities at the end of the Civil War. In the years following the
war, a wide range of industries, including construction, hospitality, law, and medicine, led to the growth of a powerful black middle class. The city’s highly educated and economically prosperous black professionals, business owners, and church leaders resulted in an active black voting population (Sanford 2017, Strub 2007). Crump successfully courted black voters by promising public works projects that benefited black communities and publicly admonishing openly racist political gatherings (Dowdy 2006). He also included influential black leaders in his inner circle, and sought their opinions on issues regarding predominantly black neighborhoods. Under Crump, Memphis was portrayed as a model Jim Crow city. A city where “separate, but equal” was enforced, but multi-racial harmony was possible (Dowdy 2006).

Although his supporters celebrated Crump’s influence as a time of harmony and acceptance, the “benevolent paternalism” of the Crump era subverted the mechanisms that kept racial inequality in place (Sanford 2017). In his memoir, Black Boy (2007 [1945]), acclaimed author Richard Wright recounts his childhood experiences in Crump influenced Memphis during the 1920s. Wright depicts a city where poor, black residents were fearful of the police and local leaders, subjects to frequent violence, and unable to find employment or food. Like many new arrivals to the city in the first half of the twentieth century, Wright, his mother, and his brother moved to Memphis from Mississippi after his father left the family in order to find work in more prosperous parts of the country. The family lived in loud, poorly ventilated, tenement housing. They frequently skipped meals and Wright’s mother worked irregular hours for poverty-level wages. Wright spent his youth working odd jobs at local bars and juke joints. He lived in constant fear that local bullies would rob him of what little food and money he had
been able to acquire for his family. In addition to the issues he faced in his neighborhood, Wright and his friends spent their time avoiding contact with Crump’s corrupt business associates and the city’s violent police force (Wright 2007 [1945]).

While Crump publicly promoted unity, his administration strictly adhered to the “separate, but equal” boundaries of Jim Crow segregation. When black elites approached the administration about creating a park for black residents who were barred from whites only parks, Crump agreed. The city built Douglass Park for black residents in 1913. The park was located on the very edge of the city, making it inaccessible to those who did not have transportation or money to ride the trolley. Unlike many of the parks located in white neighborhoods throughout the city, Douglass Park did not receive funds that would allow the community to pay for maintenance (Sanford 2017).

In 1935, when Memphis became the second city in the United States to institute a public housing program, Crump associates proactively sought funds to build block housing for the city’s poor residents (Lauterbach 2016a). The zoning for the new public housing blocks forced middle class black homeowners out of their neighborhoods (Sanford 2017, Gritter 2010). When influential black community members challenged the city’s new housing programs, they were expelled from Crump’s inner circle. When black elites questioned Crump or his associates, they were censored, or publically slandered in the press (Strub 2007, Lauterbach 2016a). Through the mid-twentieth century, Crump cronyism destroyed physical representations of black power and wealth in the city through policies and laws that advantaged white residents.

In 1953, as part of a routine training session, the Memphis fire department burned, and then demolished, an old mansion located in a predominantly black neighborhood on
South Lauderdale Street in South Memphis. The house had once belonged to Bob Church, one of the South’s first black millionaires, an ardent Republican, and a confidant of E.H. Crump. Church had been an influential political figure in the city’s black churches and promoted Crump policies. When Crump no longer needed Republican allies in the black community, Church was accused of spreading radical social agendas and as a consequence lost many of his business holdings and contacts. The dismantling of Church’s fortune, and the burning of the home that he built were viewed by black Memphis residents as a systematic dismantling of black power in the city (Preston 2016).

In the 1960s and 1970s, Memphis played an important role in the Civil Rights Movement. The sanitation workers strike and the subsequent assassination of Martin Luther King Jr. are the city’s most recognizable civil rights moments. However during the fight for civil rights, residents throughout the city participated in sit-ins, protests, and the Freedom Rides that targeted communities further south. The city’s powerful and affluent historically black churches were instrumental in providing funding and safety for high profile civil rights leaders (Honey 1993, Robnette 2000). Church communities played an important role in local civil rights efforts. Not only did church leaders use their influence to organize members of their own communities, churches also continued the tradition of creating safe spaces for black community members engaged in the struggle for civil rights (Peniel 2009). Black middle class youth, largely educated at historically black colleges and universities (HBCUs) throughout the South, formed a local resistance group known as the Invaders. The Invaders’ commitment to local resistance efforts were inspired by other Black Power organizations and leaders, including Malcolm X, the Black Rangers, and the Black Panthers. Like many other Black Power groups during the Civil
Rights Movement, they also became targets of the U.S. government and the FBI. Well established faith-based power structures showed little support for the Invaders (Sanford 2017). Many of the alliances built during the Civil Rights Movement are still active in the city today and play an important role in continuing an anti-racist dialog.

Twenty-first century Memphis is a sprawling metropolis encompassing nine counties in three states. The city now extends far beyond the Mississippi River. While the river is still an important part of Memphis’ history and image, it is not necessarily central to residents’ daily routines. Memphis is as much a rural space as it is an urban space. The smaller communities and neighborhoods that comprise the larger metropolitan area are joined together by highways and interstates crisscrossing current and former farmland. In the twenty-first century, Memphis is still a diverse, tense, and heavily segregated city. Physically, the city is built on a modified spoke and wheel design that extends for miles to the east, south, and north of the river. Poplar Avenue, one of the city’s major east/west arteries, reveals a diverse cross-section of the city.

Poplar Avenue begins near the banks of the Mississippi River, in the city’s neon encrusted, New Orleans inspired, Beale Street tourist district. Beale Street, once the home to numerous black-owned businesses, is now filled with bars, gift shops, and carnival-like attractions promoting the history of the local music industry. Exiting downtown and traveling east outside the city’s core, Poplar Avenue winds through tangled streets and overpasses. The road runs alongside railroad tracks, past abandoned warehouses, and run-down strip malls that once serviced the prosperous cotton and textile industries. Barren parking lots have been transformed into pop-up retail spaces, selling

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3 See Appendix A, Figure 1.
4 See Appendix A, Figure 2.
everything from bootlegged movies and clothing, to fresh produce and barbecue. These impromptu retail spaces are located at major intersections linking Poplar Avenue to the city’s low-income and working class, predominantly African American, North and South Memphis neighborhoods.

Soon the road narrows in order to accommodate the newly painted bike lanes that run alongside well-maintained sidewalks and streets. Renovated Craftsman style homes, pre-war apartment buildings transformed into luxury condominiums, and kitschy boutiques and restaurants demarcate Memphis’s aggressively gentrified, mostly white, Midtown neighborhoods. As Poplar Avenue climbs a slight hill, Midtown’s tree line abruptly ends. Midtown’s lush greenery gives way to the pavement, gas stations, and fast food restaurants that serve as an entrance to East Memphis. Rows of poorly maintained strip malls adorned with LED lights house pawnshops, gun stores, soul food kitchens, and check cashing outlets. This section of East Memphis is a mixture of residential and commercial spaces. Signs posted along the street advertise work and housing in a number of different languages. East Memphis is an economically diverse part of the city, and the central branch of the public library and sterile, high-rise office buildings create a physical barrier between East Memphis’ low and middle-income neighborhoods.

Poplar Avenue once again widens as it stretches into a large, commercial retail district. This section of the road serves as a central shopping and entertainment space for middle class, mostly white, Memphis residents living near the city’s universities, older affluent neighborhoods, and suburbs. As this retail corridor ends, Poplar Avenue splinters. The main road crosses over I-240 into the Memphis suburbs. Poplar Avenue winds the length of Germantown, one of the city’s oldest affluent suburbs. As it
continues to travel east, Poplar Avenue eventually branches into a number of smaller roads that travel past large estates and into smaller, rural communities.

**Research Objectives**

Data was collected during the initial introduction of new federal healthcare guidelines accompanying the ACA. In 1994, Tennessee became one of the first states in the nation to privatize their state-level public sector healthcare programs (Mirvis et al. 1995). Over the past two decades, the system of services, known as TennCare, have included a range of services, most notably coverage for the state’s 1.6 million Medicaid and CHIP recipients (Kaiser Family Foundation 2017). Since the availability of TennCare services is linked to contracts negotiated between the state and private health insurance companies, eligibility guidelines and services covered by TennCare change frequently. I chose systemic lupus erythematosus (SLE), the most common form of chronic autoimmune syndromes known as lupus, as the vehicle through which to explore the challenges of navigating the TennCare system. Since the symptomatic expression of lupus is frequently case specific and changes over the course of an individual’s life, documentation of symptomatic flares and access to consistent, reliable medical services is paramount to receiving a diagnosis and maintaining a good quality of life (Zell Gillis et al. 2007, Yazdany et al. 2012). This project documented social factors; including racism, gendered exclusion, and class hierarchy that affect chronically ill African American women’s ability to treat their lupus using the TennCare system.

There were three overarching research questions guiding this project. First, I was interested in exploring how women living with lupus determine their daily survival strategies. I began by exploring how living with lupus affected individual women’s daily lives. The daily survival strategies for chronically ill women extended beyond their
ability to access medical facilities and medication (Mullings and Wali 2000, Adair 2002). Lines of inquiry for this question included an exploration into women’s economic stability, experiences with racism, and their ability to call upon personal and professional social networks during times of illness. Instead of recording the lived experience of pain, I was interested in documenting the pragmatic, material ways women with lupus cared for themselves during symptomatic flares.

Second, I was interested in exploring the impact women’s personal and professional networks had on their ability to create sustainable self-care strategies. Living with lupus is not an autonomous experience, since women with lupus must rely on an extensive network of support (Whitehead and Williams 2001, Mendleson 2003, Williams et al. 2017). This question was originally focused around the ways in which networks support women with lupus as they navigate clinical experiences. I was ultimately only able to interact with women in clinical spaces sporadically. By the end of my first year in the field it was apparent that personal spaces, not clinical spaces, shaped women’s definitions of lupus as an illness and influenced the self-care strategies they employed to cope with lupus flares. Lines of inquiry and observation tied to this question explored what public and private places women with lupus identified as spaces that promoted self-care and what role larger neighborhood organizations played in caring for chronically ill members of their community.

Finally, I was interested in how the introduction of the ACA could possibly impact the TennCare system. This question included interviewing not only women using the TennCare system as their primary care provider, but also the women who provided information to TennCare clients. This line of inquiry focused heavily on the experiences
of social workers, staff in low-income clinics, and Medicaid caseworkers. This question began as an attempt to understand the tensions that existed between healthcare workers and their clients. However it ultimately grew into an exploration of the barriers healthcare workers faced during a time of change and uncertainty. Although the narratives of healthcare workers are not included in the following ethnographic chapters, their responses to questions regarding gender exclusion and racism were similar to the responses given by the women living with lupus.

This project used an intersectional analytical framework. Intersectionality recognizes that individual women’s experiences and social locations are shaped by larger, overlapping social categories including race, gender, class, nationality, sexuality, and age (Crenshaw 1991, Collins 2000, McCall 2005). This approach draws attention to the fluidity of social categories by linking historically based forms of inequality to existing social, political, and economic institutions (Crenshaw 1995, Hankivsky and Cormier 2011, Risman 2004). An intersectional approach does not merely examine difference, it provides a framework to identify and analyze oppression (Davis 2016, Cho et al. 2013).

The women who participated in the project hailed from diverse backgrounds and educational histories. They were affluent, middle and working class, and working poor. They ranged in age from twenty-two to seventy-three. Although their individual experiences with oppression were different, the women all agreed that racial oppression and exclusion were important to their daily experiences.

**Project Overview**

Data for this project was collected between August 2013 and March 2015. Follow-up interviews and additional data collection were conducted during the summer
of 2015. Final analysis began late July, early August 2015. There were two interview samples for this project, and seventy-two individual interviews. Fifty-one interviews were conducted with women living with lupus, and twenty-one interviews were conducted with healthcare workers. My primary sample consisted of women who had formally been diagnosed with lupus, or were living with active lupus-like symptoms. State healthcare workers and social workers employed by Tennessee’s private Medicaid program, TennCare, were interviewed about changes in state and federal healthcare programs during the introduction of the ACA. Additionally, the social workers I interviewed legitimated my presence in low-income neighborhoods. Although these women’s stories are not featured in the final version of this dissertation, their contribution to this project was significant since they served as liaisons and introduced me to community members working with projects that linked poverty and poor health. Their responses to questions regarding their experiences with racism and the strategies they employed in order to navigate racism in their daily lives were similar to the responses given by the women living with lupus.

I drew my samples from residents living in Memphis, Tennessee and the surrounding metropolitan area. The city of Memphis is located in Shelby County, Tennessee, however the Memphis metropolitan/statistical area includes nine counties spread across the states of Tennessee, Mississippi, and Arkansas (U.S. Census Bureau). Since residents living in all nine counties use health resources located in the city of Memphis, it was important to interact with residents living in northern Mississippi and eastern Arkansas. TennCare services are only given to Tennessee residents and fifty-six

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5 See Appendix B for outline of research phases.
interviewees lived in Tennessee. Fourteen of the twenty-six Mississippi residents interviewed revealed they were currently listing family members’ Tennessee residences as their primary address in order to gain access to TennCare or other healthcare resources. An additional seven women living in Mississippi reported they had claimed Tennessee residence at some point during their adult lives in order to use TennCare services. Travel between the three states was fluid, since many residents lived in one state and worked in another.

All seventy-two individual interviews were conducted with women. I was in contact with healthcare workers for three months before they were approached for interviews. Healthcare workers viewed me as a colleague and we frequently discussed academic literature on inequality. Middle class women with lupus knew me for approximately six months before we agreed to an interview. On average, the middle class women fell into an age cohort of thirty-five to fifty. Since I was part of that age cohort, we were able to relate to one another as peers who had similar experiences with Tennessee’s healthcare and education systems during our youths and early adulthoods. Working class and working poor women interacted with me for approximately twelve months before we discussed individual interviews. I generally allowed these women to approach me if they were interested in being interviewed.

Fifty-seven of the seventy-two women I interviewed self-identified as African American or black. Two healthcare workers born and raised in Sudan also identified as black. While African Americans comprise sixty-three percent of the city’s population, several factors contribute to the high percentage of African American women interviewed for this project. Entry-level healthcare workers, or workers who are assigned caregiving
roles are frequently women (Smith 2010, Susser 1997). African American women are more likely to occupy low-status, or lower wage professional positions than their white colleagues (Duffy 2005, Williams 2004). African American women are also four times more likely to live with lupus than other group of people in the United States (Toloza et al. 2011). Since they are also the group most likely to live in poverty in the United States, they are also the largest demographic using public assistance programs (Morgen et. al. 2010, Collins and Mayer 2010). Additionally nine interview participants identified as white, two identified as Latina, and two identified as Korean American.

The two research samples drew from women from different socio-economic backgrounds. Healthcare workers were middle class or working class, while the lupus sample ranged from middle class to working poor. Although some women interviewed disclosed their financial earnings, class is defined more broadly than socio-economics. Education and home ownership were two categories interviewees used to identify class. Of the fifty-one participants living with lupus, nineteen women owned their homes and thirty-two lived in rental properties. All homeowners were over forty years old, and all but two were married and living in two income households. Middle class homeowners were concentrated in East and North Memphis neighborhoods, while working class homeowners were more likely to live in South Memphis or northern Mississippi. Twenty-eight women with lupus claimed they had been transient or homeless at some point in their adult lives.

Forty-eight of the fifty-one women in the lupus sample had completed high school or obtained a GED. The remaining three women had completed education through the

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6 Class status determined by self-reported data.
eighth grade. These women were all over sixty-five at the time of their interviews.

Women in the thirty-five to forty-nine age cohort had the highest levels of education and were more likely than women in other age cohort to work in professions where they had access to private health insurance or long-term TennCare enrollment. These women had the widest range of educational experiences and the broadest access to state education programs during their youths and young adulthoods. Women in the youngest age cohort experienced the greatest disparities in educational opportunities. Women in their early to mid-twenties had access to college and vocational training at far higher rates than women in their late-twenties and early thirties. Differences in educational opportunities frequently caused tensions between women in the younger and middle age cohorts.

Pseudonyms are used in order to protect the identities of research participants. Participants were allowed to choose their own pseudonyms. In order to protect the privacy of research participants, community identifiers such as the names of churches, schools, or offices have been changed or omitted. Memphis is divided into quadrants identified by the four cardinal directions. Within those quadrants people identify themselves and others based on neighborhood affiliation. My time was divided between North, South, and East Memphis. West Memphis is located in Arkansas. It is geographically and socially separate from other parts of the city. My time in West Memphis was limited.

Due to racial and class based tensions in Memphis, geographic identifiers are important to the accompanying narratives. Identifiers such as North, South, and East Memphis, as well as Northern Mississippi, are used to create a context for narratives.
discussing race and racism. When discerning conversations regarding issues of race and class, especially in the early months of my fieldwork, potential research participants used these directional descriptors until they were comfortable enough to discuss specific locations or neighborhoods. Throughout the following chapters, Northern Mississippi is used in reference to all narratives connected to DeSoto or Tunica Counties. Reference to specific counties, offices, or meeting spaces where I observed healthcare workers or participated in ACA strategy sessions have been omitted.

**Data Collection**

*Participant Observation:* Participant observation allows the researcher the opportunity to collect detailed field notes, which are then used to help contextualize the information gathered in formal interviews, as well as create ongoing relationships with research participants (Bernard 2006, Emerson et al.1995). As part of my initial exploration of the city, I began spending time in public spaces in and around healthcare facilities. This included the waiting room of the city’s only public hospital, waiting areas in grocery store clinics, and community health fairs. The purpose of these activities was not to recruit participants. Rather, I was interested in what resources were available to under- or uninsured residents and to what extent people were using those resources. Due to the restrictions placed on many TennCare plans, I was interested in learning where TennCare clients were seeking services. Since I was not using these spaces to speak with

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7 North and South Memphis neighborhoods are coded as black, while East Memphis neighborhoods are considered white, or occasionally Latino. The suburbs are coded as white. Within my research samples, indicating that someone lived in Midtown was considered an insult. This was likely connected to the gentrification that had occurred in Midtown neighborhoods during and after the Recession. Although I lived in a racially integrated, working class, East Memphis neighborhood, I was often labeled a “Midtown girl” during my first six months in the city due to both racial and class markers.

8 Over the course of this project I conducted interviews with northern Mississippi residents in the towns of Olive Branch, Southaven, Hernando, Tunica, and Clarksdale.
specific people about their experiences, I cannot speak to whether or not clients felt these
types of facilities provided quality care.

Interestingly all of these spaces shared one important feature, they all lacked
privacy. While clients were granted a moderate level of privacy when they met with a
physician, sensitive discussions regarding the health of poor clients was frequently
conducted in public. When the emergency room was busy, receptionists, nurses, and
orderlies called for clients using loud voices. Caseworkers explaining benefits to clients
regularly had to raise their voices in order to be heard over the ambient noise in the room.
Physicians were observed huddled at the edges of waiting rooms discussing ill or injured
clients’ conditions with loved ones. Clients who were waiting on transportation might sit
in the waiting room for hours after they had been released. They talked candidly with one
another about their illnesses and injuries. Waiting spaces in grocery store clinics were
usually located in open shopping areas. In some cases, clients were able to sit partially
shielded from shoppers in pharmacy waiting areas. However, most chairs or benches
connected to the clinics were located at the end of shopping aisles featuring personal
hygiene products or over the counter medications.

Health and wellness fairs arranged potential clients in groups or lines according to
their specific needs. Clients sat in chairs, leaned against walls, and socialized with one
another as they waited for their turn. When clients’ names were called they handed the
appropriate healthcare worker their paperwork and were led to semi-private spaces in
school gymnasiums, public libraries, and church fellowship halls. While some services
were conducted privately on mobile units in parking lots, it was not out of the ordinary to
see clients have their vitals taken, report their medical histories, or weighed in public.
Once I had established regular contacts, I began to actively participate in activities that would facilitate further introductions. I began volunteering at two citywide organizations that focused on addressing issues of economic inequality in underserved communities. Volunteers in these organizations were predominantly middle class black and white women. Working class and working poor volunteers representing North and South Memphis churches were also highly visible in these organizations. Through these organizations I began to meet contacts working in churches with strong community outreach programs. I began interacting with church staff and volunteering for church community outreach events. During this time I also began shadowing state employees working with TennCare clients.

The final stage of participant observation involved engaging with lupus support groups and spending time in participants’ personal homes. During this time I was introduced to the larger support networks that care for women with lupus. I attended family gatherings, assisted with meal preparation, and helped put children to bed. I was invited for holidays and “ladies night” activities. I became recognizable to business owners in my own neighborhood and talked with them about the issues facing our neighbors and community. I was invited into closed spaces with healthcare workers with whom I had formed a close bond.

**Group Settings:** Group settings played an important role in long-term participant observation, building rapport, and recruiting potential participants. Group settings and conversations also gave me a unique opportunity to observe the power dynamics in interpersonal relationships. I did not actively organize group activities or focus groups. I was invited into different spaces over the course of my time in Memphis. For the purpose
of this project, group settings can be divided into two categories. The first type of group setting I observed were casual interactions between groups of friends or colleagues. These interactions occurred in public common spaces, such as break rooms, waiting rooms, and shared activity spaces within organizations or offices. Since these spaces were public, I was able to observe and take notes with relative anonymity.

The second type of group setting was organized around a shared goal or purpose. Common examples of these types of settings include social events organized by research participants, topically specific professional strategy sessions and meetings in state offices, and illness related support groups. Participants in these settings were made aware of my presence and my research objectives. They were allowed to ask questions and refuse my presence if they felt uncomfortable. Staff meetings concerning the ACA and TennCare were frequently audio and video recorded in order to share information with rural counties that did not have regular representation in state government training sessions. In these cases, I was able to access recordings as a matter of public record and did not need additional consent.

Support groups played an integral role in my ability to meet and speak to women with lupus. In most support group settings my role was as a silent observer. Over the course of my research I had contact with three support groups. One group in East Memphis and one group in North Memphis were specifically tailored to address lupus related issues. The third group encouraged participation from community members living with any type of chronic pain condition. The chronic pain support group was affiliated with the North Memphis lupus support group. I was allowed to audio record the East Memphis group on fifteen occasions over the course of sixteen months. I attended
the chronic pain support group for eighteen months and was given permission to record meetings with pre-planned topics related to TennCare or changes to federal healthcare policies. I did not record the North Memphis lupus support group, but I was allowed to take notes. I built rapport with established members of each group, however organizers of the East Memphis lupus support group and North Memphis chronic pain support group asked me not to attend meetings with large numbers of new members or during times organizers knew in advance that members needed private, emotional support.

**Interviews:** Over the course of this project I conducted both semi-structured and structured interviews (Bernard 2006, Emerson et. al 1995). Semi-structured interviews were conducted with research participants with whom I had regular contact. These interactions were conversational and occurred over the course of several meetings. They were not recorded using audio equipment, however I frequently took detailed notes. In cases where note taking would interrupt the flow of the conversation, I wrote detailed journal entries in my field notes shortly after the conversations concluded. Early in my fieldwork, these conversations were also used to shape and reorganize the research schedule used for formal interviews.

This approach not only allowed participants to shape and guide the direction of questions, it also gave me valuable insight into issues facing participants as the political landscape in the United States changed. Although questions about these changes had not been part of my initial research questions, they were important to the context in which people spoke about health (Burroway et al. 1991, Sanjek 2002). As my research goals shifted away from clinical settings, and began to focus on community support networks, this informal style of interviewing gave me the opportunity to include lines of
questioning that included inquiries into current political topics. Semi-structured interviews also gave me the opportunity to decipher coded language that was used to discuss sensitive topics related to classism and racism.⁹

Formal interviews consisted of a series of open-ended questions that allowed participants to control the direction of the conversation. They were recorded, transcribed, and coded for analysis. Forty-five of the seventy-two formal interviews were conducted with women who had also participated in semi-structured interviews. Over the course of my fieldwork, the research schedule was modified to reflect changes in research questions. These shifts were most notable in interviews conducted with women living with lupus. I discovered the primary concerns articulated by my research participants were different than the concerns expressed in existing social science literature on autoimmunity and chronic pain.

The academic work on autoimmunity has drawn largely from samples of middle class or affluent white women living in major metropolitan areas in the United States, Canada, and England (Greenhalgh 2001, Jackson 1999, Heshusius 2009, Barker 2005). Despite living in different countries that used different healthcare systems, women interviewed for social science studies of autoimmunity shared similar feelings of isolation from friends and family and anxiety over interacting with healthcare professionals. Women interviewed for existing social science literature on autoimmunity and chronic pain focus heavily on feelings of loneliness, frustrations over their inability to predict symptomatic flares, concerns over whether or not they “look sick enough” to be

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⁹ Discussing the plots of Tyler Perry movies was one way women were able to express their opinions about social issues related to race, class, gender, and faith without using examples from their own lives.
considered ill, and tensions between clients and their healthcare providers (Nettleton 2006, Werner and Malerud 2003).

While women in this project did experience feelings of isolation from loved ones or degraded by physicians, they were more concerned about meeting basic needs such as food, shelter, and childcare. Since most of the women I interviewed for this project had limited access to consistent healthcare for some, or all, of their adult lives, their understanding of their illness was loosely affiliated with biomedical models of disease. They wanted to receive care from a trained professional, but peers and family more heavily influenced their definition of lupus than clinicians. African American women’s experiences with racism, both inside and outside healthcare settings, also influenced their relationship with their own personal health and the methods they used to mediate their symptomatic flares.

I primarily met women with lupus through lupus or chronic pain support groups, or family or friends who were my acquaintances, neighbors, and co-workers. Although I did not formally interview any friends or family of women with lupus, many were quick to give their opinions regarding self-care strategies for loved ones with lupus, or interjected their own opinions of TennCare during recorded interviews. While one of my initial goals had been to document women’s experiences with lupus in clinical spaces, the constant presence and interest of friends and family shifted my focus towards non-clinical support networks. Interview questions directed at healthcare workers were originally framed within the context of client relationships. Over the course of the project, questions were modified to focus more on the workers’ individual professional experiences with
bureaucracy and poor communication between state and federal programs that created gaps in coverage.

**Positionality and Building Rapport:** Memphis is a heavily segregated city undergoing extensive gentrification. Residential neighborhoods, schools, and recreational spaces were often segregated by race or ethnicity. Workplaces were also segregated in terms of position and power. Black employees were more likely to occupy low-wage or low-status positions, while white employees held supervisory positions, or positions that required specific education or training. Both these factors played a role in where I was able to live and how I was able to interact with participants. When I arrived in Memphis in the summer of 2013, I had identified neighborhoods of interest in both North and South Memphis. I was unable to secure housing in either neighborhood. Rental offices at apartment complexes were hesitant to show me units, and I was asked why I was interested in living in the neighborhood. Most apartment complexes in the city are heavily fortified. Security gates, on sight cameras, and locked entry to public spaces like swimming pools and fitness rooms are advertised as desirable, luxury accommodations. When I contacted potential landlords leasing individual properties in these same neighborhoods, I received few replies. The influx of white residents into neighborhoods with historical ties to the music industry or political activism in the 1960’s made existing residents wary of newcomers.

I eventually moved into a small unit in a large, working class apartment complex in East Memphis. It was one of the few properties I visited that was not gated. When I signed my lease, I was shown a map and given a block of apartments to choose from. The apartments were all in the same block of buildings. Within two days of moving into my
apartment I had met all but two of my neighbors. White tenants, three of whom were long-term residents, occupied seven of the eight units in my building. An elderly Asian man who was also a long-term resident occupied the eighth unit. During the twenty months I lived in the complex, I had three African American neighbors, all of whom lived in their units for less than eight months.10

Segregation also had an impact on my initial attempts to recruit research participants. Since TennCare recipients tend to receive multiple forms of public assistance, potential participants asked that we meet in spaces far from their homes or places of employment. They expressed concern that an unaccompanied white woman entering their homes or visiting their workplaces would lead neighbors and co-workers to gossip about whether or not the visits were connected to state social services or law enforcement. As the months passed, and I became a familiar presence at local eateries and neighborhood events, I was able to enter homes as a friend or co-worker. I also attended many public events with a close male friend that many participants assumed was my boyfriend or husband. Since local churches with conservative views regarding gender sponsored many of these events, male gatekeepers were more receptive to my presence if I attended events with a man. Although my friend was also white, he was raised in a working poor household in Mississippi, was an active participant in a local motorcycle club, a member of the Mechanics Union, had extensive knowledge of local music history, and had lived in South Memphis for close to two decades.

10 Elderly white residents in my block of units sent several petitions and letters to other white residents asking us to speak to management about the possibility of building a fence across a field that separated our units from a block of units occupied by black residents. The white residents were concerned that a group of black youth who cut through breezeways in order to access fast food restaurants and convenience stores at the entrance of the complex might vandalize units or break into their vehicles.
In several instances being female worked to my advantage. Men were more likely to hold managerial or supervisory positions in state offices than women. Their workspaces were close to one another and they focused their professional social interactions with other people in power. Since I was a woman interested in talking to lower level female employees about their daily lives, male supervisors largely ignored my interactions with other women. Female supervisors did express a superficial interest in my project, but were ultimately not interested in the lines of questioning or the project outcomes. Men in all settings were regularly patronizing, but few were openly confrontational. I was able to build rapport with a number of supervisors in state offices because we were all University of Tennessee alumni, and we were able to shared similar stories of our college experiences. There were also several female supervisors who acted as gatekeepers to lower status employees. I built rapport with many of these women because we were of the same age cohort, education level, and shared political perspectives. Although I spent most of my time in the company of African American employees, when I was in state offices I frequently overheard racist conversations in break spaces when there were only white employees present in the room.

My contact with male gatekeepers in African American communities was limited. In many cases, after initial meetings with pastors or community organizers, I was redirected to speak with female administrative staff. I spent most of my time in churches and community organizations with women and youth. Because my research questions were not viewed as relevant to many men, and it was not considered socially acceptable for me to spend time with men who were not accompanied by their wives, my time with men in most settings was limited. The female administrators and staff held a great deal of
informal power, and were viewed as leaders amongst their colleagues and peers. These women were also instrumental in introducing me into networks where I was able to meet women with lupus who had lengthy experiences with TennCare. They also played an important role in legitimating my presence in their churches and organizations, and introduced me to important social networks within their communities. The youth played an important role in explaining new social movements and sharing how social change was happening at the community and neighborhood level in Memphis.

**Research Samples**

This project had two distinct research samples, women living with lupus and healthcare workers providing guidance and service for TennCare clients. Fourteen interview participants were also identified as key informants. On average my contact with key informants lasted fourteen months, however several key informants participated throughout the entirety of the data collection process. From September 2013 until December 2014, my time with key informants included shadowing their daily professional duties, volunteering for local non-profit and faith based organizations with social justice missions, participating in social activities at personal residences, and providing transportation to doctor’s visits. Seven healthcare workers and three women with lupus who consented to be recorded in group settings, declined to be interviewed individually. Twenty-four of the seventy-two women who gave their time for personal interviews also participated in follow-up interviews between March and July of 2015.

*Overview of Lupus Sample:* Over the course of this project, I interviewed fifty-one women who identified as lupus sufferers, however they were not all formally
diagnosed with lupus. The women described their illness using one of four terms: lupus, lupus symptoms, lupus-like symptoms, or rheumatism. Thirty-two participants had formally been diagnosed with lupus at the time of their initial interviews. These women had the highest levels of education and access to private health insurance through an employer or spouse. Nineteen of the women interviewed identified themselves as lupus sufferers, however they had not been formally diagnosed. Women over sixty tended to use the words lupus and rheumatism interchangeably, and described family histories of chronic pain conditions as rheumatism. Twelve women without formal diagnoses, who described themselves as lupus sufferers, were actively seeking care in hopes of receiving a diagnosis. These women referred to their symptoms as “lupus-like” when sharing their illness experiences in support groups, but privately identified their illness as lupus.

Of the fifty-one women interviewed for this project, forty-five identified as African American or black, four identified as white, and two identified as Korean American. The nineteen women who had not received formal lupus diagnoses were all African American. Research participants ranged in age from twenty to seventy-three, with the largest age cohort falling between thirty-five and forty-nine. On average women sought care for symptoms for seven to nine years before receiving a formal diagnosis. Five to seven years is the national average. For women over sixty diagnosed with lupus, average time to diagnosis was ten years or more (Askanase et al. 2012).

Forty-four women used TennCare services at some point in their adult lives. Chapter Four will provide a more in depth discussion of the TennCare system, however it is important to note that changes in the TennCare system between 1999 and 2005 had a

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11 See Appendix C.
significant impact on the type of care available to clients (Chang and Steinberg 2014).\textsuperscript{12}

TennCare is a state-level, income based, public sector healthcare system (Mirvis and Chang 2003). Women reported using TennCare services for a wide range of care not associated with lupus, including pregnancy, birth and family planning, mental health care, prescription medication programs, and cancer screening and treatment. Six participants were on permanent disability, twenty-three had been denied disability at some point in their adult lives, and fifteen were actively seeking disability status at the time of their interviews. Thirty-six women reported disruptions in their care, restricted access to care, or loss of coverage as the result of program restructuring. At the time of their interviews, twenty-four women were on TennCare\textsuperscript{13}, thirteen were privately insured, and fourteen were without insurance coverage. Eight of the twenty-four women covered by TennCare were in jeopardy of losing their coverage and had been encouraged to seek options through the ACA’s federal healthcare marketplace. Of the fourteen women who were uninsured, six women experienced gaps in coverage in 2014 due to inconsistencies between state and federal programs. These women did not qualify for TennCare Medicaid, however they did meet federal guidelines for Medicaid eligibility. Their requests for coverage through the federal healthcare marketplace were redirected back to the TennCare system. Tennessee residents who fell into this gap were eventually covered by TennCare, however waited an average of eight weeks before they gained access to TennCare services.

\textsuperscript{12} See Appendix D.

\textsuperscript{13} TennCare Medicaid provides coverage for Medicaid eligible residents in Tennessee. While women living in Arkansas and Mississippi used public services and facilities in Memphis such as emergency rooms or health department funded clinics, they were unable to access TennCare unless they could provide proof of Tennessee residency.
Memphis is a diverse, and dynamic city. The following chapters highlight the complicated lives of African American women living with hard to diagnose and treat chronic illnesses. Memphis’ unique history of both paternalism and resistance continues to create tension for chronically ill people who are seeking healthcare through the TennCare system. Despite continued struggles with local paternalism and visible racism, the women who gave their time and stories to this project were not fatalistic about their lives. They expressed frustration and outrage at the state of healthcare in their communities, the state, and the nation. They shared their experiences with one another in order to create a roadmap to question and resist stereotypes. They drew on their faith, their families, and their communities for support. They found ways to question authority and confront racism. Most importantly they did not view themselves as victims.
The Anthropology of Civil Rights

North American anthropology has a long history of addressing issues concerning the origins of racial categories. These questions have contributed to the interest contemporary anthropologists have in confronting inequalities in social policies in the United States. Nineteenth century anthropology largely engaged in projects of categorization and hierarchy. Physical anthropologists focused on anthropometric measurements to determine fitness and intelligence between groups, while archaeologists and sociocultural anthropologists were interested in creating social hierarchies based around a rigid definition of complexity (Baker 1998). Franz Boas challenged these long accepted anthropological assumptions about race and difference. Boas asserted that differences between culture groups were not biological, but instead grew out of a myriad of factors, ranging from, but not limited to, the way environmental differences shaped survival strategies and how hierarchy affected the normalization of social practices within a group. By focusing on contemporary North American populations, Boas asserted racial inequality was the result of uneven access to power and resources, not biology (Boas 1909).

During the same period of time, sociologist W.E.B. DuBois argues that slavery led to the systemic oppression of black Americans and served as the foundation for poverty and inequality in the United States. DuBois (1994 [1903]) uses the term double consciousness to describe the experiences of black Americans who existed with conflicting personal identities. He argues that black Americans have always lived in a society that ignores their needs due to the violence and oppression of slavery. Even after Emancipation, black Americans continued to live in a world that excluded their
contributions since racial inequality had become institutionalized in the United States. DuBois argues that double consciousness exists for people who exist in a space where they are expected to behave like free citizens while regularly being stripped of their rights as citizens.

DuBois was also one of the first scholars to contextualize power hierarchies in the United States using whiteness as a guiding framework. DuBois situates the power of whiteness in the growth of capitalism. During capitalist expansion, being white served as psychological compensation for all white U.S. residents, despite their socio-economic circumstances (DuBois 1994 [1903], Baker and Patterson 1994). Slavery was the most egregious exploitation of black labor in the early history of the United States. However, blackness continued to serve as an exploitable currency during Jim Crow segregation in the early twentieth century, and has persisted in the neoliberal era of the late twentieth and early twenty-first centuries. These continued inequalities can be observed through large gaps in labor and income between whites and blacks, racial profiling by legal institutions, and the rise of the mass incarceration (Mullings 2001, 2005, Guinier and Torres 2002, Schneider and Schneider 2008).

Together DuBois and Boas became allies in public, academic discourses challenging biological definitions of race. They each argued biological difference was a problematic way to organize human social interaction. Boas wrote that since humans have never been geographically isolated, and their continued survival depends on sharing knowledge and resources, difference in physical appearance should not be linked to political power or social capital (Boas 1909). Boas also argued that racial hierarchy in the United States was the product of erasing the histories of indigenous people in favor of
a western European nationalist narrative that perpetuated the oppression of native peoples and fostered xenophobic attitudes towards immigrants (Baker 2010). DuBois challenged biological assumptions about race by examining institutional barriers. Access to education, health resources, and economic opportunities were all used to frame DuBois’ argument regarding the continued exclusion of black Americans in the United States at the beginning of the twentieth century (DuBois 1915).

At the end of the Civil War, Jim Crow laws were used to keep black and white communities segregated throughout the United States. While the laws claimed “separate, but equal” consideration for all U.S. citizens, Jim Crow laws disproportionately politically and economically benefited white communities (Gilmore 2008, Rushing 2009). The laws restricted access to voting for black citizens by enforcing literacy guidelines, which not only excluded semi- and illiterate members of the community from the ability to vote, it also prohibited the poor from running for office or participating in public juries (Gilmore 2008). Jim Crow laws also resulted in the unequal distribution of basic needs including housing, education, and healthcare (Wailoo 2001). These laws insured that public funds needed to upgrade neighborhood sanitation systems and build schools and hospitals were kept in white neighborhoods (Rushing 2009). Since neighborhoods were legally segregated, black residents were not able to access or use resources located in white neighborhoods (Boyd 2008). Over the course of the twentieth century, social science in general, and anthropology specifically, played an important role in confronting segregation and championing civil rights.

In the first half of the twentieth century, ethnography was used to challenge discrimination in the legal system. Early generations of lawyers working for the National
Association for the Advancement of Colored People (NAACP) were trained in ethnographic methods and encouraged to use ethnography in court cases in order to show evidence of the exclusion of African Americans (Baker 1998). Historically black colleges and universities (HBCUs), most notably Howard University, encouraged students to use social science methods to professionally question and challenge legal apparatuses that excluded people of color. Well-known HBCUs also created spaces for scholars of color to research and write about the struggles of communities of color throughout the United States (Baker 1998).

In response to the legacy of legal segregation and social policy influenced by the culture of poverty model, twentieth century U.S. anthropology sought to present poor communities of color in the United States as complicated, dynamic, and resilient. These studies critique the culture of poverty model by illuminating the ways in which historical inequalities such as slavery and legal segregation are transformed into contemporary systems of policy and law that exacerbate racism in the United States by excluding people of color from powerful, white, economic, political, and social spaces (Mullings 2015, Maskovsky 2006). Important works in the cannon of U.S. studies in the twentieth century explore issues of racial inequality. St. Clair Drake and Horrace Cayton’s ethnography *Black Metropolis* (1993 [1945]) is an extensive study of life and inequality in the predominantly African American Chicago community, Bronzeville. Carol Stack’s ethnography *All Our Kin* (1974) is a study of kinship, community, and support in a poor, African American community known as The Flats. Drake and Cayton, as well as Stack, use relationships with poor urban residents, built over long periods of time, to illustrate how poor communities build networks to ensure survival despite inequality.

By the late twentieth century, anthropologists became interested in how rapidly changing global relationships affected local communities. Through critiques of the U.S. healthcare and judicial systems, U.S. based anthropologists demonstrate how marginalized people are able to navigate inequality by creating networks within their own neighborhoods in order to circumvent the unequal distribution of resources (Mullings and Wali 2000). While recognizing the origins of oppression is important to understanding inequality in the United States, anthropology also needs to recognize and confront white supremacy in an academy that values white voices over those of scholars of color.
(Harrison 1995, Brodkin et al. 2011, Mullings 2005, 2015). U.S. anthropologists call for a grounded set of theoretical and methodological frameworks that offer a bottom-up approach to ethnography (Jones 1995, Susser 2010, Glick Schiller 2011). This form of ethnography is designed to not only draw attention to structural inequality, it also has the potential to speak across disciplines and engage in pragmatic discussions of ways to address persistent poverty.

Urban Anthropology

The long history of segregation in U.S. cities has had a lasting impact on the unequal distribution of resources between black and white communities. The creation of the National Housing Authority (NHA) in 1934 led to a number of policies that kept legal segregation in place and further institutionalized racial inequality in the United States. In the 1930s, the NHA created public housing neighborhoods and enacted a practice known as redlining to keep communities segregated. Redlining is the practice of denying services, either directly or indirectly through local policy, to communities of color. This denial of resources included changes in zoning that kept healthcare facilities, banks, and grocery stores out of poor neighborhoods and denying individual home loan requests (Massey and Tannon 2017, Mendenhall 2010).

Both during and after Jim Crow, real estate agents and community planners used blockbusting as a tactic to keep neighborhoods segregated. Blockbusting plays on white fear of integrated neighborhoods. Blockbusters would introduce potential black homeowners into established white neighborhoods. They would then encourage established white homeowners to sell their properties at a reduced cost. (Orser 1994, Hamer 2011). Real estate agents who participated in blockbusting encouraged white property owners to sell their homes in urban communities in order to purchase larger,
lower priced homes in rapidly expanding suburbs. The agents then solicited the urban listings to black clients. It was then believed the remaining white residents would be inclined to sell their homes at reduced rates and leave the neighborhood because they connected racially integrated neighborhoods with low property values (Hanlon 2009, Lacy 2007).

The anxiety over integrated communities extended beyond property value. White residents living in integrated urban communities also believed that access to resources such as public schools, parks and playgrounds, and retail establishments would decline with the increased presence of African American neighbors. This fear of decreased property values and violence in integrated communities led to a climate of secrecy and a temporary devaluation of all the property in the many urban neighborhoods (Pattillo 2008, Lacy 2007). The artificially devalued homes were then sold to black clients who purchased the properties with inflated mortgages.

The practice of blockbusting became illegal after the Fair Housing Act was passed as part of the Civil Rights Act of 1968. Despite federal laws that prohibited blockbusting, the practice persisted. Additionally, new forms of predatory lending were utilized, including adjustable rate mortgages, which targeted people of color (Rugh and Massey 2010, Segrue 2014). African American homeowners disproportionately lost property when the housing market collapsed in 2009 (Mendenhall 2010). The Recession also created a larger need for rental property in low-income African American neighborhoods, while foreclosed properties were purchased by white developers (Dymski et al. 2013, Maharidge and Williamson 2011).
Suburban flight and foreclosures are not the only factors that perpetuate inequality in urban neighborhoods. Existing class dynamics within neighborhoods have a significant impact on the survival strategies of the poor. The U.S. neighborhood serves as a physical, social, and cultural space where power, identity, and discourses on race relations are played out in a public forum (Mullings 2001, Boyd 2005, Bolles 2001). Class stratification frequently intersects with racial inequality to create additional barriers for those who experience multiple levels of marginalization. Elites living in urban neighborhoods with ties to particular interpretations of history, employ strategic essentialism to combat stereotypes of urban communities.

Historically black neighborhoods use the shared experiences of racism and segregation to build community narratives around their spaces (Boyd 2008, Checker 2005, Hartnell 2017). Shared experiences of racism serve as a form of strategic essentialism used to write a cohesive narrative of a specific place. These shared histories of place can also be used to organize community resistance to racism. However, socioeconomic standing, education, and familial ties all inform who defines the boundaries of those community narratives (Modan 2007, Checker 2008). The power present in the strategic essentialism of place then plays an important role in the construction of the public image of that space, as well as reinforces control of the physical environment by local elites (Sanjek 1998, Low 2006, Modan 2002).

Nostalgia narratives play an important role in building community pride around a shared history. Oftentimes the narrative includes moments of overcoming oppression. The social history of Harlem, particularly the depiction of the Harlem Renaissance as a time of high culture and African American cosmopolitanism, serves as one example of a
nostalgia narrative. This image of Harlem relies heavily on a specific situational reading of history and a homogenization of local residents (Mullings 2003). However, the mythology of Harlem also ignores the levels of hierarchy that exist within the neighborhood at any given time. Michelle Boyd (2008) argues that a nostalgia narrative which creates Harlem, and the urban neighborhood in general, as a fully modern and progressive space, is a deliberate political move staged by the black middle class as a response to neoliberal discourses on urbanization and gentrification. This nostalgia, coupled with a situated history created by elite members of the neighborhood fosters a narrative which allows middle, and upper, class residents living in the community to act against neighbors who do not subscribe to or fit that narrative.

The undercurrent of classism in communities with histories of marginalization extends beyond conflicts over housing. Civic engagement is also affected by this unequal distribution of power. Delmos Jones and Steven Gregory examine community boards and neighborhood meetings as an illustration of the power relationships that exist between community members and neighborhood elites. In the neoliberal era, racism is frequently coded as classism. Class differences do have an impact on who is and who is not able to make policy. The intersections of class and race create different consequences for poor people of color (Gregory 1992, 1999). Gregory and Jones establish the boundaries for inequality in urban U.S. communities along racial lines. Ethnographic examples of inequality referenced in each author’s work, range from the introduction of ordinances that target the poor to the control of local community boards by neighborhood elites. These relationships, like the discourses that facilitated blockbusting, are frequently tied to historical patterns of racial discrimination.
The nostalgia narrative facilitates a space for local elites to control the physical environment through gentrification and exert a form of control and surveillance over local residents through community level policies, such as those associated with property upkeep and ownership (Gregory 1999). Community level elections, city ordinances that serve to police the appearance of individual properties, neighborhood watch associations, and tax structures that favor homeowners over renters all serve as examples of how affluent and middle class community members control space and create barriers for poor neighbors (Modan 2007, Lacy 2007). Community boards often serve as gatekeepers. In Gregory’s ethnographic account, white property owners use political and social privilege to make decisions for the entire community. The board controls property maintenance guidelines, the creation of neighborhood associations, and petitions presented to local government regarding zoning laws. While the board claims the goal of the ordinances is to keep absentee landlordism out of their neighborhood, they are also enacting policies that favor owners over renters. This class-based action is also a form of segregation, since homeowners are, for the most part, white, while renters are people of color (Gregory 1998).

For Jones the inequality present in the interactions between members of the community and community boards takes place at an institutional level. Jones (1993) writes that institutionalized racism drives much of the inequality present in U.S. social institutions. This racism is expressed through the barriers people of color must face as they attempt to access resources offered by public programs. Jones’ case study focuses on tensions that result after a debate over access to resources in an urban public school
system, including a Head Start program. Initially the program’s administrators are white and program participants are predominantly people of color.

Racism is present in the language used by board members as they described the rationale behind community members’ choices to participate in or avoid the school programs (Jones et al. 1992). Community activists called for a more balanced representation on the board in hopes of alleviating racial tensions, however the divide between program coordinators and the community persisted even after representation on the board became more diverse. Jones argues that the tensions, while tied to larger issues of racism in the community, are also connected to power dynamics that favor privileged community members. Access to the community board electoral process, which helps monitor the school programs, is controlled by local elites. Underlying the racial tension in this community exists a division between the privileged and the poor.

The nostalgia narrative facilitates a space for local elites to control the physical environment through gentrification and exert a form of control and surveillance over local residents through community level policies, such as those associated with property upkeep and ownership (Gregory 1992). Although Harlem residents may use the neighborhood to employ a form of strategic essentialism that combats racist ideas tied to people of color living in urban communities, stratification among and across social groups living in the neighborhood creates a new level of marginalization for individuals who do not fulfill specific social roles (Boyd 2008). Former felons, single mothers, and members of the community thought to be involved in informal economies such as those associated with drugs or prostitution are frequently used as straw man examples of “bad” residents by community members and neighborhood boards (Mullings and Wali 2000,
Sieber 1987, Tach 2009, Hartnell 2017). In these relationships class dictates whose version of history becomes public and who has the authority to speak for the group as a whole.

**Intersectionality**

Feminist and anti-racist approaches to anthropology specifically, and social science more broadly, has long drawn attention to the importance of difference. While early anthropologists focused on the importance of respecting difference, late twentieth century feminist scholars argue that recognizing difference should be a catalyst for social change. Anthropology and feminist studies have long been sites of inquiry where universals have been used to foster alliances between and among groups of people. However, these alliances do not transcend, or even adequately address, issues of difference. Instead, power hierarchies within alliances frequently subvert tensions within groups and silence marginalized voices (Crenshaw 1991). Patricia Hill Collins (2000) argues the politics of difference serves as a more useful way to conceptualize the future of an anti-racist and anti-sexist discourse, as opposed to an identity politics framework that relies on the motifs of multi-culturalism or gender mainstreaming. Acknowledging differences in specific divergent histories and social locations is key to addressing conflicts between and among groups, as well as valuing and protecting different points of view (Collins 2000, hooks 1984). Intersectionality provides a space in which to examine the multiple, overlapping sites of marginalization that contribute to social inequality.

Intersectional frameworks are not merely a device to draw attention to difference; they are dynamic models that can be used to identify and respond to systems of oppression (Risman 2004, hooks 2001, Higginbotham 1992). Deconstructing social relations using an intersectional approach is particularly useful when examining
inequality in the United States. Intersectionality theorizes that subjects are physically marked by any number of social categories, including gender, race, class or nationality (Crenshaw 1995, Collins 2006). Intersectionality illuminates the material constraints produced by social exclusion at the macro-level that manifests as racial and gendered marginalization in everyday interactions (Mullings and Shultz 2006, Acker 2006). An intersectional approach “studies-up” by critically examining macro-level constraints, without losing the voices and experience of individuals living with multiple forms of marginalization (Mazzi and O’Brien 2009, McCall 2001, McClaurin 2001). In this sense an intersectional approach draws attention to and challenges the racism, sexism and class stratification which manifest in employment and housing discrimination, unequal pay, educational opportunities, and access to health care (Morgen 2002, McCall 2005, Becker 2007). For anthropologists and feminist scholars studying inequality, an intersectional perspective also acknowledges the ways in which one aspect of the intersectional model, such as race or gender, can be exploited for political purposes or conversely form a double marginalization depending on the circumstances (Collins 1998, Verloo 2013).

Early intersectionality studies focused on identifying, recognizing, and addressing difference in the individual experience. Current scholarship examines how intersectionality can be used as a tool for coalition building. Sumi Cho, Kimberle Crenshaw, and Leslie McCall (2013) argue that scholars and intellectuals should not only continue to actively debate the theoretical and methodological aspects of intersectionality, but also suggest that intersectionality can be a useful tool for political intervention. They propose a collaborative intersectionality wherein scholars use an intersectional model to speak and collaborate across disciplines (Cho et al. 2013).
Angela Davis (2016) argues that while it is of paramount importance to stay close to the meaning behind the early intersectional works of scholars such as Crenshaw, hooks, Collins, Higginbotham, and others, intersectionality can and should be used as an organizational tool. Davis calls for an “intersectionality of movements” (Davis 2016), where the theory and methods used by early intersectional theorists to organize and resist. Intersectionality creates a space to address difference and privilege within organizing bodies, with the intention to create social movements that address deep or subversive forms of inequality (Acker 2006, Hancock 2007, Carasatis 2013). The intersectionality of movements allows different groups with similar resistance goals to support one another and show compassion for the different ways in which people are marginalized under neoliberalism. Not only are unified numbers needed to bring about significant social change, but focusing on an intersectionality of movements also challenges the ways intersectionality is now being used to justify U.S. definitions of individual exceptionalism (Rabkin 2012, Dhamoon 2011). As an approach to analyzing difference between and across movements, an intersectional approach draws attention to the dynamism of social categories and explores how social boundaries change over time (Crenshaw 1995, Hankivsky and Cormier 2011, Thomas-Houston 2005).

**Health Inequalities and Bureaucracy**

2009), and the potential for premature death for those who are unable to receive care or whose conditions are left unmanaged (Lane 2008, Manderson and Smith-Morris 2010). Although current public discourse argues that recent economic growth has nullified the effects of the 2008-2009 Recession, uncertainty for the poor and near poor has encouraged policy makers to advocate for the reformation or elimination of existing social safety nets in order to curtail spending nationwide (Viladrich 2012, Hall and Rosenbaum 2012, Horton et al. 2014).

Access to healthcare does not guarantee access to services for the chronically ill. Healthcare in the United States functions as a two-tiered system (Becker 2004, 2007). A top tier that services the wealthy and professionals who are able to access health insurance through employers, and a bottom tier comprised of a number of fluctuating public sector healthcare programs (Becker 2007). Clients participating in public sector programs, most notably Medicaid, are blamed for their inability to access and use private health insurance (Getrich et al. 2017, Fletcher 2014). Medicaid recipients are viewed as a burden to an already overextended system since they are more likely to call for ambulatory services due to lack of personal transportation or use emergency rooms as primary care facilities due to their limited access to primary care physicians and clinics (Guttman et al. 2003, Galbraith et al. 2012). The discourse in health responsibility is akin to culture of poverty insofar as it frames chronic poor health as a set of personal choices or learned behaviors (Rabkin 2012).

By framing poor health and the high rates of chronic illness amongst the poor in the United States as a cultural or behavioral issue, policy makers are able to ignore the institutional factors that contribute to chronic health conditions (Maskovsky 2001,
Mullings 2005). Underemployment or irregular work hours, environmentally unsafe housing, and access to food or safe spaces for physical activity all contribute to chronic poor health (Mullings and Wali 2000, Betrisey 2009). People of color are more likely than their white peers to live in poverty and use public sector healthcare programs (Becker 2004). Race then plays a critical role in the public’s perception of who makes good choices and who makes poor choices regarding personal health. African American women have the greatest likelihood of experiencing multiple chronic illnesses, which are frequently diagnosed in later stages that could result in permanent disability or death (Mullings and Wali 2000, Lane 2008, Rousse 2009).

In addition to the existing two-tiered system, the increased privatization of public sector healthcare programs at the beginning of the twenty-first century has created additional bureaucratic issues impeding pathways to effective care nationwide (Rylko-Baur and Farmer 2002, Lamphere 2005). Many privatized Medicaid programs control access to healthcare resources through managed care organizations (MCOs). MCOs create partnerships between for-profit and not-for-profit healthcare organizations, private insurance companies, and state level healthcare programs (Ameringer 2008, Sherman et. al 2009, Hoffman 2006, Quadagno 2006). In theory, managed care fosters competition and quality control among MCOs that compete for contracts and clients by offering the widest variety of services at the lowest cost (Lopez 2005, Lamphere 2005, Kano et al. 2009). However, managed care creates uncertainty for clients and administrative bureaucracy for providers due to frequently changing eligibility guidelines, enrollment caps, vague descriptions of services covered by existing plans, and a lack of standardized billing protocol between MCOs (Lamphere 2005, Lopez 2005).
Healthcare providers working within privatized Medicaid programs are faced with additional paperwork in order to satisfy state and individual MCO requirements, complicated billing procedures, and conflicts between insurance companies and providers over client referrals and medical necessity (Pohlem and Becker 2006, Wagner 2005). Clients participating in MCO mediated Medicaid programs are confronted with frequent changes in eligibility status, maintaining coverage as individual MCO contracts expire, poor administrative communication regarding changes to individual policies, and high deductibles and user fees (Becker 2004, Boehm 2005, Willging et al. 2004, Rosenbaum 2012).

An expanded definition of access to healthcare needs to consider not only the availability and continuity of medical care, but also considers needs not directly connected to the healthcare system. This broad range of needs, including, but not limited to, stable income, safe housing, and healthy food sources are all connected to long-term good health (Mullings and Wali 2000, Lane 2008). Conversations regarding the economics of healthcare should not be limited to the cost to the state or the cost of health insurance provider. While the ACA policies implemented in 2014 did seek to address these concerns, ACA programs were still mediated through private health insurance providers. Access to health insurance and access to effective health services are not the same. Additionally, an expanded definition of access to healthcare also needs to consider how racism and gender exclusion contribute to the interrelated conditions of poverty and chronic health problems (Mullings and Shultz 2006, Rouse 2009, Nguyen and Peschard 2003, Geronimus and Thompson 2004, Leigh and Wheatley 2011).
Drawing on both the works of early intersectionality theorists, and Davis’s remarks on the intersectionality of movements, intersectionality is an important part of current debates on race and exclusion in the United States. The methodologies present in an intersectional approach can be harnessed to build and strengthen relationships amongst oppressed people. Placed in a broader political economic framework, intersectionality allows for an exploration of chronic illness that juxtaposes individual’s experiences with inequity in their daily lives against larger social processes, such as racism, sexism, and ableism, that serve to create and reinforce bureaucracy in existing and proposed healthcare programs and policies. The following chapters will use ethnographic examples to explore both inequality and community building in economically diverse, predominately African American neighborhoods.
“Recently I’ve been hit with this level of enormity...how so much has changed in such a short time and how it has real consequences...but it happened in a way that seems like nothing has changed, like life has always been this way...like there’s no real history behind it...The first time we talked about healthcare and lupus and insurance I went home and thought ‘If the conversation we just had is accurate, then all of this...the lupus, the insurance, the gaps in care...these things have all happened within my lifetime and that just can’t be right?!’...But when I put the pieces together, when I really think about my life...I realize I am kind of a walking, talking, healthcare history lesson...That’s a bit unsettling because I feel like I’ve been in the middle of it this whole time...but it was subtle...I’m smart, I’m observant...but I never really took note of the changes as they happened around me...”

- Patrice

The Road to Privatization
Healthcare is a deeply personal and political issue in the United States. Health inequalities are the product of larger historical patterns of exclusion and oppression (Nguyen and Peschard 2003, Brabay Jackson and Williams 2006, Mullings 2002).

Unequal access to healthcare for African Americans, especially African American women, has resulted in higher rates of late stage diagnosis and even death due to accelerated disease progression connected to a lack of access to consistent healthcare (Krieger et al. 1993, Geronimus 1992, Mullings and Wali 2000, Becker et al. 2004). The United States’ reliance on private health insurance as the nation’s primary healthcare delivery system is a fairly recent phenomenon (Becker 2007, Quadagno 2006). During the latter half of the twentieth century and the first decades of the twenty-first century, the relationship between health insurance and access to healthcare has become increasingly complicated. State-level public sector Medicaid and Medicare programs become more reliant on funding agreements with private health insurance companies in order to fill economic gaps and provide care for poor and elderly residents (Maskovsky 2001, Rylko-Baur and Farmer 2002, Horton et al. 2014). The ACA sought to address inconsistencies
in healthcare coverage by expanding health insurance options through federal and state-level health insurance exchange programs. However, access to health insurance does not guarantee access to the care needed to maintain a good quality of life for the chronically ill. By framing health inequalities as only the result of economic disparity, healthcare debates ignore other social factors that contribute to health inequalities, most notably racism.

Over the course of the twentieth century, healthcare delivery in the United States has undergone dramatic changes. The institutionalization of private health insurance and the privatization of health services at both the state and federal level have transformed how U.S. residents understand and use health services (Boehm 2005, Willging et al. 2004). Private health insurance was first introduced in the nineteenth century by railway companies offering catastrophic care and injury packages to passengers who were cautious about rail travel (Hoffman 2006). In the early twentieth century, while a number of European nations began taking an interest in implementing national private health insurance programs, the newly formed American Medical Association (AMA) was opposed to implementing a healthcare system based on private insurance in the United States (Beland and Hacker 2004).

By the late the late 1920s, the United States officially entered the private health insurance market when the military began requiring compulsory health insurance enrollment for soldiers and organized labor began using insurance benefits as a bargaining tool for members working in fields with high occupational hazard rates (Murray 2007). The next two decades saw both economic collapse and growth in the United States. Private health insurance was once again suggested as a possible solution to
the cost of providing healthcare to the large number of U.S. residents who had been
displaced and unable to meet their basic needs during the Depression. The AMA
continued to argue against the possibility of a nationwide transition to a private health
insurance system. Their concerns ranged from a breakdown in the patient-doctor
relationship to increased bureaucracy within the medical profession (Quadagno 2006).

After World War II, the U.S. economy began to grow rapidly and employers
began offering health insurance in order to recruit skilled laborers. This favorable shift
towards private health insurance initiated the pattern of employer-based health insurance
benefits programs (Murray 2007, Blumenthal 2006, Fletcher 2014). At the same time,
technological advances in medical testing and treatments, as well as the introduction of
new pharmaceuticals, changed medical science in the U.S. These new advances were
accompanied by an increased cost of medical care. Early partnerships between medical
researchers and private industry paved the way for future relationships between private
insurance corporations, pharmaceutical manufacturers, and healthcare providers

The intensification of market-based forms of healthcare in the United States at the
day of the twentieth century has transformed the process of accessing healthcare into a
series of consumer choices. This shift towards patient as client or consumer also
transforms access to care from a human right to a series of individual decisions (Rylko-
Bauer and Farmer 2002). Using a market-based consumer model of care, the ACA was
designed to provide more health insurance options at lower costs to the consumer.
However, by equating access to health insurance to access to healthcare, market-based
models of healthcare ignore the reality that health insurance does not guarantee
affordable or constant care (Fletcher 2014, Getrich et al. 2017). Ethnography provides an opportunity to explore the complexities of access issues for vulnerable populations in the United States. Communication gaps, bureaucracy, and structural inequality all contribute to under- and uninsured U.S. residents’ ability to use local healthcare resources, even in a time of expanded care (Lamphere 2005, Horton et al. 2014, Getrich et al. 2017).

Through the stories of two African American women in their sixties living with lupus, the following passages detail how the illness known as lupus, and the U.S. healthcare system, are always in a state of flux. Changes in the healthcare system, including how practitioners diagnose and treat lupus, have influenced how both women understand their illness and are able to secure care for their symptoms. Patrice was diagnosed with lupus in the 1970s as a participant in one of the nation’s first large cohort lupus studies. Rosemary lived with active lupus symptoms her entire adult life before receiving a diagnosis in the 1990s. When they were interviewed, each woman had been living with a lupus diagnosis for more than two decades. Their ability to maintain a good quality of life while living with a debilitating chronic illness is directly tied to their class status, which in turn informs the type of care they have received.

**A Continuously Changing Illness: Patrice’s Story**

The history of lupus is closely tied to changes in scientific inquiry and the development of western medicine. As early as the thirteenth century, scholars of science observed a distinct reoccurring rash on the arms, legs, and faces of people throughout Europe. Discoid shaped skin lesions frequently accompanied these rashes. The cluster of related symptoms was named lupus, by physician Rogerius, because the lesions were believed to resemble the puncture wounds caused by wolf bites (Benedek 2007, Wallace 2009). Although lupus was first believed to be an acute illness of unknown origins that
could affect any person at any time, chronic occurrences of this cluster of symptoms were more widely observed in woman than men.

Between the fifteenth and seventeenth centuries, physicians and scientists continued to observe and document lupus. During this period of time, lupus was still believed to be an acute or chronic dermatological condition. The documentation of lupus rashes were frequently observed on the bodies of women engaging in intense manual labor, or activities that involved exposure to extreme temperature changes (Potter 1993). By the eighteenth century, class based assumptions about the illness changed. Physicians were no longer actively looking for signs of lupus on the bodies of the poor and working class. Rather, by the late eighteenth century, lupus rashes were linked to other chronic conditions including pain, faintness, and memory loss (Wallace 2009, Hirschhorn and Greaves 2007). This combination of symptoms was attributed to the sensitive nature of upper class women. The symptoms were considered a response to emotional stimuli and were treated as a psychological condition (Potter 1993).

Class based assumptions about lupus shifted once again during the nineteenth century. As doctors were learning more about infectious diseases, lupus symptoms were believed to be a form of tuberculosis. Infectious diseases disproportionately affected the poor since they often lived in close quarters, in substandard housing, and with limited public and household hygiene options (Potter 1993). Since lupus rashes were observed on multiple residents living in the same household, it was believed lupus was contagious, but not fatal. In 1856, medical researchers created the first classification of lupus erythematosus, a biological phenomenon that included a wide range of symptoms including joint pain the rashes (Wallace and Lyon 1999). This was the first time lupus
was considered a multi-faceted illness, and the first time the illness was officially named and documented in medical literature and textbooks (Benedek 2007).

The twentieth century brought about several significant changes that continued to shape the definition of lupus. The developing medical fields of rheumatology and immunology in the 1940s and 1950s changed how scientists and physicians defined autoimmunity (Benedek 1997, Scolfield and Oates 2009). The discovery of the LE phenomenon in 1948, laid the groundwork for the first clinical tests used to identify autoimmune syndromes. The LE phenomenon, also known as LE factor or LE cells, presents as macrophages that engulf otherwise healthy cells. LE cells can attack any part of the body (Holman 1960). The anti-nuclear antibody test (ANA) was developed to identify the presence or absence of LE cells. ANA results that indicate high levels of LE factor are still considered the most reliable clinical test used to diagnose lupus. However since ANA tests present on a spectrum it is challenging to issue a definitive clinical diagnosis for lupus (Bertsias 2013, Yu et al. 2014).\(^\text{13}\)

Advances in pharmaceutical technology in the twentieth century also meant that new therapies were available to lupus sufferers. The production of synthetic medication in the 1920s and 1930s made prescription medication available to a larger segment of the population (Wallace and Lyon 1999, Scolfield and Oates 2009). However, it was not until the late 1940s and early 1950s that researchers began to develop new classes of medications used to treat a wide range of chronic illnesses. These developments in both research and technology worked in tandem to create new definitions of illness and new ways to treat those illnesses. By the late twentieth century, newly categorized chronic

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\(^{13}\) Women who attended the lupus support groups I observed believed there was a better chance of receiving a high ANA result if the test was conducted during an active flare.
pain conditions and autoimmune syndromes, including lupus, were treated with corticoid steroids, anti-inflammatory medications used to treat rheumatoid arthritis, and anti-inflammatory drugs traditionally used to treat malaria (Wallace 2007, Benedek 2007). 14

In 1971, the American College of Rheumatology created the first comprehensive clinical disease profile for systemic lupus erythematosus (SLE), the most common form of lupus. The criteria highlighted fourteen of the most common symptomatic manifestations of SLE (Cohen et al. 1971). The criteria included a wide range of symptoms, including chronic widespread pain, rashes and skin abrasions, and chronic kidney infections. The criteria also featured a number of laboratory tests, including those identifying protein markers associated with chronic renal conditions and high levels of LE factor identified by ANA testing (Scolfield and Oates 2009). As part of an ongoing clinical discussion of the complications of diagnosing autoimmune syndromes, a small number of university medical schools across the United States dedicated research space and funding to study the diagnostic process and validate the new SLE criteria. The University of Tennessee Medical School in Memphis was one of the first institutions to conduct a large cohort study designed to evaluate the SLE diagnostic criteria (Trimble et al. 1974). Patrice was one of the women who participated in that study.

When I first met Patrice, she was a retired nurse who continued to volunteer her services at a South Memphis clinic. Patrice was especially interested in the clinic’s bi-monthly services for low-income residents living with chronic kidney issues. Services at the clinic ranged from blood work to dialysis, and participants could pay on a sliding

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14 Since most of the medications used to treat lupus are available in generic formulas, Medicaid or Medicare cover most, if not all, of the cost of basic prescriptions. TennCare limits the number of prescriptions a client can access quarterly, so the women I interviewed who needed additional medications for additional chronic illnesses such as migraine headaches or hypertension, frequently rationed their medication between eligibility cycles.
scale. In her late fifties, Patrice’s lupus had accelerated and she began experiencing chronic renal issues. Her own issues with chronic kidney infections and lupus nephritis led her to seek out volunteer opportunities near her home where she could use her professional skills to provide compassionate care for other African American women.

With a combination of her savings and a short-term disability program, Patrice had been able to retire at sixty-three in order to address her health needs. In 2014, Patrice was sixty-six and still considered herself active and healthy. In her retirement she engaged in a number of civic activities ranging from volunteering at a community food bank to reading and recording current event stories that could be distributed to the blind.

Patrice first began experiencing pain in her late teens. She initially dismissed her pain as stress related. Patrice hailed from a middle class family and she was the first person in her family to attend college. She assumed her exhaustion and gastrointestinal issues were the result of her poor diet and late night study habits. During her sophomore year in college, she began having headaches. Her headaches improved after she had her vision examined and was fitted for glasses. Patrice described her symptoms as “mild” through most of her twenties. By the time she moved to Mississippi to attend nursing school, her headaches had returned. Patrice once again assumed her lethargy, exhaustion, and headaches were the result of her rigorous study schedule. When she returned home to Memphis to start her career she began experiencing joint pain. Her exhaustion intensified, and she began to experience muscle weakness. As a nurse, Patrice had access to colleagues working in a number of medical fields. Due to her family history, she was quickly diagnosed with arthritis and given prescriptions to help mediate her pain.
Patrice was a Memphis native who had been born during Jim Crow segregation and it was important to her that she used her professional skills to help other Memphis residents who had suffered during segregation. As desegregation began to change the client base in Memphis hospitals throughout the 1960s (Wailoo 2001), Patrice took a position working in an integrated emergency and intensive care unit. She recognized that she had been hired, in part, to provide care for women, poor whites, and the few African Americans who were admitted to the facility. Although her clientele changed as her career matured, she was rarely assigned white men as clients.

Patrice first learned about the lupus study from a colleague and friend, a white nurse named Sandy. Sandy encouraged Patrice to contact the researchers since she had been previously diagnosed with arthritis at a young age and met several of the study’s participation criteria. Patrice’s arthritis diagnosis had come from a university facility, and the university had records of her diagnosis, so she was eventually eligible to participate in the study. Patrice did not believe she was seriously ill and was hesitant to explore the option of becoming a study participant. She was still unsure, even after she met with physicians who confirmed her previous arthritis diagnosis. She felt the other participants she met during screenings had experienced more prolonged periods of illness, so therefore were more likely to have lupus and more likely to need the care promised through the study. She was also skeptical that lupus was really a legitimate diagnosis.

“I was really one of the first women I knew who was actually diagnosed with lupus…Before lupus was a disease people knew about, there were a lot of names for diseases that were similar…Or possibly those patients did have lupus, we just didn’t have a name for it yet…It’s kind of hard to say…But I’ve always had my suspicions that sometimes doctors just kind of make up a diagnosis so they have something to treat…So I kept asking the doctors how did they know? How did they know that my specific symptoms meant I had lupus and not something else? I have seen a lot of
women during my career who’ve come into the emergency room with similar health problems and no one ever looked at them and said, ‘You know what, I bet you have lupus’…They were just treated with ibuprofen, cold packs, or anti-itch creams… maybe they got fluids if they came in with dehydration related to chronic kidney infections or prolonged diarrhea…but most of them didn’t even get that, especially if they weren’t white…I’m sure even more didn't come to see a doctor at all…”

Patrice continued to be guarded in her interactions with researchers after she began participating in the study. Her own professional career had exposed her to the ways in which black bodies were used in medical research, and she was familiar with a number of local stories that corroborated her concerns. The Memphis metropolitan area served as one of the first research sites for large cohort sickle cell studies in the 1950s and 1960s. Although these studies did lead to the opening of clinics in several poor, black Memphis neighborhoods, clients frequently participated in clinical studies in order to gain access to basic medical care (Wailoo 2001). Local political paternalism frequently focused on racial uplift and the presence of these clinics was framed as a way to promote racial equity to members through health education (Strub 2007, Wailoo 2001).

Similar negotiations between poor blacks and medical researchers were taking place throughout the Mid-South. The infamous Tuskegee Syphilis Experiment targeted poor, rural black men in Alabama. Study participants were promised food and basic medical care in exchange for their participation. Researchers were interested in the long term effects of syphilis, so study participants were given placebos, however were not given medication that could curb their symptoms or cure the illness (Hoberman 2012). The study was originally designed to last six months, however researchers and institutions interested in collecting longitudinal data allowed the project to continue for nearly forty years so that researchers could observe the long term effects of the illness.
Researchers denied participants potentially life saving medication, even after penicillin was widely used nationwide to treat a number of common ailments, including syphilis (Charlotte and Brookes 2015).

The history of medical experimentation as a form of black exploitation weighed heavily on Patrice. During her time as an emergency room nurse, she had attended clients who had reactions to medications while participating in drug trials. These individuals came to the emergency room because they were unable to contact research physicians. She had heard horror stories from neighbors and clients who lost loved ones who were unable to get immediate medical help due to segregated hospitals and clinics. Patrice was particularly outraged by the way black women were treated. She personally knew women who had been forcibly sterilized, and had cared for women who had experienced life threatening health crises resulting from unsafe abortions. Knowledge of history, and her personal experiences and observations, factored into Patrice’s decision to participate in a medical study.

“Even after I went through the initial screenings, I was still hesitant to participate in the lupus study…I mean all the people I encountered were real nice, real respectful…I felt like most of them respected me as a professional…But Tuskegee isn’t too far away from Memphis, so it kind of has it’s own urban legend status around here…I’m sure similar ‘research’ like Tuskegee probably happened in the real poor places close to us…down [Highway] 61…maybe all over Mississippi…those ‘researchers’ just never got caught so we will never know if anything heinous happened in these small towns…People talk, they know their history…I’m not an extremist. I believe in the healing power of medicine. I don’t think white people are evil by nature…I know a lot of good white doctors and nurses who really care about people and want to treat all people no matter their skin color…But I’m still surprised, I mean I shouldn't be, but I am, when they are shocked or hurt when black folks question their intentions…like somehow that black person’s concerns about their own safety or health is about that specific white person…[White people] act like it’s some kind of personal attack on their character when it’s not about them at all…I’m guessing those types of
white folks just ignore history or have never just taken the time to figure out where black folks concerns are actually coming from…We all know black folks in the South are especially vulnerable because of the history here, we aren’t naïve…”

Patrice’s concerns were echoed by all of the older women interviewed for this project. When women with lupus learned a lupus study that had been conducted in their own community they did believe it led to a better understanding of their illness and possibly more treatment options. However, they also expressed concern about whether or not people living with lupus went untreated so that doctors could study the long-term impact of the illness. In 1982, revised clinical criteria consolidated the list of fourteen lupus markers down to eleven. The criteria includes seven symptoms, or clusters of symptoms identified by a physician through a physical examination, and four laboratory procedures. Symptoms include the distinct malar butterfly shaped “lupus” facial rash, discoid skin lesions, photosensitivity, oral ulcers, arthritis or chronic joint pain and swelling, seizures or neurological disruptions, and inflammation of the membranes around the heart and lungs. Laboratory based procedures include hematological conditions identified through a complete blood count (CBC), renal disorders identified through microscopic protein casts found in urine, a positive result on an anti-Smith antigen test, and a positive ANA test (Tan et al. 1982). These criteria continue to serve as the diagnostic guidelines used to identify the four syndromes classified as lupus: lupus erythematosus (LE) also known as discoid lupus, drug-induced lupus, pediatric lupus, and systematic lupus erythematosus or SLE, the most commonly diagnosed form of the illness (Elman et al. 2017, Rubenstein et al. 2017, Ball and Bell 2011).

The diagnostic criteria established in 1982 are still widely used for diagnosing lupus in the twenty-first century. Although an additional revised criteria was proposed in
1998, it was never tested or validated (Petri et al. 2012). In 2012, an international group of lupus researchers working under the title The Systemic Lupus Collaborating Clinics (SLICC) began the extensive process of revising the American College of Rheumatology’s (ACR) classification criteria. Using case studies from lupus patients collected by researchers in the United States and Europe, SLICC has created a new set of diagnostic guidelines (Petri et al 2012). The revised guidelines, introduced in early 2017, include a broader definition of chronic pain that is not exclusively linked to arthritic conditions, a more involved exploration of neurological phenomena, including chronic depressive symptoms frequently reported by lupus sufferers, and the inclusion of biopsy results used to diagnose lupus nephritis (Bertsias et al. 2013, Yu et al. 2014).

Even though lupus can be diagnosed based solely on repeating patterns of symptomatic flares, physicians rely heavily on clinical tests to make a definitive diagnosis. Physicians still largely base their diagnostic decisions on ANA testing. To better understand antibody levels, researchers have created an ANA panel that consists of a battery of blood and DNA testing (Thong and Olsen 2017, Khan et al. 2017). Despite these new ways of identifying lupus, individuals still live with active, reoccurring symptoms for approximately five to seven years before receiving a formal diagnosis (Al Sawah 2015).

Social and environmental contributions to the frequency and severity of lupus flares have also been of increasing interest to clinical and public health researchers. Clinical researchers have questioned why so few current lupus studies include people of color, when rates of lupus appear at higher rates in communities of color than predominantly white communities (Alarcon et al. 2001). In 1993, The Lupus In
Minorities: Nature vs. Nurture (LUMINA) study was established to address concerns presented by the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS) regarding racial and ethnic disparities in morbidity and mortality rates of U.S. residents living with lupus (Alarcon 2008). The study, coordinated between the Universities of Alabama, Texas, and Puerto Rico, sought to examine the genetic and environmental differences that contributed to advancing lupus symptoms and compromised quality of life for lupus sufferers (Bertoli et al. 2006). One significant finding in the study was that poverty, not genetics, was a key factor in understanding why lupus disproportionately affects people of color and why people of color are more likely to suffer from severe lupus symptoms (Alarcon 2008).

The Lupus Outcomes Study (LOS), conducted in the 2000s and 2010s specifically sought to connect advanced lupus symptoms with conditions of poverty (Zell Gillis et al. 2007, Yelin et al. 2017a). Conducted by public health researchers at the University of California at San Francisco, the LOS study has been examining how living conditions, access to healthy and clean food and water, and ability to access consistent healthcare contribute to the frequency and severity of lupus symptoms (Trupin et al. 2008, Jullian et al. 2009, Panopalis et al. 2008). Research has revealed that clients enrolled in Medicaid programs are less likely to receive the consistency of care needed to diagnose and treat long-term lupus symptoms (Yazdany et al. 2012). The study also finds that people with lupus who have spent even a short time living and working in impoverished conditions will have permanent tissue and muscle damage when compared to those who have not experienced poverty (Yelin et al. 2017b).
Patrice’s story mirrors many of the stories told by other middle class, professional women I met. Although her lupus diagnosis came about in a unique fashion, she was able to find reliable care most, if not all, of her adult life prior to her diagnosis. As she aged her symptoms became more regular and severe, but because she had received consistent care after her diagnosis her symptoms progressed slowly. Patrice’s status as an educated professional granted her access to more comprehensive treatment options and respect from other professionals which decreased the barriers she faced when navigating the healthcare system. At two points in her life, Patrice’s symptoms became so severe she needed to temporarily leave her job. The first time this happened she was able to use the personal days and sick time she had accumulated at work to spend several weeks recovering. The second time, a colleague helped her find a short-term disability program that gave her the chance to be at home for close to a year.

Patrice had been able to accumulate savings and retire with a pension. Most women under fifty who participated in this project did not have access to retirement plans through their employers and were not able to accumulate savings regardless of their professional status. As her symptoms began to intensify in her sixties, Patrice maintained economic stability, which meant that she was able to establish a consistent self-care routine at home. She had also been able to access long-term care health insurance from her last employer, which she used as a supplement to her Medicare. While Patrice did experience both racism and sexism in her professional life, as well as her role as a client, her education and class privilege did allow her to care for herself in such a way that she was able to monitor and treat her illness as problems arose. For African American women
who do not have the financial means to receive quality care, the circumstances
surrounding their illness are much different.

A Social History of TennCare: Rosemary’s Story

The TennCare system has had a significant impact on the way Tennessee
residents, especially chronically ill residents, were and are able to secure consistent health
care. Like Patrice, Rosemary was born during the final decades of Jim Crow segregation.
Rosemary grew up in South Memphis and explained she never realized her family was
poor until she was an adult. She remembered a childhood where there were always
neighbors to visit, walking to the drug store to buy candy with her friends, and
occasionally going to the movies to avoid the oppressive heat and humidity. Since both of
her parents worked, Rosemary spent most of her summers living with elderly relatives in
Hernando and Clarksdale, Mississippi. She hated her time in northern Mississippi
because it was rural and “there was nothing to do and no one around.”

Rosemary began experiencing brief periods of chronic, widespread, pain and
intense menstrual cramps in her mid-teens. In Mississippi, her grandmother made her hot
herbal tea and gave her a hot water bottle to ease her cramps. She told Rosemary the pain
was simply part of becoming a woman. At home in Memphis, her mother measured
illness based on whether or not Rosemary had a fever and was able to attend school or
church. Since the pain episodes did not meet her mother’s illness criteria, Rosemary was
told her pain was “all in her head.” Rosemary recalled how the poorly ventilated, hot
church and her mother’s heavy perfume triggered headaches that made her nauseous. She
regularly missed Sunday dinners during her teens. She also remembered being unable to
complete schoolwork because she became lethargic by the end of the week.
In her early twenties, Rosemary’s pain episodes abated, and she assumed her pain and headaches were linked to puberty. Her pain once again became frequent and intense by the time she reached her mid-twenties. At nineteen, Rosemary married her on-again-off-again high school boyfriend when they discovered she was pregnant. She experienced a miscarriage six weeks after she was married and over the next six months her pain episodes briefly returned. Rosemary lost two additional pregnancies by the time she turned twenty-five. When she made an appointment to see a local doctor after the third miscarriage, she was told the miscarriages were likely tied to her advancing age. When she asked the doctor about her chronic pain, she was told the pain was likely a psychological reaction to her inability to have children. Following each pregnancy, Rosemary noted that her pain symptoms became more frequent. After her second miscarriage she began to regularly experience swelling in her legs and hands. Her headaches returned in her late twenties. When they subsided in her early thirties, she blamed them on seasonal allergies. Rosemary continued to ignore her symptoms until the birth of her son William.

“I remember there was this story a few years back, it was on the national news and everything. It was about how more babies died in Memphis than anywhere else in the United States…It said that living in Memphis was as bad as living in a poor country in Africa…It makes me mad the way people beat up on Memphis, but maybe there’s also some truth…There’s a whole lot of poor people here who can’t get the things they need to survive, like food or a home…And I lost four babies all in all myself…When William was born I didn’t have no insurance, and come to think of it, I don’t know how we paid for it…But it couldn’t have cost a whole lot or I would’ve remembered it cause we didn’t have no money…But there were also more clinics for poor folk too back then, in the 80s…I went to a couple of those clinics to make sure everything was ok during my pregnancy…I was “high risk” because of the other miscarriages and cause I was close to thirty, so I was gettin’ kind of old to have babies…but I had to work and I didn’t have no money so I missed a lot of appointments
cause sometimes they scheduled them for times I couldn’t go… and [ex-husband] had to work too… and he was the only one who could drive at the time… so I wasn’t real good at keeping appointments because I didn’t have no way to get there… I got a lot of grief for [missing appointments] from all the doctors and nurses in the hospital when William was born cause he was too small and couldn’t breath on his own for a couple of days… but it is what it is and he’s a grown man now, and there wasn’t much I could’ve done differently.”

When Rosemary and her husband divorced, her life changed. Like many divorced women, not only did Rosemary lose a second household income, she also lost her access to regular healthcare (Mullings 2001, Williams 2004). Rosemary had been able to finish high school, but with a vocational degree in typing and transcription. By the mid-late 1980s her skills were becoming obsolete and she could not afford schooling that would train her in new computer-based fields. Following the divorce, her ex-husband initially kept up with child support, helped find childcare for William, and paid for most of William’s healthcare needs. However as manufacturing jobs left the state in the 1990s, he moved to Houston and cut off contact with Rosemary and William.

Rosemary eventually found steady employment working a wide range of customer service jobs, however her positions were frequently temporary or part-time. While many full-time employees were offered health and retirement benefits packages, Rosemary was consistently overlooked for positions that offered advancement. As the cost of healthcare began to rise, Rosemary and her co-workers argued over whether higher wages or health insurance was more important. Rosemary soon found herself in a paradox experienced by many working class and working poor Americans. Her wages were too low to pay for her monthly household expenses, but she technically made too much money to qualify for most state or federal public assistance programs.
Rosemary prioritized William’s needs over her own health. As an adult, she rarely saw a doctor unless her pain kept her in bed for more than three days. She did not have a regular general practitioner prior to the introduction of TennCare. When she was sick she often went to the emergency room. She hated going to the emergency room because she felt she was treated with indifference or disdain. Her delays in seeking care meant that her symptoms for any illness were more severe when she finally saw a doctor, and her expenses for treatment were higher (Rouse 2009, Mendelson 2006, Mullings 2002).

With healthcare costs rising nationwide, state level government began designing and implementing their own healthcare programs. In 1990 the state of Tennessee conducted an assessment of state’s medical costs. The assessment estimated that approximately one quarter of the state’s 4.9 million residents were either under or uninsured (Cooper 1996). The state’s poor national health ranking, large numbers of counties reporting high levels of persistent poverty, and largely absent state tax structure meant that the state was unable to carry the cost of a large uninsured population. This resulted in a collaborative effort between the state of Tennessee and health insurance conglomerate Blue Cross/Blue Shield. The state and the insurance company worked together to create a system that would allow private health insurance companies the opportunity to contract with the state in order to provide competitively priced health insurance for the state’s uninsured population. The program was called TennCare (Mirvis et al 1995).

TennCare was introduced statewide in 1994 as a tiered system that covered a myriad of health needs. TennCare was an umbrella term used to describe a large number of health services. While TennCare is largely associated with Medicaid and CHIPS,
between 1995 and 1999 short-lived TennCare programs also offered short-term health insurance for young adults, mental health and addiction services, hospice care, and temporary disability for Tennessee residents living with debilitating chronic illnesses (Mirvis and Chang 1996, Livengood et al. 1997). Over the years TennCare has been supported by a number of major health insurance companies. While Blue Cross/Blue Shield still offers the most sought after TennCare package, known as BlueCare, United Healthcare, Alliance Healthcare, and Cigna have served as major TennCare contributors in the 2000s (Gordon Bonnyman and Garr 2014).

In the late 1990s, the state widely advertised TennCare as the healthcare model of the future (Mirvis et al. 1995). Based on the premise that the costs of healthcare will self-regulate based on demand, TennCare was designed to create competition amongst health insurance providers. It was believed that health insurance companies would compete for state contracts. The state would then choose a number of plans based on cost and available services. Clients would ultimately drive the healthcare market by logically choosing the most inexpensive, comprehensive plans. In addition to promising healthcare coverage to underserved residents, TennCare also promised to bring new jobs to the state (Garthwaite et al. 2014).

Both expectations produced problematic results once TennCare was operational. While TennCare did create jobs, most of those jobs required a college education or extensive professional training. Private sector TennCare jobs did little to change the labor market statewide. The state also created new positions to meet the bureaucratic needs of TennCare, but those jobs with the state saw high turnover rates. State employed TennCare workers quickly burned out due to inefficient management, frustrating levels of
bureaucracy, and heavy caseloads (Mirvis and Chang 2003, Connelly et al. 2006). Clients also had very little input in their care. While the initial TennCare enrollment literature promised options based on clients’ needs and choices, by early 2000 TennCare placed clients in insurance tiers based on a number of factors, including age, income, household size, and disability status (Phelps 2001, Myers 2007). Under certain circumstances, most notably disability status, clients were able to request programs that offered more comprehensive care. Strict enrollment caps accompanied many of the programs offering comprehensive care, thus making those programs largely unavailable to new clients, or clients whose coverage had changed due to income requirements (Thompson 2009). As TennCare contracts with specific insurance companies ended, the insurance companies were given the option to leave the program or renegotiate their contracts. Dozens of insurance companies have left TennCare over the last twenty years, citing financial loss or bureaucratic restrictions (Phelps 2001, Smith 2001, Mirvis and Troyer 2003).

In 1993 and 1994 the state ran a massive media campaign advertising new TennCare programs. The goal was to enroll the state's entire uninsured population into a TennCare program. Rosemary remembered the commercials, billboards, and advertisements on public transit, but she claimed she never received TennCare mailers with enrollment information. She and William moved more than a dozen times over the course of a decade. While they remained in the city, they lived in six different neighborhoods in South and North Memphis. Rosemary’s inconsistent employment history meant that she and William were eligible for some food and housing assistance. However since her address and income fluctuated, she was never enrolled in a program
for a significant amount of time. Since Rosemary was not meeting with a caseworker on a
regular basis to receive public assistance, she was not given information about her
TennCare eligibility.

Rosemary first learned about her own TennCare eligibility after William broke his
arm during football practice in 1995. She was at work when she received the call telling
her William had been driven to the emergency room by one of his coaches. When she
arrived at the hospital, she learned that William had broken his wrist and she was relieved
he had no other injuries. Once William’s arm was in a cast, his coach offered to take him
out to eat while Rosemary met with one of the hospital’s social workers. Rosemary
described her mood as frustrated and defensive. She had prepared for the social worker to
question her competence as a parent. Instead the social worker talked to Rosemary about
her healthcare options. After talking to Rosemary about the TennCare options available
to both her and William, the social worker set up a second meeting so they could work on
the enrollment paperwork. She told Rosemary to call her if she could not make the
appointment and they would reschedule. She assured Rosemary that she was used to
working with clients who had irregular work hours.

A week later Rosemary met with the social worker and she and William were
both enrolled in TennCare programs. The social worker told Rosemary the
documentation of their meetings, and the enrollment forms, could be used to make a
retroactive claim to the hospital for William’s emergency room visit. Rosemary’s
symptoms had been getting progressively worse since William finished elementary
school in the early 1990s. Her female friends and family assured her chronic pain was
related to her sadness as a mother whose child was becoming more independent. They
told her they too had experienced pain as their children needed them less, and promised the pain would subside when she found social outlets for herself. Rosemary had little time for social activities since she worked two jobs, and she attributed her constant levels of exhaustion to lack of sleep, stress from work, and the responsibility of caring for her son alone. Over the course of 1996 and 1997, Rosemary’s health began to deteriorate. Her pain episodes became more frequent, and she developed deep muscle pain that restricted her mobility. She spent most of the summer of 1996 bedridden.

The following fall Rosemary and William moved in with a cousin so that Rosemary could recuperate and focus on one job instead of two. Rosemary felt her health was improving, and took a job as a manager at a fast food restaurant. Her schedule was irregular and she frequently worked overtime when employees called in sick or quit. Less than a year after taking the job, Rosemary began missing work due to pain episodes. When she was able to work a full shift, intense headaches made her dizzy and nauseous. She also began to experience a lack in concentration that she described as “brain fog.”

All but five of the women with lupus I interviewed described instances of “brain fog,” or “lost time” before or after lupus flares. The women differentiated “brain fog” from depression because they did not believe the fogginess was the product of sadness or isolation. Instead, they described the phenomenon as a period of suspended animation, where they lost track of time, felt disconnected from their bodies, or were unable to think clearly. They also did not view “brain fog” as a way to block pain, because the experience itself was a lack of feeling rather than a way to cope with intense feeling. Women described common examples of “brain fog” including sitting down to read a book or watch television during daylight hours only to realize it was night and they had
no memory of sleep, consistently arriving at work late or missing important meetings because they were positive the time they read on the clock was the same as their arrival time, when in fact they were several hours behind, and standing or sitting transfixed in one place for a prolonged period of time as they struggled to remember simple information such as their addresses, telephone numbers, and children’s names.

Rosemary’s “brain fog” began interfering with her work. Her inability to concentrate caused her to make repeated bookkeeping errors that eventually led to the loss of her job. Rosemary’s termination worried her cousin, because Rosemary was well organized and good with numbers. She urged Rosemary to seek medical care because her episodes of “brain fog” were becoming more frequent. Although Rosemary’s healthcare had been covered by TennCare for almost two years, she had never sought care for her symptoms. She was unsure how to use her coverage since she had never had a primary healthcare provider. She was also concerned that she would accumulate large medical bills if she sought care for health concerns that were not covered by TennCare. She continued to avoid seeking care until she began experiencing back and abdominal pain so severe, she had a neighbor take her to the emergency room.

Rosemary was diagnosed with a severe kidney infection. She was given antibiotics and follow-up referrals to specialists covered by TennCare. She was relieved to learn that TennCare covered a large percentage of her emergency room costs and most of her prescriptions. During her trip to the emergency room, Rosemary once again met with a hospital social worker. The social worker helped her make appointments and explained her TennCare coverage. The social worker set up an appointment for Rosemary to meet with a general practitioner (GP) working out of a county public health
facility. Rosemary’s TennCare required that referrals to specialists had to be made by the GP. Since she was feeling better, Rosemary considered skipping the appointment since she did not like seeing doctors. She was anxious to see if there was a way for her long-term health to improve. She described her first GP as “chatty and nervous.” But she was also happy that she was able to see a female doctor. She felt another woman would be more sympathetic to her health concerns.

Due to the nature of her kidney infection, her chronic pain, headaches, and persistent nausea, Rosemary’s GP referred her to a number of specialists. By the end of her visit, Rosemary had appointments with a gastroenterologist, a neurologist, and a rheumatologist. For the next eighteen months Rosemary was shuttled between appointments by her cousin and neighborhood friends. Rosemary found it challenging to make and keep appointments with specialists. Since few specialists in West Tennessee accepted TennCare clients, Rosemary frequently waited for months to schedule appointments that fit with the doctor’s schedule and her TennCare billing cycle. She kept a calendar taped to her refrigerator to keep track of her appointments and the specific limits of her TennCare coverage. In the fall of 2000, after almost four years of delayed, cancelled, and rescheduled appointments, Rosemary was diagnosed with lupus.

Following her diagnosis, Rosemary’s doctors encouraged her to begin the process of applying for different TennCare plans designed to assist clients with disabilities. If Rosemary was able to claim lupus as a disability, she would be eligible for TennCare programs that covered a wider range of providers and less restrictive prescription plans. By the end of 2001, Rosemary had been receiving consistent care for her lupus symptoms for more than a year. She had no additional trips to the emergency room, experienced no
reoccurring kidney infections, and was on a medication regimen that greatly curtailed her chronic pain episodes. Additionally she was prescribed medication for hypertension, received regular mammograms, and had three irregular moles removed and biopsied from her neck and back.

Rosemary felt good about her health, the providers who were caring for her, and had begun the process of collecting the documentation and letters of reference she needed in order to apply for disability. Rosemary had also secured a “good” job as a shift leader at a large box retail store. Although her job did not offer health insurance or other benefits, Rosemary was happy with her pay. She was able to move into a newly remodeled public housing townhome. William had graduated from high school, secured a job at the casinos in nearby Tunica, Mississippi, and had a serious girlfriend. He came home and helped his mother with the household duties when she experienced lupus flares. He also provided financial assistance by occasionally paying her utility and phone bills, and bringing groceries when he was in town.

Rosemary spent two years with mild lupus symptoms. However in early 2002, she received a letter informing her that her TennCare coverage had changed. The insurance provider covering her services was leaving TennCare, and the new insurer did not cover some of the services she was using. Additionally many of her physicians would no longer be accepting appointments from TennCare clients. Since Rosemary had experienced shifts in TennCare coverage before, she initially ignored the notices. She believed she would be able to find a new GP who would make recommendations to new specialists. Although Rosemary was frustrated that she had to start over with new doctors, she was determined to make follow-up appointments. She was feeling healthy
and did not want to experience gaps in her treatment. During the first half of 2002, Rosemary struggled to find a new GP. Her former GP had moved out of state and she spent several months contacting her physicians for recommendations and records. Even after Rosemary believed she understood the boundaries of her new coverage, she soon learned about the limits placed on her coverage as a result of TennCare restructuring.

“...It was summer, I think it was like 2002, must’ve been, cause that’s when a bunch of things changed...I went to the doctor for my skin cause it was real bad that summer...I went to the doctor I’d always gone to and they wouldn't see me...I had an appointment...I told the girl at the desk I’d had that appointment scheduled for like two months...I had to take off work to go...and she told me I didn’t have the right kind of insurance no more...Like I don't think they took nobody from TennCare no more, but she didn’t say it like that...I think she just kept saying ‘your insurance’ cause she didn’t want nobody knowing poor people came in there...cause everyone just thinks TennCare is for poor people...But I really didn’t understand what she was saying about insurance so I kept asking questions...I asked why didn’t no one call me to tell me...She just said my insurance should’ve done that...I laughed and said real loud so everyone could hear ‘TennCare ain’t gonna call nobody’...She just looked real uncomfortable and told me if I wanted to make another appointment I could, but I would have to pay for it if I didn’t have new insurance...After that a lot of places didn’t even give me the option to pay for an appointment to see doctors I’d been seeing for years. Some just told me they didn’t take TennCare no more and hung up...Some let me see the doctor, but didn’t tell me they didn’t take TennCare...They just let me see a doctor and then sent me a bill I couldn’t never pay...It’s gotten way harder to see anyone, any kind of doctor, if you have TennCare...No one wants to treat people on TennCare...some of them doctors treat us like we’re dirty if we’re on TennCare...”

In 1999, several major investors left TennCare when their contracts expired. This pattern persisted through the 2000 calendar year (Azier et al. 2000). TennCare clients like Rosemary were initially able to retain their benefits due to their Medicaid eligibility. However the services offered to TennCare clients fluctuated from year to year depending on new health insurance contracts. Rosemary had accepted these fluctuations as a normal
part of accessing healthcare. In 2002 TennCare experienced its first large-scale eligibility shift. Funding for existing TennCare programs became tenuous, prescription drug programs were significantly curtailed, and several essential services were eliminated for adult clients receiving TennCare as part of the state’s Medicaid program. Approximately 140,000 adult TennCare clients lost their coverage during the first phase of the restructuring (Mirvis et al. 2002, Mirvis and Chang 2003). Private practices became hesitant to accept TennCare clients due to the program’s economically uncertain future.

As part of the restructuring, existing programs were divided into two categories: TennCare Medicaid, which serviced low-income residents, and TennCare Standard, designed to meet the needs of non-Medicaid eligible residents who qualified for TennCare services (Mirvis and Chang 2003, Larson and Williams 2003). This division changed eligibility standards. Between 2002 and 2003, an additional 100,000 existing TennCare clients either lost their coverage or found their benefits streamlined (Myers 2007, Heisler et al. 2005). Rosemary lost her coverage during this phase of the restructuring since her salary disqualified her from Medicaid. With William’s help, she spent the next eight months fighting to regain her coverage.

Rosemary was eventually able to enroll in a TennCare Standard program due to her documented chronic illnesses. Since she had been enrolled in TennCare since 1995, she was comfortable navigating many of the system’s uncertainties. The personal connections she had made with social workers and healthcare workers over the years, and her fastidious file maintenance system, allowed Rosemary the ability to regain her TennCare coverage. Her TennCare Standard coverage was greatly limited in comparison
to her original benefits. She was not financially or emotionally prepared for the bills that began arriving in her mailbox the following spring.

A number of physicians had continued to provide care for Rosemary while she was working through her eligibility issues. Staff in those offices assured her that she was not the only client experiencing these issues and they did not want clients to have to forfeit care because the state could not make decisions. Rosemary was technically uninsured during the eight months she was fighting to re-establish her coverage. Many of her existing doctors continued to make appointments with her, telling her they would re-submit her insurance paperwork when her TennCare coverage was approved. In the spring of 2003, Rosemary began receiving large bills for appointments, treatments, and prescriptions she had received during the period of time her coverage had lapsed.

Tensions over the future of TennCare continued to escalate, and 2005 became one of TennCare’s most tumultuous years. Then Tennessee governor, Phil Bredeson, oversaw the program’s largest restructuring. Prior to taking a role in politics, Bredeson held a number of roles in the healthcare industry ranging from managing an international pharmaceutical company, to serving as the CEO of a Nashville based health insurance provider. Under Bredeson, TennCare’s commitment to comprehensive services came second to economic returns that benefitted insurers. In January 2005, the Bredeson administration made sweeping cuts to TennCare eliminating coverage for 323,000 adult TennCare clients, and vastly curtailing benefits to the 396,000 remaining adults enrolled in the program (Thomson 2009, Chang and Troyer 2009). Changes included limiting physician and hospital availability, cutting off access to specialists in a number of high tech fields, and extensive revisions to prescription drug programs (Schneider 2004).
These changes were met with outrage, and Tennessee residents staged public protests in Nashville during the summer and fall of 2005 (Connelly 2005, Nashville Business Journal). Even as public outcry grew, TennCare suspended new applications for adults who were not pregnant, and began the process of curtailing benefits to remaining TennCare clients. Over the 2005 calendar year approximately an additional 190,000 residents enrolled in TennCare Standard either lost their benefits entirely, or were taken off TennCare’s prescription medication and wellness plans (Myers 2007, Braverman et al. 2008). Gaps in coverage soon became clear for young adults who were no longer able to claim benefits as minors, adults like Rosemary living with multiple chronic illnesses, and individuals who had been receiving regular services for mental health or addiction issues (Hill and Wooldridge 2006). By February 2006, TennCare covered roughly half the number of clients it had in 1996 (Farrar et al. 2007, Tarazi et al. 2017).

Rosemary’s relationship with the TennCare system became tenuous by the end of 2005. She feared the new set of client restrictions would interrupt her coverage like it did in 2002. Rosemary began strategically planning her options. She organized her notes and medical history, asked her doctors for records or recommendations, and began making phone calls to reestablish contact with healthcare workers she knew around the city. She made a list of doctors she needed to see before the new TennCare structure was introduced. She investigated which facilities might continue to take new clients who were enrolled in TennCare. She even began rationing her medication so she knew how many days she could skip a dosage before she began to feel the effects of being without medication.
In the summer of 2005, Rosemary received a letter in the mail informing her she was no longer eligible for TennCare. She would be able to retain her coverage until the end of the year, but was encouraged to find alternative options before then. She continued the disability application process with the help of legal services sponsored by a local church. In early 2006 she gave up on her disability application after becoming frustrated with what seemed to be constantly changing eligibility guidelines. Without consistent care, Rosemary’s health began to rapidly decline. Between 2006 and 2008, she went to the emergency room seven times for severe kidney infections. In one instance she was hospitalized for several days when doctors identified an unusual heart murmur.

Rosemary soon found herself unemployed and deeply in debt. She lost her job in the fall of 2006 due to numerous absences. By 2007, the severity of her symptoms kept her from maintaining a regular work schedule and she became chronically unemployed. Since she was not able to access reliable, affordable healthcare, Rosemary accumulated more than $60,000 in medical debt in less than three years. As interest on her unpaid medical bills grew, and her debt was transferred from lender to lender, $60,000 became more than $85,000 by the end of 2010.

In 2009, William, his wife, and their three children moved back to Memphis after William lost his job. The family also lost their northern Mississippi home when the real estate market fell and the Recession began. In early 2011, Rosemary’s mobility was severely limited when her rheumatoid arthritis began to warp her fingers and toes. She moved into a two bedroom apartment in South Memphis with William and his family. Rosemary and William were each able to file for bankruptcy in 2011. The bankruptcy
eliminated most of Rosemary’s medical debt, but it also left her with no personal financial safety net, and poor credit that kept her from finding a her own apartment.

When I met Rosemary and her family in 2014, the entire family was primarily living off of Rosemary’s daughter-in-law’s salary as a corrections officer. In the summer of 2014 William and two high school friends started an unlicensed handyman business. The three men left their homes everyday before dawn in hopes of finding work mowing lawns, painting houses, and working as movers. Since the men were paid in cash they were frequently paid less than they originally agreed upon with their clients. They also had to cover the cost of their gas, equipment, and supplies, which cut into their personal earnings. Rosemary ran an informal daycare out of their apartment during the week. When her pain levels were low, she pressed and braided hair in the kitchen at night.

By 2014, Rosemary was back on TennCare. Her recent history of chronic unemployment, and her bankruptcy, had placed her back on the state’s Medicaid eligibility list. Although Rosemary technically had healthcare through TennCare, her options were limited to state-run health clinics and boutique style clinics housed in local grocery stores and pharmacies. These facilities were not equipped to handle the ongoing needs of a client with lupus. Since Rosemary was in her sixties, and living with numerous chronic illnesses, a local non-profit was working with her to figure out her best Medicare options.

Rosemary’s story was not unusual for working poor residents in North and South Memphis. Although she and her son had both been able to successfully graduate high school, neither one had been able to maintain living wage employment for more than five years. They were only able to eliminate debt created by conditions of persistent poverty.
by declaring bankruptcy, a decision that furthered their exclusion from formal economic systems. The relationship between poverty and health affected Rosemary’s ability to care for herself while living with multiple chronic health problems. Every year Rosemary assembled her documents in anticipation of receiving notices that would eliminate her healthcare and social services. Rosemary’s inability to continue visiting the same practitioners, using the same facilities, and having access to medication intensified the symptomatic expression of her multiple chronic health conditions. Despite her struggles with the healthcare system, Rosemary was optimistic about the ACA.

TennCare, The ACA, and the Future

The introduction of the ACA was met with mixed reactions throughout the state. Patrice and Rosemary were optimistic that the introduction of the ACA would reshape TennCare. Both women hoped the new health insurance exchange programs would resemble early TennCare programs which offered more comprehensive care, less restrictive prescription drug plans, and additional accommodations for the elderly, chronically ill, and disabled. Rosemary was excited that new healthcare measures were being instituted under a black president, because she felt Barack Obama better understood the needs of black residents than former white presidents. Patrice was eager to hear details about whether state level health insurance exchange programs would encourage more hospitals and physicians to accept new clients because the exchanges and Medicaid expansion would provide more options for Tennessee residents who had few or no options outside TennCare.

State-level elected officials challenged the ACA from the very beginning. Governor Bill Haslam argued against Medicaid expansion in the state of Tennessee on the basis of state’s rights. Haslam argued that Tennessee already had a state run Medicaid
program and ACA guidelines were an encroachment on the state’s right to distribute healthcare in any way they saw fit (Harrington 2013). During the introductory phase of the ACA, the governor announced the state would forgo the proposed federal Medicaid expansion, and would opt out of all federal programs that sought to establish health insurance exchange programs (Goodnough 2013, Locker 2014). The Tennessee Medical Association and state hospital board responded to the governor’s decisions by arguing that declining federal money set aside for state-level Medicaid expansion could have disastrous consequences for already overburdened public hospitals and clinics (Goodnough 2014, Fletcher 2015). They argued that TennCare’s unstable infrastructure, and regularly changing eligibility guidelines, had created gaps for under- or uninsured residents living in the state’s poorest communities (Tarazi et al. 2017, Gordon Bonnyman and Garr 2014).

In 2015 the Kaiser Family Foundation released an evaluation of the impact Medicaid expansion had during the first year of the ACA. The report revealed that amongst states that chose to forgo Medicaid expansion, Tennessee experienced the largest gaps in coverage and the longest wait times for enrollment in either federal or state programs since the introduction of the ACA (Kaiser Family Foundation 2015). During the summer of 2015, the federal government pressured the state to find a solution to the coverage gaps, or face federal intervention (Kaiser Family Foundation 2015, 2017). The state responded with a proposed program called Insure Tennessee. Insure Tennessee was designed to fill coverage gaps and meet federal requirements by adhering to federal insurance exchange guidelines which reduced the cost of prescription drugs, created affordable and fair coverage options for individuals with pre-existing conditions, and
provided health insurance benefits for children living in low-income, uninsured households (Sher 2015).

The program was introduced for a vote in December 2015. State representatives overwhelmingly voted in opposition to the program, and Insure Tennessee was quietly dismantled in early 2016 before programs began accepting clients (Daniels 2016). In late 2016, United Healthcare confirmed rumors that it was leaving the federal healthcare insurance exchange programs purchased by Tennessee residents. Current enrollees are able to keep their coverage through 2017, but coverage will be suspended January 1, 2018 (Fletcher 2016). Kaiser reports that as many as 81,000 Tennesseans will lose coverage if they are unable to find alternative options (Kaiser Family Foundation 2017). While United’s decision does not have a direct impact on current TennCare recipients, the United health insurance plans were among the lowest cost plans offered to Tennessee residents who did not financially qualify for TennCare (Tarazi et al. 2017).

Patrice and Rosemary each have complicated relationships with their health. Over the course of their lives both women lived through changing definitions of what it meant to live with lupus. Their long-term health was also directly influenced by changes in the healthcare system. Structural racism impacted their experiences with lupus and their ability to navigate changes in the healthcare system. Patrice and Rosemary were both born black in the South during Jim Crow segregation. Their early experiences with lupus symptoms were shaped by segregation. Although the number of African American physicians providing services in Memphis was unique to large southern cities during Jim Crow, facilities and resources were still limited or were accompanied by additional barriers or expectations to participate in medical studies (Wailoo 2001).
Both women were raised in households where they were taught to ration their resources and ignore physical pain. Patrice and Rosemary each began experiencing pain episodes in their late teens and early twenties. Both women initially dismissed their symptoms, attributing their pain to long hours at work, poor eating and sleeping habits, and environmental irritants. Patrice experienced prolonged periods of remission during her thirties and early forties, while Rosemary’s symptoms grew increasingly worse as she aged. Each woman lived with worsening symptoms for a decade or longer before she received a diagnosis.

While legal segregation created barriers to Patrice and Rosemary’s lupus diagnoses, class played a significant role in their healthcare options as adults (Becker 2007, Willging 2005). Patrice’s middle class upbringing, education, and later professional contacts granted her access to a wide range of treatment options. Her ability to consistently take advantage of a variety of health services throughout her adult life allowed her to maintain a quality of life with lower levels of pain. She experienced few dramatic fluctuations in her health until she reached her early sixties. Patrice’s hesitance to participate in one of the nations’ earliest lupus studies was tied to her understanding of history and the exploitation of black bodies for medical experimentation (Hoberman 2012, Wailoo and Pemberton 2006). She eventually made the decision to participate because she felt her own professional knowledge informed her understanding of the project’s clinical goals and granted her a certain level of control over the limits of her long-term participation. Through the study she made contact with physicians specifically trained to identify and treat lupus immediately after her diagnosis. The progression of her illness was slow due to her access to employer based private health insurance, her ability
to afford produce and unprocessed food that reduced many of her symptoms, and workplace medical leave programs that allowed her to maintain her quality of life while caring for herself during particularly long periods of pain.

Working professionally in healthcare also gave Patrice unique access to colleagues with specialized knowledge. As a trained nurse, she was able to navigate changing labor patterns that left many others in the state unemployed. Patrice benefited from the TennCare system both professionally and personally. During the mid-1990s, she was given a signing bonus and increased pay because she was interested in working in public healthcare facilities that treated TennCare clients. She was also able enroll in a short-term TennCare program in the late 1990s when her symptoms became severe and she was forced to take a leave of absence from work.

By contrast, Rosemary lived in an impoverished neighborhood. She had limited access to healthcare throughout her adult life, which furthered the progression of her illness (Geronimus 1992, Mullings 2002). Until she was enrolled in TennCare in the mid-1990s, Rosemary had sought care through emergency rooms and critical care clinics. Although she was not in critical condition when she used the emergency room, her lack of access to preventative care meant the symptoms associated with her chronic illnesses were severe, and therefore expensive. Even after Rosemary was enrolled in TennCare, her status as a privately insured individual did not guarantee that she would be able to access providers who were specifically trained to treat lupus. Rosemary’s path to developing a proactive lupus self-care routine has been complicated. As Rosemary’s TennCare benefits changed, or she experienced interruptions in coverage, she returned to seeking primary care in emergency rooms.
Rosemary’s lupus diagnosis was related, in part, to her participation in early TennCare programs. Since her medical requests were channeled through a specific provider there was constant documentation of her chronic health issues. This documentation allowed her general practitioner to make referrals to specialists trained to treat lupus. Even though Rosemary did have access to a large network of healthcare providers during the first five years of the TennCare program, she waited for weeks or months for appointments. These delays in care meant that Rosemary’s symptoms went untreated for significant periods of time between appointments. As the TennCare system changed, Rosemary was left with fewer and fewer primary care options. When the ACA guidelines went into affect in 2014, Rosemary was enrolled in TennCare’s least comprehensive program. Her access to ambulatory and emergency care was limited, she was only able to access primary care through state run clinics which were only open during the week, critical care clinics located inside grocery stores, and pharmacies that were open on weekends and after normal business hours. Her prescription services were capped at seven medications, only two of which could be brand name.

Racism and lower-class status compounded Rosemary’s chronic poor health (Mullings and Wali 2000, Becker et al. 2004). Access to heath insurance and health services was only one component to Rosemary’s ability or inability to create a sustainable self-care routine. Her lifelong struggles with chronic poverty accelerated her lupus symptoms (Yelin et al. 2017a). Her inability to secure living wage work for more than brief periods of time during her adult life meant that she struggled to find affordable and safe housing and transportation. When she was able to work full-time, she frequently worked two jobs, both with irregular work schedules. While Rosemary was eligible for
public assistance when William was young, her access to groceries became limited as William aged and she was no longer eligible for public assistance programs that only provided care for adults with children. Since Rosemary lived with chronic poverty, unemployment, and illness she was unable to secure savings that would allow her to create a self-care buffer when her symptoms became too severe for her to work. Her bankruptcy due to medical debt also hurt her credit, which she needed in order to find new housing and pay bills.

In 2015, both Patrice and Rosemary were in their mid-sixties and were exploring their Medicare options. Patrice had retired in 2013 when her flares became more frequent. She was enrolled in Medicare and had been able to secure long-term health insurance through her final employer. Although her lupus symptoms were advancing, she still lived an active lifestyle, volunteering at the kidney clinic, engaging in civic activities, and going on daily walks with her dog. She was able to freely schedule appointments with different specialists and worked with them on her long-term health goals. On days when her flares were particularly intense, she sat in a reclining chair in her living room dozing and watching television. She had a large network of friends who cared for her when she was unable to care for herself.

In addition to applying for Medicare, Rosemary was once again working with a local faith based organization skilled at assisting seniors in need of TennCare resources. Rosemary was hoping Medicare would give her a larger pool of providers and access to services she needed in order to care for all her health issues. She continued to work out of the apartment she shared with her family. Over the course of 2015 her mobility became increasingly limited. William was in the process of applying for public housing options
that would allow her as an individual, or the entire family, the ability to find a first floor
apartment or a small home that was handicapped accessible. In addition to lupus,
Rosemary had been diagnosed with hypertension, fibromyalgia, rheumatoid arthritis, and
asthma. She had recently been forced to stop cooking meals for her family and doing
chores around the house when she developed gout. Her pain levels were constant,
although she said some days were better than others.

Patrice and Rosemary’s stories overlap in many ways, but ultimately poverty
significantly alters Rosemary’s long-term health outcomes. Patrice’s middle class status
meant that she had consistent healthcare throughout most of her adult life. Even during
times when she was between jobs, her modest savings allowed her to maintain the same
quality of life. In her sixties, her lupus symptoms were mild to moderate, and she
reported that her lupus disrupted her daily routine for roughly a week out of every month.
Rosemary’s symptoms were severe. She reported constant levels of pain and exhaustion.
Her lupus symptoms were complicated by her additional chronic illnesses.

The United States continues to focus on a healthcare system that works
exclusively through private health insurance. The ACA framed private heath insurance as
the solution to the nation’s problems with chronic poor health, even as programs
promised to provide more comprehensive care to individuals and families without access
to healthcare. On paper, Rosemary has been covered by a health insurance provider for
the second half of her adult life, yet she had been unable to access many of the services
she needed. Lupus researchers who sought to find an explanation of the illness’
proliferation in communities of color eventually concluded that their observations were
linked to persistent poverty, not a genetic pre-disposition for lupus. Patrice and
Rosemary’s stories are representative of the responses many women I interviewed gave when asked to describe their personal medical journeys with lupus. They were apprehensive to participate in a system where unequal access to resources was normalized. They were skeptical of their quality of care and the intentions of their providers in clinical settings. In order to navigate these uncertainties they relied on others for care and support. Chapter Five documents how those networks shape the experience of living with lupus by addressing inequality and racism through sharing and circulating knowledge regarding the diagnostic process and self-care strategies.
“Getting up every morning with lupus is kind of like working a crossword puzzle. Sometimes the puzzles are easy and you finish feeling smart and right proud of yourself. Sometimes they’re hard and you spend your day toiling away, only to toss it in the trash when it becomes too frustrating...living with lupus is a mixed bag...I like Words with Friends because it makes solving puzzles a group activity...I like support groups because no one else really understands what it’s like to live with pain unless they’ve lived with it themselves...”

- Ms. Retta

The Inequality of Local Policy

The end of the twentieth century saw a decline in state sponsored social service programs throughout the United States (Morgen et. al 2010, Pfeiffer and Chapman 2010). With an increased focus on economic solutions to social problems, the responsibility for social and economic wellbeing shifted from a partnership between the state and the citizen, to a discourse that excused the state from its responsibilities by blaming citizens for poverty (Maskovsky 2001, Collins 2008). In Tennessee, this shift led to the increased privatization of a number of traditionally state sponsored systems. In the 1980s and 1990s, the state of Tennessee began offering contracts to private companies for a number of state services, including public works projects, utilities, welfare, and healthcare. Of these services, TennCare is the largest and most widely documented system still in operation. While programs like TennCare affect communities at the state level, local political decisions maintain inequality at the community level. In 2013 and 2014, the city of Memphis and Shelby County proposed, or enacted, several policies that not only cut off resources to the poor, but created larger economic divides between poor black city residents and wealthy white county residents.

With the exception of Nashville and Davidson County, the state of Tennessee’s major metropolitan areas have established divisions between city and county governments. Divisions between cities and counties have resulted in a steady flow of
money and resources into communities with existing concentrations of wealth and power (Harrison 2007). In Memphis, this division benefits Shelby County’s wealthy suburban incorporated townships. With independent tax structures, systems of government, and police forces, the Memphis suburbs are able to create both an economic and physical barrier between themselves and city residents. According to census data, Memphis ranks fifth in the nation for income inequality (Proctor et al. 2016).15

In the fall of 2013, Memphis Mayor A.C. Wharton’s office proposed a significant sales tax increase for the city. If enacted, the new tax would have raised the city’s flat tax rate from the state’s established 9.25% to 9.75%, the highest percentage the state allows. Representatives from the mayor’s office claimed the 9.75% sales tax would generate additional revenue from the city’s downtown tourist industry. Proponents of the increase argued that the tax was necessary since county residents were already paying for many of the city’s infrastructure projects through property taxes. (Hammond 2013, Anthony 2013). Since the surplus revenue would be used to help fund Pre-K programs in the city’s poor North and South Memphis neighborhoods, county residents also objected to increasing the sales tax countywide since they would not directly benefit from the new sales tax (Memphis Business Journal 2013, Philips 2013).

Opponents of the bill argued that by keeping the elevated sales tax within the city limits, Memphis’s poorest residents would be paying one of the highest flat tax rates in the nation. The city’s weak public transportation system and high levels of chronic unemployment meant poor Memphis residents had few options for food, medication, and

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15 The cities with the highest level of income inequality are New York City, Miami, Los Angeles, Houston, and Memphis (Glassman 2017). With a city population of approximately 650,000, and a county population of approximately 930,000, Memphis is half the size of the next smallest city on the list.
household goods outside their neighborhoods. The increased sales tax would create even more economic insecurity for city residents who were already struggling to afford rent and household necessities (Settles 2013, Tri-State Defender 2013). Approximately 30% of residents living in the city of Memphis are living below the poverty line, compared to 22% in Shelby County. Although both city and county numbers reflect higher rates of poverty at the state and national level in comparison to metropolitan areas of similar sizes, African American residents live in poverty in Memphis at much higher rates than white residents (Delavega 2015).

Though the sales tax initiative ultimately failed, the city continued to support projects that further marginalized the city’s poor (Baker 2013). In early 2014, the mayor’s office proposed the city of Memphis purchase AutoZone Park, a downtown stadium that hosts the city’s minor league baseball team. Located at the edge of the downtown Beale Street tourist zone, the mayor’s office argued purchasing and renovating AutoZone Park would generate revenue from tourism that could be used for city improvement projects (Sheffield 2014). City council members were given documents pertaining to the purchase only days before they were expected to vote on the decision. Those who opposed the project were concerned that money would be taken from other projects, including the renovation of an abandoned department store that was scheduled to be transformed into an education and job training center in South Memphis (Sells 2014). The proposal passed in late January 2014, and the city of Memphis paid twenty-five million dollars for the stadium (Brown 2014).

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16 Within Memphis city limits, 34% of impoverished residents are black, while 14% are white. In Shelby County, 31% of black residents are living below the poverty line, compared to 8% of white residents. 47% of black Memphis residents living in poverty are children (Delavega 2015).
Also in 2014, Shelby County won its final legal battle to create independent, suburban school districts. The school districts had first been proposed in the early 2000s, however the city had repeatedly brought legal action against the county, blocking redistricting efforts (Pohlman 2010). Each time the proposal came to a vote, the motion was struck down. Residents and city council people representing predominately black city neighborhoods argued that allowing the predominantly white suburbs to form independent school districts was a form of segregation (Eaton 2014, Bauman 2017). Throughout the fall of 2013 and the winter and spring of 2014, public events concerning the potential redistricting were held throughout the city and county. Public forums were tense as residents representing both sides of the issue met to voice their concerns to elected officials. In March of 2014, a federal judge dismissed a lawsuit opposing the redistricting. The municipal districts of Arlington, Bartlett, Germantown, Collierville, Lakeland, and Millington were given permission to create the new districts beginning in the 2014-2015 academic year (Times Free Press 2014). In addition to the new school districts, the 2014-2015 academic year saw more than a dozen school closures throughout the city. These closures disproportionality affected low-income South Memphis neighborhoods (Hammond 2013b, Kebede 2017).

Although state resources are becoming scarcer, the number of people needing assistance is growing. Increasing gaps between the wealthy and the impoverished in terms of education, labor, and health in the U.S. during the first decades of the twenty-first century make the needs for these resources even more immediate (Durrenberger 2007, Morgen and Maskovsky 2003, Collins and Mayer 2010). In the absence of state resources, private and non-profit organizations are becoming responsible for the poor.
State and local governments throughout the United States are now relying on the same pool of resources used by governments in the developing world.

**Who Fills the Gaps? Faith and Community in Memphis**

Non-governmental organizations (NGOs) often provide basic needs, inducing food and healthcare, to the residents of poor nations whose governments are unable or unwilling to provide resources to their citizens (Pfeiffer 2004, Smith-Nonini 2000, Schuller 2012). Faith-based or private benefactors in the United States and Europe frequently fund these organizations who export western Protestant Christian values as part of their humanitarian aid packages (O’Brien 2017). Since many of these organizations view their participation in humanitarian engagement as an extension of their own political and moral belief systems, those seeking aid must conform to the expectations of the benefactors as a survival strategy (Elisha 2011). As state funding for anti-poverty programs is regularly curtailed due to budget concerns, poor neighborhoods in the Southeastern United States are relying heavily on aid packages and assistance provided by private or non-profit philanthropic organizations (Rodriguez 2007, Adams 2013). In the Mid-South, those organizations are largely faith-based, or at the very least connected to a larger network of Christian organizations. These organizations frame addressing issues of poverty as a component of their Christian mission and identity.

With state-level resources on the decline in the last three decades, philanthropic and faith-based organizations have increasingly filled the gaps state-sponsored programs once covered. In his study of East Tennessee mega churches, Omri Elisha (2011) illustrates how suburban Evangelical Protestants use community outreach and intervention as an extension of their Christian identity. The introduction of church-sponsored service programs into poor U.S. neighborhoods utilize frameworks similar to
those used in international mission work (Weiss 2001, Elisha 2011). Poverty is framed as a moral weakness that can be overcome with hard work, prayer, and conspicuous consumption (Hackworth 2012).

Faith-based philanthropic organizations are powerful entities in poor Memphis neighborhoods. The most recognizable international organization in the city is The Salvation Army. With three major facilities designed for community outreach and a half dozen thrift stores in the Memphis metro area, The Salvation Army is a powerful organization delivering services to the poor. Memphis experienced two exceptionally harsh winters in 2014 and 2015. The city was poorly equipped to handle the weather. Schools were closed due to frigid temperatures, emergency shelters were opened, and neighborhoods all over the city were left without water when pipes burst in many neighborhoods. While the city struggled to assemble workers and resources, The Salvation Army was able to collect and distribute clothing, water, and medicine to the most affected communities within days of the initial emergencies.

Local anti-poverty organizations, including the Mid-South Food Bank and the Metropolitan Interfaith Alliance (MIFA), are welcomed into low-income communities with less apprehension than national and international organizations. During my time in Memphis I volunteered in four churches located in North and South Memphis neighborhoods. I met the women who allowed me into spaces through volunteer opportunities at The Mid-South Food Bank and MIFA. Founded by a group of rabbis and Christian ministers in the 1960s, during the Civil Rights Movement, MIFA’s original

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17 St. Jude’s Children’s Research Hospital and La Bonheur Children’s Hospital are both internationally recognized research facilities located in Memphis’s downtown medical district. While these two hospitals are high profile philanthropic entities in the city, they are not facilities associated with local levels of community involvement.
goal was to promote economic and political equity through social justice and direct action. MIFA’s current goal is to “support the independence of vulnerable seniors and families in crisis through high-impact programs,” and “welcome and respect all people.

Act with integrity. Value individual initiative and ability. Serve individuals and the community as an act of faith. Balance humanitarian goals with sound business practices” (mifa.org). MIFA volunteers and staff frequently live in the communities they service and local houses of worship support many of the program’s initiatives. Besides their citywide Meals on Wheels program, MIFA also heads high profile initiatives to bring attention to the high cost of utilities throughout the city. With the help of the city’s professional basketball team, the Memphis Grizzlies, MIFA collects money to help low-income residents pay past due bills and high summer and winter utility bills.

Although MIFA volunteers and staff represented a wide array of religious backgrounds, the contacts I met through my volunteer work were primarily affiliated with large, African American, Protestant Christian churches. I recognized that these churches served as gatekeepers in many of the neighborhoods where I wished to conduct interviews. The churches were accustomed to working with, and vetting, researchers interested in working in their communities. They were comfortable allowing researchers into their spaces and had well-established research boundaries. These churches not only legitimated my presence in several neighborhoods, but also served as a protected public/private space for research participants who did not want to be interviewed in their homes, work, or healthcare settings. In order to respect the boundaries of organizations and churches servicing vulnerable groups of people in the city, I did not pursue more than casual relationships with churches and faith based organizations that were hesitant to
interact with a white researcher. My longest ongoing relationships were built with a
group of women attending chronic pain and lupus support groups at a large Baptist
church in a community I have named Morningside. Ms. Lena, the church’s secretary
facilitated my entrance into the groups and helped me build relationships with a diverse

group of women living with chronic pain. I do not believe I would have had such intimate
access to this space if it were not for the fact that Ms. Lena was living with lupus. Ms.
Lena, and many of the other women attending Morningside Baptist Church support
groups, were also interested in participating in this project because they felt lupus
organizations used images of women of color in promotional material, but did not take
into account how being a woman of color affected their ability to care for themselves
during lupus flares.

**Morningside Baptist Church**

African American churches play an important role in community outreach
programs throughout the city of Memphis. Morningside is an economically diverse,
historically African American neighborhood, located in North Memphis. Morningside
Baptist Church serves as both a community gathering space and humanitarian resource
for poor North Memphis residents. The church’s commitment to civil rights issues and
antiracist politics is a continuation of the larger mission of African American churches to
provide support, shelter, and safety for African Americans throughout the United Sates
(Blum 2017).

After Emancipation, African American churches were one of the few places
where freed blacks could find refuge and support. The churches not only offered spiritual
support, shelter, and food but also provided protection. They facilitated safe passage
across the country and helped new arrivals find homes and jobs (Livingston Adams 2017,
African American churches spread quickly throughout the South in the years following the Civil War. The city of Memphis served as a gateway between the South and the Midwest and North in the years following Emancipation (Wailoo 2001, Rushing 2009). In the late nineteenth century Memphis’s growing African American middle and professional classes financially backed Baptist and African Methodist Episcopal (AME) Churches across the Mid-South. The churches and their memberships created a powerful political history that linked church involvement to antiracist movements in Memphis throughout the twentieth century (Wailoo 2001, Honey 1993).

African American churches were a visible force for social change during the Civil Rights Movement. Like many generations before them, young African American activists used churches as gathering spots to organize and share information about protests and sit-ins. During the Civil Rights Movement themes of economic and political inequality were not only used to energize congregations during sermons, they were used to mobilize community members. Churches became political power bases for African American neighborhoods, and church leaders became the public faces of the Civil Rights Movement (Jabir 2017, Marable 2007, Robnette 2000). African American churches also became sites for numerous acts of racial violence as white supremacist groups threatened congregations and bombed African American churches throughout the South (Collins 2006). In Memphis, large, organized, powerful African American churches served as spaces where unions, students, and traveling civil rights leaders met and shared ideas (Brondo and Lambert-Pennington 2010).

Morningside Baptist Church’s older congregation members were quick to share stories of the church’s role in the Civil Rights Movement. The church hosted a number of
events throughout the year that encouraged community members to share pictures and mementos, along with their personal experiences with the Civil Rights Movement. Guest speakers engaged with children in Sunday school classes, teaching them about Morningside’s role in promoting social justice throughout the city. The church also boasted a robust Civil Rights archive that they made available to the community on a limited basis. Current and former residents traveled from across the country to attend Morningside Baptist Church’s annual homecoming and holiday events.

In the early decades of the twenty-first century, African American churches have served as spaces of financial and emotional support in low-income communities. Although providing care and resources for disenfranchised African Americans has always been central to many churches’ missions, the need has increased as federal funds have been cut or redirected away from anti-poverty programs (Harris and Ulmer 2017, Hackworth 2012). Federal policies focusing on reform, aimed at reducing both the cost of services and the government’s responsibility to cover the welfare of its citizens have resulted in the decline of programs designed to feed, educate, and provide healthcare to the poor (Morgen et al. 2010, Collins and Mayer 2010). In impoverished neighborhoods throughout the city of Memphis, low-income residents have few options for support outside faith-based organizations. Churches are now not only providing basic needs to the poorest residents in the community; they are also providing job training, legal assistance, and healthcare for those who have no other options.

Morningside Baptist Church’s large sanctuary was standing room only on Sundays. The adjoining fellowship hall welcomed thousands of Memphis residents over the course of a calendar year. In addition to providing a space for worship, Morningside
Baptist Church also created a number of spaces for the community. The church hosted a diverse selection of support groups throughout the week. Alcoholics Anonymous (AA), Narcotics Anonymous (NA), and Al Anon groups had dedicated spaces in the fellowship hall. Each group held meetings three times a day, seven days a week. The church also hosted a wide variety of illness or issue themed support groups. Faith-based support groups for community members struggling with grief, illness, single parenting, aging, divorce, and incarceration all had high weekly attendance rates. The church also sponsored a wide variety of adult education classes, ranging from SAT prep and GED classes to English as a Second Language (ESL) classes, and resume building workshops.

Morningside Baptist Church took a specific interest in the community’s youth. Many established church members served as foster parents for children in the neighborhood who were removed from their homes. These foster parents believed it was better for the children to stay in African American homes in a familiar community, surrounded by neighbors, rather than be placed in homes in other parts of the city. Girl Scout and Boy Scout troops, Vacation Bible School, and a weekly gathering of Big Brothers/Big Sisters all stressed community building for youth, while also offering informal, free childcare. Church members and their children were also heavily involved in sports. Morningside Baptist Church boasted its own little league and softball league teams, three football teams that accepted boys aged four to thirteen, and a boys and girls soccer team. In 2014, church staff was also considering partnering with a northern Mississippi 4-H chapter to start a youth urban gardening program.

Legacy and mentorship were important components to Morningside Baptist Church’s commitment to community building. Although the church hosted a number of
events open to the whole community, middle class and affluent church members controlled the legacy and mentorship programs. Leaders in both programs were intent on presenting the Morningside community in general, and Morningside Baptist Church in particular, as places where African Americans were viewed as educated, politically engaged, and economically prosperous. Education, professional networking, and community engagement were the primary goals of both programs. Morningside Baptist Church worked with local black sororities and fraternities on fundraisers and networking opportunities. Fundraisers were advertised throughout the church and community. However, since most fundraising events required a donation or entrance fee, only middle class and affluent church members were able to attend the events. Alumni from several prominent HBCUs, including Howard, Spelman, Morehouse, and Fisk all hosted networking events for current students and alumni. The church worked with these alumni groups, as well as alumni groups led by church members who had graduated from local universities, to find summer internships for students interested in community outreach, education, civil rights issues, and law. Through legacy and mentoring events, the church celebrated its continued engagement in middle class interpretations of civil rights oriented issues.

I began volunteering at Morningside Baptist Church in the fall of 2013. The church’s connections with local high school and university volunteer programs meant they had a constant stream of free labor. The church staff counted on student volunteers who were completing semester long projects so that they could focus their paid employees on outreach and fundraising projects. These short-term volunteer opportunities gave students material to complete projects or papers while allowing staff the ability to
control their access to vulnerable populations. The volunteer projects also provided free advertising for the church’s wide range of community programing. The process began with church staff assigning students tasks. My initial task was to help prepare meals and supervise high school volunteers in the church’s community kitchen. Before Christmas 2013, I was asked if I would be willing to pick-up and deliver donations from a grocery store near my East Memphis neighborhood. I continued to serve as a grocery courier for the church’s community kitchen until the winter of 2015.

Ms. Lena and I built a relationship quickly. We had similar political views on poverty, a shared love for cooking, and had similar stories of personal loss. I began to work with other members of the church staff in the early months of 2014. During my initial months volunteering at Morningside Baptist Church, I was also accompanying a group of state employed health educators who were hosting ACA information sessions around the city. Morningside Baptist Church served as the meeting space for many of these events so church staff was able to place me as a working professional outside their experiences with me a church volunteer.

I began sitting in on the church’s weekly chronic pain support group early in February 2014. Although weekly meeting attendance fluctuated between ten and fifteen members, there were roughly two-dozen semi-regular or regular members. When I began attending the group, members were told that if they were uncomfortable with my presence I would leave. They could communicate any of their discomfort to organizers so that the concerned party would remain anonymous to me. I was already well acquainted with many of the regular participants who I knew through the church’s community outreach programs. I had been volunteering at the church and spending time conducting
participant observation in the church offices on a weekly basis for four months before I began attending the chronic pain support group. I attended the group at least twice a month for fifteen months.

I knew Ms. Lena also organized a lupus support group. While the chronic pain support group was open to the public and met on a different day each week in order to accommodate the irregular work schedules of many members, the lupus support was closed to the general public and their meeting times corresponded to days of worship in the church. New members had to be invited into the group by Ms. Lena or her co-organizer Ms. Retta. Unless interested parties had a long-standing relationship with the church, or church members, they usually attended the chronic pain support group regularly for months before they were invited to join the lupus support group. Ms. Lena invited me to attend the lupus support group after I had been a regular participant in the chronic pain support group for six months and been affiliated with the church for roughly a year.

In addition to the two Morningside Baptist Church groups, I also participated in an East Memphis lupus support group comprised of women living with lupus, their families, and their larger support systems. The women who attended the Morningside Baptist Church lupus support group all self-identified as African American or black and ranged in age from twenty-one to sixty-six. The East Memphis group prided itself of its racial and ethnic diversity. Regular attendees ranged in age from fifty to sixty-seven. Most listed their primary residences in middle class neighborhoods, and several were retired. The East Memphis group met primarily on the weekends at members’ homes or local restaurants. Many members of the East Memphis support group had built
friendships with one another through events hosted by the Lupus Foundation of America (LFA) or other lupus specific organizations. I have chosen to focus the narratives in this chapter around the women who attended the Morningside Baptist Church lupus support group because I had the longest sustained contact with this group of women. This support group was also the most economically diverse group with the largest range in ages. Although there were numerous differences between the two groups, acknowledgement that the severity of African American women’s lupus flares was linked to their exclusion for the U.S. healthcare system was a common theme in both groups.

“A Close Knit Kindred”: The Morningside Baptist Church Lupus Support Group

Morningside Baptist Church’s lupus support group met twice a month after church services held on Wednesday evenings or Sunday mornings. There were twenty women associated with the group18, but a core group of fifteen women regularly attended at least one meeting a month. Ms. Lena and Ms. Retta organized the meetings, led the group’s opening prayer, and took notes during the meetings. Meeting notes were then available to group members at the beginning of each week. Ms. Lena kept hard copies of the notes in her desk in the church’s office and Ms. Retta made the notes available to members through the group’s email chain and private Facebook group. The purposes of meeting notes was to keep members who were unable to attend meetings engaged in conversation and provide information about resources shared by other members during meetings. Since the lupus support group did not garner the same attention or attendance as some of the church’s larger support groups, they were often asked to give up their

18 Ms. Lena, Ms. Retta, Ms. Candice, Ms. Wendy, Quan, LaToya, Tanisha, Mercedes, Leia, Cassie, Naomi, Rachel, Grace, Charmaine, and Ms. Kitty were the group’s regular participants. Ms. Janice was still considered a voting member of the group even though she lived in another city. Four women, who asked not to be identified or interviewed, attended meetings less frequently. Their limited attendance was not related to ongoing research for this project. All of the women participating in the Morningside Baptist Church lupus support group gave consent before I began attending meetings.
space in the church’s fellowship hall. However since Ms. Lena created and maintained the church calendar, and had keys to the church offices, the sanctuary, and the fellowship hall meeting rooms, she was able to reserve space for the group. Although they had a number of options throughout the church, the women regularly met in the employee break area or conference room attached to the church’s main office. The church provided a small budget that Ms. Lena used to purchase refreshments for all the support groups. Instead of using church funds, Ms. Lena and Ms. Retta used their own money to purchase refreshments for the lupus support group. Since the group was small and met after church services, they frequently provided a full meal which ranged from pizza to salads and sandwiches depending on the coupons they had collected over the course of the week. Some of the other older members also discreetly contributed money to cover the cost of food, however Ms. Lena did not ask the group for money because she did not want the women who did not have discretionary funds to feel obligated to pay for the meal. Although all the women knew that Ms. Lena and Ms. Retta were paying for the food, they all praised Ms. Lena for her ability to purchase so much on such a limited budget.

Four of the group’s five founding members were always in attendance. Ms. Lena, Ms. Retta, Ms. Wendy, and Ms. Candice were all in their late-fifties to mid-sixties. The women were all Morningside residents and had been active members in the church for most, if not all, of their adult lives. A fifth founding member, Ms. Janice, moved to Chattanooga to live with her daughter in 2012 after her flares became more frequent and debilitating. The five women communicated regularly by phone and Ms. Retta emailed Ms. Janice support group notes. After their weekly phone call to Ms. Janice, the four
women remaining in Memphis regularly expressed their own concerns about how they would care for themselves if and when their own health deteriorated.

The lupus support group was a closed group. Existing members discussed and voted on whether to approach potential new members. Ms. Lena was generally the first point of contact for new members, but all members were encouraged to share information about the group with other women with lupus. The women wanted the group to remain a female-centered space, so men were not allowed to attend. The one exception was Ms. Lena’s teenage foster son Rashaad. Rashaad worked in the church offices after school and helped Ms. Lena manage the support group schedule, prepare rooms in the fellowship hall for meetings, and set up and clean up refreshment stations before and after meetings. While Rashaad was allowed to be in the space when the support group was in session, his role was to make the women comfortable and take food orders. He was not an active member of the group, nor did he participate in the group’s conversation unless he was directly asked to respond to a question. When I began attending the group, I often sat in a corner of the room with Rashaad since we were not considered official members.

When Ms. Lena first invited me to attend the lupus support group, she warned me that I might find the meetings “a bit chaotic.” Unlike the other support groups offered through the church, the women in the lupus support group did not sit in a circle. Support group participants were encouraged to position their bodies in postures that would alleviate their pain. Since the group recognized that each woman’s pain experience was unique, support group members reclined on furniture, leaned and pushed against

19 All but two of the younger women in the group used heteronormative, biological definitions of female when asked how they determined what constituted a “female centered space.”
doorframes, walked around the room, or occasionally lay on desks or conference room
tables. It often took the newer members of the group several months to become
comfortable enough to participate in self-directed movement activities. Traditional
support groups meeting in the fellowship hall featured a moderator who directed
conversation and generally allowed only one participant to speak at a time. Other
members of the group were encouraged to give non-verbal hand signals as a form of
support and encouragement. The women in the lupus support group did not sit silently.
While Ms. Lena and Ms. Retta organized meeting times and locations, leadership roles
during meetings shifted depending on the members in attendance. The women’s
communication style was dynamic and energetic. They talked over each other, held side
conversations, and shouted at each other across the room when another member said
something they found inspiring.

Ms. Retta explained that movement was an important part of the way the original
members of the group had bonded with one another. They wanted to keep movement a
central part of their meetings, because they believed supporting each other was more than
simply listening to one another. Supporting other women in pain also meant becoming
comfortable with how different women expressed the physical pain in their bodies. Ms.
Wendy explained that her ability to express pain during the support group meetings was
not only an important part of her own self-care, but also a way to confront social
expectations of women raised in conservative, religious households.

“When you’re raised as a good Christian woman, you’re taught from a
young age to make your body small and non-threatening…You’re told to
cross your legs, develop good posture but don’t look arrogant, avert your
eyes when talking to men you aren’t related to, and speak in a soft
voice…You have to watch your tone…I was always told being restrained
in the way you act and speak is an important part of giving and receiving
Respecting privacy and each individual woman’s personal expression of pain was an important part of the group’s dynamic. The older women in the group shared Ms. Wendy’s opinion on the relationship between respectability and religious posturing. They viewed the support group as one of the few places they could express themselves freely. Four women admitted they did not feel comfortable allowing their husbands or children to see them in pain. Twelve of the fifteen women described themselves as “Christian” and felt that their faith affected their acceptance of other group members’ experiences. The other three women, Quan, Tanisha, and Mercedes, each cited the group’s focus on religion as a reason they had been hesitant to join the support group. Ms. Wendy, Ms. Retta, and Rachel were the most affluent women in the group, and all had careers or were retired. They each cited privacy as a reason they felt comfortable
moving and vocalizing their pain in the lupus support group. During their interviews they each expressed that the time they spent in the support group was the only time they felt they could freely communicate how their pain affected their daily lives. They each also cited attention to physical appearance as a way they hid their pain from loved ones and colleagues. Three younger members of the group, LaToya, Naomi, and Leia, all cited self-consciousness as a reason they wanted their activities in the group to stay private. Eight of the fifteen women in the Morningside Baptist Church lupus support group cited discomfort with their bodies or physical appearance as a reason they valued the group’s privacy. Six of the fifteen women, who were also involved in church activities, feared judgment from other church members if the support group was perceived as chaotic. Ms. Lena explained she tried to reserve the main office conference room because the church offices were located on the opposite side of the building from the fellowship hall and the public restrooms. She believed this additional level of privacy would allow the women to feel more comfortable moving and expressing their emotions.

The women regularly debated membership guidelines during meetings. Identifying oneself as a lupus sufferer was the only formal requirement the group maintained during their debates. Obtaining a formal lupus diagnosis was not required for membership, but it was encouraged. All support group participants, regardless of age, felt that lupus was the issue that brought them together. Thus receiving, or actively seeking, a lupus diagnosis was a requirement for membership. Women who attended the chronic pain support group who did not specifically identify as a lupus sufferer, or show interest in seeking a lupus diagnosis, were not invited to join.
The women who were invited to join the group usually spent a significant amount of time volunteering in the church, participating in one or more of the church’s adult education programs, or attending the chronic pain support group prior to their invitation to join the lupus support group. Tanisha was the one exception. Her partner Samuel’s family held prominent positions within church leadership. Samuel worked for a local anti-poverty non-profit organization and had a close personal and professional relationship with Ms. Lena. Samuel, Tanisha, and Tanisha’s children attended holiday services and the church’s annual homecoming. Through these activities Tanisha had developed relationships with the lupus support group’s founding members. She was invited to join the group even though she did not live in Morningside, had never been a formal member of the church, and did not regularly attend other church sponsored support groups.

Although the women were adamant that a formal diagnosis did not determine whether or not an individual had lupus, there were subtle power differences between those who had been diagnosed and those who had not. Of the group’s fifteen core members, nine had received a formal lupus diagnosis and six were actively seeking a diagnosis. While all the women identified their illness as lupus and all used the word flare to identify their symptoms, women who had received a formal diagnosis frequently referred to the undiagnosed women’s illness episodes as lupus-like symptoms. Women who had received a formal diagnosis spoke with more authority, and their opinions on illness were regarded as being more objective and informed than the opinions of women who had not received a diagnosis. Group members were also more likely to question the validity of statements regarding treatment made by women who had not been diagnosed.
Mercedes was the only group member who directly mentioned this dynamic without outside prompting during an individual interview. She had been formally diagnosed with lupus, but had formed close friendships with many of the women who were still in the diagnostic process. She felt that founding members regularly disrespected the women who had not been diagnosed.

The women generally agreed that racism and gender inequality affected their access to medical care or their ability to find sustainable solutions to treating lupus flares. The intersections of class and age created tension amongst the group. Most notably age and class played important roles in discussions about membership recruitment, diagnosis, and the posturing and behavior of some of the group’s younger members. Older women were interested in recruiting and encouraging younger women to join the group. They viewed this as an extension of the church’s mentoring program. Younger women were interested in seeking out and including women of all ages who had not received a formal diagnosis, especially working poor women. They also wanted to expand the group and possibly include women who had been diagnosed with other illnesses, but believed lupus was the primary source of their pain. On average, support group members over forty who had been formally diagnosed with lupus had lived with their diagnosis for more than a decade. In comparison, women under thirty-five who had been formally diagnosed had lived with their diagnosis for five years or less. At thirty-three, Rachel was the only exception. She received her diagnosis in her early twenties while covered by her ex-husband’s military health insurance. However by the time she began attending the

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20 See Appendix D.
support group she was divorced and struggling to find consistent care for her symptoms through TennCare.

Ms. Retta had earned a bachelor’s degree and several advanced teaching certifications, however the other founding members had no formal education beyond high school. Although Ms. Wendy did not have post-secondary education, she had built a successful career within her family’s entertainment management business. Before retiring, she ran public relations campaigns for local gospel singers and musicians. She regularly mentioned this when she felt group conversations were favoring the opinions of more formally educated members. Regardless of their age, eight of the fifteen women had formally graduated from high school. The remaining seven had received their degrees after participating in one of the church’s GED classes. Three of the younger women who attended the group, Naomi, Grace, and Charmaine were attending vocational classes at local community colleges and Leia was enrolled in a local university. Leia was the only woman under thirty who was raised in a middle class household. Her family had been active in Morningside Baptist Church for four generations.

Besides identifying as a lupus sufferer, discussing how racism served as a barrier to healthcare in general, and lupus treatments specifically, was an unstated requirement for membership. The struggles associated with being chronically ill in a city that was spread out over a large geographic area was also a regular topic of discussion. Meetings also reserved time to discuss faith as a form of healing and resistance. In her recent study of women with lupus in Ecuador, Ann Miles (2013) documents how women living with lupus use faith as a way to cope with and understand their illness. The women in Miles’s study use their faith as a way to understand their physical suffering by associating their
pain to the suffering of biblical figures (Miles 2013). The women of the Morningside Baptist Church lupus support group also used prayer as a form of meditation and pain relief. However, their attention to faith was largely framed within the context of community building and racism. The women drew on the history of African American churches and neighborhoods as spaces of physical and emotional support in the face of economic and social oppression (Taylor et al. 2017, Thomas-Houston 2005). They were interested in how faith could aid women of color who faced additional exclusion as the result of living with a chronic illness (Hatfield-Timajchy 2007, Harvey et al. 2016).

Meetings always began with a group prayer and a moment of reflective silence. Ms. Lena or Ms. Retta usually led the group in prayer, however they always offered the other women the opportunity to serve as the prayer leader. The women had a guiding set of ground rules. New members were given a handout with the rules, but were asked not to publically share the handout unless they were recruiting new members. The rules were largely related to the concepts of respect, support, and privacy. They included basic guidelines such as “do not promise a cure” and “do not use judgmental language when talking about others forms of self-care.” Group participants were also asked not to “judge or mock personal expressions of physical pain,” and “respect and honor the stories of other members.” Acknowledging economic privilege when discussing treatment options was the last rule on the list. The women were told not to “give advice,” because advice could be perceived as patronizing. Rather, they were encouraged to share personal strategies for symptom alleviation. Once one woman began sharing her own strategies, others would usually join the conversation by debating the merits of different methods. If the group discussed dietary changes, physical exercise, or prioritizing periods of rest,
they frequently prefaced their comments by acknowledging how systems of privilege might affect their ability to access healthy food or take time off from work or parenting to rest. During every meeting members brought up emotionally charged topics. While issues related to gender or racism generally ended with hugs and words of encouragement, when debates began over diagnosis, one or more members of the group quickly changed the subject. The women appeared uncomfortable to discuss the tensions connected with the power dynamic that existed between the diagnosed and undiagnosed.

**Diagnosis is Personal, but is it Important?**

Members of the Morningside Baptist Church’s lupus support group were sharply divided over the importance of receiving a formal lupus diagnosis. Ms. Candice, Ms. Wendy, Tanisha, and Leia had all been formally diagnosed with lupus, but were skeptical that receiving a diagnosis changed their opinions of their overall health. Ms. Candice was in her mid-sixties and Ms. Wendy was “twenty-nine plus a few” in the spring of 2014 when I began regularly attending group meetings. They both had lived with active lupus symptoms for over ten years before healthcare professionals began exploring lupus as a possible explanation for their chronic pain. Leia was twenty-one and had been diagnosed less than two years before she began attending the meetings. She admitted part of the reason she was hesitant to accept her lupus diagnosis was because she did not want to think about living with a chronic illness for the rest of her life. Tanisha was thirty-six and was unconvinced a formal diagnosis was going to change her ability to access healthcare or receive fair treatment from healthcare providers. When asked if they believed receiving a lupus diagnosis from a doctor was important, the remaining eleven women answered they believed it was very important. Since most of the group believed diagnosis was an important part of living with lupus, their debates on the topic usually revolved...
around the circumstances associated with diagnosis. Eight women believed receiving a
diagnosis was important to their own personal understanding of pain and suffering.
Twelve responded that the diagnosis mattered because it determined the type of care they
were able to access.

Ms. Lena felt strongly that receiving her lupus diagnosis helped her make
decisions regarding her personal health. She also felt her diagnosis gave her a way to
explain her flares to others.

“When I got the lupus diagnosis, I was like, ok I can work with that… It
gave me a place to start… I could start looking for information, I could
talk to people, I began to meet other women with lupus and build
friendships… I could tell my friends and family what it was too, even if
they didn’t know what it was specifically, like if they didn’t know lupus
was an autoimmune disease, they had probably heard the word lupus
before… Or they knew that it was that disease Toni Braxton has, cause
she’s a lupus spokesperson… After I got my diagnosis, if people asked me
what was wrong, I could say I have lupus… I have a real chronic health
condition… I could tell them it’s a disease that causes a lot of
pain… People are more sympathetic if I tell them I have a disease… Cause
I have this disease called lupus they understand that’s why I don’t feel
good, or can’t come to work some days, or can’t help with the
housework… It’s because I have this real thing that I can’t control… I’m
not making it up… It isn’t going to go away in a few days if I get a good
night’s sleep, or take a self-care day … This is something I will deal with
every day for the rest of my life… It’s not a head cold, or seasonal
allergies, or pain that you might get if you’ve done too much exercise…
It’s always there, and it’s unpredictable… I think my [daughter] has lupus
too, she has a lot of the same problems I have… but she doesn't care if she
gets diagnosed… That’s really frustrating for me as her mother… I want
her to be well… She doesn’t think it’s going to change her life for the
better so she just doesn't care…”

For Ms. Lena, diagnosis was important because, in part, it legitimated her illness
to others. For women living with chronic pain conditions, the ability to appear “sick” or
“well” to healthcare professionals and support networks affects whether others perceive
their illness as legitimate. Ms. Lena was able to give a name to her symptoms. Because
that name was associated with an illness recognized by the healthcare community, she believed her larger social networks recognized her pain to be the result of a legitimate medical condition (Werner and Malerud 2003). By naming her symptoms “lupus,” Ms. Lena was able to navigate personal and profession networks where her illness disrupted her everyday activities. She believed listening to her body and engaging in a varied self-care routine that included long periods of silence and rest were a vital part of her daily lupus treatments. She also felt that her diagnosis alleviated any guilt she might harbor when she asked for time off from work or could not help with household chores.

Ms. Candice was often one of Ms. Lena’s most vocal opponents during discussions of diagnosis and self-care. Although Ms. Candice respected the importance Ms. Lena placed on recognizing how her activity level affected her flares, she also critiqued how models of self-care were classed. Ms. Candice identified as a working class woman. In her late forties she had been forced to leave her job in an industrial bakery where she had been employed for almost twenty years. The temperatures on the factory floor and long hours of standing intensified her pain and lengthened the time of her flares. She spent the next fifteen years baking and working in the kitchen of a barbecue restaurant owned by her brother-in-law. She was able to take time off from her job when her flares became severe. During her brief periods away from the restaurant she cared for her nieces and nephews while their parents worked. The small savings she and her husband had accumulated allowed her to leave the formal workforce in her early sixties, while he continued to work as a union ironworker.

Ms. Candice also identified Ms. Lena as a working class woman. When she questioned Ms. Lena’s reliance on certain forms of self-care, she often did so in order to
draw attention to Ms. Lena’s white, middle class interpretation of self-care. When other women in the group suggested self-care strategies they found on lupus websites, Ms. Candice always remarked that she felt self-care strategies marketed through national lupus organizations were designed to shame working class and working poor women who were unable to engage in self-care strategies that involved money or leisure time. Ms. Candice had been diagnosed with lupus roughly a year after leaving her job at the bakery. In 2014, she was in her mid-sixties and had lived with active lupus symptoms since her early thirties. She lived with symptoms for approximately fifteen years before receiving her diagnosis and another thirteen years after her diagnosis. She was skeptical receiving a diagnosis had produced positive outcomes for her overall health and reported no significant difference in her health after her diagnosis. Ms. Candice believed a lupus diagnosis benefited physicians and the healthcare industry more than it benefitted individual sufferers.

“Is it ok for me to say ‘I don’t know?’ when I’m asked if the diagnosis is important?...I’ve had these health problems for most of my adult life, and I’m in my sixties, so that’s a long time… But I’ve always known women, women in my family, with rheumatism, so sometimes I wonder if there’s really any difference? Are these clusters of symptoms just called lupus because it’s more convenient for the doctor?… Do I have rheumatism? Did they have lupus?… My symptoms are like theirs, I learned how to live with this by caring for these women, my mother, my Auntie…They were strong women, even when they were in pain…I didn’t really go looking for a lupus diagnosis like a lot of the women here… I was told I had lupus… I got kidney infections all the time, I kept getting dizzy at work, I broke out in rashes…I think the doctors didn’t really know what to do with me… I was a sick African American woman so they surely had some

21 After Ms. Lena attended a chronic pain conference in late 2013, she became interested in adding mindfulness workshops to the church calendar. She was particularly interested in activities marketed for people living with chronic pain, including classes that focused on homemade natural cleaners and soaps, anti-inflammatory meal preparation, and yoga. None of the other women in the group were interested in these activities. Even women who identified as middle class did not feel these activities would improve their quality of life. They felt that these types of classes were designed to cater to white women with disposable incomes.
assumptions about that… But I look educated, I spoke well, whatever that’s supposed to mean…Cause of [husband’s] job I had health insurance. I passed for middle class… I didn’t fit their definition of sick, African American women, their stereotypes of drug users or welfare mothers…So they [doctors] didn’t know why I was sick, or how to treat me… Eventually I was told I had lupus… They needed to put something in my file, so they gave me a vague white lady disease… Something they could write on a chart and give me medication for so I’d stop bothering them… Lena and Retta get mad at me when I call lupus a white lady disease because that diagnosis means a lot to them… But that’s how I see it… African American women have always lived with chronic pain… long before anyone called it lupus… I think it’s only called lupus now because a bunch of white people started having problems that interfered with their lives and a bunch of white doctors needed to call it something so they could bill the insurance companies…”

Access to health insurance and economic stability factored heavily into support group members’ diagnostic status and their opinions regarding the importance of diagnosis. Ms. Retta, Ms. Candice, Rachel, and Leia all received diagnoses while privately insured. Ms. Retta had received health insurance through her employer until she retired and began receiving Medicare. Ms. Candice and Rachel had each received spousal health insurance benefits. Leia had been covered under her parents’ insurance policy until she began college where they paid for her student health insurance. The four privately insured women had the most differing perspectives on the importance of receiving a formal diagnosis. Ms. Wendy had never been insured and had never been enrolled in TennCare. She paid for her care in cash. Ms. Retta and Rachel felt their diagnosis gave them a platform to discuss their illness, build relationships with other lupus suffers, and communicate their needs to their support systems. Ms. Candice strongly believed that her lupus diagnosis was a way for clinicians to dismiss her ongoing health concerns, and Leia was unsure if her diagnosis would make a significant difference in her adult life.
Ms. Lena, Mercedes, Tanisha, and Naomi had all received a lupus diagnosis while enrolled in TennCare. Ms. Lena’s journey to her lupus diagnosis was similar to Rosemary’s. Her long-term participation in TennCare provided her physicians with a long, well documented medical history as she sought care for her symptoms. However, the regular changes to the TennCare system also left her uninsured for long periods of time. Tanisha had been enrolled in TennCare as part of the foster system in the 1990s. She was able to enroll in TennCare as an adult during her first pregnancy in 2001. Mercedes and Naomi were both under thirty and had qualified for TennCare Medicaid in the early 2010s. The women who had received their diagnoses through the TennCare system were the most supportive and encouraging to the women who had not received diagnoses.

Quan, LaToya, Cassie, Grace, Charmaine, and Ms. Kitty had not received formal lupus diagnoses. In 2013 and 2014 LaToya, Cassie, Grace, and Charmaine were all uninsured, and were not eligible for TennCare benefits. They had each been enrolled in TennCare as minors or young adults. Although each of the young women qualified for TennCare by the summer of 2014, their new TennCare eligibility was connected to the fact that each woman had been denied coverage through ACA affiliated federal programs. Quan had spent six years incarcerated. During that time she had received limited medical care and had few employment options once she was released. Ms. Kitty suffered from a number of physical and mental health conditions. She spent most of 2014 living in a local homeless shelter. She disappeared before Christmas 2014, and church members began looking for a long-term care facility to house her in February 2015 when she was found living in an abandoned warehouse in northern Mississippi.
Other members of the group echoed Ms. Candice’s sentiments regarding the treatment of African American women in clinical settings. Eight of the nine group members under forty had been accused of drug seeking behavior during emergency room visits associated with intense flares. Five women over fifty reported being tested for, or accused of having HIV at some point in the diagnostic journey. All of the women felt the care of white women was prioritized over their own care, even with physicians with whom they had close relationships and had been treating their lupus for years. The older women and middle class women felt they had more power to control their clinical experiences, and were given more opportunities to access care without additional bureaucratic barriers. While the middle class and working class women could disagree on the importance diagnosis played in their individual lives, they also understood that the stakes were higher for members of the group who did not have economic means or access to regular care.

**The Importance of Diagnosis?: Access to Care**

Although not all the women in the Morningside Baptist Church lupus support group who had received a formal lupus diagnosis were middle class, all of the women who were struggling to receive a diagnosis were working poor. For the women who had not received a diagnosis, the ramifications were more immediate and severe. Women who do not have the ability to seek out preventative care or do not have access to consistent, reliable care live with untreated chronic health problems for longer periods of time before receiving a diagnosis (Pohlman and Becker 2006). Once they do seek medical care, poor women of color, are diagnosed at later stages of disease progression, which offers fewer treatment options and higher morbidity and mortality rates (Rousse 2009, Lane 2008, Becker et al. 2004). Conversely, accessing healthcare is only one component of living a
healthy life. Poor African American women are more likely to live in environmentally unsafe conditions, occupy positions as transient employees in the low-wage work force, and experience racism in both professional and personal spaces. These social factors contribute to their disease burden at the time of diagnosis and overall quality of life (Geronimus and Thompson 2004, Galbraith et al. 2012, Adair 2002). LaToya and Quan were both working poor women who attended the Morningside Baptist Church lupus support group. Neither woman had been formally diagnosed with lupus. In 2013 and 2014, both women were seeking care that would hopefully result in a diagnosis.

LaToya was a thirty-three-year-old Morningside resident who was not a church member, but had participated in community programs sponsored by the church since her youth. As an adult she worked in an elder care facility with strong ties to the church. LaToya had been living with severe headaches, gastrointestinal issues, and chronic pain since she was a teenager. Her symptoms began shortly before her eighteenth birthday, several months after her mother’s death. She attributed her pain to the stresses of working while trying to attend high school. LaToya dropped out of high school during her senior year and her headaches and pain subsided. In her mid-twenties LaToya began attending AA meetings and a grief support group at Morningside Baptist Church. Her pain episodes had returned and this time she attributed her pain and exhaustion to the challenges she faced in recovery. As her pain episodes became more regular, another woman who attended her AA meeting suggested LaToya talk to members of the church’s chronic pain support group. She began attending the chronic pain support group in 2011 and was invited to join the lupus support group in the fall of 2012. Around the time she joined the lupus support group, LaToya was regularly missing work because the physical
requirements of her job were beginning to take a significant toll on her physical health. LaToya had not been diagnosed with lupus when she began attending the chronic pain support group, but the women in the lupus support group encouraged her to seek a diagnosis in order to gain access to more comprehensive healthcare.

“I try not to go to the doctor unless things are really bad…I feel like cause I’m in recovery they [doctors] already think they know who I am…It’s like they be like, I bet she’s on drugs or something cause she’s an alcoholic… and I know people don’t think I’m sick neither, I know my supervisor don’t… When I first learned about lupus from Ms. Retta and the lupus group, I went to work and told her [supervisor] I thought I might have this disease called lupus… and it made sense, the lupus makes things hard… It’s why it’s hard for me to remember things sometimes. Why I can’t get out of bed some days, or my arms just go rubbery when I’m tryin’ to lift clients… She just looked at me sideways, she thought I was trippin’… She asked me if I’d gone to the doctor and I said I’m working on it…I’m tryin to get on TennCare… She told me they couldn’t do nothing for me… like make special accommodations for me with clients without a doctor’s note…A couple months later I fell out real bad and had to go to the emergency room and they put me lots of medicines…Ms. Retta came and got me from the emergency room and sorted my meds for me…I have to report all the meds I’m on to work cause they drug test us and I don’t know what shows up on the tests…And they want to know what we’re on cause they want to make sure we ain’t stealin meds from the clients…I’m always a little scared that I’m gonna get fired cause something I ain’t got no control over is going to happen and I’m gonna get blamed cause I take a lot of meds and I’m in recovery…So it’s like they expect the worst to happen with me…I want the doctors to tell me I have lupus so I have it in writing somewhere…documentation…So people know I’m really sick and not just tryin to avoid work or steal stuff…”

LaToya and many of the other women who had not been diagnosed with lupus found themselves in precarious positions in the workplace. Without a statement from a physician verifying their chronic illness, they were ineligible for medical accommodations including restricted lifting or set hours for scheduled shifts. The women who had not been diagnosed were more likely to be working poor and work in low-wage jobs with few options for accommodations even with medical documentation. LaToya’s
personal history of addiction created additional challenges for her work life. As part of her recovery, LaToya wanted to be transparent about her alcoholism. However she believed her supervisors and co-workers monitored employees who were in recovery more closely than employees with no documented history of addiction. While she had to disclose information to her employers, she was hesitant to discuss her personal history with her co-workers.

She was also frustrated that she did not feel she could speak frankly with a physician about her concerns. LaToya frequently refused to take medications that could help reduce the intensity of her symptoms because she was concerned the medications would interfere with her recovery. She felt that when she told a physician she was in recovery they would link her pain to her history of addiction rather than view it as a symptom of another chronic illness. She was embarrassed to discuss personal health issues with healthcare professionals because she felt they judged her. Since she did not have a regular healthcare provider, she never had the opportunity to build a trusting relationship with a physician who was skilled at treating patients in recovery. LaToya also resented the lack of privacy she experienced in many of the clinics and hospitals she used as primary care facilities so she avoided seeking care until her symptoms were so severe she needed immediate medical intervention.

Like many of the other working poor women who attended support groups at Morningside Baptist Church, LaToya’s job was physically demanding, and she was expected to keep flexible schedule availability. Lack of sleep, irregular eating patterns, and physical exhaustion made it nearly impossible for LaToya to monitor whether her symptoms were related to lupus or her erratic schedule. When other members of the lupus
support group suggested she keep a journal detailing her lupus flares, she always replied she did not journal because she did not know what lupus was supposed to “feel like.” She also refused to participate in journaling exercises because she did not feel she had the time or energy to document her daily aches and pains.

As a former felon Quan faced a unique set of challenges during her diagnostic journey. Quan was a tall, heavily tattooed, quietly intense woman who began experiencing mild pain episodes in her late teens. She attributed her pain to her transient, young life moving between foster homes. Her symptoms became more regular after she was incarcerated in her mid-twenties. During her six-year prison sentence, Quan’s pain episodes escalated in frequency and severity. Her options for healthcare and pharmaceutical pain relief were limited in prison. Quan found ways to hide her pain from guards and other inmates. She modeled good prisoner behavior so that she could have access to open dorm bedding, semi-private bathrooms, and labor options that gave her the opportunity to sit when she felt weak or fatigued.

Upon her release, Quan received short-term benefits through TennCare. While this meant that she technically had access to healthcare, there was also a six-year gap in her medical history. A year and a half after her release, she began experiencing intense, debilitating pain episodes that resulted in several emergency room visits. She had been hesitant to pursue care for her chronic pain symptoms because she did not know the limits of her TennCare coverage and she was unsure if or how she could access her medical records from her period of incarceration. Because her physicians did not have access to her medical records during her time in prison, she had no formal documentation of her four lupus related hospitalizations during that six-year period. An emergency room
physician who had attended to Quan’s needs on several occasions suggested that her symptoms might be related to an autoimmune syndrome. He gave Quan a recommendation for a rheumatologist who took TennCare clients. Quan lost her TennCare coverage shortly after the emergency room visit and never contacted the rheumatologist for a follow-up visit. She also had no access to private health insurance because her status as a felon limited her employment opportunities.

Quan moved into a group home in Morningside and soon found employment at Morningside Baptist Church. The church hired a number of former felons who struggled to find regular employment. These off-the-record employees took on custodial duties, maintained the church grounds, helped prepare meals for the church’s community kitchen, and transported elderly church members to and from church events. As part of their employment, former felons were expected to attend one or more of the church’s adult education classes and were highly encouraged to join the church in fellowship. Since Quan did not consider herself religious, she decided to take a GED prep course, a course on finance and budgeting, and began attending the chronic pain support group.

“See here’s the thing… I’m not all up in the Jesus… I don’t know if I even believe in God … But the people here at Morningside are good people, they do good for people, and a I think of a lot of them as real friends, even if Jesus is what it’s ‘bout for them… I joined the first group [chronic pain group] cause I knew if I joined some group, any group, people wouldn’t bug me so much ‘bout going to church or joinin’ one of the prayer groups…I don't want to be disrespectful but I ain't havin none of that…I didn’t want to join none of the groups for folks who’ve been to prison neither… those groups are either all about Jesus or all about actin’ hard… and I ain't neither of those things… so I joined the first group [chronic pain] cause I already knew some of the people who went and I liked them…They also didn’t seem to feel sorry for theirselves…The thing I like about both the groups [chronic pain and lupus support group] is that they just don’t sit around and talk ‘bout being sick… they try to do things… solve problems… Since I’m workin’ at the church all the time, Lena’s been helpin’ me get some stuff together to file for disability… I
don’t want to have to go on disability, cause I kind of think that makes me look weak, I want to work… but my pain is just getting worse and it’s been hard for me to do things, like mow the grass or carry too many things… If I can get a lupus diagnosis then I can start finding other ways to feel better…Hopefully ways that don’t involve so many drugs…Lena’s been helpin’ me find some other things to do so maybe I don’t have to take so many pills… But I have to find somethin’ else, anythin’ else cause my body can’t keep goin’ like this…”

LaToya and Quan had both formed close relationships with older members of the support group who strongly believed that receiving a diagnosis was the pathway to receiving medical care and creating individual self-care strategies. These relationships had a significant impact on the way each woman described her current experiences with lupus and her commitment to accessing regular healthcare. Ms. Retta and LaToya had developed a close friendship soon after LaToya joined the chronic pain support group. LaToya described Ms. Retta as her second mother. The other women teased LaToya when Ms. Retta showered her with physical affections and praise since Ms. Retta was serious and “not a hugger.” Ms. Retta and LaToya talked on the phone or texted daily, and Ms. Retta and her husband took LaToya and her son to breakfast after Sunday services. Ms. Retta also provided childcare for LaToya during weeks she worked overnight shifts. Ms. Retta’s opinions regarding healthcare in general, and lupus specifically, were reflected in LaToya’s narratives about her illness. LaToya was committed to receiving a diagnosis because she knew that a confirmed diagnosis would grant her more access to healthcare. She also sought a diagnosis so that she could better navigate a physically demanding professional environment. Like Ms. Retta, LaToya strongly believed that her ability to access healthcare was tied to the ways in which healthcare professionals engaged in racial profiling. Despite their frustrations with the healthcare system, Ms. Retta and LaToya were both committed to a pharmaceutical based
treatment regimen to improve their quality of life. LaToya also hoped receiving a diagnosis would build a stronger bond between herself and the other women in the support groups she attended. In 2014, LaToya was not only seeking a lupus diagnosis, she was also in the process of pursuing a formal membership at Morningside Baptist Church.

Quan’s everyday self-care strategies were heavily influenced by her relationship with Ms. Lena. Since both women worked at the church, they frequently ate lunch together and spent time discussing their illness. Ms. Lena and Quan were both proponents of non-medical interventions when symptoms became intense. This did not mean that either woman refused biomedical treatments; rather they shared a belief that poor women needed to have non-medical strategies in place in case they could not afford medical care or were turned away from medical facilities. Ms. Lena would often bring homemade, anti-inflammatory soup to share with Quan at lunch. When she had extra money, Ms. Lena bought Quan unscented detergent and soap. She knew Quan would not accept the items if they were presented as gifts, so Ms. Lena claimed the church had received additional donations or she had accidently purchased extra detergent when she did her weekly grocery shopping.

On days when Quan was suffering from a flare, Ms. Lena made sure her work tasks were not physically rigorous. Rashaad kept a small collection of teas, cold packs, and over the counter medications hidden in the staff break area for days when Ms. Lena was experiencing flares. Most afternoons after school he could be found in the break room preparing a snack and making tea for both Ms. Lena and Quan. Rashaad helped Quan with tasks around the church when he knew she was in pain. The pair was often
seen slowly walking the edge of the church parking lot discussing local hip-hop artists and picking up trash. Quan was aware that the church staff was making accommodations for her illness. She said she felt humbled for the support system she had in the church staff.

Because LaToya and Quan had close relationships with founding members of the Morningside Baptist Church lupus support group, they were given subtle privileges within the group. Ms. Retta and Ms. Lena shared aspects of the group’s history with LaToya and Quan in ways they did not communicate with the other women. Older, more established group members also listened to LaToya and Quan’s concerns more intently and they received more pragmatic advice for navigating the healthcare system. Ms. Retta offered to accompany LaToya to doctor’s visits, while Ms. Lena was active in Quan’s search for documentation for her disability case. Although the founding members viewed these relationships as forms of mentorship, not all the women who attended the group received individualized attention. Sentiments that the group favored members who built close relationships with one or more of the founding members were particularly strong amongst the younger women.

Transitions

During the summer and fall of 2014, the Morningside Baptist Church lupus support group began to splinter. Age and class played heavily into the differences that had begun to create tension between many of the older and younger women in the group. Although the entire group was invested in creating a space that recognized the ways in which economic inequality could affect individual lupus self-care strategies, each participant’s opinions regarding quality of life issues related to lupus were guided by different class identities. The younger women argued the older women’s adherence to
strategies that involved dietary and behavioral changes were middle class, exclusionary, and oftentimes cost prohibitive. The older women countered these criticism by asserting the younger women were not open to exploring self-care strategies that required a long-term commitment or involved addressing the emotional issues connected to living with a chronic illness.

Ms. Retta and Ms. Lena approached their daily routines differently, however each woman’s approach to treating her lupus symptoms was framed though middle class narratives of self-care. Ms. Retta believed that prompt and consistent biomedical intervention, including regular visits to medical specialists and adherence to a daily pharmaceutical regimen was the most effective way to manage her daily symptoms. Even though Ms. Lena questioned class based assumptions connected to strict biomedical intervention, her own approach to treating her lupus symptoms grew out of her interest in middle class mindfulness and spiritual self-care frameworks. LaToya and Quan’s personal connections to Ms. Retta and Ms. Lena lead to their adoption of middle class self-care models that closely resembled the models used by their older mentors.

The women who did not have a personal connection with an older mentor expressed frustration that the older women equated one’s ability to create sustainable self-care strategies with socio-economic security. Tanisha and Mercedes were particularly adamant that socio-economics and education were not the only markers of class that created obstacles for African American women living with lupus. They were vocal about their concerns that the group’s desire to create broad categories of shared inequality in order to foster an atmosphere of inclusivity actually subverted many of the subtle class linked differences within the group. The two younger women felt the way the
group framed “effective” self-care strategies could be interpreted as oppressive and judgmental. They also believed the older members of the group were more concerned about presenting a “respectable” image to the outside world, rather than turning their attention inward towards to needs of other women with lupus. Self-care suggestions that included putting on make-up or visiting the salon to feel better about oneself or weight loss suggestions were frequently met with resistance. The younger women felt Ms. Retta was particularly harsh in her interactions with members of the group who did not adhere to a conservative, faith based discourse. Ms. Retta would regularly correct the younger women’s grammar, encouraged them to sit up strait, and not behave in a way she described as “ghetto.”

Interpersonal tensions had been building between Ms. Retta and Mercedes over the course of 2014. Both women were vocal, bold, and opinionated. Mercedes was the only young woman in the group who regularly challenged Ms. Retta’s authority during group meetings. Although the young women who aligned themselves with Mercedes were frequently silent during these confrontations because they did not want to become targets for Ms. Retta’s criticisms, they also became more actively engaged in cross-generational group conversations when Mercedes controlled the direction of the conversation. Ms. Retta’s influence with the group’s older members affected Ms. Lena, Ms. Wendy, and Ms. Candice’s opinions of Mercedes. The divide within the group was not based solely on age. LaToya and Rachel also expressed concerns with the way Mercedes interacted with other members of the group. Naomi, Cassie, Charmaine, and Leia looked to Mercedes for leadership and support.
The older women felt Mercedes’s provocative clothing and heavy make-up was “inappropriate” for a church setting. They also objected to her constant use of her cell phone, her “coarse language,” and her regular smoke breaks during meetings. Mercedes admitted her confrontational persona within the group was intentional.

“Sometimes the old church ladies get me so heated, I kinda do stuff on purpose just cause I know it’s gonna get to them, especially Ms. Retta…like lots of times I go smoke when she starts lecturing cause I don’t want to hear it and I know she don’t like smoking …Like I don’t think she’s a bad person or nothin’…I don’t hate her, I do think she cares about people even though she’s a hard ass…but she’s just so bougie and you know she used to be a teacher so she still acts like we’re her students or somethin’…I’m grown…we’re all grown…I may be kinda hood, but it don’t mean I ain’t grown…I’m kind of proud of it…ain’t nothing wrong with bein’ a little hood and I shouldn’t have to be ashamed of it…But bougie black folk don’t like that much…Like if I’m hood they look bad or something…somehow it means they look bad to other people I guess…I don’t do nothing disrespectful…Ok that’s not true, going for smoke breaks when Ms. Retta is talking is disrespectful [laughs]…I don’t curse no one in the group, I don’t curse in the church or group even though I curse a lot on my own…I eat the food we have at the meetings and don’t complain cause I know Ms. Lena and Ms. Retta is trying to take care of everyone…I don’t ask if we can have something else that isn’t gross and full of vegetables…I say thank you…I don’t make fun of none of the other women in the group…Sure I complain about how the church ladies act, but I don’t talk bad about none of their problems …I like hearing everyone’s stories about lupus and do listen even if they think I don’t…[Ms. Retta] just likes to make it look like she’s got it all figured out…I like to remind her she don’t…”

Mercedes felt her formal lupus diagnosis granted her power during many of the group’s clinical discussions about lupus. Mercedes’s lupus diagnosis story was similar to many of the other women I interviewed who had received a diagnosis while enrolled in TennCare. Mercedes had been enrolled in TennCare Medicaid in her early twenties. She began seeking care for chronic pain she believed was related to severe menstrual cramps after she lost her job due to an excessive number of absences. Mercedes was diagnosed with endometriosis, but her pain episodes persisted after she began taking medication to
address her illness. Since her gynecologist had kept detailed records of her symptoms, she referred Mercedes to a rheumatologist who eventually diagnosed her with lupus. Soon after her diagnosis, her enrollment in TennCare was terminated. In 2014 she had been living with untreated chronic lupus symptoms for close to five years. Because her diagnostic journey was similar to many of the other women in the group who had received a formal lupus diagnosis, Mercedes felt comfortable engaging in conversations about the diagnostic process. She also felt comfortable challenging other members who presented their personal experiences as objective truth. Since her current experiences with the healthcare system were similar to the uninsured, undiagnosed, women in the group, Mercedes presented herself as a spokesperson for the group of women struggling to maintain good health.

During one particularly tense meeting in early September, Mercedes expressed frustration with her inability to predict flares. She was frustrated because her symptoms had changed over the last year, and she feared her anxiety over her inability to predict and treat her flares was intensifying and prolonging her pain episodes. Ms. Retta responded that Mercedes’s concerns could be addressed by making lifestyle changes that included healthy eating, exercising, and finding a way to stop smoking. Mercedes responded that Ms. Retta was being condescending and argued that poor people did not always have the resources to purchase healthy food or the time to exercise. Since women in the group regularly raised their voices when debating each other, especially Ms. Retta and Mercedes, the other women initially ignored the exchange and continued their own routines and conversations. When it became apparent that the conversation had devolved
into a series of personal attacks between the two women, Ms. Lena physically placed herself between Mercedes and Ms. Retta in order to shift their attention onto other issues.

Over the next two weeks, Ms. Lena individually talked to, or met with, most of the women in the group. She was concerned that the personal attacks Ms. Retta and Mercedes had leveled against one another would create gossip within the group and change the dynamic during meetings. She felt uncomfortable contacting Mercedes directly, but did convey her concerns for Mercedes’s health and well being through Leia. Ms. Lena was in regular contact with Tanisha during the weeks following the confrontation. Tanisha was a calm, analytical woman in her mid-thirties who was liked and respected by both the younger and older women. She served as a liaison between the two groups during the transition.

Tanisha reached out to the younger women, encouraging them to continue attending the group. Mercedes attended one more meeting before severing her ties with the group. Cassie and Naomi continued to attend semi-regularly. They maintained good relationships with most of the other women in the group. They stayed active in the group’s Facebook page and shared pictures of their children and updates about their lives. They commented positively when other women posted comments or pictures to the page. Leia’s contact with the group became less frequent. She lived in a dorm on campus on the other side of the city, and began returning to Morningside only during school holidays. When she was home she attended church with her family as well as support group meetings. Ms. Lena and Ms. Wendy were both close friends with Leia’s grandmother and shared stories about her college progress with the other women. Ms. Lena and Ms.
Wendy were also instrumental in censoring Ms. Retta’s continued comments regarding her feelings on virtual support groups.

By early 2015 the women had settled into a new routine. Ms. Lena was in the process of recruiting new members and the founding members were planning a trip to visit Ms. Janice in Chattanooga. Quan and LaToya were still in the process of seeking their lupus diagnoses and were both still regular support group members. Quan had been able to find a job cleaning offices at night. She liked her job because it was quiet, there was no heavy lifting, and she could sit when she needed. She had been able to save enough money to rent her own apartment. The younger women continued a regular text chain, and tried to meet occasionally for lunch or coffee, but had not created the social media platform they had proposed in the fall of 2014. They seemed content with their lives, and even Mercedes harbored no ill will towards the other members of the group. She felt her time with the lupus support group was an overall success. Even if Morningside Baptist Church had not been the right space for her to express herself she still felt her time with the group allowed her to build close, lasting, friendships with other members. Tanisha had become increasingly active in the Black Lives Matter movement. Rashaad and Leia had begun attending events with her.

Each time the women of the Morningside Baptist Church lupus support group met, they deepened their nostalgia narratives of illness, health, and resistance. Class and age played an important role in the power dynamics that existed within the group. Older women and middle class women were frequently more vocal during support group meetings, thus they also controlled the group’s narrative. The founding members presented the group as an equitable space where members could freely express their
emotions and ideas. This was the narrative Ms. Lena used when recruiting new members. Conversely, many of the younger women in the group felt that the narrative crafted by the older women was paternalistic and rigid.

The women’s ability to find success in that system was, in part, connected to their decision to accept the group’s lupus narrative. While the group’s narrative claimed that a formal lupus diagnosis was not important for membership, diagnostic status did appear to affect group dynamics during meetings. Women who had received a lupus diagnosis had more power in directing conversations during meetings than women who had not received a diagnosis. Although the older women often controlled the direction of conversation, younger members with confirmed diagnoses had power in challenging the institutional narrative. Mercedes’s diagnostic status allowed her to be confrontational and challenge authority. Cassie and Naomi agreed with many of Mercedes’s comments, however their status as undiagnosed granted them less power in conversations. Leia’s diagnosis and class status allowed her remain somewhat neutral during confrontations. Her personal narratives were never challenged, but she was also never asked to take sides when tensions built between those who had been diagnosed and those who had not been diagnosed. Tanisha was also able to maintain a position of neutrality between different groups of women engaged in interpersonal conflicts, however her place in the group also resulted from the fact that she was perceived as a non-judgmental person.

Subscribing to the group’s narrative of community, support, and mentorship had more important consequences for working poor women. LaToya and Quan each benefitted from the relationships they built with older, more powerful group members. Those relationships granted them easier access to resources they could use to improve
their quality of life. Quan’s employment record and connections to Morningside Baptist church eventually resulted in formal employment and economic independence. In the spring of 2015, a church member who offered legal services to former felons began working with her to design a resume and cover letter so that she could find more stable and prosperous employment opportunities. He was also consulting with colleagues about her disability case. LaToya had been able to use the church’s adult education programs to gain new skills. She was interested in moving into a job with more regular hours and less physical labor. In the fall of 2014, LaToya was taking evening computer classes and a class in business management. Ms. Retta offered to babysit so that LaToya could focus on her studies. Both Quan and LaToya received a lupus diagnosis by the end of 2015.

Cassie and Naomi, two undiagnosed women who did not have strong personal relationships with older church members were still undiagnosed by the end of 2015. All the women who participated in the lupus support group viewed discussions about their health as forms of political expression. They talked about how racism affected poor health. They shared stories about self-care that reflected a deep knowledge of the history of African American women’s exclusion from different systems of health and healing. They intimately understood how unsafe and unfair living and working conditions affected the progression of their illness because they experienced these things in their daily lives. They knew that a constant low-level of stress, stemming from any number of sources, including interpersonal conflict and professional racism, affected their ability to anticipate and treat lupus flares. They strategized how to manage serious symptoms associated with lupus because they knew their access to medical care would likely be delayed. They also all believed, despite their differences in privilege and
positionality, that communicating and caring about one another was central to maintaining a good quality of life.
“I think it’s interesting that when we talk about health we always talk about a specific issue...and it has to be a polarizing issue, an issue you can point to someone and say ‘It’s your fault’... No one really talks about health in a broader context...When I say broad context, I don’t mean preventative care either...I mean well-being, taking care of each other...No one ever stops to ask what would happen if we stopped blaming people for having health problems and started valuing their humanity...Why aren’t we angry about injustice?...Why aren’t we angry that there are people literally living with unnecessary physical pain because our society thinks they deserve it if they aren’t rich?!...Why do we, as a country, believe it’s ok for members of our brethren to be hungry and fear violence in their daily lives?...How are these things ok?... I think the fact that we don’t see each other as human beings, deserving of love and respect is the biggest health crisis our country is facing right now...”

-Anita

Chronic Pain

The relationship between chronic pain and western systems of medicine is complicated. Social science literature on chronic pain has largely focused on the lived experience of pain and the individual illness experience. This approach to pain has been used to critique a system of healing that devalues symptomatic expressions of illness, including pain, in favor of placing confidence in the practice of diagnostic process and laboratory procedures (Becker 1997, Barker 2005, Rosenberg 2002). Social science has traced the authority given to biomedicine through narratives of both acute and chronic pain. This authority exercises violence upon bodies, strips them of individual histories, and institutionalizes suffering as a product of poor choices and weak mental constitution (Mol 2003, Scarry 1985, Biehl and Moran-Thomas 2009). Feminist scholars argue that this system of suffering and blame is gendered, as male bodies are perceived as normative and healthy, while female bodies in pain are presented as abnormal or ill (Rapp 2000, Harding 1991, 2006, Fausto-Sterling 1992). As women’s bodies become medicalized, their pain and suffering is viewed as somatic rather than biological, and
women’s individual power is questioned in clinical settings (Martin 2009, Greenhalgh 2001).

Biomedicine both shapes, and is shaped by, social interactions creating paradoxes for individuals living with hard to define chronic illnesses. For individuals seeking a diagnosis, the visibility of suffering or the legitimation of suffering through the diagnostic process, is vital in order to gain access to resources (Dumit 2006, Zavestoski et al. 2004). However, since the collections of symptoms associated with chronic autoimmune related illnesses are not easily identified through laboratory testing, the legitimacy of suffering is frequently called into question (Lipson 2004, Shavers et al. 2010, Clarke and James 2003).

There are also pragmatic concerns tied to chronic pain. Women with lupus must not only contend with the uncertainty of symptomatic flares but must also find a way to live day to day with fluctuating levels of pain (Miles 2009, Mendelson 2003, Goldstein 2000, Hatfield-Timajchy 2007). Living with chronic illness forces women to reevaluate their physical stamina, renegotiate their place within their social networks, and often forces them to reorganize their lives in order to accommodate their illnesses (Crooks et al. 2008, Wendell 2001). The side effects that accompany medications used to mediate symptoms associated with autoimmune syndromes can result in new symptoms including increased fatigue, digestive issues, or cognitive dysfunction (Barker 2011, Whitehead 2006).

The gendering of autoimmunity and chronic pain affect the client/physician relationship in clinical settings (Barker 2005, Greenhalgh 2001). Women seeking medical care from physicians, or support from their social networks, must shape their
explanations of their illnesses to meet the expectations of others. If they appear “too-well” then they run the risk of being denied medical treatments that could help manage their symptoms (Clarke and James 2003, Ring et al. 2005, Werner and Malerud 2003). If they appear “too-sick,” or if they are unable to participate in activities they once enjoyed, they face the possibility of alienating friends and loved ones who do not understand the severity of their illness (Werner et al. 2004, Nettleton 2006, Jackson 2005, Miles 2013). While these explorations of chronic pain and autoimmunity challenge normative social categories of wellness and illness by examining spaces of exclusion, those spaces are still largely documented from the perspective of middle class whites with access to private health insurance.

People of color, particularly African American women, face more intense scrutiny when seeking medical assistance (Mullings 2002, Geronimus 1992, Adair 2002). Since the diagnostic process used to identify chronic pain and autoimmune syndromes is frequently based in a healthcare provider’s interpretation of loosely related symptoms, racist stereotypes influence the diagnostic process and may obstruct pathways for care for people of color suffering from chronic pain (Rousse 2009). When seeking care for chronic pain, African American women are frequently asked questions regarding their own sexual practices or the sexual practices of their partner(s) and are subjected to STI or HIV testing as part of the diagnostic process. African American women seeking relief from chronic pain are also frequently accused of drug-seeking behavior (Hatfield-Timajchy 2007, Rousse 2009, Whitehead and Williams 2001). African American communities have created informal support networks as a way to address issues of violence and racism (Guttman et al. 2003, Meyers 2007, Thomas-Houston 2005). The
following passages detail how African American women living with lupus use intergenerational support networks to provide self-care for lupus symptoms and engage in resistance to structural racism. Not only are these women challenging racial inequality, they are also creating alternative pathways from dominant white social narratives in order to support one another.

**Alternative Narratives and the Margins: Lupus in Popular Culture**

Lupus Foundation of America’s (LFA) promotional material released in the 1970s and 1980s referred to lupus as “the uncommon, common illness.” Current promotional material continues to assert that lupus is not “uncommon,” but because the illness is rare, but rather awareness for the illness is low and receiving a diagnosis is challenging thus resulting in the perception that lupus affects a small percentage of the population (Lupus Foundation of American). Recent public health studies have also begun to argue that social and environmental factors, such as clean and safe living conditions, air pollutants, access to healthy food, and access to reliable healthcare, play vital roles in the severity and frequency of lupus symptoms (Yazdany et al. 2009, Panapolis et al. 2008, Julian et al. 2009). Factors such as healthcare access also have a significant impact on oftentimes irreparable damage to the kidneys, heart, and lungs at the time of diagnosis (Zell Gillis et al. 2007, Trupin et al. 2008). Additionally, those living with lupus frequently live with multiple chronic illnesses, such as diabetes or hypertension. Individuals living with lupus symptoms are often diagnosed with other illnesses, ranging from rheumatoid arthritis (RA) to fibromyalgia, before receiving a lupus diagnosis (Stockl 2007, Barker 2011).

Despite the claims made by national lupus advocacy groups about the general public’s knowledge of lupus, thousands of lupus sufferers and their support networks are actively engaged in conversation with one another. When I began the preliminary phase
of this project in 2010, there were five major English-text online lupus forums available in the United States. Each forum had a subscription base of more than 3000 people and active membership of between 500 and 1000 members.\textsuperscript{22} High volume message boards and forums have sub-boards dedicated to helping lupus sufferers talk to friends, loved ones, colleagues, and doctors about their illness. These sub-boards contain topics such as “Do I have lupus?” “What is lupus?,” “What to know when you go to the doctor?,” and “Now what, how to tell someone you have lupus.” All five forums boasted international populations; however two forums focused on subscribers from the United States, one was advertised as a “North American” forum\textsuperscript{23}, and two were based in Europe.

Discussions of lupus vary greatly between white and black American media. Television programs on major broadcast networks, marketed to predominately white audiences, present lupus as a mysterious illness that causes confusion and emotional harm. An early “creature feature” episode of the popular 1990s science fiction series \textit{The X-Files}, sends characters Mulder and Scully on an exhaustive journey to find a humanoid monster who has been attacking unsuspecting urban-dwellers (\textit{The X-Files} 1996). The pair eventually learns the monster is in fact a severely malnourished and deformed child who has recently lost their mother due to complications of lupus. While lupus is not the

\textsuperscript{22} These numbers are based on public statistics available on most internet forums. I used these statistics to gage the activity level on the forum so as to monitor daily use. These statistics included numbers pertaining to overall membership, number of active user posts within a twenty-four hour period, number of active threads within a twenty-four hour period, and number of overall public threads featured on the forums. Three of the five forums I frequented also provided lists of active usernames. All five forums promoted public communication, as well as private individual or group settings. I did not engage individual forum members since I was not recruiting research participants, I only used public settings on the forums I visited because my interest lie in the language people with lupus used to articulate their health needs and concerns.

\textsuperscript{23} In this case “North America” meant the United States and Canada.
focus of the episode, the woman’s illness is mentioned as a possible source of her child’s physical and mental disabilities.

Media writers in the 1990s and early 2000s have also used the public’s vague understanding of lupus as a comedic device. George Costanza, the neurotic and hypochondriac best friend of Jerry Seinfeld on the television show *Seinfeld* diagnoses himself with lupus after he suffers reoccurring aches and pains that his doctor tells him are not related to a heart attack (*Seinfeld* 1991). In an episode of *The Simpsons*, residents of the fictitious town of Springfield eagerly participate in a lupus awareness run despite the fact that the town’s residents are confused as to why they are participating in the race (*The Simpsons* 2003). In 2015 Jon Stewart, then host of *The Daily Show*, referred to the television news channel *Fox News* as “the lupus of news.” *The Daily Show* writers incorrectly identify the origins of lupus as a viral infection. However, their sentiment asserts that like an autoimmune syndrome that signals the body to attack itself despite evidence that it should do otherwise, *Fox News* takes one piece of polarizing political information and repeatedly attacks it without context (*The Daily Show* 2015).

The most recognizable reference to lupus in recent popular culture comes from the television show *House M.D.*. The premise of the program revolves around a team of skilled specialists working together to diagnose and treat life threatening “mystery” diseases. Under the tutelage of the ornery and confrontational character, Dr. House, each week the team of physicians is presented with a case that the hospital cannot identify. The team then debates the validity of a large number of potential diagnoses. In the first two seasons of the show, lupus was always one of the first differentials proposed by the team. The suggestion, and then constant rejection, of the lupus diagnosis week after week.
eventually resulted in a reoccurring gag. The physicians who suggested lupus as a possible diagnosis were mocked, ridiculed, and/or subject to physical assault by their peers. The continued references to lupus eventually led to the catchphrase “It’s not lupus. It’s never lupus.”

This catchphrase was featured as an internet meme and began appearing on merchandise promoting the television program. However in instances where lupus could be a potential diagnosis, Dr. House and his team used the term SLE\textsuperscript{24} during differential strategy meetings. During the program’s fourth season, the team successfully diagnosed a patient with lupus. However, because the patient was young, white, and male, they initially missed the diagnosis (House M.D. 2007).

Charles Briggs and Clara Martini-Briggs (2016) argue that marginalized groups are able to challenge white, normative social and medical standards by creating narratives about health and health crises that rely on local knowledge. That local knowledge is communicated through the exchange of knowledge between individuals and groups as well as media outlets. The culmination of this information sharing system results in a bottom-up approach to addressing health crises created by the people most directly affected by the issues. Media aimed at African American audiences presents lupus as a frustrating but manageable illness, rather than a mystery or joke. Media sources created for and by African Americans target the middle and working classes. Running parallel to white media outlets, black media outlets not only serve to critique their white

\textsuperscript{24} Although lupus is clinically divided into four distinct categories depending on the bodily systems affected during the diagnostic process, systemic lupus erythematosus, or SLE, is the most common form of the syndrome. SLE accounts for approximately ninety-five percent of diagnosed cases of lupus in the United States (Wallace 2009). The term SLE is largely used in clinical literature. Popular culture outlets will occasionally use the term “systemic lupus,” in place of lupus.
counterparts but also present material specifically framed from and for African American perspectives (Di Leonardo 2007, 2012).

Mainstream African American media outlets such as Jet, Essence, and BET have all featured articles about African American celebrities with lupus or links to sources designed to educate or provide support options for people living with lupus. Tabloids aimed at African American audiences feature stories of celebrities rumored to be ill with sickle cell disease or lupus. R&B singer Toni Braxton has been repeatedly praised for her role as a high-profile spokesperson for lupus. Her daily struggles with the illness are central to many of her interviews (Braxton 2015, Kreps 2016). Prayer chains appeared on social media within days of rapper Snoop Dogg’s announcement that his seven-year-old daughter was diagnosed with lupus (Garcia 2010). Tabloid journalists chronicled actor and comedian Nick Cannon’s mysterious hospitalizations for unknown kidney problems in 2011 and 2012. Although Cannon initially denied the connection between his chronic kidney issues and lupus, in December 2015 he began posting pictures on social media detailing his latest hospitalization and the lupus treatments he was receiving (Jefferson 2016, Miller 2017). Several publications also gave a virtual eye roll and a response of “that’s not a thing” to pop-singer Lady Gaga’s tearful admission on Larry King Live in 2010 that she had been diagnosed with “borderline lupus” (Larry King Live 2010).

As I began to recruit participants for this project, African American Memphis residents were eager to share what they knew about lupus. They told me stories about sisters, mothers, cousins, friends, and friends of friends who had lupus and promised to introduce me to people all over the city. They asked me if I believed, or could confirm,
rumors that certain celebrities had lupus. Many also told stories of families who had been financially and emotionally devastated by lupus or the debt families faced after their loved ones died from complications of their illness. People began directing me towards websites aimed at an African American clientele that featured lupus inspired art, hairstyles, and nail art. Many of these websites also featured strong, black bodies accompanied by the words “lupus warrior” to celebrate the bodies that continued to fight despite living with crippling pain (The Lupus Foundation of American, Black Doctor).

Of the women with lupus I interviewed, thirty-two of the fifty-one responded that they had a family member, or close friend of the family who suffered from lupus, or symptoms similar to lupus. All but three of the African American women interviewed had spent a significant amount of time during her life caring for a chronically ill loved one. Nineteen responded that they had served as caregiver for another woman with lupus or a similar arthritic condition. Thirty-six women interviewed said they were not anxious or scared when they began experiencing symptoms themselves. Twenty-six women suspected they had lupus before they began seeking a diagnosis. Sharing knowledge about illness and creating survival strategies that focused on family and community, rather than biomedicine, was foundational to their understanding of what it meant to live with lupus.

**Lupus in the Family: Lorraine and Kendra’s Stories**

Thirty-two of the fifty-one women with lupus that I interviewed for this project claimed they knew someone else in their family who had either been diagnosed with lupus, lived with symptoms they identified as lupus, or had lived with a chronic pain or arthritic condition with symptoms similar to lupus. Twenty-one of those women took on caregiving responsibilities for a family member who was living with or had lived with lupus or a chronic
pain condition. Caregiving responsibilities ranged from preparing meals, providing transportation to doctors visits, and childcare to end of life care. Twenty-seven women reported that their own self-care routines were modeled, in part, after the self-care routines they observed in their loved ones. Twenty-three women who had family members with lupus reported knowing another woman who had lived with lupus or chronic pain eased the fear and uncertainty of their own chronic pain.

Lorraine was born in the 1940s and grew up poor in northern Mississippi. She was the youngest of seven children and described her childhood as hard but joyful. As the youngest member of the family, she watched her parents and siblings work as sharecroppers, caregivers, and day laborers, but was never forced to engage in manual labor herself. Lorraine’s mother suffered from rheumatism and spent most of her adult life cleaning houses for wealthy, white Memphis residents. Lorraine remembered her mother rising early in the morning, finding rides with neighbors heading to the city to sell produce, and returning home long after most of her children had gone to bed. When she returned home at night her hands and feet were so swollen she could barely walk. During the hottest months of the summer and the coldest months of the winter her mother could not work. Her skin would become covered in painful blisters, and she was lethargic and forgetful.

Lorraine left school in her early teens. By the time she was ten-years-old, she was already responsible for maintaining the household while her parents and siblings worked. One of her duties included serving as the primary caregiver to her sister Angela. Angela was eleven years older than Lorraine and suffered from a chronic, debilitating illness that kept her in bed most of her life. The family built a small room onto the back of their home so that Angela had privacy and access to the backyard outhouse. Angela rarely left her room since the
swelling in her arms and legs caused her great pain and the sun further damaged her cracked and blistered skin. Lorraine’s responsibilities for Angela’s daily care included preparing meals, changing the linens on Angela’s bed, and bathing Angela when her skin was able to withstand temperature changes. Lorraine was easily frustrated by her responsibilities and resented her role as the family caregiver.

“I’m kind of ashamed of how I acted when I was young. I didn’t know nothin bout how bad Angela suffered, but now I do… I just knew she had some horrible disease that didn’t go away and no one knew what it was… She scared me. I didn’t think she was human sometimes… I’m ashamed of that now… Her room was always dark… just a sliver of light… She’d be propped up on that bed all sweaty and ashy… I hated that room, the strange noises, the smells, the darkness…Near the end I had to take out the bucket we left in the room for her to do her business in… I was angry that I had to do those things…The smell of it all’s still in my head…I didn’t want to do it no more… I never told no one, but I wished we could’ve sent her to one of them nursing homes like my sister Mable worked in… Sometimes I wished she’d die… and then when she did die, I thought it was my fault… But I realize now I was a child and sometimes children get filled up with foolishness… When she was dying we all knew it… We just made her as comfortable as we could… After Angela passed, none of us never went back in that room… When it started to leak we didn’t fix it. That room fell apart over the years when it rained… It became a pile of trash on the back of the house…”

Lorraine was married to her husband John by the time she was nineteen. She had two successful pregnancies and four miscarriages throughout her twenties. When Lorraine gave birth to her third child Kendra in the mid-1970s, she was thirty years old. With each successive pregnancy Lorraine began to experience longer periods of weakness and joint pain. In her thirties she also began struggling to remember how to perform daily tasks such as making phone calls or ironing clothes. Shorty before she learned she was pregnant with Kendra, Lorraine noticed her skin began feeling rougher, drier, and more fragile. She began experiencing hair loss and light sensitivity. She started to worry that she was developing the same illness her mother suffered from, but instead attributed her physical ailments to stress
and grief. Her father had recently passed away and most of her siblings had left the Mid-South. This meant Lorraine and John had taken on the responsibility of caring for Lorraine’s elderly mother whose mobility was limited due to her advanced arthritis.

While Lorraine was pregnant with Kendra, the family moved from Tunica, Mississippi to South Memphis so that John could take a job working on the airport tarmac. Lorraine’s skin cleared during her pregnancy and she had more energy. John’s new job provided increased economic security and Lorraine was able to stay at home and focus her attention on caring for her mother and children. After the birth of her forth child three years later, Lorraine experienced swelling in her hands and feet that was so severe she was unable to grasp with her hands or carry her children without extreme pain. As she entered her late thirties, her rashes and skin irritation also returned and she kept several jars of shea butter around the family’s home to try to keep her skin from cracking or forming painful blisters. While her children were at school, Lorraine often spent afternoons in bed or sitting in a reclining chair in the living room with her feet elevated to help control the swelling.

During this time Lorraine’s mother’s also developed dementia and she began calling Lorraine by her sister Angela’s name. As Lorraine’s own health began to deteriorate, she thought about the frustration and fear she had experienced caring for her sister. She did not want her own poor health to affect her family’s household dynamic in the way she felt her sister’s illness had affected her childhood home. She also did not want her own children to have to care for her in the same way she had cared for Angela. Lorraine created and executed a family organizational plan that allowed her to care for her own health needs while her children attended to the household duties.
Each of her four children was assigned household chores that would allow Lorraine to supervise from her chair or her bed. She posted a weekly list to on the family’s refrigerator in case she was experiencing a painful flare and was unable to assign chores. Her two daughters helped clean the apartment and care for their grandmother, while her two sons were responsible for grocery shopping and running errands for the family. John had taken on a second job unloading trucks at a warehouse three nights a week. Lorraine and her mother taught all four children how to cook. Twice a week, the two women and four children created family meal plans that would provide enough food for the family to freeze or re-heat on nights when John was working late or Lorraine’s symptoms kept her in bed.

Although Lorraine never graduated from high school, she felt education was important and pushed her children to preform in school. When she was feeling well, Lorraine sat with her children while they completed their nightly homework assignments. She began working through the assignments on her own as a way to improve her own reading and math skills. All four of her children graduated from high school, however Kendra excelled academically and graduated with honors. She also played softball, basketball, and enjoyed long distance running. Kendra and her siblings were the first people in their extended family to graduate from high school, and Kendra was the first to attend college.

Kendra was accepted to a large state university on a track scholarship. Additionally, she was awarded a scholarship for women of color pursuing careers in engineering. She described her freshman year in college as the best year of her life. As a student athlete, her schedule was full since she had to keep up with her rigorous training and her academic coursework. She continued to excel academically and was excited to pursue a career in engineering. Kendra’s social life also took on new dimensions when she pledged the school’s
chapter of the Alpha Kappa Alpha sorority. She began to make friends with middle class and affluent students and was invited to attend events designed as networking opportunities for young, African American scholars. She found time to casually date several high profile, male student athletes, but was not interested in pursuing a serious relationship until she finished college.

Kendra’s life changed at the beginning of her sophomore year when she began to experience headaches and unexplained joint pain. The pain soon spread throughout her body. Her pain was accompanied by increased fatigue and lethargy. She believed the pain was an indication she was out of shape and needed to train more efficiently. The more intensely she trained, her pain became more pronounced. By the end of the fall semester, her pain became chronic and began to interfere with her running. It also affected her ability to keep up with her coursework and her grades began to drop. She told her trainers about the pain and they immediately scheduled an appointment with a physical therapist. They also suggested she make appointments at the student health clinic to get a general physical, blood work drawn, as well as a gynecological exam to rule out any other serious health issues.

“I tried to ignore all the symptoms, but I knew something just wasn’t right… I went to see a couple of doctors at student health… I was hoping they would just tell me there was nothing physically wrong with me… I was a good athlete in descent shape… So I figured they would tell me the pain and fatigue were the product of stress, because I think all college students have some level of fatigue and burn-out because of stress…and that’s exactly what they told me, I was taking on too much, I needed to manage my time better, I needed to rely on my support system if I felt overwhelmed, that kind of stuff… I’m sure that’s what they tell all college students… So I did what I could because I wanted to feel better… But as time went on it didn’t really get better… I know what my body should feel like when I’m running, and it was just off… At first just a little off… Like my legs would feel a little too heavy, or I would go to turn a curve on the track and my body just couldn’t keep up with my legs… It was like nothing was in synch, my brain wasn’t in synch with my body, my body parts weren’t in synch with the things they had been conditioned to do…”
“I tripped and fell a lot too…It was upsetting when I couldn’t do hurdles anymore because that was always my favorite…But my rhythm was getting worse…One part was always moving just a little faster than the other, but I couldn't quite figure out which part was fast and which part was slow…I started to have joint pain and headaches, mostly in the mornings…I started to wonder if I had migraines and arthritis like my mom because these things run in families…I had watched my mom deal with it for years…If she felt bad one morning she always seemed to be fine by the end of the day or the next morning…The possibility of having some kind of health problem like that was frustrating, but not scary because I thought it was just inconvenient, not life altering…”

As Kendra’s coordination issues became more pronounced, her trainers and coaches became more concerned. She was referred to a number of specialists in university’s sports medicine program, where her x-rays and MRI revealed her joints were showing signs of arthritis. Her doctors were not surprised by the results given her family history of arthritic conditions and the intensity of her training. Kendra was assigned to a new physical therapist that was trained to assist athletes with arthritic conditions. She diligently attended her physical therapy sessions and worked to incorporate new strength training exercises into her daily routine. The university coaches began training her with balance activities. These new training methods had little effect. Kendra continued to train through the winter; however her speed was steadily declining, her coordination became impaired, and her pain episodes became more frequent. Shorty before spring break, Kendra was asked to meet with her coaches.

“I was really nervous going into that meeting because I knew I was getting worse…and I was angry at myself because I was doing everything I could and nothing was working…I had no control over my body…What made it worse was I knew how much time and energy people were putting into me. I knew my coaches genuinely wanted me to be successful and feel good, not just as a student athlete, but as a person…I felt bad because I felt like there were so many people that believed in me and I was letting them down, I was failing them and myself…My coaches and trainers were there, but the meeting was run by administrators in the athletics program…People who didn’t know me, who hadn’t been around while I was struggling to get better…They were the ones who did all the talking…”
“They asked me if I still wanted to be in the track program…They told me I was in danger of losing my scholarship…There was this one guy, I can’t remember his exact title, but the African American athletes all hated him because he was an out in the open racist…and there were a lot of us, he was the minority, so it kind of boggles my mind that no one ever checked him. I don’t think he thought he was racist though…Everyone knew he said things like the football players better be grateful for what they had because if they didn’t have their scholarships they’d still be in the ghetto. And this was because they hadn’t won a national championship in a couple of years…Once he said the members of the women’s basketball team were basically using university money as a kind of welfare system since they couldn’t seem to manage a win at the SEC level…When the meeting started, he basically just laid into me and gave me this whole bullshit history of how glorious the university track program was and how I was bringing the whole thing down…Like one sick twenty year old was going to destroy a legacy they built over decades…I was so pissed off…The whole time he talked I was trying not to cry because he basically shamed me for being sick…A couple of trainers who’d worked with me since the beginning stood up for me, but it didn’t matter…I mean it mattered to me personally, but it didn’t change how he talked to me or how the administrators treated my case…”

The administrative officials suggested that Kendra be placed on probation, with the possibility of expulsion from the track program if her performance did not improve by the end of the academic year. Her trainers and coaches decided to send her for additional medical tests before making the decision to dismiss her from the team. Kendra’s physical therapist requested that she visit a doctor for blood work designed to identify autoimmune syndromes. When her ANA test came back positive in a high percentile, Kendra was referred to a number of specialists housed in the university medical school. Her student health insurance covered the cost of most of her visits. Over the course of the spring semester she was able to see a neurologist, an immunologist, and a team of rheumatologists who were skilled with treating autoimmune syndromes. Kendra was quickly diagnosed with lupus and was placed on a medicinal regimen that slowly lessened the intensity of her symptoms. She began to see positive progress in her strength and agility training. Her privileged place as a student athlete
meant she had access to physical and occupational therapy, acupuncture, and a staff nutritionist who helped her craft an anti-inflammatory diet that worked with her busy schedule and intense training routine.

Kendra was beginning to feel better and planned to return to the track team the following fall semester. Despite her improving health, her academic work had suffered. She had failed one class central to her major that jeopardized the future of her academic scholarship. She had received three incompletes over the course of the academic year and had been given summer extensions to complete missing assignments. She had also missed important enrollment windows that meant she was unable to enroll in classes crucial to making progress in her major until the first day of the upcoming semester. Although administrators in the athletics department were able to give her official medical documentation for her absences, Kendra ended her sophomore year on academic probation. While she had been away at school, Kendra’s parents and younger brother had moved back to Tunica. When she returned home to northern Mississippi for the summer, she found it challenging to maintain the health regimen recommended by her doctors. Her parents were not able to financially help her maintain her restricted diet. Their home did not have air conditioning and her skin irritations intensified.

Kendra did not have access to the exercise equipment that made her pain more manageable and her pain episodes became more frequent and intense. She was also unable to complete her missing assignments because the closest university library was more than an hour away and internet connections were scarce in northern Mississippi in the late 1990s. Her anxiety over her inability to complete her coursework caused her to become irritable and argumentative with her family. Additionally she had to travel several miles to the closest
pharmacy, only to learn they would not accept her student health insurance from an out-of-state university. Kendra spent the summer without access to most of the medication or resources she had come to rely on at school. Her overall health began to decline and Lorraine became increasingly worried that her daughter’s deepening depression would worsen when she left home and went back to school. Lorraine began teaching Kendra many of the self-care strategies she used on a daily basis and told her stories about caring for Angela.

Once she was back at school, Kendra’s health continued to decline despite the fact she once again had access to medication, healthcare professionals, and an academic support system. Her headaches and light sensitivity made it impossible to concentrate in classrooms with fluorescent lighting, and the side effects from her medications made her nauseous. Kendra was once again frequently missing class and her grades began to suffer. She received notes from instructors encouraging her to find a tutor or a study group. She did not reach out to any of her mostly white, male engineering classmates because she felt they already judged her academic ability and she did not want to appear weak to her peers. The anxiety over possibly losing a prestigious scholarship due to her faltering GPA made her symptoms worse. She withdrew from a support group she had been attending for chronically ill first generation college students. She eventually also lost her position on the track team. While several trainers continued to contact her because they were personally concerned about her physical and mental health, she did not return their calls. Once she left the track program, Kendra no longer had access to the dietary and specialty healthcare resources she had been offered as a student athlete. With no additional income of her own, she was unable to purchase food and over the counter medications to help mediate her symptoms.
As a student athlete and upperclassman, Kendra had been able to secure a single dorm room with a private ensuite bathroom that was traditionally reserved for a residence assistant. She did not have a roommate. This meant that if she did not seek out companionship she did not have regular, daily contact with any of her friends or peers. Her friends and sorority sisters tried to visit her at her dorm and invited her to social gatherings. As Kendra’s depression deepened, she became more withdrawn and her friends eventually stopped calling and extending invitations. Without an active support system to help her cope with her illness on a daily basis, Kendra began to lose track of time and spent most of her day in bed. She rarely showered because the water hurt her skin, and her hair became unruly and matted. Kendra left the university for winter break and never went back. When she arrived home, Kendra’s parents were shocked by her personal appearance and frightened by the state of their daughter’s general health.

“John and I were shocked… I was sick… I was angry… Not at her… I was so angry that no one stepped up, no one saw how bad she got, or maybe no one really cared… how could no one care enough to help her?!…Kendra’s always been a little sad, even as a child…she’s troubled…but I could’ve never thought in a million years I would see her like that… I had to sit down and get myself together… I was going to make her better… or at least I was gonna try… I couldn’t do nothin bout the mental stuff really, but I could teach her to take care of herself… like my momma did for me… So I cleaned her up… I showed her how to take a bath without disturbing her blisters… I had done it before, but I did it again, I felt real guilty like maybe I didn’t teach her the right way before so that’s why she didn’t do it when she was away… I cut all the matts out of her hair… She was half bald for a while… it was a sight… but she didn’t care… that’s what worried me the most… she didn’t care… She would just lay in her room all day… it made me think about Angela, and that’s no way to live…”

For the next year Lorraine cared for Kendra at home and helped her find professional care for both her physical and mental health needs. While living in South Memphis, Lorraine had worked part-time at a small soul food restaurant catering to the needs of the men working
at the airport and neighboring industrial industries. The restaurant was an informal operation, run out of a building that also housed an auto body shop. The building’s owner and his business partner realized many of their employees lived in northern Mississippi and had no regular access to TennCare. They allowed their northern Mississippi employees to claim one of the business’s Tennessee addresses as their primary address in order to enroll in TennCare. Lorraine reached out to John’s half sister, who agreed to allow Kendra to use her North Memphis address so she could enroll in TennCare while still living with her parents in Mississippi.

Kendra was initially denied TennCare coverage three times. First she was denied coverage for financial reasons. Although her university scholarships were not income and did not pay her a stipend, they did cover her room and board, which initially disqualified her from TennCare Medicaid. Her education was cited as the reason her second application was denied. Kendra’s academic history indicated she had the ability to finish college, which meant she should also be able to maintain full-time employment. When she went to appeal the decision, her caseworker told her TennCare was for those who had no other option, and she should finish school and find a good job instead of relying on Medicaid. Her third application was denied because she did not have a documented work history in Tennessee.

After struggling with uncontrolled lupus flares and major depression for more than five years, Kendra was eventually able to enroll in TennCare. Her existing documented lupus diagnosis granted her access to the medication she needed without having to wait for appointments with new doctors. Kendra said it took almost a year and half for her new medication to regulate her pain and depression so that she could resume her normal activities. She moved to Memphis and lived with her aunt and uncle for two
years while she worked and completed an associate’s degree in computer programming. She was able to find IT work while she completed her degree, however her jobs were temporary or entry level and did not offer health insurance, sick leave, or other benefits. Once she was enrolled in TennCare, Kendra lived in constant fear that she would lose her benefits. She took jobs that paid less than a living wage because she was concerned her income was close to an income threshold that would disqualify her for TennCare.

When I met Kendra in 2013, she was thirty-six and in divorce proceedings. She had no children. She had graduated with a B.S. in computer science from the University of Memphis in 2010 after almost ten years of taking courses as a part-time student due to the frequency of her lupus flares. Upon graduation, she had secured a job as an IT support worker for a major, national retail chain. Her job came with a flexible schedule, which allowed her to work from home when she was experiencing lupus flares. Even though she had a college degree and a well-paying job with health benefits, Kendra still struggled financially. Almost half her monthly income was split between payments she owed on her student loans and the outstanding medical debt she had accrued while she was uninsured. The bank account she shared with her soon to be ex-husband had been frozen until the divorce was finalized, so Kendra rented a small, one bedroom apartment in East Memphis. In addition to her own needs, Kendra also provided her parents with monetary support. Lorraine and John had taken on guardianship of their two young grandchildren after their oldest daughter’s incarceration. Each month Kendra paid for a family cell phone plan and covered her parents’ utility bill in the summer and winter. Both Lorraine and John lived with multiple chronic illnesses and took several
medications on a daily basis. When Lorraine ran out of medication, Kendra rationed her own medication so that her mother did not have to miss a dose.

More than half the women with lupus I interviewed shared stories similar to Kendra’s. Kendra’s background growing up in a working poor household was similar to LaToya and Rosemary’s stories insofar as the severity and frequency of each woman’s symptoms made managing long-term employment and economic stability nearly impossible. Rosemary and Kendra both also struggled with the burden of medical debt which interfered with their economic and class mobility. Kendra was one of three women with lupus I interviewed from a working poor background who was able to finish college and secure reliable employment with professional pay and benefits. However despite her professional success she still lived an economically unstable life. She provided monthly financial support for her family and her personal assets were unavailable due to her pending divorce. Additionally she was paying on student loan debt and paid several hundred dollars a month for medication. These financial responsibilities meant she was unable to accrue savings to cover the cost of an emergency or start a retirement fund.

For Kendra and Lorraine, living with lupus was a family legacy. Although Lorraine’s mother and sister Angela were never formally diagnosed with lupus, Lorraine saw the similarities in the illness she observed as a child and the illness she and her daughter lived with in 2014. Kendra’s diagnosis eventually led to Lorraine’s diagnosis since their symptomatic manifestations were similar and Kendra had a well-documented history of illness. Intergenerational support networks played an important role in how all of the women with lupus created self-care strategies. Lorraine and Kendra’s stories are
representations of dozens of stories women told about the ways in which they learned about their illness and learned to care for themselves by caring for others. Lorraine was able to teach her daughter how to care for her physical needs in the same way her mother had taught her. In times of crisis, Kendra was able to rely on her family for emotional and physical support. Kendra was also able to care for her mother as her symptoms advanced with age. While Lorraine and Kendra, and many others women I interviewed, found comfort in support systems that intimately understood what it meant to be chronically ill, there were also women with lupus who did not want to be identified with their illness and searched for acceptance and belonging in different ways.

**Questioning the System: Tanisha and Leia’s Stories**

Despite their family’s economic insecurity, Kendra was able to independently care for her lupus symptoms because her family had a long history with the illness. Lorraine was able to help her daughter create a self-care plan that took into account the possibility of facing long periods of time uninsured or treating symptoms without access to medication. Kendra’s well-documented medical history and formal diagnosis also helped Lorraine obtain her own diagnosis. Since multiple members of their family had experienced similar symptomatic patterns, Lorraine and Kendra could draw on a large network of extended family to assist with the physical and financial burden of living with an unpredictable chronic illness. Their story is unique in the sense that they traced lupus directly through a specific family lineage. Women who were estranged or had limited contact with their families not only faced challenges accessing familial disease histories, they also had to build support networks from other places.

Fifteen women with lupus interviewed for this project had spent part or most of their young lives in the foster system. Women who had grown up in the foster system,
and those who had become estranged from family as adults, had to build networks of support in other ways. Tanisha’s definition of family was largely constructed through the personal relationships she developed as a youth and into adulthood. Tanisha was born in South Memphis but spent most of her childhood and youth in and out of the foster system. Her mother was an alcoholic with a pattern of turning to abusive romantic partners for support. Tanisha and her older brother had been physically abused by several of their mother’s boyfriends during their childhoods. Tanisha was removed from her mother’s custody three times, and at thirteen she became a ward of the state and lived in foster homes until she turned eighteen. Once she reached adulthood, Tanisha intentionally moved to North Memphis to avoid regular and sustained contact with her family. Tanisha’s brother had spent time in prison, and in 2014, she was concerned he would go back to prison due to his involvement in the informal economy stealing cars and selling drugs. As a parent herself, Tanisha wanted her children to know about their family, but she wanted to maintain strict physical and emotional boundaries with her mother and her brother.

Tanisha experienced her first pain episode shortly after her fifteenth birthday. By the time she turned sixteen, her pain episodes had become more regular. She hid her chronic pain from her mother and foster guardians by instigating verbal and physical fights at school. Her fighting resulted in suspensions that lasted between two and ten days. During her suspensions, Tanisha was able to stay home unsupervised and care for herself by sleeping, taking long Epsom salt baths, or self-medicating with marijuana. When Tanisha turned eighteen and was released from foster care, she struggled to secure
full-time employment. While she was occasionally able to sleep on friends’ couches for short periods of time, she also slept in her car, or stayed at a local homeless shelter.

“The whole system is fucked up you know, the foster system for sure, but everything else too…It’s messed up how they just throw kids out on the street when they turn eighteen…Like they ain’t human beings, like they ain’t still kids…I know you think you're grown when you’re eighteen, but you’re not… And if you’re black and poor, forget about it, the system is set-up to fuck you over from birth… I started having pain when I was a teenager… But I was also sleeping in strange houses, sometimes in beds that didn’t fit me… or couches… a lot of these homes didn’t even have a bed for me…So not only do you feel uncomfortable cause it ain’t your home, but it’s obvious these people see you as disposable or a way to make a quick buck … So of course I felt like shit all the time… I barely slept, my defenses were always on high, I ate crap, I didn’t feel like anyone cared if I lived or died… I didn’t trust no one…Same with the shelter system, that shit just ain’t safe, especially for women…That’s no way for any human being to live… I had no way of knowing whether I was in pain because something was wrong with me physically, or because I just had a really shitty life… When I first started going to Lena’s group they asked me if I’d ever learned pain management by seeing how the women in my own family dealt with it… I laughed… seriously, I know it’s disrespectful, but I laughed… I said yeah women in my family are always in pain… they’re always high or coming down off of something… Maybe some of them lived with lupus, I don’t know… They probably don’t know either… When you’re always fucked up on something it’s probably hard to know where the pain is coming from…”

Tanisha discovered she was pregnant at nineteen. She had been able to find a small North Memphis house to share with two roommates. She was also able to enroll in TennCare for pre-natal services. In her early twenties, she briefly considered using her TennCare coverage to see a doctor who could treat her chronic pain. Her pain episodes were becoming more severe and she was missing work and fighting with her daughter’s father. She ultimately did not pursue the option to see additional TennCare physicians after speaking to a number of friends and family members who told her horror stories of their own experiences with TennCare clinics.
At twenty-two Tanisha met her first husband, Lamar. The two dated for almost three years before they decided to get married. Soon after they married, Tanisha discovered she was pregnant with twins. During her pregnancy Tanisha’s pain episodes were sporadic, but she developed rashes on her legs and arms that left scars. Since the pain did not interfere with her daily life, she did not mention it when she went to the neighborhood clinic for her pre-natal visits. Tanisha remained relatively pain-free until her sons were nine months old. One afternoon, while babysitting for a friend, Tanisha experienced a flare so severe she fell in the bathroom and could not move. When her daughter Jenné arrived home from school, Tanisha asked her to call a family friend to take care of the younger children. She then asked for the phone so she could call Lamar to take her to the emergency room.

Lamar took Tanisha to the emergency room and they waited for almost two hours to see a doctor. Tanisha’s pain was intensified by Lamar’s agitation over the long wait. When they finally did get to see a doctor, Tanisha described him as blunt and rude. She did not have an issue with his abrupt bedside manner, however she was offended by many of his suggestions. Instead of performing a physical exam and asking Tanisha questions about previous health issues or possible environmental exposures, he asked her if she was pregnant. He then asked her a number of questions about her sexual history. He told her that a number of STIs could be responsible for her chronic pain. She told him she only had one sexual partner and they were in a committed, monogamous relationship. When she refused to comply with the suggestion for STI screening, the doctor told her there was nothing he could do for her. Lamar asked the doctor if he could at least give Tanisha something for her pain. The doctor replied that he could not give her a
prescription since she was not interested in pursuing his course of diagnosis. Tanisha could tell Lamar was getting angry, so in order to avoid further confrontation she told him she was feeling better and asked him to take her home. Tanisha left her emergency room visit still in pain and feeling exhausted and defeated.

Thirty-six African American women with lupus I interviewed reported they had been accused of drug-seeking behavior at some point in their adult lives when visiting the emergency room for lupus flares. Women under forty were more likely to have been accused of drug seeking behavior or tested for STIs as a possible source of their chronic pain. Older women admitted they had probably also been tested for a number of health issues they were unaware of, but because they were not asked to sign release forms they did not know what types of tests were performed without their permission. Tanisha spent one month relatively pain free before she was hit with another debilitating flare.

Over the next two years Tanisha visited the emergency room more than a dozen times. Her illness took a toll on her family. She was unable to work full-time since her flares were unpredictable. The family could not live on Lamar’s salary. They were forced to apply for public assistance, and Lamar and Tanisha were deeply embarrassed they could not financially provide for their family. The couple began to argue regularly, which once again intensified Tanisha’s symptoms. Tanisha and Lamar eventually separated and divorced. They shared custody of their two sons, and Lamar was willing to care for all three children when Tanisha was too sick to leave her bed.

Over the next five years Tanisha tried to find solutions to her chorionic pain that did not involve prescription medication. She and Lamar remained close friends and co-parents and Lamar continued to treat Jenné as his own biological daughter. Tanisha
eventually secured a part-time job working in the receiving department of a large grocery store. Her initial position offered limited benefits and her new salary jeopardized her TennCare eligibility. Tanisha was in the process of being diagnosed with lupus during the 2005 TennCare restructuring. Her doctors were able to appeal her case and confirm her diagnosis so she could stay on TennCare after the restructuring. She eventually received a promotion, and her new full-time position included paid sick leave and health insurance, as well as a semi-regular schedule. She was hesitant to sign up for health insurance because of the payroll deductions, however eventually decided to enroll herself in one of her employer’s plans. Including her children on the plan was prohibitive due to her salary, but she was able to keep the children enrolled in TennCare.

Tanisha met her current partner Samuel when he came to pick-up donations at the grocery store where she worked. Samuel was a middle class, clean-cut man from Morningside. He had a college education and worked for a local anti-poverty non-profit organization. Initially Tanisha was not interested in his flirtations. When the two eventually began dating, Tanisha experienced a series of serious flares that kept her bedridden for several weeks. She did not want to tell Samuel about her illness, so she stopped returning his calls in hopes he would breakup with her. Instead, Samuel gave her some space but continued to be a constant figure in her life. When Tanisha finally shared her illness history with Samuel, he introduced her to Ms. Lena.

Tanisha and her children began accompanying Samuel and his family to events hosted by Morningside Baptist Church. Although the family did not live in the Morningside community, Tanisha’s children quickly made new friends after joining church sponsored sports teams. Tanisha enrolled in two evening professionalization
classes. In 2012, she also began attending the lupus support group. Tanisha was only able to attend meetings sporadically at first because of her hectic work and home schedules, but both Lamar and Samuel encouraged her to attend the group and provided child care so she could interact with other women who were living with the same health issues.

In the fall of 2014, Tanisha joined the group of young women who split from the Morningside Baptist Church lupus support group. At thirty-six, Tanisha did not feel either group offered her the kind of support she was looking for. She had always been hesitant to join the group because she did not view herself as religious. She was not comfortable with the focus on prayer and was not interested in changing her own spiritual beliefs. She also felt the older women placed too much value in their lupus diagnoses. Tanisha also did not feel she could relate to the younger women. While she enjoyed socializing with the young women, she did not feel the new social media support group was a good option for her either. She admitted she was not particularly interested in gossiping about celebrities or trading make-up tips. Tanisha decided she needed to find a new support system with people who shared her political beliefs.

“I don’t think Morningside is my place… I do stuff at the church cause that’s where Samuel grew up and the kids have good friends there now and that’s important… But those are Samuel’s people, not mine… I’m not much of the church type… Me and Lena are good. I’m good with all of them, all those women are good people… They care about each other, even Retta and Mercedes care about each other… They understand that black women have to look out for each other cause no one else will do it for us… I really value that part of what’s happening at Morningside… But they also think too much like white folks sometimes… Maybe I just can’t deal cause I’ve spent so much… all… of my life getting fucked by rules made by white folks so it’s hard for me to sit around with a group of black women and talk about these things like we all don’t know what’s really going on… like health insurance… even talking about healthcare in a bills and payments kind of way… all of that stuff is for white folks. Black folks
ain’t ever had it, so we don’t think much about it in the same way… at least I don’t… Maybe it’s cause I’ve seen too much too young… But it’s like this. When a white woman starts having pain, she goes to the doctor ‘cause she’s got insurance… and cause she trusts him… and you know it’s usually a him… he tells her it’s lupus… he gives her something to help… And then she tells people she has lupus ‘cause that’s how the insurance companies, and the pill companies, and the doctors make money… Cause she needs a way to tell people that her pain is a real life disease…”

“When a black woman has pain, she sits at her Auntie’s kitchen table and they talk about the world… all the things in the world the cause black women pain… she goes there ‘cause she knows her Auntie has the same problem… the pain… and her Momma wouldn’t understand, cause she don’t have it… and then her Auntie, her cousins… hell the whole damn neighborhood tells her what’s wrong… cause for some reason it’s their business too… and she knows she has lupus ‘cause lots of people’s got it, and they’ve had to live with it for a long time… without the insurance people, and the doctors, and the pill companies tellin them it’s lupus… That’s why I don’t think [Morningside] is the right place for me to be right now… The women here are talkin bout lupus like the white women do… not like how black women should…”

Leia was another young woman who left the Morningside Baptist Church lupus support group because she did not feel the group met her needs. At twenty-one she was the youngest member of the group. Like Tanisha, she did not feel the older women’s definition of illness matched her own experience, nor were her interests similar to those of the other young women in the group. Leia was born and raised in a middle class Morningside household. Both sides of her family had been members of Morningside Baptist Church for multiple generations. Her father and her uncle on her mother’s side of the family were both deacons in the church, and her maternal grandmother was the current matriarch of a group of older women who organized and oversaw social events at the church. Leia’s parents both held advanced degrees and worked in administrative positions at separate colleges in Memphis. Leia was their only child and they stressed the importance of education and learning.
Leia enjoyed reading and learning and excelled academically. She was shy and withdrawn with new people, but became bubbly and affectionate with people she considered friends. She was bullied and teased in high school because she was a “nerd,” but chose to remain in a public high school in Morningside rather than attend a private high school selected by her parents. Since she had grown up in Morningside, she was concerned if she attended a private high school her peers would shun her from neighborhood social activities. She already felt awkward around other neighborhood youth due to her class status and interests. She was concerned that attending a private school would create further anxiety when she socialized with neighborhood friends and peers.

Leia described her lupus journey as “boring.” The summer before her junior year in high school, Leia began to experience headaches and joint pain. Light hurt her eyes and her skin became sensitive to soap and heat. Her mother bought scent-free products for the house and disposed of her father’s favorite scented candle. She also scheduled an appointment with an optometrist to evaluate whether or not Leia’s headaches were related to changes in her vision. By mid-summer Leia was regularly so exhausted she could not get out of bed for days at a time. She began quickly gaining weight and her mother made an appointment with the family doctor.

The doctor conducted a physical and asked Leia questions about her pain and exhaustion. He suggested she begin taking birth control pills because he believed her pain, exhaustion, and weight gain might be the result of polycystic ovarian syndrome (POS). He told Leia the hormones in the birth control pills should help with her exhaustion and pain. Once she was feeling better he encouraged her to find an exercise
routine she enjoyed so she could lose weight. Leia did have more energy by the time she returned to school the following fall and she assumed her medication was working.

By the time Leia entered midterms in October, her headaches and exhaustion had returned. She missed several family holiday events in the fall and winter because her pain was regularly accompanied with a low-grade fever her parents assumed was a virus. By the end of the semester Leia was struggling to stay awake in class. She managed to keep her 4.0 average, but barely completed two of her finals due to exhaustion. She returned to the doctor and he ordered blood work. Once again he and Leia discussed her pain and exhaustion. He gave her mother a referral to a rheumatologist because of their family history with rheumatoid arthritis (RA), although he was skeptical her health issue were autoimmune related due to her age.

As the spring semester began, Leia struggled to stay awake in class. Light hurt her eyes and triggered her headaches. Her fever persisted and she became dehydrated easily. By late spring her initial rheumatologist referral turned into visits with a wide range of specialists. Leia missed school regularly due to illness or visits to the doctor. Her teachers emailed her assignments and her parents helped her with her homework. She continued to turn in assignments on time and maintained her grades. Her parents documented her illness and visits to specialists and the school allowed Leia to take medical leave. She was diagnosed with lupus in March of 2011, one month before her eighteenth birthday.

After her diagnosis Leia's senior year in high school went smoothly. She graduated with honors in 2012. Before her diagnosis, Leia's goal was to attend Temple University. After her diagnosis, her parents encouraged her to stay closer to home. She
agreed to attend the University of Memphis if her parents would allow her to leave home and live in the dorms. The summer before her freshman year in college, Leia began attending the Morningside Baptist Church lupus support group. She had been attending the chronic pain support group for nearly a year before Ms. Lena convinced her to join the lupus support group. Leia enjoyed the company of the women in the group, but she never felt entirely comfortable. As the youngest member of the group she felt she was treated like a baby. She was also uncomfortable expressing her frustrations with her family because Ms. Lena, Ms. Retta, Ms. Wendy, and Ms. Candice were all friends with her grandmother, aunts, and mother.

As the support group was beginning to split in the fall of 2014, Leia was entering her sophomore year in college. She had agreed to join the new support group with Mercedes, Cassie, and Naomi, but like Tanisha she did not share the other women’s interests. Leia’s college social group was mostly white and she often felt as if her friends did not understand her concerns or experiences. She began searching for new social outlets where she felt her voice would be valued.

“I’m thinking of becoming more politically active, maybe that’s where I fit in, I don’t know yet…I don’t really feel like I fit in anywhere. I’m a nerd, I like comic books and sci-fi and video games, I’m a history major and I’m also good at math…It’s not cool to be a nerdy black girl …And I don’t really like hip-hop culture either. I mean I get it and I don’t think it’s a bad or anything, but it’s not what I’m into. Because I don’t like the things black teenagers are supposed to like, like rap music and basketball, I didn’t really have many friends in high school…It’s kind of the same thing with Mercedes and the girls in the support group. I like them and they accept me as one of the group, but all they talk about are hair extensions and getting their nails done and sex… College has been a little better than high school. There are more people like me. I have a really good group of friends and we can all be nerds together…But they’re all white so I still don’t really feel like they get what I’m going through…”
“My lupus makes it worse…It’s like if you took all the things society says makes women ugly and put it into one disease that’s lupus…My medication made me gain so much weight…I have keloids everywhere…I hate to look at myself…My white friends don’t get it, they don’t understand why I’m self-conscious…They just keep saying stuff like ‘but big black women are so confident and sassy, black men love big women’…and I want to say ‘y’all no one wants to be called big and that other stuff is really kind of stereotypical and racist’…but all I ever say is something like ‘have you ever met anyone who would describe me as sassy,’ or ‘I just want a boyfriend whose nice to me and likes the same things I do. He doesn’t have to be black’…So maybe getting involved with some other stuff would be good for me…Tanisha and Samuel invited me to go to some Black Lives Matter stuff with them…I know Rashaad’s been going too…I feel comfortable with them and they are my friends so maybe that’s is a good option for me to not feel so awkward and out of place…It seems like it might also be a place where I might meet other black nerds who’ve had the same experiences as me…I feel like people are trying to say something that’s bigger than themselves and I like that too…I want to be part of something that is more they centered and less me centered…I don’t really want to spend all my time trying to pretend I’m confident when I don’t feel like it yet…I’m ok just being part of the group right now…”

The events that unfolded in Ferguson, Missouri in the summer and fall of 2014 changed the dialog about race and racism happening in Memphis. The impact of racism and the legacy of the Civil Rights Movement were regular topics of conversation within faith-based and social justice groups across the city. These organizations did not discuss these issues quietly; rather, they created public spaces where white residents were confronted with a regular public discourse on racism. This public discourse on racism focused on the city’s specific role in the Civil Rights Movement. Even when conversations or debates focused on the work that needed to be done to combat twenty-first century racism, discussions began with a history of the Civil Rights Movement. After Ferguson, there was a sense of urgency in the need to address not only police violence, but also a number of structurally racist systems in the United States.
In August and September 2014, I began noticing flyers attached to community and church bulletin boards advertising consciousness raising groups or encouraging community members to join or follow new civil rights leaders on social media. Black Lives Matter signs became more prominent in the front yards and car windows of Morningside residents. Older members of the community greeted youth wearing Black Lives Matter t-shirts warmly. Neighbors greeted each other loudly, but spoke softly to one another at community events, most notably the public hearings to discuss the school district restructuring. I had been attending many of the South Memphis school closing forums with Gloria, a sixty-five year old retired schoolteacher whose father had been a well-respected minister at a South Memphis church during the Civil Rights Movement. Gloria’s lupus had kept her from standing in protest in the 1960s, but she was excited to see a new generation of young people show interest in political engagement. She felt it was important for her generation to show support for, and solidarity with, the next generation of civil rights activists.

As a white researcher, these were not spaces I had access to, nor did I ask research participants to bring me into these spaces or discuss their experiences in these private spaces. Younger women usually avoided talking about their participation in new social movements if and when research questions moved in that direction. Tanisha and I had an ongoing conversation about politics and racism. While we continued to speak about social issues in abstract terms, or how they applied to the people we knew on a personal basis, she also said there were issues that were private to her and she was not willing to discuss them with anyone who was not African American. I respected her boundaries on these issues and it did not have significant consequences for our relationship.
Rashaad was excited to share his new interest in political movements. He helped organize “die-in” protests at his high school, decorated his backpack with Black Power imagery, and joined two youth centered consciousness raising groups. He began working with the church archives after school so he could learn more about local contributions to the Civil Rights Movement. Rashaad and his friends had also suggested conducting an oral history project that would include interviews with local Black Power leaders for their U.S. history class. His excitement for these projects stemmed from the fact that he felt that his peers were currently the targets of many of the high profile cases of police violence and he felt it was important to speak out on these issues. Ms. Lena was concerned about Rashaad’s safety. She feared his involvement in protest movements might make him a target for violence.

Leia began attending Black Lives Matter meetings and events with Tanisha and Samuel. She eventually started making connections with social justice groups on campus. She said she sometimes felt guilty that her new political life meant that she did not have enough time for her white friends, but she also decided if they could not accept her commitment to anti-racist politics then they may not be real friends. On July 10, 2016 Leia, Rashaad, Tanisha, Samuel and more that a thousand other Memphis residents participated in a Black Lives Matter protest that stopped traffic on I-40 between Tennessee and Arkansas. The protest, which culminated in protesters blocking traffic on the Hernando DeSoto Bridge lasted for several hours and raised new questions regarding racial justice in the city. Leia and Rashaad felt the experience as exhilarating, while Tanisha said, “it’s a start.”
Conclusion

For neighborhoods impacted by persistent poverty, building community around a shared caring for one another is a survival strategy. For women living with lupus, kin networks and community connections are important to maintaining a good quality of life. Downward economic mobility related to the chronic symptoms associated with lupus was a common theme in many of the narratives I collected. Even with the privilege that accompanied her college education, Kendra struggled financially during her time as a university student and after she graduated. Although her scholarships paid for her basic needs on campus, she had no additional income to purchase everyday care items used to help her with lupus flares. Since her family was poor, they were unable to provide financial support. Kendra lacked a consistent support system on campus that could help care for her during long periods of illness.

Unlike her middle class peers, whose parents and family could travel when needed, neither Kendra nor her mother owned a personal vehicle. Her parents owned one car that her father needed for work. Lack of personal transportation not only meant Kendra could not go home when she fell ill, it also meant she was unable to leave campus to purchase items that might improve her quality of life. When she returned home, attending college was prohibitive without taking out student loans. Even after completing college and finding a stable, middle class job, Kendra was still not able to reach middle class status. Her student loan payments and the money she used to help support her parents meant that there was no money left for emergency savings.

Lorraine, Kendra, and their extended family formed a network to care for the chronically ill women. Relatives opened their homes to Kendra as she tried to finish school and allowed her to use their addresses in order to access TennCare while she lived
in Mississippi. Lorraine and John had offered relatives similar assistance when they lived in Tennessee. Lorraine cared for Kendra and taught her how to care for herself when she experienced lupus flares. Once she was a working professional, Kendra helped provide financial assistance to her family. She made sure her mother’s prescriptions were up to date and frequently paid for her mother’s medication. Kendra took her mother to doctor’s visits and rationed her own medication so that her mother did not go without.

The hope that came from building deep interpersonal connections with other people who shared their experiences with physical pain and social exclusion was also an important theme in the stories told by women living with lupus. Tanisha and Leia’s friendship began because each woman was looking for a community that did not focus on illness. While their relationship began at Morningside Baptist Church, their friendship deepened as they became more invested in anti-racist social movements. They also formed familial bonds with Ms. Lena’s son Rashaad. Rashaad came into Ms. Lena’s home at thirteen, and she was able legally adopt him six months before he turned eighteen. While Ms. Lena worried about Rashaad’s personal safety as his interest in political engagement grew, Tanisha assured Ms. Lena that she would keep him safe. Tanisha took on a sisterly role with both Rashaad and Leia. Rashaad and Leia looked to Tanisha for guidance and assurance, and Tanisha relied on them to help organize and run her community canvassing campaigns when she became too sick to work.

Each of the women relied on larger networks of support, and fluid definitions of family as a form of self-care. However this did not mean they were accepting of a system that forced them to struggle to maintain their health on a daily basis. They were also frustrated, hurt, angry, and cynical about their experiences as African American women
in the United States. Some women like Kendra, expressed feeling angry and hopeless. Others, like Rashaad, were excited about what the future held. Tanisha was resolute in her desire to remake the system rather than reform it. 2014 and 2015 were socially turbulent years throughout the United States. Instead of approaching that turbulence with trepidation, many Memphis residents used their own experiences of exclusion and relationships they built for support and survival as a catalyst for social commentary regarding racism.
This project began as an exploration of how chronically ill women with limited access to healthcare resources navigate state-level healthcare programs. It became a project that used narratives of poor health and chronic pain to document resistance to racism in the United States in the first year of the ACA. The stories women shared with me also revealed how long-held beliefs regarding racism in the United States were part of a larger, nationwide political shift interested in confronting structural racism. The women I interviewed were frustrated and angry, but they were not content to change themselves to fit the boundaries of the existing system. They were determined to create a new system that no longer excluded or shamed them. Even though the narratives featured in this dissertation are primarily drawn from a close-knit group of people, those stories are representative of the responses given by a large majority of study participants in both samples. This decision to focus on a small number of people was based, in part, in a desire to illustrate the importance of multigenerational, interpersonal relationships.

Geography played an important role in this story as well. The city of Memphis’ well-established black professional and middle classes, along with the city’s role in the Civil Rights Movement, provided a unique opportunity to document the ways in which Memphis residents challenged the white supremacy present in local politics and policies. The past few years have seen a renewed interest in discussions of race and racism throughout the United States. Long before these conversations were occurring nationally, Memphis residents were drawing on the city’s unique history of resistance through music, art, and political activism in order to address local issues that perpetuated racial inequality. While this public discourse is an important part of the city’s social fabric, it
should not be romanticized. The public discourse on racial inequality is countered by a discourse rooted in the city’s equally long history of white paternalism. The “progressiveness” of Crump era politics promised to address inequality, but instead reinforced segregation and did not produce solutions to structural racial inequality. By focusing on citywide projects that ultimately served to benefit wealthy communities and reinforce segregation, A.C. Wharton’s local policies in the first half of the 2010s served as a continuation of Crump era paternalism.

New and old civil rights leaders challenged many of the local policies that perpetuated inequality, especially those pertaining to poverty and unemployment. Local media outlets regularly focused on structural racism in city policies. Local news affiliates featured stories and articles that questioned the motivation of city sponsored development initiatives, polled the community, and challenged those in power. Communities hosted public forums that allowed citizens to voice their opinions. In late 2013 and early 2014 healthcare policy and the ACA was an important topic of interest in these forums. Public forums concerning the separation of county and city school districts hosted by both the city and local social justice organizations drew large crowds that packed school gymnasiums during the first half of 2014. Churches, faith-based organizations, and local justice based non-profits regularly hosted events aimed at alleviating persistent poverty and addressing racism. These philanthropic organizations frequently supplemented or took the place of city and state-level social service programs in poor neighborhoods. The link between poverty and racism was frequently used to illustrate how and why the high poverty rates in the city disproportionately targeted predominantly black neighborhoods. By the end of 2014 Memphis residents were also becoming politically engaged in
national anti-racist campaigns. Support for Black Lives Matter grew throughout the city and young people like Tanisha, Leia, and Rashaad engaged in a number of political activities. Not only did they participate in the citywide public protest movement, they also used their new political interests as a way to build intimate, interpersonal relationships with other members of the community committed to addressing issues that affected their lives.

Beyond the scope of individual neighborhoods and city of Memphis, changes in healthcare policy in the state of Tennessee over the course of the last twenty to thirty years serves as an example of the affects the privatization of public services has on poor communities throughout the United States. The history of TennCare serves as a cautionary tale of the affects of privatized healthcare. The first year of the ACA saw many of the same administrative and bureaucratic issues TennCare encountered in the early and mid-1990s. Like the ACA, TennCare programs have been politicized, thus information about programs designed to assist those with limited care options are lost as politicians debate semantics. Both TennCare and the ACA were proposed as economic solutions to health inequality in the Untied States. Both systems rely primarily on private insurance companies to provide resources to uninsured members of the population. Since the early years of TennCare, these agreements have caused fluctuations in costs to the state and clients, regular changes to eligibility guidelines, and limited access to facilities and providers. While the structure of the TennCare system provides the illusion of a stable framework for residents needing health services, the frequent changes creates ambiguity for clients who rely on TennCare.
As one of the longest continuously running privatized public sector healthcare programs in the United States, TennCare has experienced a number of changes. Because contracts between the state and private health insurance companies are renegotiated regularly, TennCare has had to revise, restructure, and reevaluate its programs and service providers on a regular basis. This means clients using TennCare services are not able to make long-term plans for their health. While ACA programs are still in their early stages of development, many of the same issues have begun to arise as health insurance providers begin to reevaluate their participation in state and federal health insurance marketplace programs. Promises to repeal the ACA by the current administration have created additional anxieties for public service clients as they try to parse out the difference between partisan political rhetoric and reality.

A critique leveled against the ACA has been whether or not enrollment in a health insurance plans really guarantees that a client will be able to afford or gain access to the healthcare resources they need. The regular restructurings and general level of confusion connected to navigating TennCare demonstrates a potential future for healthcare systems that rely on private industry to determine the types and quality of care available to the general public. Poor communication, bureaucracy, and frequently changing eligibility guidelines have obstructed pathways to care of TennCare recipients since the programs’ inception. Since the state of Tennessee chose not to expand Medicaid under the ACA, coverage gaps began to appear by the summer of 2014. Tennessee residents, who had been denied TennCare coverage in the past, were initially also denied coverage through the federal healthcare marketplace. While these individuals and families were eventually enrolled in either a state or federal health insurance program, delays in coverage meant
that these individuals spent part of 2014 uninsured. Like Rosemary, many of these uninsured individuals questioned the limits of their coverage and feared the financial ramifications of seeking care while uninsured. It is also important to note that despite the public discourse asserting the failings of the ACA, these issues with gaps in coverage were largely the result of poor communication and bureaucracy with the TennCare system, and not necessarily directly related to a failure in the federal healthcare marketplace.

In recent years, anthropologists have begun exploring what comes after neoliberalism. Neoliberal social policy proposes economic solutions to social issues through privatization and the deregulation of markets (Rylko-Baur and Farmer 2002, Becker 2007, Boehm 2005). The privatization of a number of social services at the end of the twentieth century has granted private industry greater decision-making power over U.S. residents. Relationships forged between the state and private industry has had particularly lasting consequences for the poor (Maskovsky and Morgen 2003, Kano et al. 2009). The women whose narratives are featured in this dissertation are already beginning to conceptualize the long-term effects of neoliberalism in their daily lives. Although addressing the question of what comes after neoliberalism was not a foregrounding research question for this project, the collaborative effort between the women who gave their stories for this research and myself do attempt to address new responses to neoliberalism. The anthropology of civil rights and the anthropology of resistance both serve as frameworks to better understand how people work towards goals of an anti-racist society through forms of everyday resistance.
An anthropology of civil rights illuminates the relationship between early U.S. anthropology and critical studies of race. Early twentieth century anthropology took an active position critiquing how biological constructs of race were actually socially constructed forms of racism. An anthropology of civil rights also takes into account the ways ethnography has been used to legally combat racism and segregation, as well as serve as a platform to support anti-racist projects. Ethnography documents how history can be passed down from generation to generation and how knowledge can be shared in order to build an anti-racist dialog. The stories told by the women of the Morningside Baptist Church lupus support group demonstrate the challenges of building and maintaining multigenerational coalitions. Tensions between the older and younger members of the group created an uneasy dynamic, but the women all believed addressing issues of structural racism in the healthcare system was paramount to changing their healthcare experiences. Even though many of the younger women chose to leave the group, the split was ultimately amicable. Despite their differences in opinions, the women still actively supported each other’s struggles with racism both inside and outside the healthcare system. An anthropology of civil rights not only documents the complexities of these relationships, it opens a public space for people of color to tell their own stories.

An anthropology of resistance includes a broader definition of resistance that is not confined to public demonstrations. Leith Mullings (2013) argues that ethnography can be used as a tool of resistance. Because anthropological methods encourage building relationships with research participants that are based in trust and respect, ethnography has the potential to address inequality through collaboration with research participants. The collaborative relationships I built with many of the women who shared their time and
stories with me during and after my time in Memphis allowed the project to change as their lives and experiences changed.

Patrice and Ms. Candice’s questioning of the intentions behind their lupus diagnoses, Tanisha’s recognition that racism is institutionalized in the foster system and the healthcare system, Mercedes’s desire to confront class-based tension within her support group, and community building programs sponsored by Morningside Baptist Church all serve as acts of resistance. An anthropology of resistance allows marginalized people to craft their own narratives of support and survival, rather than relying on theoretical frameworks crafted by white scholars. Respondents who participated in this project frequently talked about how their knowledge of lupus and their self-care strategies originated from friends and family, rather than doctors and clinical spaces. Although they did want access to medical care, respondents wanted their medical care to compliment and support their existing routines rather than the other way around. The women with lupus who participated in this study were proud of the illness narratives they created and shared with one another as alternative forms of knowledge. The methodological tools used to craft ethnography have the potential to also create frameworks for pragmatic problem solving thus creating a pragmatic use for ethnography.

This project has produced new potential research questions for future consideration. Every woman with lupus I interviewed, regardless of her age, race, socio-economic status, or education initially dismissed her chronic pain. Women often delayed seeking medical care for years because they attributed the pain to issues including seasonal allergies, pre-menstrual syndrome, professional stress, interpersonal issues, or lack of sleep. Roughly half the women did attribute some of their physical pain to
emotional pain such as the loss of a loved one, post-partum depression, or undiagnosed or diagnosed mental health issues. However they also made distinctions between the pain they associated with lupus and the pain they associated with other health issues.

Although all fifty-one women did believe the intensity of their lupus flares was tied to psychosocial stress or environmental irritants, each woman was also adamant her pain was the result of a chronic physical illness and not limited to an expression of emotional or psychic pain. This overwhelming response raises a number of interesting questions. One of the most intriguing questions produced from these interviews is why do women normalize chronic pain? Why is pain seen as something that must be endured, rather than something that needs treatment? How is the acceptance of chronic pain tied to larger social attitudes in the United States regarding individual exceptionalism and the relationship between physical and mental weakness?

In addition to thinking about why women ignore chronic pain, I am also interested in potentially exploring how “self-care” models are classed and racialized. The women of the Morningside Baptist Church lupus support group talked at length about self-care. As a group they almost unanimously rejected activities like yoga and stretching because they felt these activities were middle class and white. They regularly discussed how African American women’s approaches to self-care needed to include addressing everyday forms of racism. However class played an important role in how they discussed their own self-care routines. LaToya became frustrated when the other women tried to convince her that she should create a standardized self-care routine through journaling. The relationship between time and money was important to LaToya in a way it was not for her middle class peers. She was shocked that other women in the group took a day off when they
experienced flares because she felt staying in bed or making time for relaxation was a luxury, not a necessity. Working poor women overwhelmingly reported they believed taking a day off to recover from a flare was a form of privilege. Similarly, Quan viewed the fragrance-free items Ms. Lena gave her as a luxury, while Leia viewed these items as a necessity. Venus’s observations about the ways in which the popular Spoon Theory model for managing chronic pain is not applicable to black women’s lives demonstrates the relationship between race and privilege. Venus, and many other women with lupus interviewed for this project, actively distanced themselves from lupus organizations they felt privileged white women’s illness experiences.

The United States was headed towards a significant social and political shift when I completed my fieldwork in 2015. Social unrest throughout the country created additional spaces for Memphis residents to become politically active. Social movements like Black Lives Matter created space for working poor and working class members of the community to voice their opinions. Young people like Leia and Rashaad were actively seeking out opportunities to organize and communicate with like-minded youth. Tanisha’s personal experiences and beliefs had always influenced her political positionality. In the months following the events in Ferguson, she and Samuel began to actively seek out spaces to speak out against racism. Samuel described their interest as a “grounded intellectualism” and the couple began hosting gatherings so that a close group of their friends could explore specific issues. The group read both fiction and non-fiction, watched films, and shared new discoveries while learning about current social issues. Tanisha’s future, like many of the other women featured in the project was full of
uncertainty, however she was able to face that uncertainty with optimism because of the people she kept close.
Figure 1 Tri-State area highlighting the Memphis metropolitan area and specific locals in northern Mississippi.
Figure 2 Map of the Memphis metropolitan area with sections of the city and suburbs mentioned in the text identified.
APPENDIX B: Overview of the Research Phases

<table>
<thead>
<tr>
<th>Phase</th>
<th>Timeframe</th>
<th>Activities</th>
</tr>
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</table>
| **Phase I** | August 2013 - October 2013 | - Participant Observation in Public Clinical Spaces  
- Began Shadowing Social Workers  
- Learned City  
- US Government Shutdown  
- Volunteered at MIFA and Mid-South Food Bank  
- Received IRB Approval |
| **Phase II** | November 2013 - April 2014 | - Began Volunteering at Morningside Baptist Church  
- Attended ACA Public Forums  
- Attended ACA-Related Meetings for State Workers  
- Began Sitting in on East and North Memphis Support Groups  
- Began Interviews January 2014  
- Concluded Interviews with Healthcare Workers in Late April |
| **Phase III** | May 2014 - September 2014 | - Began Working a Part-Time Job in Community  
- Began Observations at South Memphis Kidney Clinic  
- Began Attending Morningside Baptist Church Lupus Support Group  
- Began Attending Social Gatherings with Healthcare Workers |
| **Phase IV** | October 2014 - March 2015 | - Interviewed 32 of 51 Women with Lupus  
- Conducted Followup Interviews  
- Attended Holiday Gatherings with Research Participants  
- Exit the Field in Late March |
| **Phase V** | April 2015 - August 2015 | - Returned to Lexington, KY  
- Conducted Followup Interviews via Phone  
- Attended TennCare Meetings in Nashville, TN  
- Organized and Analyzed Data |
APPENDIX C: Lupus Study Sample

### Research Population Age Breakdown

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Count</th>
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<tr>
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</tr>
<tr>
<td>35-49</td>
<td>20</td>
</tr>
<tr>
<td>18-34</td>
<td>16</td>
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### Overview of Research Sample Demographics

#### Ethnicity

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<tr>
<th>Age Range</th>
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<th>Korean</th>
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<td>1</td>
<td>1</td>
</tr>
<tr>
<td>35-49</td>
<td>16</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
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<td>16</td>
<td>0</td>
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#### Education/Class

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<th>College Degree</th>
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<td>2</td>
<td>3</td>
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<tr>
<td>35-49</td>
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#### Rental/Home Ownership

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<td>18-34</td>
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#### Insurance Status

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<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>35-49</td>
<td>10</td>
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<tr>
<td>18-34</td>
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<td>0</td>
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#### Diagnosis Status

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<td>7</td>
</tr>
<tr>
<td>18-34</td>
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</tbody>
</table>
APPENDIX D: TennCare through Time Graph

TennCare Enrollment for the Research Population

Number of Enrolled

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<tbody>
<tr>
<td>50+</td>
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<td>14</td>
<td>10</td>
</tr>
<tr>
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<td>10</td>
</tr>
<tr>
<td>18-34</td>
<td>2</td>
<td>6</td>
<td>6</td>
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</table>

Time
APPENDIX E: Morningside Baptist Church Lupus Support Group

### Overview of Morningside Baptist Church

<table>
<thead>
<tr>
<th>Private Insurance</th>
<th>Age</th>
<th>Lupus Diagnosis</th>
<th>Education</th>
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<tbody>
<tr>
<td>Leia</td>
<td>22</td>
<td>Y</td>
<td>College</td>
</tr>
<tr>
<td>Ms. Retta</td>
<td>65</td>
<td>Y</td>
<td>College</td>
</tr>
<tr>
<td>Ms. Candice</td>
<td>66</td>
<td>Y</td>
<td>High School</td>
</tr>
<tr>
<td>Rachel</td>
<td>38</td>
<td>Y</td>
<td>High School</td>
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<table>
<thead>
<tr>
<th>TennCare</th>
<th>Age</th>
<th>Lupus Diagnosis</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grace</td>
<td>31</td>
<td>Y</td>
<td>Vocational Training</td>
</tr>
<tr>
<td>Tanisha</td>
<td>36</td>
<td>Y</td>
<td>High School</td>
</tr>
<tr>
<td>Ms. Lena</td>
<td>57</td>
<td>Y</td>
<td>GED</td>
</tr>
<tr>
<td>Mercedes</td>
<td>27</td>
<td>Y</td>
<td>GED</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Not Insured</th>
<th>Age</th>
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<th>Education</th>
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<td>Naomi</td>
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<td>Vocational Training</td>
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<tr>
<td>Charmaine</td>
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<td>Vocational Training</td>
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<tr>
<td>Ms. Wendy</td>
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<td>Y</td>
<td>High School</td>
</tr>
<tr>
<td>Quan</td>
<td>36</td>
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<td>GED</td>
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<tr>
<td>LaToya</td>
<td>33</td>
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<td>GED</td>
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<tr>
<td>Cassie</td>
<td>27</td>
<td>N</td>
<td>GED</td>
</tr>
<tr>
<td>Ms. Kitty</td>
<td>50-55</td>
<td>N</td>
<td>Unknown</td>
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  2009
- Bachelor’s of Arts, Anthropology
  University of Tennessee, Knoxville, TN
  2007
- Bachelor’s of Arts, Theater
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  2000

Research Awards and Grants

- Lyman T. Johnson Odyssey Award for Community Outreach
  University of Kentucky Student Government Association, 2010
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  University of Kentucky, Department of Gender and Women’s Studies, 2010

Academic Awards

- Kentucky Graduate Scholarship
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- McClinton Scholarship
  University of Kentucky, Office of Adult Student Services, 2010
- Department of Anthropology Legacy Travel Grant
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University Positions

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- Anthropology 101 – Introduction to Anthropology (Instructor)
- Arts and Sciences 100 (Instructor)
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- Anthropology 221 – Native Peoples of North American (Teaching Assistant)
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