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The Associated Risk Factors That Lead To The Onset Of Sarcoidosis In Black American Women

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Abstract

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MS, Troy University, 2005

BS, Albany State University, 1997

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

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Abstract

Sarcoidosis is a disease characterized as noncaseation granulomas. Granulomas are clusters of cells that form a discrete nodule. This research was important because Black American women develop saroidosis at a higher rate than any other race. The purpose of this phenomenological qualitative study was to examine the impact of sarcoidosis in the lives of Black American women diagnosed with the disease and to consider how occupational experiences may have contributed to participants' development of sarcoidosis. Research states that domestic work such as cleaning, when performed on a daily basis or as an occupation, can contribute to adverse health effects. The framework of this study utilized the transtheoretical model of behavior change while the overall research questions centered on the effects of sarcoidosis on the quality of life of Black American women. This qualitative research included interviews with thirteen Black American women diagnosed and living with sarcoidosis at various stages. Data were collected using the software tool HyperRESEARCH. Both purposive sampling and snowball sampling technique was used for this research. Data were gathered using a general profile of the lived experiences of women with sarcoidosis. The findings revealed that the common lived experience that has potentially put Black American women at risk for developing sarcoidosis is bleach. My recommendations for further research would be to expand the locations of participants to across the United States. The implications for positive social change may result from broader knowledge of the disease through education, even for those who are not at risk for developing it. Chronic sarcoidosis can be fatal if untreated.

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Dedication

I want to dedicate this study to my mother, Gloria Jean Tolbert-McIntyre. She was the inspiration of this dissertation. The topic was created for and inspired by her battle with sarcoidosis, the proposal was written for and inspired by her fight against sarcoidosis. My goal was to perform the research and save her, and sadly it did not happen. She lost her fight to sarcoidosis, and I lost my will and my focus when I lost her.

The 18-month hiatus this dissertation waited in needed to happen. I was lost. I was depressed. I gained weight. I gave up. And then one day as I was talking to my grandmother, she said, “Your mother would not want you to quit, and even though you were not able to save her, you have the chance to save someone else’s mother.” I felt like it was my mother speaking to me through my grandmother. I re-sparked my desire to finish my dissertation and obtain my doctorate degree, and at that point, I picked up where I left off, completed the research and, over time, finished.

The celebration will be bittersweet, but please know that it was all done for you, Mama.

I love you!

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Chapter 1: Introduction to the Study

Background

Sarcoidosis is a disease that results in the inflammation of granulomas (swollen lumps) in organs throughout the human body and generally starts in the lungs (Heffner, 2007). The disease was first identified more than 100 years ago as Hutchinson's disease or Boeck's disease, but was later named sarcoidosis by Dr. Caesar Boeck using the Greek terminology *sark* and *oid* to mean *flesh-like* to describe the granulomas (Shiel, 2010). Signs and symptoms include persistent cough; shortness of breath; a vague feeling of discomfort and fatigue; fever; weight loss; small red bumps on the face, arms, or buttocks; red watery eyes; and/or arthritis in the ankles, elbows, wrists, and hands, commonly associated with bumps in the skin over the shins called *erythema nodosum* (Georgia Department of Community Health, 2010). Diagnosing sarcoidosis relies on the clinicians putting together several pieces of information (Sharma, 2005). The cause of sarcoidosis is unknown; however, several risk factors such as race, ethnicity, and age have been identified. Black Americans have a higher incidence of sarcoidosis than White Americans, and Black women more than Black men (Shiel, 2010). Black people are three to four times more likely to contract sarcoidosis, and may have a more severe disease than people who are White (King, 1999).

Jonathan Hutchinson (1823-1913) is one of the pioneers of sarcoidosis studies (James & Sharma, 2002). He initially chose to become a surgeon, but throughout his career studied ophthalmology and diseases of the chest and skin. In 1869, he treated one of the first known cases of what is now known as sarcoidosis in a patient who presented with purplish skin lesions and gout (James & Sharma, 2002). The lesions were neither tender nor painful and did not ulcerate. Hutchinson documented the lesions and treated the lesions with an ointment of lead and mercury (James & Sharma, 2002). In 1877, Hutchinson tied together clinical observations, radiographic patterns, and histology information and documented the lesions in his first published account titled "A Case of Livid Papillary Psoriasis" in his *Illustrations of Clinical Surgery* journal (James & Sharma, 2002, p. 417).

Caesar Boeck (1845-1918) was a Norwegian dermatologist. In 1899, he described the first dermatologic case of sarcoidosis as involving skin changes and general destruction of lymph nodes (Enersen, 2010). That same year he published his pioneering article called "Multiple Benign Sarkoid of the Skin." That article today is described as the start of modern sarcoidosis research (Enersen, 2010). As a dermatologist, Boeck saw patients who often presented with skin lesions. His research of the lesions brought him to document that they had a fleshy feel to them and were benign. He titled the lesions *sarkoid* because he felt they resembled benign sarcoma, a type of cancer that develops in tissues like bone or muscle (American Cancer Society, 2010). It was his subsequent research and publications, however, that gradually revealed the systemic nature of the disorder. Boeck, along with other dermatologists and scientists from other specialties and parts of the world including France, Germany, Denmark, and Sweden, made their discoveries known in the late 19th and early 20th centuries (Armstead R. Christian Foundation for Sarcoidosis Research, 2009).

Household items such as cleaning agents, for example, window, bathroom, and kitchen sprays, are being identified as possible causes of sarcoidosis (Heffner, 2007). The problem has been that Black women perform the same cleaning tasks that people of all other races perform around their homes; however, they still have a higher prevelance of sarcoidosis in the United States. It may be possible that Black American women were taught from past generations to rub deeper, scrub harder, or use more of the chemical when cleaning. Perhaps Black American women use cleaning agents in a way that increases their exposure to these agents, leading to increased rates of sarcoidosis. It may be a combination of environmental exposures and genetic factors.

History has identified records that verify jobs Black people were given after the abolition of slavery. The Black woman was never held at a high status in American society (West, Williams, & Siegel, 2000). Many Black women were employed to serve as the domestic helpers to White women in the White household. They were given the name *mammy* by White Southerners to redeem the relationship that Black women had with White families (Pilgrim, 2000). The duty of the mammy was to cook, clean, and care for the children. The term mammy has since evolved to other titles like maid, nanny, and housekeeper (Romero, 2002). From 1877 to 1966, America’s race-based, race-segregated job economy limited most Black women to menial, low paying, and low status jobs. Black women found themselves forced into one job category, house servant (Pilgrim, 2000). After the emancipation of slavery, the labor market for Black women also proved to be a difficult. Black women entered the needle trades in New York in the l900s, as a cheap source of labor for employers, and in Chicago in 1917, Black women had to be willing to work for lower wages (West et al., 2000).

Problem Statement

Domestic work such as cleaning, when performed on a daily basis or as an occupation, can contribute to adverse health effects (Ala-Mursula et al., 2006). Currently, a definitive cause of sarcoidosis has not been identified; however, several risk factors such as race, ethnicity, and age have been identified (Shiel, 2010). Black American women are two times more likely to develop sarcoidosis than Black American men, and 10 to 17 times more likely to develop the disease than Whites (Cleveland Clinic, 2010). Pathologists are trying to link the cause of sarcoidosis to an infection or reaction to a foreign particulate in the lungs. In cases of pulmonary sarcoidosis, the foreign particulates are not able to be seen under a microscope and are therefore known as nanoparticulates (less than a micrometer in largest dimension). Larger particles are cleared from the lung efficiently by mucociliary transport (Heffner, 2007). Many nanoparticles are found in household items and are able to be absorbed topically or ingested through mist residue. Once inside the body, the nanoparticles are able to accumulate in different organs because the body has no way to eliminate them. In time, this may lead to a buildup of the nanoparticulates, which form clusters in the lungs and cause the infection or inflammatory reactions (Heffner, 2007).

Since Jonathan Hutchinson’s first sarcoidosis study, there has been a significant number of studies done that focus on specific types of sarcoidosis. Examples include research on sarcoidosis of the; lungs, skin, eyes, heart, kidneys, liver/spleen, thorax, nervous system, musculoskeletal system, and reproductive system. Of those specified studies, however, few have included Black American women diagnosed with those particular types of sarcoidosis as primary participants. In 1995, a group called the Black Women's Health Study (BWHS) out of Boston University was established to research the various health problems that black women are more likely to develop than other races. It wasn't until 2011, however, that BWHS published information related to sarcoidosis in Black women.

Purpose of the Study

The purpose of this phenomenological qualitative study was to examine the impact of sarcoidosis on the lived experiences of Black American women and to consider how occupational experiences may have contributed to participants' development of sarcoidosis. According to The U.S. Department of Health and Human Services Office of Women's Health, "of all minority groups, Black Americans have a significant difference in health risks when compared to other minority groups (Womenshealth.gov, 2012). Black Americans have more disease, disability, and early death as well." Some illnesses and diseases that are of major concern for Black American women are asthma, breast cancer, heart disease, sexually transmitted infections, and HIV/AIDS. Although there is a temptation to attribute racial differences in health to genetics, some health adversities may actually be the result of environmental differences that include diet, occupational exposures, and socioeconomic status (Wesley & Judson, 2006).

Research Questions

A research question guides and centers your research. It should be clear and focused, as well as synthesize multiple sources to present your unique argument (Porush, 1995). The research questions for this qualitative study are as follows:

RQ1: How does sarcoidosis affect an individual's physical and psychological health?

RQ2: How does sarcoidosis affect the lived experiences of Black American women? How does life change after being diagnosed with sarcoidosis?

RQ3: What impact does sarcoidosis have on quality of life (impacts on mobility, relationships, activities of daily living)?

RQ4: What common lived experiences potentially put Black American women at risk for developing sarcoidosis?

Conceptual Framework

The transtheoretical model of behavior change developed by Prochaska and DiClemente (Jezewski et al., 2009; Prochaska & DiClemente, 1986) addressed the issue of an individual's degree of readiness for change. This model notes the five stages of change individuals use to address their troubled behavior. The five stages are (a) precontemplation, (b) contemplation, (c) preparation, (d) action, and (e) maintenance. Individuals with sarcoidosis are likely to experience each of these stages.

Precontemplation is the act of having no intention to take action (Prochaska & DiClemente, 1986). Upon initial diagnosis, some believe that the most efficacious treatment for acute pulmonary sarcoidosis is patience because most experience spontaneous resolution of symptoms (Cox, Davis-Allen, & Judson, 2005). Contemplation is the mindset of intending to take action (Prochaska & DiClemente, 1986). After being diagnosed with sarcoidosis, physicians are required to recommend a limited but growing list of anti-inflammatory medications. Patients have the option to take the medication or not (Cox et al., 2005). Preparation is when a person intends to take action and sets a date when the action will take place (Prochaska & DiClemente, 1986). After being diagnosed with sarcoidosis, individuals must accept that a lifestyle change is required and prepare to change their diet and exercise (National Heart, Lung, and Blood Institute [NHLBI], 1995). Action refers to the follow-through process of changing overt behavior (Prochaska & DiClemente, 1986). Individuals with sarcoidosis must learn to live with the disease, and that requires finding ways to cope with everyday activities (NHLBI, 1995). Maintenance is when an individual has changed overt behavior for six months or longer (Prochaska & DiClemente, 1986). After learning how to live with sarcoidosis, this stage requires adhering to sensible health measures (NHLBI, 1995).

Nature of the Study

In this qualitative study I used phenomenological methodology to examine the lived experiences of Black women with sarcoidosis in order to better understand how these experiences may increase their risk for this disease as well as to explore the impact this disease has on quality of life. The study included surveys and follow up interviews with 13 Black American women diagnosed and living with sarcoidosis at various stages. The precise number of participants was determined based on the point when data saturation was reached (Creswell, 2007). A survey composed of open-ended questions was administered to each participant to obtain information about their diagnosis and current daily regimens. Follow-up interviews were not conducted to obtain clarification of survey responses and additional information was not collected.

Operational Definitions

Adverse health effect: “The causation, promotion, facilitation, and/or exacerbation of a structural and/or functional abnormality, with the implication that the abnormality produced has the potential of lowering the quality of life, contributing to a disabling illness, or leading to a premature death” (Sherwin, 1983, abstr.).

Black American women: Women of African and American descent born and living in the United States of America (Pieterse & Carter, 2010).

Repetitive generational behaviors: Performing an act (for example cooking or cleaning) in a certain way because it was taught by immediate family members of older generations (Amato, 2000).

Sarcoidosis: A multisystem disorder identified in affected organs of the human body by a type of inflammation or swelling called granulomas (Altmann & Boyton, 2006).

Assumptions, Limitations, Scope, and Delimitations

Assumptions

Assumptions are conditions taken for granted (Creswell, 2013b). In qualitative research, the researcher works with specific details before moving to generalizations, the researcher describes in detail the context of the study, and the researcher continually revises questions from experiences in the field (Creswell, 2007). A good method for uncovering assumptions in any text starts with thinking about the origins of assumptions and applying those ideas to the reading (Kies, 1995). A few key assumptions were made in the course of this study. The first assumption was that the participants would have a basic knowledge of sarcoidosis, including the signs and symptoms. The second was that all the participants would complete the interviews honestly and accurately with regard to their perceptions of the symptoms they experienced when they were diagnosed.

Limitations

A limitation is an uncontrollable threat to the internal validity of a study. Internal validity refers to the likelihood that the results of the study actually mean what the researcher indicates they mean. Explicitly stating the research limitations is vital in order to allow other researchers to replicate the study or expand on a study (Creswell, 2009). There are several limitations that were foreseen with this study. The study focused only on perceptions related to sarcoidosis and did not include any type of clinical or genetic testing or assessment. Because of this approach one limitation was the participants' understanding of sarcoidosis as a disease, and that interviews may become limited or inaccurate. Medical terminology is not always easy to understand and if the participants' physicians had not properly explained what sarcoidosis is and how it effects them, they may not have been able to clearly articulate their perceptions and experiences of having sarcoidosis as they engaged in the study. Because of the voluntary nature of the study, there was a possibility that some participants would withdraw from the study as it progressed. Participant attrition could have impacted the quality of the data collected.

This study included only a small portion of those Black American women living with sarcoidosis, thereby limiting the generalizability of the findings to the larger population. This study focused only on perceptions related to sarcoidosis and did not include any type of clinical or genetic testing or assessment.

Scope and Delimitations

The scope identified the boundaries of the study in term of subjects, objectives, facilities, area, time frame, and the issues to which the research was focused, while delimitations took all factors into account and set the rules, boundaries, and limits that must be adhered to (Creswell, 2013a). This study was bounded by the inclusion of Black American women who have been diagnosed with sarcoidosis and are living in Metropolitan Atlanta, Georgia. Black American men were excluded as the prevalence of the disease is lower and they are also likely to have been employed in other types of positions as opposed to the domestic work positions of interest in this study. Due to the significantly lower prevalence of sarcoidosis in individuals of other races, this study excluded those individuals as well.

Significance of the Study

Application to Local Problem

Atlanta, Georgia, and the surrounding suburban area has a large population of Black women. Geographical and spatial clusters of sarcoidosis have also been described in the rural southeastern United States, although problems with disease misclassification, differences in racial distributions in these regions, and study design hamper interpretation (Thomeer, Demedts, & Wuyts, 2005). Studies have shown that corporate cleaning companies in the United States in 1999 paid wages of $5 to $6 per hour on average (Boarnet & Greenwald, 1999). The median hourly wage for janitors and building cleaners in May 2012 was $10.73 (Bureau of Labor Statistics, 2013). In Chicago, as elsewhere in the United States, cleaning, cooking, and child care for pay continue to be performed by poor, immigrant, and/or nonwhite women (Graff, 2004).

Positive Social Change

Black American women are twice as likely to develop sarcoidosis as Black American men and 10 to 17 times more likely to get the disease than Whites (Cleveland Clinic, 2010). Positive social change may result from broader knowledge of the disease through education, even for those who are not at risk for developing it. The findings of this study may equip Black American women with the knowledge necessary to educate female friends, business associates, and family about the risk factors. Education may reduce the incidence of sarcoidosis and should be delivered to the public in culturally sensitive and appropriate ways. For individuals already diagnosed and living with sarcoidosis, current education would be beneficial because health information is always changing. It is important that the sarcoid population receive updated information, particularly regarding daily regimens needed to improve their life and their activities.

Summary

The first known case of sarcoidosis was described over 133 years ago (James & Sharma, 2002). It is not known when the first case of sarcoidosis occurred, but the fact that Hutchinson and Boeck took an interest in learning more about the symptoms their patients were experiencing paved the way for physicians to help save the lives of many people worldwide. Sarcoidosis affects people of all races, ethnicities, and nationalities, with greatest frequency among Black American women.

The NHLBI has identified a higher prevalence of sarcoidosis in cities on the east coast of the United States and somewhat lower incidence in rural locations. This study closely examined the lived experiences of Black American women in a major metropolitan area in the Southeastern United States. Thirteen diagnosed participants were asked to answer a series of open-ended questions via telephone one-on-one interviews. Chapter 2 presents a detailed review of the literature related to sarcoidosis, clinical definitions and diagnosis, types of sarcoidosis, treatments for sarcoidosis, and quality of life for sarcoidosis patients. In Chapter 3, I discuss the study methodology, and I present the results and conclusions in Chapters 4 and 5, respectively.

Chapter 2: Literature Review

Introduction

Since the first identified case of sarcoidosis in 1869, research continued to progress, and in 1915 the first set of lung lesions were described by a German pioneer named A. Bittorf. Twenty-two more years passed before the next progression stage, and in 1958, forty-three years after the initial description of lung lesions, the first proposal for radiographic staging was introduced by another German pioneer named K. Wurm, and clinical investigators quickly adopted radiographic staging all over the world (Sharma & Gordonson, 1975).

The diagnosis of sarcoidosis is often delayed because the symptoms are not always specific. The nonspecific symptoms are known to lead individuals to multiple subspecialists, misdiagnoses, and economic barriers to medical care among those that are high risks of having sarcoidosis (Cox et al, 2005). Black Americans (especially women) are more likely than Whites to have more severe lung diseases (Kucera, Rybicki, & Kirkey, 2003). Environmental and medical access barriers have been noted as occupational risk factors for sarcoidosis in Black Americans (Kucera et al., 2003).

Literature Search Strategy

Throughout the process of this research, several research engines were used. Search engines used for this research were; the Walden University Health Science and Nursing Research Databases, the Google Search Engine, the Yahoo Search Engine, PubMed.gov, Clinic In Chest Medicine, CHEST, and Annals of Epidemiology. Search terms used were: *who discovered sarcoidosis, sarcoidosis, what is sarcoidosis, what are* *granulomas, Sir Jonathan Hutchinson, Caesar Boeck, possible causes of sarcoidosis, sarcoidosis in Black Americans, sarcoidosis in Black American Women, history on domestic cleaning, adverse health effects, repetitive generational behaviors, phenomenological methodology, different types of sarcoidosis, treatment for sarcoidosis, treatment for pulmonary sarcoidosis, treatment for cutaneous sarcoidosis, treatment for liver/spleen sarcoidosis, treatment for neurologic sarcoidosis, treatment for ophtalmalic sarcoidosis, treatment for cardiac sarcoidosis, treatment for hypercalcemia and renal disease,* and *treatment of bone and joint sarcoidosis*.

Each search engine was used equally to search for terms. For medical journal articles, Google and Yahoo search engines were used. PubMed, Clinic In Chest Medicine, CHEST, and Annals of Epidemiolgy would appear as the result of the terms typed, and within the journals, articles that related as closely as possible to the term entered would be reviewed and used. The Google and Yahoo terms searched were: *who discovered sarcoidosis, sarcoidosis, what is sarcoidosis, what are granulomas, Sir Jonathan Hutchinson, Caesar Boeck, possible causes of sarcoidosis, sarcoidosis in Black Americans, sarcoidosis in Black American Women, history on domestic cleaning, adverse health effects, repetitive generational behaviors, phenomenological methodology, different types of sarcoidosis, treatment for sarcoidosis, treatment for pulmonary sarcoidosis, treatment for cutaneous sarcoidosis, treatment for liver/spleen sarcoidosis, treatment for neurologic sarcoidosis, treatment for ophtalmalic sarcoidosis, treatment for cardiac sarcoidosis, treatment for hypercalcemia and renal disease,* and *treatment of bone and joint sarcoidosis*. Terms searched with the Walden University Health Science and Nursing Research Databases were: *sarcoidosis, Sir Jonathan Hutchinson, Caesar Boeck, sarcoidosis in Black Americans,* and *sarcoidosis in Black American Women*.

There was not a significant amount of current research, dissertations, nor conference proceedings found on Black American women diagnosed with sarcoidosis. Only a few studies were found researching the Black American female population. For examples, article “Sarcoidosis in Black Women in the United States: Data from the Black Women's Health Study” published in the *Chest* journal in 2011 described the prevalent cases that were being studied in 1995 among black women, (Cozier et al., 2011). The article “Reproductive and Hormonal Factors in Relation to Incidence of Sarcoidosis in U.S. Black Women,” also using data from the Black Women’s Health Study [BWHS]), published in the *American Journal of Epidemiology* in 2012 was the same research; however, it also provided suggestive evidence that late age at first birth and a longer cumulative exposure to endogenous female hormones may be associated with a reduced incidence of sarcoidosis (Cozier et al., 2012a). Another study addressed the African American female population, a population that was not targeted for this phenomenological study (Cozier et al., 2012b). This study was presented in the article “Fine-mapping in African-American women confirms the importance of the 10p12 locus to sarcoidosis” published in *Genes and Immunity* (Cozier et al., 2012), which discussed assessing the associations of genetic variants in a certain region of the African American female body with sarcoidosis (Cozier et al., 2011).

Conceptual Framework

The diagnosis of sarcoidosis is often delayed because the symptoms are not always specific. The nonspecific symptoms are known to lead individuals to multiple subspecialists, misdiagnoses, and economic barriers to medical care among those who are high risks of having sarcoidosis (Cox et al., 2005). Black Americans (especially women) are more likely than Whites to have more severe lung diseases. Environmental and medical access barriers have been noted as occupational risk factors for sarcoidosis in Black Americans (Kucera et al., 2003).

There may be higher exposures to certain environmental agents in lower socioeconomic classes. In the United States, Black Americans are more likely to have a lower socioeconomic status and more “blue collar” jobs (Kucera et al., 2003). Socioeconomic factors and individuals’ access to medical care have a significant impact on health status, statisfaction with care, and overall outcomes. Lower income and education level, lack of health insurance, and more common rural geographic locations are likely to create barriers for adequate health care (Kucera et al., 2003).

Precontemplation

Precontemplation is the act of having no intention to take action (Prochaska & DiClemente, 1986). Upon initial diagnosis of sarcoidosis, some believe that the most efficacious treatment for acute pulmonary sarcoidosis is patience because most experience spontaneous resolution of symptoms (Cox et al., 2005). Data has shown that in the sarcoidosis population in the United States, the disease tends to improve or remain stable over two years in the majority of patients, which often warrants no reason to seek treatment (Judson et al., 2003).

Contemplation

Contemplation is the mindset of intending to take action (Prochaska & DiClemente, 1986). After being diagnosed with sarcoidosis, physicians are required to recommend a limited but growing list of anti-inflammatory medications. Patients have the option to take the medication or not (Cox et al., 2005).

Preparation

Preparation is when an individual intends to take action and sets a date when the action will take place (Prochaska & DiClemente, 1986). After being diagnosed with sarcoidosis, individuals must accept that a lifestyle change is required and prepare to change their diet and exercise (NHLBI, 1995). Physician consultation is needed in the preparation phase of treating sarcoidosis before any action is taken (Selroos, 1994).

Action

Action refers to the follow though process of changing overt behavior (Prochaska & DiClemente, 1986). Individuals with sarcoidosis must learn to live with the disease, and that requires finding ways to cope with everyday activities (NHLBI, 1995). Physician consultation is needed in the action phase of treating sarcoidosis before any action is taken (Selroos, 1994).

Maintenance

Maintenance is when an individual has changed overt behavior for six months or longer (Prochaska & DiClemente, 1986). After learned how to live with sarcoidosis, this stage requires the individual to adhere to sensible health measures (NHLBI, 1995). Physician consultation is needed in the maintenance phase of treating sarcoidosis (Knox, 2011).

Sarcoidosis

Sarcoidosis can affect different organs and parts of the human body. The sarcoidial granulomas cause lymph-node enlargment and can result in pulmonary involvement, cutaneous (skin) involvement, liver/spleen involvement, neurologic involvement, ophthalmalic complications, cardiac sarcoidosis, hypercalcemia and renal disease, and bone and joint involvement (Iannuzzi, Rybicki, & Teirstein, 2007).

The clinical presentation of sarcoidosis depends on ethnicity, duration of illness, site and extent of organ involvement, and activity of the granulomatous process (Wu & Rashcovsky-Schiff, 2004). The usual modes of presentation include non-specific constitutional symptoms or symptoms related to organ-specific involvement (Wu & Rashcovsky-Schiff, 2004). Between 30 and 50% of patients are asymptomatic and are diagnosed on routine chest radiographs (Wu & Rashcovsky- Schiff, 2004). One third of patients have nonspecific symptoms of fever, fatigue, weight loss, and malaise (Wu & Rashcovsky-Schiff, 2004). This presentation, however, is more common in Blacks (Wu & Rashcovsky-Schiff, 2004).

Clinical Definition and Diagnosis

Sarcoidosis is characterized as noncaseation granulomas. Granulomas (swollen lumps) are clusters of cells that form a discrete nodule (Altmann & Boyton, 2006). The nodules have a unique cellular pattern that can be seen through a microscope and can form on nearly any part of the body, internal or external (Altmann & Boyton, 2006). There are many different granulomatous diseases; Crohn's disease and tuberculosis are two (Altmann & Boyton, 2006).

Cells that make up granulomas come from the immune system. The immune system is the body's defense against diseases and illnesses. In noncaseation granulomas, the center part of the nodules (lumps) is known as macrophages (Cox et al., 2005). When foreign particles like bacteria, viruses, and/or toxic chemicals invade the body, the macrophages release chemicals that produce inflammation around the foreign substance or substances to isolate and destroy them (Cox et al., 2005).

The cause of sarcoidosis is unknown, however, several risk factors like race, ethnicity, and age have been identified. Black Americans have a higher incidence of sarcoidosis than White Americans, and Black women more than Black men (Shiel, 2010). Signs and symptoms include; persistent cough, shortness of breath, a vague feeling of discomfort and fatigue, fever, weight loss, small red bumps on your face, arms or buttocks, red watery eyes, and/or arthritis in your ankles, elbows, wrists and hands, commonly associated with bumps in the skin over your shins (erythema nodosum) (Iannuzzi et al., 2007).

Types of Sarcoidosis

Sarcoidosis can be diagnosed in two forms; *acute and chronic* (Wu & Rashcovsky-Schiff, 2004).

- Acute sarcoidosis is more common in Whites than in Blacks and usually is associated with spontaneous remission within two years (Wu & Rashcovsky-Schiff, 2004).
- Chronic sarcoidosis presents insidiously with symptoms related to the organ involved, such as cough and dyspnea from pulmonary infiltration (Wu & Rashcovsky-Schiff, 2004).

Chronic sarcoidosis commonly follows a relapsing and protracted time course. Chronic progressive disease affects 10 to 30 percent of patients. Spontaneous remission occurs in approximately two thirds of these patients. Blacks have increased rates of pulmonary involvement, a worse long-term prognosis, and more frequent relapses (Wu & Rashcovsky-Schiff, 2004).

Treatments for Sarcoidosis

The treatment of sarcoidosis is problematic for several reasons. First, the disease often remits spontaneously so that treatment with potential toxic medications may cause more harm than allowing the disease to run its natural course will (Judson, 2008). Second, sarcoidosis is a multisystem disease that may affect any organ (Judson, 2008). Therapy varies depending on which organs are involved. Third, because sarcoidosis is an uncommon disease, few randomized, controlled studies have examined treatment (Judson, 2008). As a result, the treatment of sarcoidosis is not standardized (Judson, 2008).

In pulmonary sarcoidosis, respiratory symptoms often include dyspnea, cough, vague chest discomfort, and wheezing (Iannuzzi et al., 2007). Corticosteroids is the recommended therapy used for pulmonary sarcoidosis, however, immunomodulators, and surgical interventions have also been used as alternative therapies (Wu & Rashcovsky-Schiff, 2004). It is not known whether steroids improve long-term lung function or favorably alter disease progression (Pietinalho, Tukiainen, Haahtela, Persson, & Selroos, 2002).

According to the Mayo Clinic, corticosteroids mimic the effects of hormones the body produces naturally in the adrenal glands, which sit atop the kidneys. When prescribed in doses that exceed the body's usual levels, corticosteroids suppress inflammation, which can reduce the signs and symptoms of inflammatory conditions, such as arthritis and asthma, and sarcoidosis. Corticosteroids also suppress your immune system, which can help control conditions in which the body's immune system mistakenly attacks its own tissues (Mayo Clinic, 2015). Corticosteriods can be used for treatment four different ways; by mouth, by inhaler, topically, or by injection (Wu & Rashcovsky-Schiff, 2004).

Sarcoidosis with cutaneous involvement results in a rather frustrating treatment because lesions may be refractory to treatment or may recur following successful treatment (Katta, 2002). For localized involvement, topical or intralesional steroids are used. Physicians frequently attempt to use superpotent topical steroids because of their occasional effectiveness (Katta, 2002). However, these steroids often do not adequately penetrate the skin lesion (Katta, 2002). Intralesional steroids are typically more effective, with injections repeated at two- to three-week intervals (Katta, 2002).

Treatment of sarcoidosis with liver/spleen involvement (also known as Hepatic Sarcoidosis) is dependent of clinical and laboratory disease manifestation (Karagiannidis, Karavalaki, & Koulaouzidis, 2006). Treatment should be reserved for patients who manifest this spectrum of disease. Glucocorticoid treatment is first-line therapy for hepatic sarcoidosis, improving symptoms and abnormal laboratory values but generally having no effect on progression of disease (Ayyala & Padilla, 2006). In addition to glucocorticoids, immunomodulators such as azathioprine, methotrexate, hydroxychloroquine, and infliximab have been used with some positive effects on symptoms, liver enzyme abnormalities, and hepatomegaly, but none has been shown to prevent progression of disease (Ayyala & Padilla, 2006). Ultimately, in cases of overt liver failure, liver transplantation is the definitive treatment (Ayyala & Padilla, 2006). Overall, treatment for hepatic sarcoidosis is targeted toward alleviation of symptoms but has no curative potential at this time. Focus should be on discovering the etiology of the disease to target therapy at prevention, not cure (Ayyala & Padilla, 2006).

Treatment of sarcoidosis with neurologic involvement also known as Neurosarcoidosis, occurs in approximately 5% of patients. It is considered rare as around 400 cases have been reported (Joseph & Scolding, 2007). Any neurological features that do occur frequently happen early in the course of the disease with the most common presentation being in the cranium (Joseph & Scolding, 2007). The mainstay of treatment is corticosteroids, but these often have to be combined with other immunosuppressants such as methotrexate, hydroxychloroquine or cyclophosphamide. Additionally, there is increasing evidence that infliximab is a safe treatment with good steroid sparing capacity (Joseph & Scolding, 2007).

Sarcoidosis of the eyes, known as ocular sarcoidosis can involve any part of the eye and can lead to severe impairment (Ohara, Judson, & Baughman, 2005). In America, ocular sarcoidosis is more prevalent in Blacks than Whites (Ohara et al., 2005). Ophthalmalic complications like; iritis, mutton fat, trabecular nodules, and retinal perivasculitis are not solely seen in sarcoidosis, but are suggestive of sarcoidosis (Ohara et al., 2005). Primary treatment of ocular sarcoidosis is corticosteroids (Ohara et al., 2005).

Cardiac sarcoidosis, upon clinical presentation, may include arrhythmias, pericardial or valvular disease, congestive heart failure, or ventricular aneurysms (Mori, Hanon, & Rachko, 2007). The cardiovascular system is the third most frequently involved organ system in patients with sarcoidosis (Youssef, Beanlands, Birnie, Nery, 2011). In many instances, patients with sarcoidosis of the lungs are diagnosed with having pulmonary hypertension (Youssef et al., 2011). Pulmonary hypertension is increased pressure in the pulmonary arteries. These arteries carry blood from the heart to the lungs to pick up oxygen. Treatment for both cardiac sarcoidosis and pulmonary hypertension include corticosteroid therapy (Youssef et al., 2011). Immunosuppressive agents are often combined with corticosteroids to reduce adverse effects. Anti-tumor necrosis factor-α (anti-TNF-α) therapy has been used to treat refractory sarcoidosis, and TNF-α expression has been documented at sites where sarcoid granulomas are observed, and plays a critical role in granuloma formation (Mori et al., 2007). Thus, anti-TNF-α therapy should result in suppression of disease manifestation and progression (Mori et al., 2007).

Quality of Life Issues for Sarcoidosis Patients

Quality of life (QOL) in sarcoidosis patients is impaired with respect to mobility, working capacity, and activities of daily living, especially in sarcoidosis patients suffering from fatigue and other symptoms, such as breathlessness and arthralgia (DeVries & Drent, 2007). Physical health, psychological health, social relationships, and environment, are the general facets to overall QOL. Low educational levels in relationship to these facets can bring on barriers with independence (DeVries & Drent, 2007).

Black American women who did not graduate from high school or are uneducated in any way are underrepresented. They must be literate in order to complete surveys and be able to answer questions regarding their medical histories (Cozier et al., 2011). Obtaining as much education as possible about sarcoidosis, and finding practical ways to live and cope with the disease are key factors in maintaining as normal a life as possible (Kavuru, 2011).

Sarcoidosis may exist without symptoms but is often discovered during a routine checkup (Iannuzzi et al., 2007). Usually, sarcoidosis is detected by a chest radiograph (x-ray) or through computed tomography (CT) scan of the chest, which most commonly shows enlarged lymph nodes (Iannuzzi et al., 2007). In the United States, the sarcoidosis population indicates that sarcoidosis tends to improve or remain stable over two years in the majority of patients (Judson et al., 2003). However, even though the disease can last just one or two years and require minimal or no treatment in some patients', it can span decades and require interventions in patients' with more severe cases (Iannuzzi et al., 2007). The symptoms depend on which organs the disease affects. In the chronic progressive form of sarcoidosis (severe stages) involving the lungs, results are generally shortness of breath and continuous decline in overall quality of life. Patients with neurologic or heart involvement have the poorest outcome (Iannuzzi et al., 2007).

Review of Literature Related to Research Methods

Sarcoidosis is characterized as noncaseation granulomas. Granulomas (swollen lumps) are clusters of cells that form a discrete nodule. The nodules have a unique cellular pattern that can be seen through a microscope and can form on nearly any part of the body internal or external (Altmann & Boyton, 2006). There are many different granulomatous diseases; Crohn's disease and Tuberculosis are two (Altmann & Boyton, 2006).

Cells that make up granulomas come from the immune system. The immune system is the body's defense against diseases and illnesses. In noncaseation granulomas, the center part of the nodules (lumps) is known as macrophages. When foreign particles like bacteria, viruses, and/or toxic chemicals invade the body, the macrophages release chemicals that produce inflammation around the foreign substance or substances to isolate and destroy them (Cox et al., 2005). In the 1950s, the U.S. Public Health Service offered medical screening programs that were primarily targeted toward individuals with tuberculosis. The programs were unsuccessful and as a result, doctors Irwin M.

Rosenstock, Victor J. Strecher, and Marshall H. Becker developed the Health Belief Model (HBM; Glanz, Rimer, & Viswanath, 2008).

The Health Belief Model (HBM) is characterized by what individuals believe when it comes to their own personal health and the potential outcomes that will occur depending upon their behavioral choices (Glanz et al., 2008). The HBM is the most utilized theory in health education and promotion (Glanz, Rimer, & Lewis, 2001). This particular model can be applied in any health care setting (Cohen, Scribner, & Farley, 2000).

In Georgia, there has been a dramatic decline over the recent decades in Black female domestic workers; however, due to the manifestations of southern culture (a Black domestic worker and her White employer) many older Black American women are still continuing to perform light duty domestic chores (ironing, dusting, sewing) for their employers as this is the only connection they are familiar with when it comes to other races (Graff, 2004). Studies have shown that corporate cleaning companies in the U. S., as of 1999, still pay wages of $5 to $6 per hour on average. In Chicago, as elsewhere in the United States, cleaning, cooking, and child care for pay continued to be performed by poor, immigrant, and/or nonwhite women (Graff, 2004).

"Race is often considered a key determinant of health, perhaps because of genetic influences. Race may also be associated, however, with different environmental factors that underlie risks or it may relate to combinations of genetic and environmental factors" (Wesley & Judson, 2006, p. 1). Black Americans have a higher incidence of sarcoidosis than White Americans (Shiel, 2010). Black women have a higher incidence of sarcoidosis than Black men and treatment should begin as soon as possible (Shiel, 2010). If treatment is not sought, or is delayed, the lumps can develop into scar tissue and can cause constriction resulting in chronic coughing, shortness of breath, or other symptoms. The scar tissue also affects the amount of oxygen taken in by the lungs which affects the amount of oxygen distributed to other organs of the body. Lack of oxygen to organs of the body results in fatigue and weakness and can greatly affect a person's lifestyle (Iannuzzi et al., 2007).

Summary

The scope of this study was to identify factors of sarcoidosis in Black American women and to consider both the impact the disease has on lifestyle and lifestyle on the disease. People of other races were not the focus of this work because they have a significantly lower prevalence of the disease. Black American men also have a high prevalance, but not as high a Black American women, so this population was also not be included. A qualtitative methodology had been chosen instead of a quanitative methodology because the research is focusing on lived experiences, which are best expressed in words rather than numerative terms. Chapter three details the proposed research method for this study. Components that were addressed were; research design and rationale, research questions, the role of the researcher, methodolgy, participant selection, instrumentation, procedures for recruitment, participation and data collection, setting and sample, data collection and analysis, and issues ot trustworthiness. Chapter three detailed the proposed research method for this study.

Chapter 3: Research Method

Introduction

The function of the lungs is to provide oxygen to the body. A great amount of oxygen taken in by the body is used to maintain tissue structure. Oxygen is also required for all organs of the body, and organ function is critical to the survival of all human beings. A shortage of oxygen affects every organ in the body as the deprivation of air robs the entire body of vital energy (Hurst et al., 2010). When sarcoidosis affects the lungs, lumps called granulomas form and can grow and clump together, making several larger groups of lumps. The granulomas eventually become inflamed and can affect how the lungs work (eMedTV, 2013). The lungs can become stiff and may not be able to hold as much air as healthy lungs. In serious cases, sarcoidosis can cause scar tissue in the lungs, which can affect the lungs' ability to move oxygen into the bloodstream (American Lung Association, 2010). Even with the advances over the years in research and modern medicine, little is known about sarcoidosis, its causes, and its daily impact on the lives of Black American women, a group disproportionately affected by the disease.

This chapter explains the methodology that was used to study the effects sarcoidosis has on the lived experiences of Black American women with the disease. The chapter includes a description of the research design and justifies the use of phenomenology for the study. It also includes a description of the setting and sample for the study, an outline of the data collection techniques, and an analysis of procedures for the study.

Research Design and Rationale

Research Design

For this study qualitative research methods were used, which stemmed from philosophical assumptions. Researchers bring their own worldviews, paradigms, or sets of beliefs to the research project, and these inform the research and writing related to the qualitative study (Creswell, 2007). Stemming from various philosophical perspectives, qualitative data is also useful in explaining how or why effects occurred. When determining which qualitative method to use, the choice is based on “whether it is the best method given the question being asked and with the understanding that several methods are applicable to more than one perspective” (Cox, Donohue, Brown, Kataria, & Judson, 2004, p. 997–1004). Qualitative phenomenological design has been used for a variety of purposes, including descriptions, statements, and explanations provided by the targeted audience, which can be more powerful than numbers. Because this study was intended to illustrate the lived experiences of the participants, phenomenology was the ideal approach.

Qualitative research can be approached in different ways. Narrative, phenomenology, grounded theory, ethnography, and case study are five different approaches to qualitative inquiry (Creswell, 2007). Each of these five approaches are distinct in what the researcher using them is trying to accomplish (Creswell, 2007). Narrative research primarily focuses on individuals, while grounded theory highlights lived experiences and explains why circumstances happen (Creswell, 2007).

Ethnography is intended to generate understanding of a culture, and case study focuses on systematic reasoning (Creswell, 2007).

Phenomenology is used to illuminate the specific, and to identify phenomena based on how they are perceived by the actors in a situation (Lester, 1999). In the human sphere this normally translates into gathering deep information and perceptions through inductive, qualitative methods such as interviews, discussions, and participant observation, and representing this data from the perspective of the research participants (Lester, 1999). Although other qualitative approaches are intended to explain, the phenomenological approach is intended to describe and is a perspective free from hypotheses or preconceptions (Applebaum, 2012).

Research Questions

A research question guides and centers research. Research questions should be clear and focused as well as synthesize multiple sources to present a unique argument (Porush, 1995). The research questions for this qualitative study are as follows:

RQ1: How does sarcoidosis affect an individual’s physical and psychological health?

RQ2: How does sarcoidosis affect the lived experiences of Black American women? How does life change after being diagnosed with sarcoidosis?

RQ3: What impact does sarcoidosis have on quality of life (impacts on mobility, relationships, and activities of daily living)?

RQ4: What common lived experiences potentially put Black American women at risk for developing sarcoidosis?

Role of the Researcher

The role of the researcher is less intrusive in phenomenology than in some other qualitative approaches (Creswell, 2007, p. 142). In the phenomenological approach, detailed information is gathered through discussions, interviews, and participant observation (Lester, 1999). The research methods are more flexible, responsive, and open to contextual interpretation (Merriam, 2013). As the researcher in the data collection procedure, I developed an open ended set of questions for interviews with participants. Subsequently, I interviewed participants making an effort to avoid projecting my own biases and assumptions into the process. Based on continued assessment of the data collected, I determined when data saturation had been reached and no further data was collected.

Methodology

The study took place in the metropolitan Atlanta, Georgia area, and the targeted participants for this study were Black American-born women older than 40 years of age who had been diagnosed with sarcoidosis. I intended to interview sarcoidosis patients diagnosed in different stages of the disease. Through the data I collected, I sought to understand how advanced the disease was when participants were diagnosed and how the disease affected their daily lives subsequent to diagnosis. In particular, I wanted to learn about the participants’ ongoing regimens, and how they use these regimens in order to live as normal a life as possible with sarcoidosis.

Participant Selection

Purposive sampling—when subjects are selected because of a certain characteristic they may possess (in this case sarcoidosis)—is popular in qualitative research (Siegle, 2011). Patton (1990) proposed that snowball sampling is a wise technique to use when performing qualitative research (Siegle, 2011). The snowball sampling technique identifies cases of interest from people who know people who know what cases are information-rich, good examples for study, and/or good interview subjects.

In order to use both purposive sampling and snowball sampling technique for this research, I created flyers with contact information (name, phone number, and email address). The flyers included brief background information to solicit prospective interview participants who were willing to share information regarding their experiences with sarcoidosis. The flyers identified the research project as being focused on risk factors that lead to the onset of sarcoidosis in Black American women and adaptations women make after being diagnosed. The flyers were distributed to patients at pulmonology practices where numerous sarcoidosis patients received treatment. For the sake of maintaining confidentiality, the flyers were available for individuals to pick up and take home with them. Once I spoke with a participant, I asked if that person knew of anyone else with sarcoidosis. I coded and analyzed the data as it was collected in order to determine when data saturation had been reached. Recruitment ceased after data saturation was reached, which in the end was 13 participants.

Recruitment procedures. I recruited interested Black American female participants using posted flyers that were placed in pulmonology practices that serves numerous patients with sarcoidosis. When prospective participants contacted me, I explained the study and provided statistics regarding sarcoidosis in order to help establish the importance of the study. Each participant was also told about the limited amount of published information that exists regarding Black American women with sarcoidosis, emphasizing the importance of the study and the benefits of participating.

The informed consent process served as a starting point for establishing a relationship between myself (the researcher) and participants. A participation invitation document was provided to each participant that included a written explanation of the study and provided the participants with information about their right to withdraw from the study with no personal consequences for doing so. The participation invitation document was also included with contact information for Walden University, in case participants had questions or concerns about the research process they wanted to address confidentially.

A signed informed consent form was obtained from each participant that denoted the participants' understanding of the research study and their ability to finish or withdraw from the research study without any penalty. The Walden University Institutional Review Board (IRB) ensured that the proposed research complied with the university's ethical standards as well as U.S. federal regulations. The IRB approval number for this research is: 05-06-15-0086925.

As I obtained signed consent forms, I interviewed participants. So that I could accommodate interview preferences of the participants, I offered three options for conducting the interview: phone, Skype, or in person. Each participant's personal preference regarding interview style was honored in order to help establish a positive working relationship for the participants and myself as the researcher. There is a certain distinctiveness that qualifies a researcher to serve as the data gathering instrument for a research study: awareness, flexibility, comprehension, and the ability to explain and summarize findings (Ritchie & Lewis, 2003). Adhering to these practices helped to establish a working relationship with the participants.

All interviews were recorded using an audio file software program called Audio Hijack. The recorded information was downloaded into my password protected laptop computer. The transcripts have been placed in a password protected file as well. The study is now completed, and all pertinent data has been saved on a disc and stored in a locked in a file cabinet inside of my home. The data will remain in the locked file for a period of 5 years.

Instrumentation

The data collected for this research included interview data only. Once each participant agreed to join the study, I set up an appointment time that was convenient for the participant. During the appointment set up, I notified participants that I would send them an invitation to participate (Appendix A) and that would also send them the informed consent form and explained the need to sign the consent form. Each participant agreed to be interviewed by phone, so I provided them a copy of the informed consent form via e-mail and requested that the consent form be signed and returned to me via email or postal mail prior to the interview.

Setting and Sample

Research setting. I interviewed each participant at her convenience via telephone. One exception to their flexibility was that I would not interview the participants at their homes, as this may have caused them to feel stressed about my presence in their personal space. The ultimate goals were to protect the confidentiality of the participants and to make sure that the participants felt safe and comfortable during the interview process.

Sample. Participants were selected based on their ethnicity, age, and diagnosis using purposive sampling and snowball sampling. The primary approach for recruiting participants was to post flyers in pulmonology practices at which sarcoidosis patients are known to seek treatment. The flyers were posted so that they were visible to patients and provided basic information about the study and my contact information. Additionally, when participants joined the study, they were asked if they could refer others who met the study criteria. Once contact was made, I began establishing a relationship with each prospective participants and explained to them the importance of the study and why I thought their participation would be valuable. When I spoke to the prospective participants, regardless of whether or not they agreed to participate, I utilized snowball sampling and asked them if they knew of any other people diagnosed with sarcoidosis who they felt would be willing to speak with me.

In cases in which referrals are made and contact information is provided, I made initial contact with referred prospects myself via email, by sending them the participation invitation (Appendix A). If contact information was not provided, I asked that my contact information be provided to the referred prospect. I repeated the process of asking for referrals and made contact with new prospective participants until the study was populated. I requested that all prospective participants and participants retain my contact information and share it with others who met the study criteria should they have the opportunity.

Approximately 15 to 20 participants were sought for the study, with the precise number of participants to be determined based at the point when data saturation is reached (Creswell, 2007). Currently, a definitive cause of sarcoidosis is unknown; however, several risk factors like race, ethnicity, and age have been identified (Shiel, 2010). Black American women are two times more likely to develop sarcoidosis than Black American men, and 10 to 17 times more likely to develop the disease than Caucasians (Cleveland Clinic, 2010), and this is why the study will focus on experiences of this group.

Data Collection and Analysis

Procedures for collecting data. The data collected for this research (known as the pilot study), was interview data only. Once a participant had agreed to join the study, I set up an appointment time that was convenient for the participant. During the appointment set up, I notified participants that I would send them an invitation to participate (Appendix A) and also an informed consent process form and the need to sign the consent form. If the participants agreed to be interviewed by phone, I provided them a copy of the informed consent form via e-mail and requested that it be signed and returned to me via email or postal mail prior to the interview. If the participants would have agreed to be interviewed in person, I would have presented the informed consent form at the beginning of the meeting and would have collected the signed informed consent form before the interview began. During the telephone interview, I asked a series of researcher designed questions (Appendix B) in order to elicit information about the participants' experiences as sarcoidosis patients. As needed, I asked spontaneously created probing questions to clarify or extend participant responses. I made sure to leave open the opportunity for follow up interviews if I found I needed to seek clarification. All interviews were audio recorded using Audio Hijack digital audio recording software.

After each interview, I transcribed the recording verbatim. Then I reviewed the data to look for broad trends. Being aware of such trends in the data helped enable me to be aware of the point at which I would reached data saturation. This continuing analysis process helped me stay aware of situations for which there was a need for follow-up interviews. All audio recordings and transcript files will remain maintained on my password-protected computer for a period of 5 years, and then will be permanently deleted. All electronic informed consent documents are stored on the same password protected computer for 5 years. Printed informed consent documents are being maintained in a locked file cabinet in my home for a period of 5 years. After the required holding period all digital files will be deleted and printed materials will be destroyed.

Treatment of discrepant cases. In this qualitative research, I knew it was possible that I may interview a participant with atypical experiences. The majority of my participants had some of the same experiences, while one had experiences that are completely different. The data on this one experience is being reported as atypical.

Data analysis. Data analysis is the most complex and mysterious of all of the phases of a qualitative project, and the one that receives the least thoughtful discussion in the literature (Thorne, 2000). In order to generate findings that transform raw data into new knowledge, a qualitative researcher must engage in active and demanding analytic processes throughout all phases of the research (Thorne, 2000). To analyze the data, I used both manual coding procedures and software tools. I also used open coding procedures in this study. I read each participant’s transcript and looked for important similarities in my reading (such as problems associated with working, resting, cleaning). These general categories were marked as codes (P1-P13). Subsequent to open coding, I used axial coding to break down the similarities into more specific categories such as initial symptoms and age at diagnosis. These subcategories were further divided into more specific categories based on the participants’ experiences. As the researcher, I sorted the participants’ information in to like categories using software tool HyperRESEARCH. After the data was coded in HyperRESEARCH, regrouping of data took place as necessary, I generated frequency reports to identify trends in the data. Using the data, I constructed a general profile of the lived experiences of women with sarcoidosis.

Dissemination of findings. I will share my findings with the organizations that helped me gain the participants as well as with the participants themselves. I will give them an executive summary along with a copy of my completed dissertation. Some of the participants may not be interested in the full dissertation; however, the medical professionals might be. I plan to publish my findings in a medical journal or a public health journal, and I also plan to create an informational brochure for those with sarcoidosis.

Issues of Trustworthiness

Regarding trustworthiness, credibility, transferability, dependability, and confirmability strategies have been established within this study. Ethical concerns, and IRB approval have been addressed.

Credibility

Leininger (1985) noted the importance of identifying and documenting recurrent features such as patterns, themes, and values in qualitative research. The emphasis on recurrence suggests the need to spend sufficient time with informants to identify reappearing patterns. Credibility requires adequate submersion in the research setting to enable recurrent patterns to be identified and verified. Thus, an important strategy is to spend an extended period of time with informants (Ritchie & Lewis, 2003) which allows the researcher to check perspectives and allows the informants to become accustomed to the researcher (Krefting, 1991).

Strategies that were used to establish credibility was the explanation that this research took place as a way for me to be able to identify and understand the risk factors that lead to the onset of sarcoidosis in Black American women. As the researcher, the measures I used to make sure my data was credible was prolonged involvement and persistent observation.

Prolonged involvement:

- I informed the participants of the reason why this study is so profound to me. That reason being sarcoidosis was the primary cause of my mother's death.

Persistent observation:

- I explained to the participants my observation of witnessing the time of my mother's initial diagnosis until her untimely death.
- I kept a research journal to record observations of voice tones to use with the words spoken in order to determine if they are consistent or not.
- I prepared questions so that I had consistency among the participants' interviews and their answers.

Flyers were created and distributed to patients at pulmonology practices where numerous sarcoidosis patients receive treatment. Once I spoke with a participant, I asked if that person knew of anyone else with sarcoidosis. I coded and analyzed data as it was collected, in order to determine when data saturation had been reached.

Transferability

Guba (1981) described transferability as the criterion against which applicability of qualitative data is assessed. Lincoln and Guba (1985) noted that transferability is more the responsibility of the person wanting to transfer the findings to another situation or population than that of the researcher of the original study (Krefting, 1991). Black

American women was the targeted population for this study. I explained the study and provided statistics regarding sarcoidosis in order to help establish the importance of the study. Each participant was also told about the limited amount of published information there is on Black American women with sarcoidosis, and why this study was so important. When I finished all interviews, I transcribed each interview and emailed each participant her transcript to read her own respective transcribed interview.

Dependability

Guba (1981) proposed that the dependability criterion relates to the consistency of findings. Since many qualitative methods are tailored to the research situation, there are no methodological shorthand descriptions that describe the exact methods of data gathering, analysis, and interpretation in qualitative research (Krefting, 1991). The same interview questions were asked to the participants until data saturation was reached. Data saturation was determined when I began to hear the same information from different participants. I made sure to leave open the opportunity for follow up interviews in the event that I needed to seek clarification.

Confirmability

The confirmability strategy involves an external auditor attempting to follow through the natural history or progression of events in a project to try to understand how and why decisions were made (Krefting, 1991). I established confirmability by utilizing the informed consent forms. A copy of the informed consent form was provided to each participant via e-mail and I requested that it be signed and returned to me via email or postal mail prior to the interview. If the participants would have agreed to be interviewed in person, I would have presented the informed consent form at the beginning of the meeting and would have collected the signed informed consent form before the interview began.

As stated in the participant selection section of this dissertation, the Walden University Institutional Review Board (IRB) will ensure that the proposed research complies with the university's ethical standards as well as U.S. federal regulations. Once I spoke with a participant, I asked if that person knew of anyone else with sarcoidosis. I coded and analyzed the data as it was collected, in order to determine when data saturation had been reached. Recruitment ceased after data saturation was reached, which was after the thirteenth participant. All audio recordings and transcribed files have been placed on my password-protected computer for a period of 5 years. All electronic informed consent documents have been stored on the same password protected computer for 5 years. Printed informed consent documents have been placed in a locked file cabinet in my home for a period of 5 years. After the required holding period all digital files will be deleted and printed materials will be destroyed.

Summary

Chapter 3 has included the detailed methodology that was used to conduct this study. The research design, role of the researcher, methodology and issues of trustworthiness have all been addressed. The research questions have also been provided, and the interview questions have been placed within this study as an appendix. The research consists of interviews with the targeted population. Data was recorded, transcribed and analyzed, and all information was kept confidential as required. Chapter

4 features the results and findings of the study and chapter 5 includes the conclusions, recommendations for further study, and implications for social change.

Chapter 4: Results

Introduction

The purpose of this study was to examine the impact of sarcoidosis in the lives of Black American women diagnosed with the disease and to consider how occupational and/or lived experiences may have contributed to the participants' development of sarcoidosis. Fifteen to twenty participants was the initial goal to interview for this study; however, saturation was discovered after thirteen interviews. The research questions for this qualitative study used were:

RQ1: How does sarcoidosis affect an individual's physical and psychological health?

RQ2: How does sarcoidosis affect the lived experiences of Black American women? How does life change after being diagnosed with sarcoidosis?

RQ3: What impact does sarcoidosis have on quality of life (impacts on mobility, relationships, activities of daily living)?

RQ4: What common lived experiences potentially put Black American women at risk for developing sarcoidosis?

Pilot Study

The data collected for this research (known as the pilot study) was interview data only. I posted flyers in pulmonary clinics in the metropolitan Atlanta, Georgia, regarding my study on sarcoidosis in order to recruit participants. Once a participant had agreed to join the study, I set up an appointment time that is convenient for the participant. During the appointment set-ups, I notified participants that I was sending them an invitation to participate (Appendix A) and also of the informed consent process and the need to sign the consent form. Each participant agreed to be interviewed by phone, so I provided them a copy of the informed consent form via e-mail and requested that it be signed and returned to me via email or postal mail prior to the interview. During the interview, I asked a series of researcher designed questions (Appendix B) in order to elicit information about the participants' experiences as sarcoidosis patients. As needed, I asked spontaneously created probing questions to clarify or extend participant responses. I made sure to leave open the opportunity for follow up interviews should I find I needed to seek clarification. All interviews were audio recorded using Audio Hijack digital audio recording software.

After each interview, I transcribed the recordings verbatim and then reviewed the data to look for broad trends. Being aware of such trends in the data helped enable me to be aware of the point at which I had reached data saturation. This continuing analysis process also helped me become aware of situations for which there may be a need for a follow-up interview. All audio recordings and transcripts files will be maintained on my password-protected computer for a period of 5 years and then will be permanently deleted. All electronic informed consent documents will be stored on the same password protected computer for 5 years. Printed informed consent documents will be maintained in a locked file cabinet in my home for a period of 5 years. After the required holding period, all digital files will be deleted and printed materials will be destroyed.

Setting

No personal conditions were influenced by participants or the participants' experience at time of the study that may have influenced their interpretation of the study results. Flyers were created as a recruitment mechanism to gather participants. I was contacted either by e-mail or phone, and I then scheduled a time that was convenient for the participants'. Each participant was interviewed via telephone and asked the same twelve open-ended interview questions.

Demographics

All participants interviewed lived in the metropolitan area of Atlanta, Georgia. Each participant is a Black American-born woman who had been diagnosed with sarcoidosis and had lived with the disease for a number of years.

Data Collection

Thirteen participants were interviewed to collect data for this research. For anonymity, participants were coded as P1 through P13. All participants requested to be interviewed by phone and all interviews were audio recorded using Audio Hijack digital audio recording software. There were no variations in data collection from the plan presented in chapter 3. There were no unusual circumstances encountered in the data collection.

Data Analysis

To analyze the data, I used both manual coding procedures and software tools. I also used open coding procedures in this study. I read each participant's transcript and looked for important similarities in my reading (such as initial symptoms, age at diagnosis, occupation, and cleaning agents used at work or at home). These general categories were marked as codes, subsequent to open coding I used axial coding to break down the similarities into more specific categories such as making dinner or spending time with family members. These subcategories were further divided into more specific categories based on the participants' experiences. I sorted the participant's information into like categories using the software tool HyperRESEARCH. After the data had been coded in HyperRESEARCH, I regrouped the data as necessary, and then generated frequency reports to identify trends in the data. Using the data, I constructed a general profile of the lived experiences of women with sarcoidosis. In this qualitative study I did not interview any participants with atypical experiences. The majority of my participants had some of the same experiences.

Evidence of Trustworthiness

Credibility strategies were the explanation that this research is taking place as a way for me to be able to identify and understand the risk factors that lead to the onset of sarcoidosis in Black American women. As the researcher, the measures I used to make sure my data is credible was the use of prolonged involvement and persistent observation. I used prolonged involvement

- by informing the participants of the reason why this study is so profound to me, that sarcoidosis was the primary cause of my mother's death.

I used persistent observation

- by explaining to the participants what I had witnessed from the time of my mother's initial diagnosis until her untimely death;

- by keeping a research journal during the interviews to record voice tones and expressions of meaning to compare with the words spoken in order to determine consistency; and
- by preparing questions so that I had consistency between the participants' interviews and their answers.

For transferability, I made sure that only Black American women were the targeted population for this study. I explained the study and provided statistics regarding sarcoidosis in order to help establish the importance of the study. Each participant was also told about the limited amount of published information there is on Black American women with sarcoidosis and why this study is so important. When I finished all interviews, I transcribed each interview and had each participant read her own respective interview transcript.

For dependability, I asked the same interview questions to the participants until data saturation was reached. Data saturation was determined once I began to hear the same information from different participants. I made sure to leave open the opportunity for follow up interviews in the event that I found I needed to seek clarification.

For confirmability, I utilized the informed consent forms. A copy of the informed consent form was provided to each participant via e-mail, and I requested that it be signed and returned to me via e-mail or postal mail prior to the interview.

Results

A research question guides and centers your research. It should be clear and focused, as well as synthesize multiple sources to present your unique argument (Porush, 1995). The research questions for this qualitative study are as follows:

RQ1: How does sarcoidosis affect an individual's physical and psychological health?

- "Before remission my physical health was very limited. Since remission, I have bounced back, although I am still limited on driving at night." (P3)
- "After my being hospitalized with pneumonia and released. My skin broke out with white spots all over. That was in the late spring, and the white spots came back in the summer and have still not cleared all the way up." (P6)
- "When I was younger I worked in a Histology lab and was around a lot of formaldehyde. Till this day I wonder if the formaldehyde is the reason I have sarcoidosis." (P7)
- "I worked in the hospital setting for over twenty years and in different departments. It makes me very sad that I can't pinpoint if I inhaled a chemical in a certain department or cleaned up with a chemical in a certain department that could have lead me to this." (P9)
- "My physical health is not as good as it used to be. I can do what I used to do, and I can go places I used to go." (P13)

Sarcoidosis can affect different organs and parts of the human body. Five out of the 13 participants experienced physical and/or psychological health effects. The other participants had symptoms related to other health issues prior to their diagnosis of sarcoidosis.

RQ2: How does sarcoidosis affect the lived experiences of Black American women? How does life change after being diagnosed with sarcoidosis?

- “I used to walk to work every day and would breathe in lots of chemicals from the cars that passed by.” (P4)
- “I believe being around different chemical scents could be a factor. I used cleaning agents in the cardiac respiratory department of the hospital where I worked. I am homebound now since being diagnosed with sarcoidosis. I rely heavily on my grown children to get things done around my own house.” (P5)
- “Since my sarcoidosis diagnosis I am not the same women that I used to be. I used to have lots of energy and loved walking around my neighborhood and I haven’t been able to go walking for years.” (P10)
- “Sarcoidosis has hindered my life a great deal. I can’t do the things I used to do and it really bothers me.” (P11)
- “My life has changed a lot. I still try to keep my house clean but I need help from others if I want to go anywhere.” (P12)

Sarcoidosis changes lives. Activities that individuals were once able to do they find that they can no longer do anymore.

RQ3: What impact does sarcoidosis have on quality of life (impacts on mobility, relationships, activities of daily living)?

- "I've been in remission with my lungs since 2012. For my eyes since 2010, and I have borderline issues with my joints and skin. Before remission my physical health was very limited. Since remission, I have bounced back, although I am still limited on driving at night." (P1)
- "Last year I had a skin outbreak for 8 weeks. My skin was bad and I had sores all over my legs. I had to work from home for almost 2 months, and I still work at home whenever my joints flare up." (P2)
- "My quality of life is day to day and month to month. I never feel the same every day. I am tired all the time and my daughters don't seem to understand that because I get up every day and get dressed and put on makeup. I asked them one day, 'How is sick supposed to look?'" (P8)

Since being diagnosed with sarcoidosis, quality of life has been very limited. Depending on the day and how they are feeling determines if they are able to go outside of their homes.

RQ4: What common lived experiences potentially put Black American women at risk for developing sarcoidosis?

- "When I clean my house I use Clorox clean up, Clorox bleach, and Lysol bathroom and kitchen cleaner." (P1)
- "I use laundry detergent and mostly liquid bleach." (P2)
- "My home cleaning agents are bleach and Comet." (P3)

- “I always used bleach when I cleaned up around my house.” (P4)
- “I use cleaning products at home; especially bleach.” (P5)
- “Yes, I use bleach to clean at home.” (P6)
- “No, I don’t use cleaning agents at home now and I didn’t before diagnosis.” (P7)
- “When I used to clean my house I used Pine-sol and Clorox bleach.” (P8)
- “I feel like bleach makes everything smell cleaner.” (P9)
- “I use bleach to clean up along with other cleaning agents like detergents.” (P10)
- “Bleach, Comet, furniture polish, and stuff for waxing the floors is what I use to clean up.” (P11)
- “I like to add bleach to my dish water when I was dishes, and to my laundry.” (P12)
- “I clean with Clorox bleach.” (P13)

Clorox bleach was the commonality that the majority of the participants used. I feel very strong in saying the Clorox bleach could be an associated risk factor that leads to the onset of sarcoidosis in Black American women. Tables 1–3 show the results of coding the participants’ responses.

Table 1

Open Coding of Participants' Initial Symptoms

Participant = P	Initial symptoms	Age at diagnosis	Occupation	Cleaning agents used at work	Cleaning agents used at home
P1	Cloudy Vision	47	Teacher	None	Clorox Bleach
P2	Blurry vision	50	I.T. worker	None	Bleach
P3	Pericarditis	48	Nurse	None	Bleach
P4	Cough	61	Chef	Bleach	Bleach
P5	Fatigue/ dizziness	38	Medical asst.	Bleach	Bleach
P6	Pneumonia	34	Teacher asst.	None	Bleach
P7	Flu	34	Admin asst.	None	None
P8	Swollen ankles	32	Military recruiter	None	Bleach
P9	Cough	51	Nurse asst.	Bleach	Bleach
P10	Skin rash	46	Librarian	None	Bleach
P11	Cough	38	Cook	Bleach	Bleach
P12	Cough	54	Educator	None	Bleach
P13	Blurred vision	48	Administrator	None	Bleach

Table 2

Open Coding of Participants' Sarcoidosis Stage at Diagnosis

	Sarcoidosis stage at diagnosis	Type of sarcoidosis	Still active in community	Other health problems
P1	Chronic	Pulmonary Ocular	Yes	Joint pain Hypertension
P2	Acute	Cutaneous Ocular Joints Pulmonary	Yes	Urinary track infections (UTIs)
P3	Chronic	Cutaneous Cardiac	Yes	High blood pressure Heart rhythms Lesions
P4	Chronic	Pulmonary	No	Pulmonary Hypertension
P5	Acute	Pulmonary	No	Gastrointestinal (G.I.) Problems Glaucoma
P6	Chronic	Pulmonary	Yes	None
P7	Acute	Systematic	Yes	Asthma Headaches Swelling
P8	Chronic	Pulmonary	No	Hysterectomy Dry eyes Neuropathy Depression High blood pressure
P9	Chronic	Pulmonary	No	Chronic fatigue
P10	Acute	Cutaneous	Yes	Sciatica
P11	Chronic	Pulmonary	No	High blood pressure
P12	Chronic	Pulmonary	Yes	High blood pressure
P13	Acute	Ocular	No	None

Table 3

Axial Coding Results

	Quality of life	Dependency on others
Participants	Since being diagnosed with sarcoidosis, quality of life has been very limited. Depending on the day and how they are feeling determines if they are able to go outside of their homes	All have found themselves to be dependent on others since being diagnosed.

Interpretation

Domestic work like cleaning, when performed on a daily basis or as an occupation, can contribute to adverse health effects (Ala-Mursula et al., 2006). As the researcher, I found that the occupational experiences of the majority of these participants diagnosed with sarcoidosis were not a huge factor that lead to their sarcoidosis diagnosis, the domestic cleaning habits they use at home however may be a factor. In Chapter one I wanted to understand if the problem may have been that Black American women perform the same cleaning tasks that people of all other races perform around their homes; however, they still have a higher prevelance of sarcoidosis in the United States. I questioned if it could be possible that Black American women were taught from past generations to rub deeper, scrub harder, or use more of the chemical when cleaning. I also wondered could it be that Black American women use cleaning agents in a way that increases their exposure to these cleaning agents, leading to increased rates of sarcoidosis and could it be a combination of environmental exposures and genetic factors. I found through my data collection that although environmental exposures could be a factor, the majority of my participants did not give me an indication that the environment is a strong factor.

According to the Black American female participants I interviewed, eight out of the thirteen participants at the time of their interview where living in a chronic state of sarcoidosis. Six out of the eight participants' chronic state progressed from an acute diagnosis over time two of the participants (P4) and (P9), were initially diagnosed in a chronic state due to receiving their diagnosis late after a series of testing and other possible diagnosis. The four participants that work around chemicals (P4, P5, P9 and P11) were the only participants whose job required them to work with and around chemicals on a daily basis while they also used cleaning agents in their homes. I believe both their occupations and their home life increased their changes of being diagnosed with chronic sarcoidosis at their initial diagnosis.

A diagnosis of sarcoidosis has heavily impacted the lives of these Black American participants. They have all found themselves being dependent on others since their diagnosis, and their quality of life has been very limited. For some, depending on the day and how they are feeling determines if they are able to go outside of their homes and function in their communities (P1, P2, P3, P6, P7, P10 and P12).

All of the participants except for one had similar experiences with the use of Clorox bleach as their main cleaning agent. While only one participant (P6) did not use Clorox for cleaning purposes. The participants differed their ages at the time they were diagnosed as well as what their occupations were when they were diagnosed. Ages ranged from thirty-two years of age to sixty-one years of age, and their occupations were in the Education, Information Technology, Healthcare, Dietary, Military, and Administrative industries.

In Chapter two I researched the different types of sarcoidosis that existed and how treatment was administered for each kind of sarcoidosis. In researching these different types of sarcoidosis I found that sarcoidosis can affect different organs and parts of the human body. The sarcoidial granulomas causes lymph-node enlargment, and can result in pulmonary involvement, cutaneous (skin) involvement, liver/spleen involvement, neurologic involvement, ophthalmalic complications, cardiac sarcoidosis, hypercalcemia and renal disease, and bone and joint involvement (Iannuzzi et al., 2007). This was very helpful in that the participants I interviewed were diagnosed with pulmonary, ocular, joint, and cutaneous, sarcoidosis all types of which I learned from my research. I learned that the primary treatments for sarcoidosis is corticosteroids depending on the type of sarcoidosis, how on the contrary some treatments may be, intralesional steroids, glucocorticoids and immunomodulators.

The conceptual framework I stated I would use was the Transtheoretical Model of Behavior Change. The Transtheoretical Model of Behavior Change developed by Prochaska and DiClemente (Jezewski et al., 2009) addressed the issue of an individual's degree of readiness for change. This model notes the five stages of change individuals use to address their troubled behavior. The five stages are (1) precontemplation, (2) contemplation, (3) preparation, (4) action, and (5) maintenance. Individuals with sarcoidosis are likely to experience each of these stages

Precontemplation is the act of having no intention to take action (Prochaska & DiClemente, 1986). *Upon initial diagnosis of sarcoidosis, some believe that the most efficacious treatment for acute pulmonary sarcoidosis is patience because most experience spontaneous resolution of symptoms* (Cox et al., 2005). Contemplation is the mindset of intending to take action (Prochaska & DiClemente, 1986). *After being diagnosed with sarcoidosis, physicians are required to recommend a limited but growing list of anti-inflammatory medications. Patients have the option to take the medication or not* (Cox et al., 2005). Preparation is when one intends to take action and sets a date when the action will take place (Prochaska & DiClemente, 1986). *After being diagnosed with sarcoidosis, individuals must accept that a lifestyle change is required and prepare to change their diet and exercise* (NHLBI, 1995). Action is the act of actually changing overt behavior (Prochaska & DiClemente, 1986). *Individuals with sarcoidosis must learn to live with the disease, and that requires finding ways to cope with everyday activities* (NHLBI, 1995). Maintenance is when an individual has changed overt behavior for six months or longer (Prochaska & DiClemente, 1986). *After learning how to live with sarcoidosis, this stage requires adhering to sensible health measures* (NHLBI, 1995).

Summary

Each participant interviewed was a Black American born woman living in the metropolitan Atlanta, Georgia area. They each presented with a very interesting story of their own. Their physical and psychological health has been altered since their sarcoidosis diagnosis. Their lived experiences and lives after being diagnosed with sarcoidosis have been affected and have also changed. Their quality of life has been limited and their dependency on others has increased. The common lived experience that has potentially put Black American women at risk for developing sarcoidosis is bleach. Chapter 5 will summarize this research as a whole. Discussions, conclusions and recommendations will be addressed.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this phenomenological qualitative study was to examine the impact of sarcoidosis on the lived experiences of Black American women and to consider how occupational experiences might have contributed to participants’ development of sarcoidosis. The nature of this qualitative study used phenomenological methodology to examine the lived experiences of Black women with sarcoidosis in order to better understand how these experiences may increase their risk for this disease as well as to explore the impact this disease has on their quality of life. The study included interviews with 13 Black American women diagnosed and living with sarcoidosis at various stages. Upon the conclusion of my research, I have found that the common lived experience that has potentially put Black American women at risk for developing sarcoidosis is bleach.

Interpretation of the Findings

There was not a significant amount of current research, dissertations, nor conference proceedings found regarding Black American women diagnosed with sarcoidosis. Only a few studies were found researching the Black American female population. For example, the article “Sarcoidosis in Black Women in the United States” published in the *Chest* journal in 2011 (Data from the BWHS) described the prevalent cases that were being studied in 1995 among black women, (Cozier et al., 2011). An article titled “Reproductive and Hormonal Factors in Relation to Incidence of Sarcoidosis in US Black Women” (Data from the BWHS), published in the *American Journal of Epidemiology* in 2012 used the same research; however, it also provided suggestive evidence that late age at first birth and a longer cumulative exposure to endogenous female hormones may be associated with a reduced incidence of sarcoidosis (Cozier et al., 2011). Another study addressed the African American female population, a population that was not targeted for this phenomenological study. This study was article “Fine-mapping in African-American women confirms the importance of the 10p12 locus to sarcoidosis published in Genes and Immunity” (Cozier et al, 2012) which discussed assessing the associations of genetic variants in a certain region of the African-American female body with sarcoidosis (Cozier et al., 2011). However, none of the above mentioned articles researched the associated risk factors that lead to the onset of sarcoidosis in Black American women.

The diagnosis of sarcoidosis is often delayed because the symptoms are not always specific. It was thought that there may be higher exposures to certain causative environmental agents in lower socioeconomic classes, but in my research I have found that socioeconomic class does not matter.

Limitations of the Study

There were no limitations or uncontrollable threats to the internal validity of this study. There were several limitations that were foreseen with this study. The study focused only on perceptions related to sarcoidosis and did not include any type of clinical or genetic testing or assessment. Because of this approach, one limitation was that the participants’ understanding of sarcoidosis as a disease may be limited or inaccurate. Each participant was very mindful of her diagnosis and was very literate in regard to the medical terminology that related to the type of sarcoidosis she had. Medical terminology is not always easy to understand, and if participants' physicians have not properly explained what sarcoidosis is and how it effects them, there may have been a chance that they would not be able to clearly articulate their perceptions and experiences of having sarcoidosis as they engaged in the study. However, I did not encounter any confusion or misinterpretations. Because of the voluntary nature of the study, there was also a possibility that some participants would withdraw from the study as it progressed. The participants were all committed to answering questions and all made themselves available for further interviews if I needed to have them. This study included only a small portion of Black American women living with sarcoidosis, which limits the generalizability of the findings to the larger population. This study focused only on perceptions related to sarcoidosis and did not include any type of clinical or genetic testing or assessment.

Recommendations

Sarcoidosis is characterized as noncaseation granulomas. Cells that make up granulomas come from the immune system. The cause of sarcoidosis is unknown; however, several risk factors such as race, ethnicity, and age have been identified. Chronic sarcoidosis commonly follows a relapsing and protracted time course and the treatment of sarcoidosis can be problematic. My recommendations for further research would be to expand the locations of participants to across the United States. Many of the participants I interviewed were willing to refer me to other possible participants who lived outside of the metropolitan Atlanta, Georgia, area and other states.

Implications

Positive Social Change

Positive social change may result from broader knowledge of the disease through education, even for those who are not at risk for developing it. Having the education can equip Black American women with the knowledge necessary to inform female friends, business associates, and family about the risk factors. Education may reduce the incidence of sarcoidosis and should be delivered to the public in culturally sensitive and appropriate ways. For individuals already diagnosed and living with sarcoidosis, current education would be beneficial as health information is always changing. It is important that the sarcoid population receive updated information, particularly regarding daily regimens needed to improve their life and their activities.

This study took place in the metropolitan Atlanta, Georgia, area, and the targeted participants for this study were Black American-born women older than 40 years of age who have been diagnosed with sarcoidosis. My intentions were to interview sarcoidosis patients diagnosed in different stages of the disease. Through the data I collected, I sought to understand how advanced the disease was when participants were diagnosed and how the disease has affected their daily lives subsequent to diagnosis. In particular, I learned about the participants’ ongoing regimens, and how they used these regimens in order to live as normal a life as possible with sarcoidosis.

I recommend further research be expanded across the United States.

Conclusion

As the researcher, this research had become very near and dear to my heart. In my personal life, my mother was diagnosed with chronic sarcoidosis, but the illness never got better, and she unfortunately died from the disease. Her death was very sudden and unexpected, and for the last four years, I have been devastated by the loss. This research leaves me to wonder whether, had she known what sarcoidosis was or been made aware of sarcoidosis years before her diagnosis, she could have possibly prevented the illness or at least increased her chances of not succumbing to the disease. Like the majority of the participants in this study, my mother cleaned with bleach regularly. She taught me how to clean with bleach regularly. And it frightens me that there are many Black American-born females in this country who also use bleach regularly when they clean. Bleach is not a definite determining factor that leads to the onset of sarcoidosis, but it is a vivid commonality that the participants in this study shared.

My goal throughout this study has been to bring about awareness. My hope is that the awareness will change old habits, and the new habits will aid in the prevention of sarcoidosis. Until a cure is found or an actual cause is determined, awareness is the best resource and tool to use to bring about social change regarding this disease.

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Appendix A: Participation Invitation

Title of Study: Associated Risk Factors That Lead to the Onset of Sarcoidosis In Black Women

[Date]

Participant's Name:

Dear

My name is Tiffany M. Simmons. I am PhD candidate currently obtaining my Doctorate degree in Public Health, with a specialization in Community Health Promotion and Education from Walden University. In or to complete my research program and graduate, I am required to conduct a research study and I would be honored if you would agree to participate in my study.

The objective of this research study is to identify associated risk factors that lead to the onset of sarcoidosis in Black American Women. The purpose of this study is to examine the impact that sarcoidosis has brought about in your life, and examine if occupational experiences might have contributed to the development of your sarcoidosis diagnosis.

I will gather my information by interviewing Black American women who have been diagnosed with mild, moderate, and chronic sarcoidosis. It is my pleasure to make you feel as comfortable as possible so you and I can conduct our interview either in person, by Skype, or by telephone. I will be conducting my interviews from [date] to [date]. To make sure that the transcription of our interview is accurate, our interview will be recorded. If you are not comfortable with being recorded, please let me know and I will handwrite your responses. Once our interview is complete, it will be transcribed onto paper, and sent back to me. After I receive the transcription of our interview, I will send you the transcript and ask that you read it and confirm the accuracy. At that time, you will be able to add or delete any information that does not accurately represent your contribution.

Your participation in this study will be voluntary. You will not encounter a penalty if you refuse to participate in this study. Upon deciding to participate in this study, you may withdraw your consent and discontinue participation at any time during the study without consequence. The researcher will assume sole ownership of any and all data collected for this study. All information obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your written permission.

If you find that you have any questions regarding this research or your participation, please contact me (770) 715-9916 or via email, tiffanymsimmons@gmail.com or tiffany.simmons@waldenu.edu. My dissertation mentor and chair is Dr. Bernice Kennedy and her e-mail address is bernice.kennedy@waldenu.edu. If you have any questions or comments regarding your rights as a participant in this research study, you may contact the Walden Research Center at 1.800.925.3368 (ext. 1210) or email, irb@waldenu.edu. Your identity, questions, and concerns will be kept confidential.

If you wish to participant in this study, please sign and return the attached consent form to me no later than [Date]. Also, please indicate on the consent form your interview preferences (in person, by Skype, or by telephone) and also a date and time, which would be convenient for you to participant in a half-hour interview session.

I look forward to exploring this area of research with you and truly appreciate your interest.

Sincerely,

Tiffany M. Simmons
Ph.D. Candidate, Walden University

Appendix B: Interview Questions

1. What were your initial symptoms before being diagnosed with sarcoidosis?
2. How old were you when you were diagnosed with sarcoidosis?
3. What is/was your occupation at the time of your sarcoidosis diagnosis?
4. Did your occupation include the use of cleaning agents? If so, what cleaning agents were used?
5. Do you use cleaning agents regularly at home?
6. What stage of sarcoidosis did you have when you were first diagnosed?
    a. Acute – occurrences and symptoms are dormant for periods of times
    b. Chronic – requiring on-going treatment
7. What type(s) of sarcoidosis were you diagnosed with having?
    a. Pulmonary (Lung)
    b. Cutaneous (Skin)
    c. Hepatic (Liver/Spleen)
    d. Neuro (Brain/Spinal Cord)
    e. Ocular (Eyes)
    f. Cardiac (Heart)
8. Are still active in your community since being diagnosed with sarcoidosis?
9. What has your quality of life been like since being diagnosed with sarcoidosis?
10. Are you currently taking medication for sarcoidosis?
11. Has your dependency on others changed since being diagnosed with sarcoidosis?
12. Has your sarcoidosis diagnosis lead to the onset of any other health problems?