
Theses, Dissertations, and Projects

2018

Living well in the lives of African American women with chronic illness

Gabrilla Ballard
Smith College

Follow this and additional works at: <https://scholarworks.smith.edu/theses>



Part of the [Social Work Commons](#)

Recommended Citation

Ballard, Gabrilla, "Living well in the lives of African American women with chronic illness" (2018). Masters Thesis, Smith College, Northampton, MA.
<https://scholarworks.smith.edu/theses/2084>

This Masters Thesis has been accepted for inclusion in Theses, Dissertations, and Projects by an authorized administrator of Smith ScholarWorks. For more information, please contact scholarworks@smith.edu.

Living Well in the Lives of African American Women with Chronic Illness

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

GaBrilla Ballard

Smith College School for Social Work
2018

GaBrilla Ballard
Living Well in the Lives of
African-American Women
with Chronic Illness

Abstract

Finding support for African American women with chronic illnesses is challenging. It often requires these women to identify, cultivate, and nurture practice structures that go beyond medical structures already in place to aid in the maintenance of their health conditions. Outside of these structures, the resources needed to support the women are limited. They do not include the scope of modalities necessary to address their unique health presentations and holistic need for medical, emotional and spiritual health. Additionally, intersecting systems of oppression pose challenges to African American women when trying to access resources that could support their overall well-being. This research study explores the lifestyle practices and healing practices created and sought out by African American women with chronic illnesses to support their well-being while juggling diagnosis, doctors' appointments, pain management, parenting and navigation of systems that often and unnecessarily present additional challenges and undermine quality of life.

TABLE OF CONTENTS

TABLE OF CONTENTS.....	ii
CHAPTER	
I. INTRODUCTION	1
II. LITERATURE REVIEW	3
III. METHODOLOGY	7
IV. FINDINGS.....	11
V. DISCUSSION AND CONCLUSIONS	19
REFERENCES	23
APPENDICES	
Appendix A: Consent Form.....	24
Appendix B: Interview Guide.....	27
Appendix C: HSR Approval Letter.....	28

CHAPTER ONE

Introduction

Supporting African American women who live with chronic illness to live long, healthy lives is challenging. Often, it requires these women to identify and create support structures that go beyond the social and medical structures already in place. For example, some African American women living with chronic illness, and their families, are able to access social security disability and other benefits however, there are not many other resources that support individuals and their families as they navigate chronic illness. Intersecting systems of oppression also pose additional challenges when African American women are trying to access resources that could support their overall well-being (Williams, Neighbors, & Jackson, 2008). These include internalized ideas about needing help, which also undermines their ability to seek and acquire the support they need (Abrams, Maxell, Pope & Belgrave, 2014). Additionally, the stress of doctors' appointments, diagnosis, pain management, parenting, and navigating multiple systems can add additional stress, which undermines the will to heal and thrive, unnecessarily undermining quality of life.

Purpose of the Study

The purpose of the study was to explore the lifestyle practices, themes, and life structures that contribute to the well-being of African American women living with a chronic illness. This research is important to the field of social work because it contributes to the literature and supports further research and the development of programs and institutional policies that support the well-being of African American women living with a chronic illness. This study was conducted as research requirement

for my master's degree in social work from Smith College School for Social Work and may ultimately be published or presented at a professional conference.

Research Question

What are the lifestyle practices African American women use to live well while managing chronic illness?

CHAPTER TWO

Review of the Literature

Hooks (1995) explores the intersection of healing, race, and gender. Often, the experiences of race-based trauma are not addressed as a health issue. Hooks takes an exploratory approach to her analysis of the needs specific to black women by addressing socio-historical factors, socio-political structures, and ethnographic information to construct her framework. She offers a perspective that addresses the impact of the intersection of race and gender on the lives of black women. Hooks articulates the importance of creating spaces for black women to heal.

Centering African American women's experiences in her analysis, Hill-Collins, (2000, P. xiii) writes about "being in space" with her people. Her theory of black feminist thought emerged from her work within the Black community and not alienating herself as a black scholar. Hill-Collins referred to being intellectually active as key process in developing black feminist thought, reclaiming the intellectual traditions of black feminists.

According to transactional stress theory (Hyman, Lucas & Porcerelli, 2014), stress results from the ongoing transactions between people and their environments, which leads them to perceive a lack in the biological, psychological, or social resources necessary to cope with the demands of the environment. This study examined the utility of appraisal-based versus exposure-based stress measures in linking stress to mental and physical health in low-income black women. Another relative unknown concerns the interplay between stress perceptions, physical health, and mental health in health disparities research. The researchers hypothesized that stress measures would

have a negative influence on mental health. They also hypothesized the stress measures would negatively predict mental health and that physical health would be predicted by mental health.

The limitations of this study were that it was conducted on a small, cross-sectional subset of black women and may not generalize to those outside this sample population. The study was also limited in that health status was obtained via self-report only, thereby indicating that the participants' health was a function of how they perceived and interpreted their physical health, rather than being an accurate indication of their physical health (Watson & Pennebaker, 1989).

Allostatic load is a useful construct to understand how social and environmental conditions affect health. To date, few studies have examined health –enhancing lifestyle behaviors and their potential benefits in reducing allostatic load (Upchurch Rainisch Wexler, & Chyu, 2015). The purpose of this study was to investigate the contributions of leisure time physical activity on level of allostatic load among White, Black, and Mexican American women in midlife. The study found that higher levels of physical activity were associated significantly with lower levels of allostatic load, independent of demographics. Higher socioeconomic status socioeconomic status was associated with a lower allostatic load. Adjusted prediction models demonstrated associations between greater levels of physical activity and lower allostatic load for all ages and racial/ethnic groups.

Taylor (2000) characterizes the role of support groups in the healing and recovering experiences of African American women who have left abusive relationships. She focuses on the impact of race and ethnicity on the healing and

recovery of African American women. Taylor uses a womanist ethnographic methodology to provide an in-depth exploration of these experiences. A purposive sample of African American women was recruited. These women identified as women who as survived and successfully disengaged from abusive relationships. Of the twenty-one women who participated in the study, fifteen reported the use of support groups and individual therapy as conduits for their recovery.

A study conducted by Norris & Mitchell (2014) focused on how the stress-support process operates among Black women. The findings in this study challenge the proto-typic stress-health models that fail to acknowledge social group differences in the stress-support-distress process. This research points to the need for health professionals to consider how formal support systems (for example, health promotion programs) and internal resources (For example, health education) can positively impact the health of African American women. Much of the stress related research has been done on white male bodies, despite the fact that women report higher levels of psychological distress. This study asserts that more comprehensive research is needed that focuses on African American women; specifically, the stress response in the body and the physical and psychological impact of that stress.

One study that does focus on the specific needs of African American women was conducted by Adinuba (2016). This research examined the relationship between stress (allostatic load) and stroke among African American women and found that high stroke risk factor profiles (SRFP) and high allostatic load are associated with higher risk for stroke for US born African American women. There was an increase in stroke risk by age and a decrease in stroke risk by education.

CHAPTER THREE

Methodology

This exploratory study aims to identify the lifestyle components that contribute to African American living well with chronic illness. Through a one time, one-hour long interview, the researcher identified themes, practices, and beliefs that these women identified as contributing to their well-being. The researcher allowed the participants to define what well-being is for them; rather than limit their experience with a definition I would provide.

The participants were a random sample of people the researcher new personally. The researcher recruited these women through multiple channels. Once the women were selected, the researcher's scheduled and conducted one to one and half long phone interviews, using the audio software, Call Recorder, to record the interviews, and Garage band to store and transcribe the interviews. The interview questions (see appendix B) focused on the participants' current health status, practices they use to manage their illness, support from their families, and other structures that help them while living with a chronic illness.

Sampling Criteria

Participants were women over eighteen years of age who self-identified as African American and living with a chronic illness. Participants were willing to share their experiences living with a chronic illness as described in the recruitment material (see appendix). The participants were all receiving some form of treatment for their medical condition, including with a license doctor or alternative medical practitioner.

Some of the chronic illnesses included diabetes, cancer, autoimmune disorders and bronchial conditions, such as asthma.

Informed Consent

The participants were each read an informed consent form (see appendix A) that described the study procedures, the risks and benefits of participating, and the participant's right to stop the interview at any time and/or otherwise change their mind about participating.

Data Collection and Sampling

This exploratory, qualitative study focused on identifying how African American women cope with a chronic illness. The women who participated in the study were interviewed in a one to one hour to 90 minutes interview conducted by the researcher who focused on identifying the themes that contributed to their living with a chronic illness. The participants were known to the researcher who contacted them by email to ask whether they might be interested in being part of this study Interested subjects were read an informed consent form which was sent electronically or by postal service for their signature. The informed consent form outlined the rationale for the study as well as the risks and benefits of participating. The research also made counseling resources available to participants in the event the interview raised emotions that needed to be addressed with a trained professional. After receiving the signed, informed consent forms, the research scheduled an individual interview, which was audio recorded and transcribed.

Data Analysis

I analyzed and evaluated the data (transcripts of interviews) by looking for common themes and issues. I had a framework for the analysis, which was the way in which African American women were managing chronic illness so that they could live with fulfillment and their own personal sense of productivity. This data and data analysis were grounded in the criteria used in qualitative research for enhancing trustworthiness. This includes credibility of the research findings from the perspective of the interviewees. I used member checks throughout the interview process making sure I gained feedback from the participants about what I was hearing. The second criterion of transferability is somewhat more difficult to justify given the small sample of this study; however, I did detail my research methods and hope a study with a larger sample can be done in the future. Dependability is another criterion for qualitative data research. I used the interview guide in a flexible manner so that I could incorporate questions or ideas that emerged from one interview into subsequent interviews. I did not conduct an audit to confirm or corroborate my research findings, but I did work with my research advisor throughout the process and we discussed possible bias or distortion of the findings.

I used coding as a system of organizing and analyzing the data. I developed emergent codes in response to questions such as “What is this person saying here? What is the interviewee trying to convey? While developing these emergent codes, I made marginal notes next to each code that consisted of my own questions about what the interviewee was trying to convey, as well as my own ideas that were beginning to emerge from the data analysis. This was especially important, as I am an African

American woman who has a chronic illness, and I wanted to preserve the integrity of what the interviewees were reporting as well as my own ideas, which I have included in discussion section. I kept track of the exact responses from the interviewees and wrote these under the emergent codes as evidence of the rationale behind that particular code. I went back over the emergent codes and looked for themes that would further refine the data. This resulted in collapsing some of the codes into major themes and sub-themes with data to support this configuration and analysis. The final coding demonstrates the major themes and subthemes that emerged from the data.

CHAPTER FOUR

Findings

Themes and accompanying dialogue from study participants

Chronic Illness

Diagnosis

“It’s either IBS or potentially endometriosis. So apparently GI conditions and endometriosis tend to go together, and I just learned that I have this daily history of endometriosis.

I try not to own the concept of a condition, but I will say for the sake of this that chronic anxiety and insomnia have been conditions that probably became very acute in 2010, around some crisis, but have been things I have lived with in the background since I was a child.

I have been living with my thyroid condition for about 20 years.

I have a few conditions, but mainly Sjorgrens, high blood pressure and thyroid.

I went to the doctor and they did an evaluation and they did the thyroid test and they also did a test for sugar and diabetes.

Family history

I think just talking with my mom pretty frankly about her experiences with endometriosis. She was visiting this past weekend and we talked at length about it. I really got that from her.

My mom started going to the hospital for depression and suicidality. So I understand there is a root cause around this childhood trauma that has sat with me. That was then triggered again at several points in my life from similar type things so like in 2010 my mom was very, very sick, near death; we lost our home because of conflicts with the landlord

The women in my family have all had similar struggles. My mother had severe lifethreatening depression and has been hospitalized for like 33% of her adult life and has had many suicide attempts.

Symptoms

I have acute anxiety and insomnia and it feels like dying, it's horrible. Specifically the insomnia because you can't really fake it. . so before I had a prescription I could go days without sleeping.

I always have a little rain cloud that I just walk around with, the rain cloud's always raining on me. I know how to put up my own umbrella. I know how to dress for the rain. Most days I stay completely dry and you know I forget about the raincloud and then some days, I'm just wet and I can't do anything about it.

But there was clearly critical significant damage to my body, you know initially from compression of neck muscles, body muscles, and back muscles. There was deep muscle compression.

My brain and my eyes couldn't focus on or instill an image so on some level if something was moving too quickly and know how sometimes you get blurred sensation like you're on a merry go round or something, with multiple mages and all of that, right?

There was no neurological damage because I have since had those CAT scans and so forth.

To get a diagnosis felt validating, like there's an explanation for this, even though I know myself there's an explanation for this.

Emotional response to illness

I was surprised because I knew that I took very good care of myself. It was humbling. I was afraid to be in the dark but then I was afraid to be in the light by myself because the episode happened in the bedroom when I was literally putting sheets on the bed, so I was afraid to even make a bed.

I was initially sort of overwhelmed partially just because I think it feels difficult to be in a position now where I'm like this is something that isn't just a passing thing, like this is something that could last for the rest of my life or until I choose to possibly get a hysterectomy if its endometriosis.

I notice there's probably deeper trauma work to do to resolve it but the depression creeps up, the anxiety, the worthlessness, and the hopelessness. I need to be in a generative mode, to be well but to find that balance between being generative and totally overworked and stressed has been challenging for me.

Self-Blame

I was initially sort of overwhelmed partially just because I think it feels difficult to be in a position now where I'm like this is something that isn't just a passing thing, this is something that could last the rest of my life or until I choose to possibly get a hysterectomy if its endometriosis.

Well I started graduate school and I started straight out of undergrad which I feel like it was not the wisest of me. . So yeah, I think I am in a stressful environment where my body was like, I can't do this.

The conditions that could have caused it to surface was probably stress which my doctor told me I had probably been under for many, many years. I just wasn't aware of it until it hit me really suddenly.

So I also now based on the kind of lifestyle that I had as a young woman. . The stress that I undertook probably helped to contribute to the condition surfacing.

I'm probably going to have to talk with another doctor about my SED rate. I wish Dr. had talked with e a little more about these things but he was busy trying to get me started on the medication

I've always been aware of my health. . It's just that got by me. I had routine checkups with my doctors.

Maybe it's one of those conditions that don't show up that way, but I had too many other symptoms like dry mouth dry eyes, always having a dry throat at a certain time of the year and it went on for years and that was some of the symptomatology of the diseases.

Self- Care

I actually don't talk to myself. Sometimes I do actually sometimes I do say like this is going to be okay. You know like get it together, come on get it together it's going to be okay.

I only have this body and what I do to my body now or what I do to take care of my body right now, will have repercussions forever whether or not this chronic condition persists at the level that it is, and so because of that it becomes a really big priority for me to figure out ways to make this chronic illness livable.

I have to go to the forest every morning and either go running or hiking. I do a little bit of yoga every night and then once a week, I do therapy and I do journaling at least once a week, prayer at least once a week. So I have these practices but most important, am starting my day with physical movement and ending my day with physical movement is really good for me.

The non-negotiable is physical exercise. The running, but specifically like in nature so it's like both. I run three or four miles a day, so I'll run to this spot in the woods. I'll stop and take a deep breath, pay attention to the changes in the natural environment, give thanks, turn around, run back and that just sets my day right.

I have a smoothie every morning. I also, I don't want to say I'm on a diet. I'm on a lifestyle where I'm starting to eat better, vegetables and fruit every day and not trying to eat that much meat and trying to stick with fish whether it is salmon or trout or whatever.

When I started drinking more water, my body just started to feel better.

In the nutrition class that I go to, they're teaching us different things, different ways of eating.

I was raised vegetarian and all of a sudden eating more direct sources of protein and eating meat every day, I felt a drastic improvement in my overall mood. I had a little bit more energy and I my moods swing a lot less. I could roll with the punches a little more. So now that I've noticed I'm committed to eat meat.

When I get up in the morning, I drink plenty of water at least 8 ounces and then I start eating breakfast. I try to eat something that's not going to have too many calories. Get some books on health, get some fruits and vegetables and read things that's going to help and try not to eat things that's going to put weight on.

I've usually had a buddy; there's been somebody that I've gone with that was a punctual person.

One of the ways I deal with feeling out of control is to take action, so it's helpful for me to try those things even when they don't work because I'm still in a place of agency rather than just a subject of my experience.

I try to set systems up. . I organize my house and I organize my life to allow for my randomness. So I setup up to sort of support myself for the fact that I don't really have a routine and I've never been able to stick to one.

I try to have a healthy diet.

I really do need to spend time by myself, more to kind of recuperate and recover from the experience. I often leave any interaction with any person just feeling completely exhausted and trying to prevent myself from replaying the events in my head.

I travel. I'm retired, and I travel a lot.

I think I read someone once wrote about a wounded healer. I mean I think there's like strength in having, of walking with adversity as a healer because there's a connection with the experience of others that's really important but also healing. I feel healed.

I do herbal baths in the Haitian voodoo tradition and then I pray for people also, . people call me and pull me into the present moment and put my attention on community and on the divine and that's very healing for me.

One of my coping mechanisms for trauma starting probably in the third grade was overwork and excellence because I found that I could get positive adult attention for producing outstanding school work and that became the only adult attention that I was receiving that was positive.

If I am going to conquer the disease, I have to teach myself to let go of the stress.

I work every day to try to look at things differently when the reaction I've grown accustomed to having and I know that is not working for me. I develop a technique to respond differently and I work with that every day. Some days I slip back in but then I pull myself back because I know that it's not good for me.

Support

Support of family and friends

Thankfully I have an amazing girlfriend who has been instrumental and knowing how to respond, like going to the store to buy ginger ale.

I have beautiful friends. I have an amazing sister who I can call anytime about anything and I have an amazing best friend who I can call anytime about anything so these people in my life are the anchors of support and of course, mama earth firm under our feet at all times is our best support.

As far as my husband, he supports me all the way.

There's always someone to talk to.

Medical Support

I feel supported in my condition because I have a good doctor. I have support from the medical industry and if there is more support that I need I will do the research.

Triggers

Stress of being a graduate student.

What caused me to spin out into really bad anxiety was this one year when my mother was in crisis, my marriage was in crisis, and living situation was in crisis.

At some point my body collapsed and that's when the vertigo appeared, and it gave me awareness on two levels, the psycho-emotional level because what is vertigo/ It is when the body and the mind spin out of control, right? So, vertigo on some level was also messaging, it was like a somatic messaging.

Health Care

Traditional medicine

The doctor told me that in the past we've tried to take patients off the medication and we didn't have good results.

And I believe him but there still has to be a way to get off the medication if you can teach yourself to deal with the stress that is precipitating it

A lot of people have Sjorgren's and they understand and accept it and I've accepted mine. It shocked me. I was surprised that I would have to be on medication for the rest of my life.

Alternative modalities

But then I've actually been considering acupuncture for a while.

Everything. I tried different herbs. I did massage for a while, but it was too expensive so I couldn't stick with it. I did a lot of practices that you're supposed to do. You know, no screens after this time and winding down and having a consistent bed time and don't eat after a certain time and those things were definitely helpful.

I found a therapist who would take me on a sliding scale without insurance and just recently got connected with this primary care doctor, so that I guess I am accessing some sort of mainstream care which I neglected really looking into alternative modalities extensively.

Health insurance

The other notable thing is that since I'm straight out of college on my mom's insurance and sort of in this weird negotiating point with my own health care.

Race and gender dynamics with health care providers

I'm thinking about my therapist who also a queer woman of color and how much like easier for me to have a conversation and know I don't need to explain things to her,

whereas I think my primary care doctor is a straight, white, presumably CIS gendered man and who I think feels pretty awkward asking me questions about my sexual history or if I'm using birth control or things like that .I also do reading around like ways that race factors into medicine. . .

I think I'm always fearful of being caught in the stereotype of the angry black women or being demanding or intimidating and so I think I am always a person who minimizes symptoms I have when I go to the doctor.

I have an eastern European last name; my mom is white and I think I sometimes get read as white, sometimes I get read as black, sometimes I get read as Latina and so I'm constantly trying to figure out how people are reading me and how I can get them to read me the way that I understand myself.

Medical ethics

I wish Dr. would have talked with me a little but more about these things but he was busy trying to get me started on the medication.

I was upset with the previous doctor who had not shared it with me. He had to have seen something in my estimation that would have indicated that something was off, that something was out of control, something wasn't right. Maybe it's one of those conditions that don't show up that way, but I had too many symptoms like dry mouth, dry eyes, always having a dry throat at a certain time of the day and it went on for years and that was some of the symptoms of the disease.

The fact that we have doctors that we educate, send them to school and they sit by and they allow you to get sick when they know something is wrong with you.

One nurse, she could hear one thing, but I told her that's not the way it's spelled, so that shows when a nurse is not familiar with how to spell a word, a medical word, they're not familiar with the disease and for me it was like, wow, how do I get help?

Hope

But that's what I want to do. Go to school, apply myself for child psychology and I know I will enjoy that.

I love theater and one of the things I wanted to do to start my healing process was to re-immense myself in the city and around people.

It's sort of like I always have a little rain cloud that I just walk around with but I know how to put up my own umbrella. I know how to dress for the rain. Most days I stay completely dry and I forget about the raincloud and then some days, I'm just wet and I can't do anything about it.

To get a diagnosis was validating; that's s what it felt like, . . there's an explanation for this.

CHAPTER FIVE

Discussion

The seeds for this research were planted in my undergraduate exploration of the transmission of intergenerational trauma from mother to daughter. Within this prior research, I also explored the intergenerational “gifts” or “assets” that are also passed on through our matrilineal bloodline through behaviors, beliefs and unconsciously created social and family structures. Within a similar vein, this current research on African-American women living well with chronic illness parallels with themes that emerged from my prior research on intergenerational trauma and resiliency, self-care, and creativity. This thesis research seemed a natural progression, although it focuses on another area within this notion of intergenerational transmission—chronic illness. I felt certain aspects of intergenerational transmission via genetics may have been present in this research. There were some of my subjects whose symptoms were in direct relationship to both genetics and/or trauma, some which were connected to their mothers. I am not asserting that these relationships were the cause of their illnesses, only the correlation between the development of disease and an intergenerational traumatic component. With that in mind, I suspect that the subject of intergenerational trauma and its connection to disease and healing will be more readily available for integration into the social sciences and medicine especially when considering treatment modalities.

One of my personal interests was driven by the fact that I know many African-American women who live with chronic illnesses. Many of who utilize non-traditional and/or alternative modalities to help with pain management, as well as other features of their diseases. There is an abundance of information and literature about diseases amongst African American women.

However, there is little information about how African American are living vibrant and healthy lives in the face of living with a chronic illness. Another was a desire to see more of this in the literature, which I believe can contribute to the ways in which the bodies of black women are cared for. If the academic and medical worlds have these narratives and research, there are more options for future research that meets the holistic needs of African-American women and other women of color.

The process of conducting this research was punctuated by setbacks as I experienced my own health challenges. A twist of cosmic fate would have it that midway through my research project. I became ill and was diagnosed with Systemic Lupus Erythamatosus, commonly known as Lupus, an autoimmune disease. As a result, I had to pause my research and take a medical leave. While recovering, I tried to return to the research. There were moments when I was advised to have someone else transcribe my interviews, but I decided to do it myself. Because of that decision, it made the process longer and harder. Challenges with energy and emotional readiness and availability were constant. I was too vulnerable at the time to face the reality of my own illness while tackling this subject matter. Continuing the research at that time seemed too daunting.

Once my health began to improve and my energy increase following several hospitalizations, I was faced with a new question, “Can I finish this?” Once I decided that I would continue, I was not surprised with the plethora of emotions I felt as I took in the stories of these women. I found myself looking at my research with new eyes. I would weep, laugh and listen repeatedly to certain parts of the interview, not only for the sake of the research, but for my own sake. What I thought was a necessity for the world also became one for me. Being diagnosed with a chronic illness in the midst of my research gave me a front seat into

the lives of my subjects, because I too was one of those subjects. I had become a black woman learning to live well with a chronic illness.” Some of the themes that arose within the research began to emerge within my own life and narrative of my disease. I found myself naturally finding parallel between the experiences of my subjects and my own.

Strengths of the Study

The constant narrative within the literature around black women’s health is usually one of deficit. This study accentuates the assets these women bring which is grounded and rooted in their lives as African American women. This study also offers an alternative to commonly held ideas about the strength of African-American women. The presence of vulnerability, feelings of helplessness and the ways they’ve navigated their ways out of those states of being trumps widely held stereotypes about the “Strong Black Woman.” In some ways, I was inspired to explode that myth by framing my questions as such, with the hopes of revealing aspects of African American women that are often not revealed to the public and academic worlds. This study offers an alternative as well as a different demonstration of African-American woman strength.

Additionally, I feel this study interrogates some widely held notions about the meaning of healthy and what “healing” truly is. Most, if not all of the subjects of this study will live with these illnesses for the rest of their lives. And in my summation, many of them are already living “healthy” lives and have presented practices and world-views about health and healing that would serve the lives of others who live with chronic illnesses and their providers. Hearing the voices of a marginalized group of women and seeing their strength in the face of serious health challenges offers inspiration and profound information for the support of others who do not reside at the same social locations.

Limitations of the Study

One of the key limitations of my study was sample size. The demographics of where I lived during this research limited my accessibility to the women whom I centered my research on. Even though I have access to the internet, I live in a community that is predominantly white. Lack of knowledge of the best location to post recruitment information that served African-American women in my current community posed a challenge. Being new to the area where I was trying to recruit participants also posed a challenge.

I also believe restricting my criteria to African-American women rather than Black women in general (Caribbean, Continental African, etc.) limited the stories and life experiences I was able to access in my recruitment process.

References

- Adinuba, M (2016). *Examining the relationship between stroke risk factor profiles, stress (allostatic load), and stroke among African American women by place of birth*, retrieved from <https://mdsoar.org/handle/11603/10672>, September 26, 2018
- Abrams, J., Maxwell, M., Pope M. & Belgrave, L. (2014). *Cognitive appraisal vs. exposure-based stress measures. Links to perceived mental and physical health i low-income Black families*. Detroit, Michigan: Lippincott, Williams, & Wilkins.
- Gibbs, G. R. (2016). *Analyzing qualitative data*. Thousand Oaks, California: Sage.
- Hill-Collins, P. (2000). *Black feminist thought: Knowledge consciousness and the politics of empowerment*. New York: Rutledge.
- Norris, C. & Mitchell, D. (2014). *Exploring the stress support distress process among Black women*. New Orleans, Louisiana: Sage Publications.
- Taylor, J. Y. (2000). *Sisters of the Yam: African American women's healing and self-recovery from intimate male partner violence*. Iowa City, Iowa: Informa Healthcare
- Upchurch, D., Rainisch, M, Wexler, B., & Chyu, L. (2015). *Findings from the National Health and Nutrition Examination Survey, 1999 through 2004*. Los Angeles, California: Elsevier Science
- Williams, D. R., Neighbors, H W., & Jackson, J. S. (2008). Racial/ethnic discrimination and health: Findings from community studies. *American Journal of Public Health, 98(Supplement 10): s29-S37*.



APPENDIX A
2016-2017

Consent to Participate in a Research Study
Smith College School for Social Work • Northampton, MA

.....

Title of Study: Living Well In the Lives of Women of Color Who Live with Chronic Illness

Investigator(s):

Gabrilla Ballard, gballard@smith.edu

.....

Introduction

- You are being asked to be in a exploratory research study that explores Living well as an African American woman who has a chronic illness.
- You were selected as a possible participant because you identify as a black woman who lives with chronic stress and would be willing to commit to participation in the study and the interviews it will entail.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study

- The purpose of the study is to explore aspects of your life that you feel contribute to your well-being as an African American woman living with chronic stress. I have chosen this study because African American carry a disproportionate burden of morbidity and mortality (Wood, Giscojmbé, Black, 2010) that may be associated with the burden of chronic stress. I have also chosen this study because there exists a major gap in the literature, both academically and otherwise that offers evidenced based data to support further research and the development of programs that would support the well-being of African American women.
- This study is being conducted as a research requirement for *my master's in social work degree*.
- Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures

- If you agree to be in this study, you will be asked to do the following things: Participate in a one hour long interview with me by phone, face to face or Skype. You will agree to have this interview audio recorded on a computer device.

Risks/Discomforts of Being in this Study [*choose one of the following*]

Participating in the study has the risk that you will experience some discomfort in talking about your experiences living with a chronic illness. I will make counseling resources available to you if you feel you would like to speak to someone about your illness or about your experience participating in the

study.

Benefits of Being in the Study

- The benefits of participation are that you may acquire a set of skills and practices that will support your living a healthier life that contributes to your longevity and well-being. You will also know that participating in this study and the information you provide will offer resources for other researchers and women who are living with chronic illnesses as well as their families.

Confidentiality [*choose one of the following*]

- Your participation will be kept confidential and your name will not be attached to any transcript. You will be assigned a number. All calls will be audio recorded and transcribed via audio recording software. These transcripts will be transcribed by one person who has access to the transcripts. I will keep these transcripts in a locked cabinet and will destroy them upon completion of the writing of my thesis.
- All research materials including recordings, transcriptions, analyses and consent/assent documents will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed. All electronically stored data will be password protected during the storage period. We will not include any information in any report we may publish that would make it possible to identify you.*

Payments/gift

- There will be no payments or gifts for participation in this study.

Right to Refuse or Withdraw

- The decision to participate in this study is entirely up to you. You may refuse to answer any question or withdraw from the study *at any time* (up to the date noted below) without effecting your relationship with the researchers of this study or Smith College. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. If this is an interview and you choose to withdraw, I will not use any of your information collected for this study. You must notify me of your decision to withdraw by email or phone by [*add a date*]. After that date, your information will be part of the thesis, dissertation or final report.

Right to Ask Questions and Report Concerns

- You have the right **to** ask questions about this research study and to have those questions *answered* by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, [*name*] at [*email*] or by telephone at [*phone number*]. If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may *contact the* Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent

- Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep.

.....

Name of Participant (print): _____

Signature of Participant: _____ Date: _____

Signature of Researcher(s): _____ Date: _____

.....

[if using audio or video recording, use next section for signatures:]

1. I agree to be [audio or video] taped for this interview:

Name of Participant (print): _____

Signature of Participant: _____ Date: _____

Signature of Researcher(s): _____ Date: _____

2. I agree to be interviewed, but I do not want the interview to be taped:

Name of Participant (print): _____

Signature of Participant: _____ Date: _____

Signature of Researcher(s): _____ Date: _____

Appendix B

GaBrilla Ballard
Smith College School for social work
Thesis project
Interview Guide

- What is your condition? How long have you lived with this condition?
 - What was your response or reaction when you learned that you had this condition?
 - How has this condition impacted your life?
 - Do you feel supported in your life? If yes, in what ways? How do you think having support has affected how you feel?
 - What are some of your daily practices that you intentionally use to maintain well being in your life?
 - Which practices feel most beneficial? How are the practices beneficial? Can you identify any noticeable changes in your overall sense of well being?
 - If you are on medication, how has medication helped or impacted your quality of life?
 - Have you explored alternative/complementary modalities for your condition? If so, how do you feel exploring these modalities have impacted your overall well being?
 - What was it that motivated you to explore these modalities?
10. How do you feel about your health care providers?

Appendix C



School for Social Work
Smith College
Northampton, Massachusetts 01063

February 27, 2017

GaBrilla Ballard

Dear GaBrilla,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

! Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Joan Lesser, Research Adviso

