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## How Sarcoidosis Mental Health Stories Could Affect Legislation

Dorothy Michelle Kemp  
*Walden University*

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# Walden University

College of Health Sciences and Public Policy

This is to certify that the doctoral dissertation by

Dorothy Michelle Kemp

has been found to be complete and satisfactory in all respects,  
and that any and all revisions required by  
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Walden University  
2024

Abstract

How Sarcoidosis Mental Health Stories Could Affect Legislation

by

Dorothy Michelle Kemp

MA, Walden University, 2013

BS, Savannah State University, 2010

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Policy and Administration

Walden University

August 2024

## Abstract

The problem this general qualitative study with narrative techniques addressed was the lack of empirical research about sarcoidosis mental health based on depression, anxiousness, and feeling lonely. Sarcoidosis legislation was also compared to current mental health legislation, which proposed mental health measures. This study aimed to gather secondary data of firsthand descriptions based on the impacts of sarcoidosis mental health aspects and review sarcoidosis legislation. Accumulated secondary data for this study were a collection of stories from doctors, diagnosed patients, and caregivers based on their narrative of the disease from a mental health perspective. In utilizing the advocacy coalition framework, this study focused on the coalition and its belief as it pertained to the theory. In referencing the narrative policy framework, this study focused on the narrative and its aspects in relation to setting, character, plot, and morals. Provisional and emotion coding were selected to analyze the secondary data and to illustrate the narrative of sarcoidosis mental health. In Vivo coding was also used to capture additional trends and researcher notes. Key findings confirmed that doctors, patients, and caregivers had knowledge of and had experienced the mental health aspects of sarcoidosis based on depression, anxiousness, and feeling lonely. A comparison of sarcoidosis legislation identified funding as the only corresponding factor with current mental health legislation. The positive social change from this study is the awareness of sarcoidosis and the noted mental health aspects, as well as the potential for updating and approval of pending legislation pertaining to the disease.

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## Dedication

This general qualitative study with narrative techniques is dedicated to those who have lost their lives to sarcoidosis, those who continue to live with the disease, and those who care for the afflicted ones, as well as the numerous doctors, researchers, and organizations that continue to explore this phenomenon.

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## Chapter 1: Introduction to the Study

According to the National Alliance on Mental Health (2022), in 2020, one out of every five Americans was affected by mental illness. There are three mental health elements directly associated with the disease sarcoidosis: depression, anxiousness, and feeling lonely (Hinz et al., 2012; The National Institutes of Health, 2022). Persons diagnosed with sarcoidosis continued to feel very tired even after treatment ended. Depression in association with sarcoidosis also stems from inflammation, fatigue, age, and treatments based on steroids (Groger, 2017). Sarcoidosis patients also have increased multiple psychiatric disorders associated with an impaired lifestyle (Goracci et al., 2008). However, certain activities or treatments have helped to improve mental health (The National Institutes of Health, 2022). According to the Bipartisan Safer Communities Act (2022), increased access to mental health programs has been proposed, along with increasing the number of individuals who work in mental health. This legislation may be needed for those experiencing sarcoidosis.

Although several diseases have received national attention, minimal research or public policy has focused on the mental health aspects of sarcoidosis. This general qualitative study, using narrative techniques, aimed to bring awareness to the mental health aspects of sarcoidosis and compare sarcoidosis legislation to current mental health legislation. My three primary populations consisted of doctors, diagnosed patients, and caregivers who assisted in caring for individuals with sarcoidosis. The purpose of using secondary data, which are the stories of these population sets, was for contextual and thematic analysis reference points and data triangulation. Reviewing legislation about

sarcoidosis and comparing these proposed laws to mental health legislation could allow for the development of a narrative about sarcoidosis that includes mental health.

Chapter 1 discusses the disease sarcoidosis from the position of mental health. The background briefly introduces sarcoidosis, why the study is being conducted, and introduces the Bipartisan Safer Communities Act of 2022 and some sarcoidosis legislation. The problem statement addresses the lack of data pertaining to sarcoidosis mental health. The purpose of this general qualitative study is correspondingly discussed. Also contained in Chapter 1 are the two research questions and theoretical framework, along with assumptions, definitions, scope and delimitations, limitations, and the significance of this study.

### **Background of the Study**

Sarcoidosis is a disease affecting the immune system, causing granulomas or calcifications to form within significant body organs, especially the lungs (American Lung Association, 2016; Soto-Gomez et al., 2016). Sarcoidosis is a disease with no known origin or cure and is quite difficult to diagnose (Chen & Moller, 2015; Soto-Gomez et al., 2016; Valeyre et al., 2014). However, research pertaining to sarcoidosis mortality indicated that from 1999–2016, there were 2.9 deaths in relation to sarcoidosis for every 1,000,000 individuals (Kearney et al., 2018). Data from the Cleveland Clinic in Ohio showed that more than half of the individuals diagnosed with sarcoidosis did not require treatment and improved without medical intervention (Foundation for Sarcoidosis Research, n.d.). One-third of individuals diagnosed with sarcoidosis entailed or did not need medical care (Foundation for Sarcoidosis Research, n.d.). However, one-tenth of

those who were diagnosed with the illness had a poorer quality of health that declined over time (Foundation for Sarcoidosis Research [FSR], n.d.). The decline in physical health may impair the affected organ's structure or function or even lead to death.

Although there is a plethora of researched information about sarcoidosis, the mental health outlook of the disease has not been widely studied. Fatigue in sarcoidosis is associated with problems focusing, the inability to remember, a lack of sensory awareness, feelings of sadness, and an inherent loss of interest (Hendricks et al., 2018). Sarcoidosis affects the daily lives of individuals as well as significant others. Sarcoidosis patients, along with life partners, experience stress and depression (Moor et al., 2018). Thus, there is a need for additional studies pertaining to the impact of depression and anxiety based on sarcoidosis patient clinical outcomes (Sharp et al., 2019).

There is still a lack of knowledge in understanding the disease and the need for patient data (FSR, n.d.). Understanding the disease from as many aspects as possible is also necessary. This general qualitative study, using narrative techniques, aimed to explore the mental health characteristics of sarcoidosis from doctors, diagnosed patients, and caregivers based on secondary data, which were stories told by each population set. This study also reviewed sarcoidosis legislation and compared these proposed laws to the Bipartisan Safer Communities Act of 2022. Current sarcoidosis legislation, such as Senate Resolution 443 of the 114<sup>th</sup> Congress from 2015-2016 (2016), is pending. Senate Resolution 443 calls for the following: Making April National Sarcoidosis Awareness Month, allowing for more research on sarcoidosis, bringing about education and awareness, and providing funding and services for sarcoidosis patients. This legislation



has not passed and is not considered law. The Bipartisan Safer Communities Act (2022) allows for funding for mental health awareness training, expansion of programs and facilities, and other mental health programs in relation to schools and firearms.

### **Problem Statement**

Chronic illness leads to depression for some individuals (Cleveland Clinic, n.d.). Sarcoidosis is considered a chronic illness due to the many disabling symptoms the disease displays. For instance, most sarcoidosis patients had a sense of reduced physical activity in relation to the disease (Cho et al., 2019). Sarcoidosis may make patients feel lonely, anxious, or depressed (The National Institutes of Health, 2022). Psychological symptoms prevalent among sarcoidosis patients indicate the need for depression assessments as additional therapy options (Sharp et al., 2020). Other researchers found that skin manifestations affected the mental health of sarcoidosis patients (AlRyalat et al., 2019). However, several foods may help to reduce the pulmonary inflammatory processes in relation to sarcoidosis (Bast et al., 2018) and spirituality may provide beneficial results based on health and healing (Sarcoidosis Research Institute, n.d.).

The problem this general qualitative study with narrative techniques addressed was the lack of empirical research pertaining to sarcoidosis mental health, specifically depression, anxiousness, and feeling lonely. There was also a need to review sarcoidosis legislation comparatively to current mental health legislation, such as the Bipartisan Safer Communities Act (2022), which proposed mental health measures. Accumulated data for this study were secondary and provided stories from doctors, diagnosed patients, and caregivers based on their narrative of the disease from a mental health aspect. Secondary

data were also utilized to compare sarcoidosis and mental health legislation. This study could assist in formulating a narrative that provides support and brings about awareness of sarcoidosis from an advocacy standpoint.

### **Purpose of the Study**

The purpose of this general qualitative study with narrative techniques was to gather secondary data of firsthand descriptions based on the impacts of sarcoidosis within three facets of mental health: depression, anxiousness, and feeling lonely. To do so, I reviewed the stories of three primary populations for contextual and thematic content. In extending the purpose of this research, legislation related to the disease was also explored and compared narratively to the Bipartisan Safer Communities Act (2022), which proposed mental health measures. Using a general qualitative design with narrative techniques allowed for tracking text and trends in sarcoidosis mental health from secondary data, which were the stories of the selected population sets. These stories were explored for keywords that were then categorized based on depression, anxiousness, and feeling lonely. Each population set's critical statements were also reviewed to offer a rich summary of the mental health narrative in relation to sarcoidosis.

I also compared the Bipartisan Safer Communities Act with sarcoidosis legislation. Comparing sarcoidosis legislation to mental health legislation could allow for the development of a narrative relating to sarcoidosis and mental health. I also explored how mental health was referenced in the pending sarcoidosis legislation.

### **Research Questions**

The research questions that guided this study are as follows:

Research Question 1: How do sarcoidosis stories from doctors, diagnosed patients, and caregivers impact mental health inclusion within sarcoidosis legislation based on depression, anxiousness, and feeling lonely?

Research Question 2: How does current sarcoidosis legislation compare to the Bipartisan Safer Communities Act of 2022?

### **Theoretical Framework**

The two theories employed for this study were the advocacy coalition framework and the narrative policy framework. Early in the 1980s, Paul Sabatier and Hank Jenkins-Smith initiated the advocacy coalition framework (Jenkins-Smith et al., 2014). The advocacy coalition framework (ACF) pertains to the study of policy processes based on coalitions, policy changes, and how policy processes are comprehended (Ma & Vieira, 2020). The ACF is utilized globally to understand policy processes worldwide (Pierce et al., 2020). The ACF originated from public policy research and the philosophy of sciences (Jenkins-Smith et al., 2014).

The narrative policy framework began in 2000 and is rooted in social construction and policy narratives (McBeth et al., 2014). The narrative policy framework (NPF) focuses on utilizing stories or narratives in public policy creation or development (McBeth et al., 2014). Narratives are widely used within the political realm (McBeth et al., 2012, & McBeth et al., 2014). It is natural for individuals to narrate or tell stories, and the NPF allows for understanding why narratives are necessary in helping to interpret policy (Crow & Jones, 2018). The NPF's purpose is to be able to review the essentials of narratives, the effect narratives present, and any allotted components that affect policy

implementation (Crown & Jones, 2018). The NPF addresses the value within the framing or construction of the policy itself (Jones & McBeth, 2020). The NPF indicates the importance of the influence that a narrative has on a policy (McBeth et al., 2014).

In utilizing the ACF, this study focused on the coalition and its belief as it pertained to the theory. In referencing the NPF, this study focused on the narrative and its aspects in relation to setting, character, plot, and morals. The ACF forms the basis for those involved in the coalition and what the coalition stands for, while the NPF provides a narrative of sarcoidosis. The NPF was applied to assist in understanding narrative formation within the Bipartisan Safer Communities Act of 2022 and how this formation could be relayed to the current sarcoidosis legislation. More detailed descriptions of both theories are explained in Chapter 2.

### **Nature of the Study**

The nature of this study was a general qualitative study with narrative techniques. Utilizing a general qualitative study with narrative techniques allowed for a content linguistic approach to qualitative data—exploring the words used in context and then identifying trends that revealed significant phenomena (Miles et al., 2016). The reasoning for utilizing narrative techniques was based on collecting stories about particular occurrences. Narrative study designs compile exchanges among individuals (Creswell, 2013). Participants in this study included doctors, diagnosed patients, and caregivers. Understanding the story behind the patient's illness provides insight into developing new techniques of diagnosing and therapies and a more positive patient outcome (Egnew, 2018). Narrative research showed a vital connection in how people lived and continued to

survive with illnesses (Charon et al., 2017).

I explored secondary data from websites that contained stories from doctors, diagnosed patients, and caregivers that described the aspects of sarcoidosis mental health. Stories were collected from reputable digital open-source database records. It was necessary to explore sarcoidosis mental health from the three population sets so that an accumulation of secondary data could be presented based on mental health in relation to the disease. In extending the purpose of this research, legislation related to the disease was also explored and compared narratively to the Bipartisan Safer Communities Act (2022), which proposed mental health measures. Contextual and thematic coding methods, which employ rich text from thick descriptions, were utilized for the expression of exclusive secondary data in relation to the mental health elements of sarcoidosis.

### **Definitions**

*Anxiety*: Constant feelings of extreme uncertainty and anticipation of danger or threats (Mayo Clinic, 2020).

*Anxious*: A normal response to situational stress (Mayo Clinic, 2017).

*Depression*: Several conditions in relation to mood that trigger feelings of sadness and irritability and include changes within the body and mind orientation (Riberio et al., 2017).

*Granulomas*: Inflammation that develops due to unknown antigens in the body (Lemke & Huang, 2018).

*Lonely*: The awareness of being apart from others in a social aspect (Cacioppo & Cacioppo, 2018).

*Mental health:* An individual's well-being based on the mind, instinctive feelings, and social aspects (Wren-Louis & Alexandrova, 2021).

*Nutrition:* Food or diet pertaining to health (Downer et al., 2020).

*Physical:* The body, the material self (Wang et al., 2022).

*Sarcoidosis:* A disease with no known origin or cure that causes the formulation of granulomas and affects any organ or area throughout the body (Ungprasert et al., 2017).

*Spiritual:* Human affinity to everything in the environment that conveys understanding and reasoning (Roze des Ordon et al., 2018).

### **Assumptions**

Four assumptions were inherent in this study. One assumption was that the participants' responses were truthful and honest. The second assumption was the ability to ensure that the study results were accurate. The third assumption was that the ACF and the NPF could discern that the coalition/actor(s)'s beliefs were solid and not just an immaterial idea. The final assumption pertained to using secondary data and whether this data was sufficient for the study.

### **Scope and Delimitations**

As stated, the problem this study addressed was the lack of empirical research pertaining to sarcoidosis mental health: depression, anxiousness, and feeling lonely. There was also a need to review sarcoidosis legislation comparatively to current mental health legislation, such as the Bipartisan Safer Communities Act (2022), which proposed mental health measures. The scope of this general qualitative study with narrative

techniques includes templates created by me for data collection, along with The Template for Coding a Narrative Study to analyze the impact of mental health in sarcoidosis, as well as compare sarcoidosis legislation to the Bipartisan Safer Communities Act of 2022. Both templates were utilized manually in a digitally printed format and uploaded to Delve software for computerized coding. The target population was delimited to doctors who treat sarcoidosis patients or research the illness, adult diagnosed sarcoidosis patients who have experienced mental health issues while living with sarcoidosis, and adult caregivers of individuals with sarcoidosis. The study population was delimited to doctors, diagnosed sarcoidosis patients, and caregivers who live in the United States. An assessment of mental health was compared and supported by the themes and trends presented within the narratives of sarcoidosis. The final delimitation was the exclusion of anxiety as a mental health element of sarcoidosis. Anxious and anxiety were utilized interchangeably throughout multiple research studies. A definition for anxious was not located without the word anxiety being attached to the subject.

### **Limitations**

There were four limitations pertaining to this study. The first limitation was population sampling. Purposeful random sampling was utilized for this study. However, there was a concern that the population sample would not reflect the general population the study deemed to identify. The second limitation was the sample size. The sample size may be too small to indicate the actual representation of individuals living with sarcoidosis. Future researchers may want to utilize more doctors, diagnosed patients, and caregivers when revising this study. The third limitation pertained to the use of secondary

data. Since no interviews with actual participants occurred, there was a limitation based on the information's accuracy and quality.

The final limitation pertained to researcher bias. Since I have sarcoidosis, I had to set aside any biases by excluding my personal experiences from this study through memoing. As an objective researcher, I was only looking to capture the stories of the designated population sets in relation to sarcoidosis mental health. The use of the ACF for this study showed that a social need was addressed. In using the NPF for this study, it was imperative that the researcher understood the topic thoroughly and had a wide range of knowledge on the subject being studied. Having sarcoidosis for more than 20 years allowed me to be an advocate and have full knowledge of the disease. I also understood the position on living with sarcoidosis from the perspective of others.

### **Significance of the Study**

The significance of this general qualitative study, with narrative techniques, includes exploring how sarcoidosis impacted mental health and comparing sarcoidosis legislation to current mental health legislation. This study was unique in its attempt to speak on an illness that causes lingering effects that limit physical and mental capabilities. Accumulated secondary data for this study were collected stories from doctors, diagnosed patients, and caregivers based on the experiences of the disease from a mental health standpoint. Significant findings from this study may find ways to connect to the Bipartisan Safer Communities Act to assist sarcoidosis patients in being assessed for mental health. This study's implication of social change brought public awareness of sarcoidosis mental health. In utilizing the ACF and NPF as the theoretical frameworks of



this study, an advocacy position of a narrative portrayal of sarcoidosis mental health was presented.

### **Summary and Transition**

This chapter addressed the lack of empirical research pertaining to sarcoidosis mental health—depression, anxiousness, and feeling lonely—and the need to review sarcoidosis legislation comparatively to current mental health legislation, such as the Bipartisan Safer Communities Act of 2022. The purpose of this general qualitative study with narrative techniques was to gather secondary data of firsthand descriptions based on the impacts of sarcoidosis within three facets of mental health: depression, anxiousness, and feeling lonely. To do so, I reviewed secondary data of the stories of three primary populations for contextual and thematic content. Legislation related to the disease was also explored and compared narratively to the Bipartisan Safer Communities Act. Chapter 1 included an introduction, a background, a problem statement, the purpose of the study, two research questions (RQ), two theoretical frameworks, the nature of the study, assumptions, definitions, scope and delimitations, limitations, and the significance of the study. Next, Chapter 2 addresses the literature on the topic.

## Chapter 2: Literature Review

Mental health is the condition of an individual's mental, physical, and social well-being based on their ability to operate at their greatest potential (Galderisi et al., 2017). Chronic illness impacts mental health by affecting an individual's potential, confidence, and, eventually, their comprehensive quality of life (Leung et al., 2020). Sarcoidosis is considered a chronic illness. Chronic sarcoidosis becomes evident when the disease has been in an active state for more than 2-5 years (FSR, 2022). Cognitive functions in relation to sarcoidosis could diminish an individual's quality of life (Hoth et al., 2022). There is a need for more research on the psychological symptoms of sarcoidosis based on measurable fluctuations in patient overall health (Sharpe et al., 2019).

This study adds to the existing research pertaining to sarcoidosis mental health. The problem this general qualitative study with narrative techniques addressed was the lack of empirical research pertaining to sarcoidosis mental health, specifically depression, anxiousness, and feeling lonely. There was also a need to review sarcoidosis legislation comparatively to current mental health legislation that proposed mental health measures, such as the Bipartisan Safer Communities Act of 2022. Thus, the purpose of this study was to gather secondary data of firsthand descriptions based on the impacts of sarcoidosis within three facets of mental health: depression, anxiousness, and feeling lonely.

Chapter 2 discusses the two theories coordinated with the study's purpose: ACF and NPF. Also included is a review and synthesis of applied research on sarcoidosis and sarcoidosis mental health, which contributes to the narrative of the distributed stories of the disease. The chapter also consists of how literature for this study was gathered, along

with a synthesized literature review on a history of sarcoidosis, ailments, and treatments in relation to the disease. The literature review also explores sarcoidosis and mental health legislation along with research pertaining to sarcoidosis mental health in association with depression, anxiousness, and feeling lonely. An introduction to the research instrument being utilized for this study is also included, along with the gap in research.

### **Literature Search Strategy**

In the search for literature about sarcoidosis mental health, the literature found pertained to peer-reviewed scholarly journal articles, professional digital open-source database platforms, the federal government, and competent mental health publications. Google Scholar and PubMed were utilized as literature sources, along with the Walden University Thoreau multi-database, FSR, United States Census Bureau, United States (U.S.) Congress, and Science Direct. Key search terms included *sarcoidosis*, *sarcoidosis symptoms*, *mental health*, *sarcoidosis mental health*, *sarcoidosis and depression*, *sarcoidosis and anxiousness*, and *sarcoidosis and loneliness*. The search provided over 24,000 articles, with 744 being reviewed and over 250 concerning this study's topic. All articles for this study were downloaded into Zotero, where the articles could be accessed quickly, and provide a bibliography for citation purposes.

### **Theoretical Framework**

As noted earlier, this study utilized two theoretical frameworks: the ACF and the NPF. The ACF pertained to how people and groups influenced public policy by forming coalitions that pursued a common purpose (Cairney, 2019). The NPF related to the idea

that the narrative could affect and was a part of the public policymaking process (Ertas & McKnight, 2019). Both these frameworks have been used together in past studies, with the ACF focusing on the coalition and their beliefs and the NPF providing the story behind the policy.

### **Advocacy Coalition Framework**

ACF had many contributors in its early inception. Paul Sabatier and Hank Jenkins-Smith were credited as the founders of the ACF in the early 1980s (Jenkins-Smith et al., 2014). The ACF is noted as the actions taken that pertain to policies influenced by group alliance, the modification of policies, and how the actions taken in reference to the policy are perceived (Weible et al., 2011). The ACF was influenced by the policymaking process, specifically how policies changed (Pierce et al., 2020). Although the ACF has been used worldwide in research, the theory varies. For example, observations were an issue when the ACF was used in qualitative research due to the proclaimed amount (Pierce et al., 2022).

Understanding individuals and their roles is necessary in order to grasp this theory. Based on the theoretical emphasis of the ACF, advocacy coalitions denote individuals from all walks of life who have a common ideology and come together to achieve specific goals without interference (Cairney, 2013). Some actors are considered principal within the coalition, and others are identified as auxiliary coalition actors (Jenkins-Smith et al., 2014). Although actors are separate in their roles, they work together to form a coalition. Principal actors maintain vital roles and a steadfast relationship within the coalition (Jenkins-Smith et al., 2014). Auxiliary actors are

individuals who have affiliations with coalitions but in less defined roles that were fragmentary (Jenkins-Smith et al., 2014). Coalitions impact the policy process with involved actors who make a difference in the formation and employment of policy (Schlager, 1995). Both groups promote the shared belief of the coalition regardless of their designated role within the coalition. Many advocacy groups represent and support endless causes pertaining to diseases. Advocacy groups dedicated to rare diseases have assisted in enhancing the quality of life through awareness and assistance to those suffering from unconventional illnesses (Drell et al., 2022). The coalition of actors and their shared beliefs were considered for this study.

### **Narrative Policy Framework**

The major contributors to the NPF were Paul Sabatier and Christopher Weible (Sabatier & Weible, 2014). The NPF was created to understand the connection between narratives and policy processes objectively (Jones et al., 2022). The NPF focuses on how narratives are utilized in public policy and how narratives have influenced policy outcomes (McBeth et al., 2014). The NPF is rooted in post-positivism, social construction, and policy narratives (Jones et al., 2014). Without narratives, politics would lack value and impact (Shanahan et al., 2011). Individuals use narratives to develop themselves through emotions and viewpoints, and similarly, political players use stories to provide information, persuade, and assess principal actions (Crow & Jones, 2018). Narratives or stories often accompany legislation presented in the U.S. Congress to understand better specific issues that have affected the general public. Policy narratives are stories divulged through an agent that conveys societal actions based on prescribed

data expounded by truth and allows for counsel through governance (Miller, 2020).

Narratives have been used to impact health policymaking (Fadlallah et al., 2019). Policy narratives have been used as a policy development and implementation tool by adding certain narrative proponents when the policy was created (Mintrom & O'Connor, 2018).

Policy narratives contain the main factors of a story, which are at the basis of the NPF: setting, character, plot, and moral (McBeth et al., 2014). The setting or issue for this study was sarcoidosis mental health. Character in the NPF is the individual or individuals who understand the issue presented in the narrative (McBeth et al., 2014). The characters for this study were doctors, diagnosed sarcoidosis patients, and caregivers. The plot within the NPF shows the connection among the characters and how the characters are associated with the setting (McBeth et al., 2014). The connection shared among the characters related to the doctors treating the patients with sarcoidosis and having a caregiver assist them with their illness. All characters were associated with the disease sarcoidosis. Moral, also represented within the NPF, focuses on solving the issue or providing a means for the result that would change the setting (McBeth et al., 2014). In order to change the setting, this study presented narratives of the mental health aspects of sarcoidosis.

The NPF also provided three levels of analysis: micro-, meso- and macro-levels (McBeth et al., 2014). The micro-level of analysis within the NPF pertains to the individual and the individual's independent relationship concerning policy narratives. The meso-level analysis within the NPF pertains to advocacy coalitions and groups and the relationship involving policy narratives. The macro-level pertains to how social

groups and organizations affect public policy. This study focused on the meso-level of the NPF because of the connection this level had to the ACF.

Further, several different forms of narratives include illness narratives and counterstories or counternarratives (Kirkpatrick, 2008). Illness narratives are associated with illness and the illness' implied significance, while counterstories pertain to politics and the political realm (Kirkpatrick, 2008). The NPF was selected for this study in order to create a narrative of the disease sarcoidosis from the mental health aspect in relation to depression, anxiousness, and feeling lonely. This study aimed to bring about an interest in the topic by combining the two types of narratives in one study. The ACF was combined with the NPF to show how the belief systems of coalitions are utilized narratively to help support policy formation and limit coalition inefficiency, as shown in Table 1. The provided narratives presented an example of how the coalition and its beliefs could influence policy through narrative.

**Table 1**

*ACF/NPF Combined*

Advocacy Coalition Framework	Narrative Policy Framework
Advocates – Actors/Solution	Setting – Issue
Belief – Issue/Connection Between Actors	Character – Actors
	Plot – Connection Between Actors
	Moral – Solution
	Micro Level – individual & connection to policy
Advocacy coalition of actors presenting their belief in narrative format to effect policy	Meso Level – advocacy coalition connection to policy narratives
	Macro Level – social organizations & groups' effect on policy

## Literature Review Related to Key Concepts

### History of Sarcoidosis Human Experiences

Sarcoidosis is a disease that has not been around for a long time. During the late 1800s, three European doctors were at the forefront of investigating the mysterious illness sarcoidosis: Earnest Besiner, Caesar Boeck, and Jonathan Hutchinson (Danbolt, 1958). Besiner described and named one of the first cases of lupus pernio; Hutchinson presented a case called Mortimer's Malady, named after the patient; and Boeck was the first to have attached the name sarcoid to the condition in relation to how the disease affected the skin (Danbolt, 1958). The disease was an uncommon illness that was not widely known.

Sarcoidosis is considered a rare disease that causes small areas of inflammation, or what is known as granulomas, that affect any and several organs within the body (Arkema & Cozier, 2018). The disease also has what seems like an endless display of traits. Some of the many symptoms in relation to sarcoidosis consist of chronic fatigue (Górski & Piotrowski, 2016), persistent cough (Tully & Birring, 2015), trouble breathing (Schreiber & Windisch, 2018), skin manifestations (Liu et al., 2017), eye irritants (Kansal & Dollin, 2017), inflammation and joint pain (Nessrine et al., 2014), and probable heart-related conditions (Ungprasert et al., 2017). The disease can become severe, and the development is relatively progressive. Sarcoidosis is considered systemic and could affect any or multiple organs within the body (Okuma et al., 2017) and could mimic other diseases, such as metastatic cancer (Hammen et al., 2015) or tuberculosis (Agrawal et al., 2016).



Several mysteries surround sarcoidosis. There are no known causes as to how sarcoidosis originates, but there has been research that suggests the disease is a pathogen (Esteves et al., 2016; Mirsaeidi et al., 2016; Mortaz et al., 2016; Zhao et al., 2017). Many studies have been conducted to try and find links to the disease. Granulomas have also been considered a possible cause of sarcoidosis (Fischer & Rybicki, 2015; Rotsinger et al., 2016; Timmermans et al., 2016). Antigens (Fischer et al., 2015; Celada et al., 2015), immunology and immune system response to stimulus (Chen & Moller, 2015; Spagnolo et al., 2015; Reich, 2017; Arts et al., 2018), proteins (Lavi et al., 2017), and familial ties (Besnard et al., 2018) have also been studied in relation to sarcoidosis.

Other possible links to sarcoidosis relate to external agents. Certain environmental factors have been linked with the disease sarcoidosis based on the workplace (Liu et al., 2016; Vihlborg et al., 2017; Webber et al., 2017) and atmospheric exposures (Ungprasert et al., 2016; Beghè et al., 2017; Pirozzi et al., 2018). However, not everyone has been affected by sarcoidosis in the workplace. Researchers have suggested that women and Black individuals were more susceptible to sarcoidosis mortality based on occupational vulnerability (Liu et al., 2016).

The occurrence of sarcoidosis has other distinctions based on population. According to the American Lung Association (2022), less than 200,000 incidences of sarcoidosis within the U. S. are reported yearly. Sarcoidosis affects adults (Ungprasert et al., 2017a; Park et al., 2018) and children (Milman et al., 2009; Gedalia et al., 2016). Arkema and Cozier (2018) utilized data found by Baughman et al. (2016) from a study conducted in 2016 pertaining to sarcoidosis incidence in the U.S. was 17.8/100,000 for

African Americans, 8.1/100,000 for Caucasians, 4.3/100,000 for Hispanics, and 3.2/100,000 for Asians.

The disease did not affect everyone the same way. Those with African ancestry had a higher probability of sarcoidosis than any other ethnic group (Levin et al., 2015). African American women had an advanced risk of mortality with sarcoidosis (Czerkasij, 2013; Mirsaiedi et al., 2015). Sarcoidosis combined with other health factors was not uncommon. Obesity and weight gain were highly associated with Black women and sarcoidosis (Cozier et al., 2015).

The disease sarcoidosis has been around for more than a century. There were many symptoms in relation to the disease, as well as possible causes. Treatments were available in relation to the disease. However, with no available cures, corticosteroids are used primarily in treating sarcoidosis (Soto-Gomez et al., 2016). Other therapies in relation to sarcoidosis are discussed later in the literature review. African American women seemed to be more prone to sarcoidosis mortality than any other population variable. With the provided research available, there was little information about how an individual may have experienced living with the disease. To advance the understanding of sarcoidosis, a general qualitative study with narrative techniques of the disease was necessary based on the actual discernment of individuals who live with the condition and those who treat and care for the diagnosed individual. This study later presented narratives about the mental health aspects of sarcoidosis in relation to depression, anxiousness, and feeling lonely.

## **Physical Ailments**

Experiencing ailments had been a part of having a disease, but in the case of sarcoidosis, manifestations are multifarious. Sarcoidosis has many symptoms that could physically affect the individual diagnosed with the disease (Pascal et al., 2021). Many sarcoidosis patients experienced difficult or labored breathing, which could be attributed to psychological factors (Holas et al., 2017), as well as problems with coughing (Singh et al., 2016) that brought about mental fatigue (Gvozdenovic et al., 2020). Cardio-vascular issues were not a fixed symptom of sarcoidosis (Dubrey et al., 2016; Tan et al., 2022), but the rate of mortality of individuals with neglected cardio sarcoidosis was elevated (Lynch et al., 2014; Ipek et al., 2015). Skin manifestations such as lesions (Jung & Roh, 2011), alopecia (Tsai et al., 2015; Dan & Relic, 2016), rashes (Noparstak et al., 2015), ulcers (Ohn et al., 2015), nodules and patches (Labadie et al., 2018), plaques, papules, lupus pernio (Khawar et al., 2021), and psoriasis (Petroianni et al., 2021) were all associated with sarcoidosis as well. Skin manifestations were known to affect the mental health of sarcoidosis patients (Kang & Jacob, 2016; Paolino et al., 2017). Just with these few issues, sarcoidosis exhibited a link with mental health.

Additional physical manifestations identified in relation to sarcoidosis pertained to the eyes (Saligan et al., 2010; Pasadhika & Rosenbaum, 2015; Kidd et al., 2016), gastric issues (Geamanu et al., 2016; Ghrenassia et al., 2016; Patel et al., 2017), head and neck problems (Knopf et al.; 2013; Badhey et al., 2014; Send et al., 2020), muscles, bones, joints (Spruit et al., 2005; Saidenberg-Kermanac'h et al., 2014), and urinary and bladder difficulties (Block & Kava, 2017; Hayashida et al., 2020). Pulmonary

complications while experiencing sarcoidosis were not uncommon (Tavanna et al., 2015; Li et al., 2018). Individuals diagnosed with pulmonary sarcoidosis exhibited symptoms of depression in relation to having a decreased lung capacity (Sharp et al., 2019).

Sarcoidosis had affected many organs and produced several difficulties, making the illness systemic.

Other impediments associated with sarcoidosis were identified with sensations, proper rest, and tiredness of an extreme state. Pain associated with sarcoidosis was a constant complaint among diagnosed individuals (Erb et al., 2005; Bakkers et al., 2010; Heij et al., 2012). Small fiber neuropathy, highly associated with pain, burning, and numbness, was one of the many links to sarcoidosis pain (Levine, 2018; Sène, 2018). Sarcoidosis affected the sleep of diagnosed patients (Lai et al., 2015; Mari et al., 2020), which brought about increased levels of depression, along with fatigue, functional impairment of the brain, and an overall substandard condition of health (Benn et al., 2016). Sleep disturbance was also associated with fatigue in relation to sarcoidosis (Bosse-Henck et al., 2017). Fatigue was identified as one of the most common physical embodiments of sarcoidosis (Fleischer et al., 2014; Strookappe et al., 2016; Holas et al., 2018) and is significantly associated with depression (Schnellbacher et al., 2021). Psychological counseling should be a part of treating sarcoidosis patients with fatigue (De Kleijn et al., 2011).

Sarcoidosis has many symptoms. Many of these symptoms bring about afflictions that are physically disabling. Due to the possible systemic nature of the disease, the mental health of sarcoidosis patients is easily impaired. Fatigue is the main contributing

factor concerning sarcoidosis mental health. All the symptoms reviewed in relation to sarcoidosis were common and unpredictable.

### ***Doctors, Diagnosed Patients, and Caregivers Accounts***

Fatigue was a symptom highly associated with sarcoidosis, and doctors discovered several distinctions that offset the patient's health. Scientists found several factors in relation to sarcoidosis fatigue, such as, interrupted sleep, neurological manifestations, small fiber neuropathy, medications (Drent et al., 2012), increased body fat (Saligan, 2014), and obesity (Ungprasert et al., 2016c). Other research indicated no reliable predictors of fatigue in relation to sarcoidosis (Strookappe et al., 2016). Fatigue was not easily identifiable in sarcoidosis patients based on agility. Fatigue in sarcoidosis showed no relationship to physical activity (Bahmer et al., (2018), although the capacity to exercise was diminished in diagnosed individuals (Kallianos et al., 2015). Pulmonary function tests, six-minute walk tests, and cardiopulmonary exercise testing were ways to assess oxygen desaturation in sarcoidosis patients (Chenivesse et al., 2016).

Sarcoidosis patients reported a myriad number of symptoms in connection with the disease. Individuals conveyed sarcoidosis manifestations that pertained to bone and bone marrow (Yachoui et al., 2015), ocular emanations (Pasadhika et al., 2015), the gut (Ceylan et al., 2015), joints (Moccia et al., 2016), nail abnormalities (Albers et al., 2016), thoracic implied development (Dhagat et al., 2017), and the mouth (Radochova et al., 2016). Patients had reported systemic diagnoses of sarcoidosis along with problems associated with multiple bone fractures (Sada et al., 2014), the thyroid (Okuma et al., 2017), and neurological attributes (Campbell et al., 2015).

Other symptoms identified were associated with comorbidities, deceptive resemblance of other illnesses, and isolated incidents. Sarcoidosis co-existed with other illnesses, such as Harlequin and Horner syndrome (Wong et al., 2015), mimicked cancer (Hammen et al., 2015), and even had cervical spinal cord involvement (Razdan et al., 2016). Rare manifestations of sarcoidosis identified in patients included the ovaries (Turkay et al., 2015), breast (Kochoyan et al., 2016), digestive tract (Ghrenassia et al., 2016), vagina (Şahin et al., 2016), penis (Semiz & Koback, 2017), testis (Babst et al., 2018), larynx (Tsubouchi et al., 2015), and sinuses (Joseph et al., 2015).

Several symptoms were unremarkable in association with sarcoidosis. Common manifestations of sarcoidosis noted by diagnosed individuals involved the heart (Lynch et al., 2014), lungs (Tavanna et al., 2015; Lashari et al., 2018), was pain associated (Shaw et al., 1988; Oudejans et al., 2017), and had cutaneous involvement (Ghorpade, 2015; Wollina et al., 2016). Symptoms of a neurological nature had many indicators that were present. Neurological presentations in patients with sarcoidosis were associated with facial weakness (Wiesli et al., 2000), hydrocephalus (Akhondi et al., 2003), muscle weakness, blurred vision, speaking difficulties (Gözübatık-Çelik et al., 2015), and stroke symptoms (Memon et al., 2018; Hutto et al., 2022).

There was a lack of research concerning caregiver accounts in relation to physical ailments. Sarcoidosis patients and their partners who cared for them were documented to have a decreased quality of life (Voortman et al., 2019). With the numerous symptoms observed in connection with sarcoidosis, the disease was problematic to diagnose. Some patients experienced one or several symptoms at a time. Sarcoidosis brought about a

systemic state when the disease went unchecked or was misdiagnosed. Patients of this disease experience ailments of a debilitating nature. This section still needs to discuss many other symptoms, but understanding how sarcoidosis affects the individual diagnosed should be clear.

## **Mental Ailments**

### ***Doctors, Diagnosed Patients, and Caregivers Accounts***

Sarcoidosis had ailments that affected the individual's mental health. Some of the mental ailments linked to sarcoidosis were identified as depression (Cox et al., 2004), neurological symptoms (Stjepanović et al., 2014), low mood, psychological distress (AlRyalat et al., 2019) and cognitive difficulties (Hoth et al., 2022). Depressive symptoms, anxiety, and cognitive failure were all related to fatigue in sarcoidosis (Hendriks et al., 2018). The management of sarcoidosis patients should include not only fatigue-related assessments but evaluations of cognitive functioning, depression, and anxiety should all be considered as well (Hendriks et al., 2018).

Additionally, patients relayed detailed symptoms that contributed to some neurological impairment. Individuals diagnosed with sarcoidosis had reported short-term memory defects, bipolar disorder (McLoughlin & McKeon, 1991), confusion (Baussart et al., 2006; Mubarik et al., 2018), headaches, mental status change (Guglani et al., 2009), cognitive deficits (Mariani & Shammi, 2010), frontotemporal dementia (De Maindreville et al, 2015), and migraines (Gelfand et al., 2018). Equally important, caregivers were noted to experience specific mental changes like their diagnosed partner. Partners of individuals diagnosed with sarcoidosis displayed anxiety and psychological distress

(Moor et al., 2018). Depressive symptoms for the partner were nought, but the individual diagnosed displayed a depressed mood (Voortman et al., 2019)

As mentioned, doctors had diagnosed certain sarcoidosis patients with some mental ailment. Moreover, diagnosed sarcoidosis patients reported specific issues that affected their cognitive ability. Although partners of patients did experience anxiety and psychological distress, there was a lack of research that discussed caregiver accounts of neurological issues based on caring for someone with sarcoidosis.

### **Treatments and Response**

Sarcoidosis has no cure, but there are diverse treatment methods. Anti-inflammatory medications (Pereira et al., 2016) and corticosteroids (Khan et al., 2017; Comisar et al., 2019) were commonly used to treat sarcoidosis. Other therapies in relation to sarcoidosis consisted of antibiotics (Takemori et al., 2014), immunotherapies (Hamzeh et al., 2014; Celada et al., 2015; Misra et al., 2016), oral antifungal medications (Terčelj et al., 2014), fungal soap (Saylam Kurtipek et al., 2016), chemotherapy (Şahin et al., 2016), topical laser treatments (Al-Niaimi, 2017), and radiation therapies (Lapa et al., 2018). Some of these various treatments are related to the many manifestations of the disease.

Consequently, the treatments associated with sarcoidosis did not come without complications. Corticosteroids, such as glucocorticoids, were known to have metabolic complications and a higher potential for cardiovascular disease in sarcoidosis patients (Khan et al., 2017). Severe infections would occur when three or more immunosuppressants were utilized to treat sarcoidosis, which involved neurological or



cardiac complications (Duréault et al., 2017). Just treating the disease was not enough. Individuals diagnosed with sarcoidosis needed to be assessed for treatment failure, which pertained to the inability to tolerate a particular drug, possible toxicity of the drug being prescribed, or relapses of the disease itself (Obi et al., 2022). The treatment of sarcoidosis needs to be implemented through various therapies, including observation of disease development and any other difficulties that may or may not arise (Melani et al., 2021).

Some sarcoidosis treatments, while available, contributed to additional complications for the diagnosed individual. When certain medications were utilized together, specific mental impairments came about, but there was a lack of research on how sarcoidosis medications affected one's cognitive ability. Therapies for sarcoidosis needed more in-depth evaluation along with disease progression.

### ***Doctors, Diagnosed Patients, and Caregiver Accounts***

Doctors had invested in new courses of action when exploring sarcoidosis treatments. Drug therapies in relation to other diseases, such as arthritis, Crohn's disease, and psoriasis, were being utilized for sarcoidosis treatment due to the shared commonality of the diseases (Chiarchiaro et al., 2016). Neurostimulants were considered as a treatment for fatigue in patients diagnosed with chronic sarcoidosis, but future studies need to be explored in this therapy category (Atkins et al., 2017). One treatment was extreme due to the progression of the disease. Heart and lung transplantation was the last line of therapy for sarcoidosis patients who may have been diagnosed with cardiac or pulmonary sarcoidosis in a chronic state and facing mortality (Soto-Gomez et al., 2016).

Experimental therapies needed to be considered when other more common forms

of sarcoidosis treatments were unsuccessful (Al-Kofahi et al., 2016). Not all treatments were successful, and may even worsen the patient's condition. Specific biological agents, such as golimumab, were noted to have caused intracranial infection in a sarcoidosis patient (Misra et al., 2016). When sarcoidosis was diagnosed, a gauge of all organ involvement needed to be made for treatment to be considered (Prasse, 2016).

Medications were not the only therapy needed in treating sarcoidosis patients. Some treatments incorporate the patient's involvement in understanding their disease and conducting activities to help prevent further disease progression. Individuals diagnosed with pulmonary sarcoidosis were not likely to participate in self-management of their disease (Bloem et al., 2022). Stress had a strong relationship with pulmonary disorders, and specific coping strategies needed to be put into place for sarcoidosis patients to deal with mental tensions (Holas et al., 2023).

Caregivers were also included in the therapy of sarcoidosis patients based on their needed role within the patients' therapy. The health providers' function in supporting sarcoidosis patients' self-management needs to be explored (Bloem et al., 2022). To successfully manage sarcoidosis, patients need to understand their disease, be aware of the emotional factors involved, maintain relationships with family and friends, and ensure any spiritual or religious needs are met (Page, 2008). Partners of individuals diagnosed with sarcoidosis needed support based on the partners' overall health (Moor et al., 2018).

With all the many treatments recommended for sarcoidosis patients, the therapies do not come without caution. Some treatments were effective, while others were profound or resulted in supplementary injury in relation to mental health. Doctors,

diagnosed patients, and caregivers all needed to be actively involved in the therapy process of treating sarcoidosis in order to project outcomes for the disease. There was a lack of research that pertained to sarcoidosis treatment and its connection to mental health.

### **Sarcoidosis Legislation**

Sarcoidosis is a disease that exists, but not much is discussed about the illness from a societal aspect. This section discusses legislation that has been passed in relation to the disease. Other pieces of legislation that were pending concerning the illness were also included. In reviewing legislation about sarcoidosis, it was necessary to visit the Congressional digital database to identify what had been introduced and eventually passed in relation to the disease.

This study focused on legislation pertaining to sarcoidosis awareness and mental health. Reviewing legislation pertaining to sarcoidosis and comparing it to mental health legislation could allow for the development of a narrative about sarcoidosis and mental health. Several pieces of legislation referenced National Sarcoidosis Awareness Day along with Senate Resolution 443 of the 114<sup>th</sup> Congress for 2015-2016, which pertained to making April National Sarcoidosis Awareness Month, were reviewed. The Bipartisan Safer Communities Act of 2022 was discussed to provide a perspective on mental health legislation today. The review of sarcoidosis legislation was necessary to show the lack of mental health inclusion being addressed in the policy formation in relation to the disease.

#### ***National Sarcoidosis Awareness***

**National Sarcoidosis Awareness Day.** The first piece of legislation reviewed

was House Concurrent Resolution 429 of the 107<sup>th</sup> Congress for 2001-2002, which pertained to establishing September 24, 2002, as National Sarcoidosis Awareness Day (2002). House Concurrent Resolution 429 was introduced in the House on June 26, 2002, and sponsored by Rep. Carolyn C. Kilpatrick, a Democrat from Michigan. House Concurrent Resolution 429 was referred to the House Committee on Energy and Commerce on the same day of its introduction, then referred to the Subcommittee on Health on July 16, 2002, but further action has yet to be taken.

The next piece of legislation reviewed was House Joint Resolution 399 of the 103<sup>rd</sup> Congress for 1993-1994, pertaining to establishing August 29, 1994, as National Sarcoidosis Awareness Day (1994). House Joint Resolution 399 was introduced on August 8, 1994, and sponsored by Rep. Sanford D. Bishop, a Democrat from the state of Georgia. House Joint Resolution 399 was also referred to the House Committee on Post Office and Civil Service on the day it was introduced, but further action has yet to be taken.

The next legislation reviewed was House Joint Resolution 309 of the 102<sup>nd</sup> Congress for 1991-1992, which had become Public Law No. 102-94, establishing August 29, 1991, as National Sarcoidosis Awareness Day (1991). House Joint Resolution 309 was introduced on July 18, 1991, and sponsored by Rep. Jim Slattery, a Democrat from Kansas. House Joint Resolution 309 was passed by the House on August 1, 1991, measured, and signed in the Senate on August 6, 1991, and presented to President George H. W. Bush on August 7, 1991. President Bush signed the resolution on August 14, 1991, and became Public Law No. 102-94 on the same day making the 29<sup>th</sup> of August National

Sarcoidosis Awareness Day.

The next legislation reviewed was House Joint Resolution 519 of the 101<sup>st</sup> Congress for 1989-1990, which pertained to establishing August 29, 1990, National Sarcoidosis Awareness Day (1990). House Joint Resolution 519 was introduced on March 14, 1990, and sponsored by Rep. Jim Slattery, a Democrat from Kansas. House Joint Resolution 519 was passed in the House on August 4, 1990, passed in the Senate on October 16, 1990, and presented to President George H. W. Bush on October 24, 1990. President Bush signed the resolution on October 31, 1990, becoming Public Law No. 101-481.

The final piece of legislation this study reviewed pertaining to National Sarcoidosis Awareness Day was House Amendment 706 of the 101<sup>st</sup> Congress for 1989-1990. The amendment pertained to establishing August 29, 1990, as National Sarcoidosis Awareness Day (1990). House Amendment 706 was introduced on August 8, 1990, as an amendment to House Joint Resolution 519 and sponsored by Rep. Tom Sawyer, a Democrat from Ohio. House Amendment 706 was agreed to in the House without objection on the same day of its introduction, but no text supporting the legislation was available.

**National Sarcoidosis Awareness Month.** The next piece of legislation this study reviewed was Senate Resolution 443 of the 114<sup>th</sup> Congress for 2015-2016, which pertains to establishing April 2016 as National Sarcoidosis Awareness Month (2016). Senate Resolution 443 was introduced on April 27, 2016, and sponsored by Sen. Charles Schumer, a Democrat from New York. On April 27, 2016, the resolution was referred to

the Committee on the Judiciary on April 27, 2016, but further action has yet to occur.

The next piece of legislation this study reviewed was House Concurrent Resolution 262 of the 111<sup>th</sup> Congress in support of establishing April as National Sarcoidosis Awareness Month, bringing about awareness of the disease through research and assisting those who may live with the condition and their families through treatment and worker policies (2010). House Concurrent Resolution 262 was introduced on April 15, 2010, and sponsored by Rep. Danny K. Davis, a Democrat from Illinois. After being introduced, House Concurrent Resolution 262 was referred to the House Committee on Education and Labor on the same day.

The last piece of legislation this study reviewed pertaining to National Sarcoidosis Awareness Month was House Resolution 1149 of the 110<sup>th</sup> Congress for 2007-2008, which pertained to establishing April 2008 as National Sarcoidosis Month (2008). House Resolution 1149 was introduced on April 24, 2008, and sponsored by Rep. Danny K. Davis, a Democrat from Illinois. House Resolution 1149 was referred to the House Committee on Education and Labor on the day it was introduced, debated on April 30, 2008, with a motion to reconsider in the House and agreed on.

Several pieces of legislation about sarcoidosis were passed, mainly dealing with awareness. Some passed legislation declared certain days as National Sarcoidosis Awareness Day. Other legislation pertaining to making April National Sarcoidosis Awareness Month was still pending at the time of this study. There was a lack of sarcoidosis legislation attributed to sarcoidosis mental health.

## **U.S. Mental Health Policy**

### ***Bipartisan Safer Communities Act of 2022***

The legislation related to mental health policies within the U.S. referenced in this study was Senate 2938 of the 117th Congress for 2021-2022, which was introduced in October 2021 in the Senate by Sen. Marco Rubio, a Republican from the state of Florida. Senate 2938 arrived in the Committee on Environment and Public Works in December 2021 and was passed and agreed upon within the same month. Senate 2938 failed to pass the House in March 2022 but later passed the House in May 2022. The Bipartisan Safer Communities Act (2022) was presented to and signed by President Joe Biden in June 2022, later becoming public law.

The Bipartisan Safer Communities Act (2022) included mental and behavioral health services that provided social inclusion to children and families; increased security for firearms background checks, firearm utilization, offenses, and convictions; and moratorium extension of regulation implementation pertaining to Medicare prescription drug benefit rebates. Title I of the act under Division A was where most of the information about mental health was located. Mental health services included expansion programs for community mental health services; Medicaid and telehealth mental health connection within schools; supporting mental health services in schools; evaluation of programs to meet all school-aged children's needs, including or excluding mental health; and grants for pediatric mental health services.

Funding went to the Department of Justice, the Department of Health and Human Services, and the Department of Education, all in relation to programs and funding for

each department individually. The Department of Health and Human Services provided funding for community block grants, the National Child Traumatic Stress Program, Project AWARE services, and monies for the National Suicide Prevention Hotline. Also, the Office of the Secretary of Public Health and Social Services Emergency Fund allotted funding for mental and behavioral health care training for those within the medical field.

### **Sarcoidosis Mental Health Experiences**

This study focused on the mental health aspect of sarcoidosis. These elements included depression, anxiousness, and feeling lonely. The disease sarcoidosis was pinpointed in studies to show how an individual's mental health could be affected. Sarcoidosis mental health experiences included neurological manifestations (Jefferson et al., 1952; Joseph & Scolding, 2007), psychological burdens (Sharp et al., 2019), and a negative impact on the quality of life (Voortman et al., 2019). Depression was the first mental health aspect discussed.

### ***Depression***

Depression was attributed to several factors in relation to sarcoidosis. Age, gender, societal ranking, and limited access were all related to depression in sarcoidosis (Chang et al., 2001). Depression, depleted mental processes, pain, and breathing struggles were attributed to fatigue, one of the most common symptoms of sarcoidosis (Hendricks et al., 2018). Symptoms of depression, anxiety, and fatigue were linked with the quality of life of an individual diagnosed with sarcoidosis (Kleijn et al., 2013). Specific physical activity showed no connection to depression or depressive elements in sarcoidosis.



Muscle training did not affect depression or fatigue in sarcoidosis (Karadalli et al., 2016).

Other studies revealed similar and additional factors which were found to cause depression in sarcoidosis. It was suggested that depression in sarcoidosis is related to biochemistry, fatigue, age, treatment, and low vitamin D concentrations (Groger, 2017). Depressive symptoms were known to be related to neurosarcoidosis, but depression and fatigue were not affected by treatment (Byg et al., 2022). Those who cared for the individual could affect the patient's health-related quality of life, and specific communication measures were necessary for improved patient outcomes (Saketkoo et al., 2021). Mental evaluation should be considered for sarcoidosis patients due to the increased probability of psychological involvement, which includes depression. (Goracci et al., 2008).

### ***Anxiousness***

When searching for peer-reviewed research that would provide insight into anxiousness in relation to sarcoidosis, there was a lack of available information. Insufficient doctor, diagnosed patient, or caregiver accounts reflected anxiousness as a relevant factor involving sarcoidosis mental health. This study does not declare that there were no studies that referenced anxiousness as a mental health element of sarcoidosis, but this research was not able to locate such studies.

### ***Feeling Lonely***

Very little was identified in the search for relevant studies that referenced feeling lonely as an aspect of sarcoidosis mental health. Although there was a lack of available accounts provided in research pertaining to feeling lonely and sarcoidosis, social isolation

(Flavin, 2015) was considered a factor when discussing individuals diagnosed with the disease. Doctor and caregiver accounts that pertained to feeling lonely were also lacking in research.

Out of the three mental health aspects of sarcoidosis, depression was found to be the most common mental health factor experienced by sarcoidosis patients. Doctor accounts of depression in sarcoidosis patients were present, but caregiver accounts were not. Anxiousness and feeling lonely lacked the necessary research to ensure these elements were a part of sarcoidosis mental health, but these aspects may need more exploration.

### **Instrument for Research**

Instruments that had been utilized to measure depression in sarcoidosis were the World Health Organization Quality of Life assessment instrument (Wirmsberger et al., 1988), the Center for Epidemiologic Studies—Depression Scale abbreviated version (Borson & Randall Curtis, 2001), and the Sickness Impact Profile (De Vries & Wirmsberger, 2005). Other tools that have been used in relation to measuring the health-related quality of life of sarcoidosis patients were the Sarcoidosis Health Questionnaire (Cox et al., 2003; Dudvarski-Ilic et al., 2009), the Quality of Well-Being Questionnaire and the Hospital Anxiety and Depression Questionnaire (Antoniou et al., 2006) to name a few.

Research instruments were adapted to collect the necessary data, as seen in the Polish versions of the Sarcoidosis Health Questionnaire, the Beck Depression, the Patient Health Questionnaire-9, and the Fatigue Assessment Scale (Górski et al., 2017). Since this

study utilized secondary data from digital open-source data resources from internet websites, no mental health questionnaires were used. This general qualitative study, using narrative techniques, utilized data collection protocols and data collection templates created by me. The data collection protocols are located in the Data Analysis Plan in Chapter 3. Data collection templates for this study are found in Appendices A and B. Creswell's (2013) Template for Coding a Narrative Study, found in Appendix C, was utilized to analyze the secondary data needed for this study, which were stories about sarcoidosis involving mental health and sarcoidosis legislation. The template was established as a content-driven concept for analyzing narrative data. No past or current studies that utilized Creswell's template could be located. More in-depth information about the templates utilized within this study is found in Chapter 3.

### **Gap in the Research**

This literature review showed the lack of research that established mental health elements associated with sarcoidosis as well as legislation pertaining to sarcoidosis mental health. There was an elevated incidence of depression among sarcoidosis patients, with the need for more research on the subject (Balaji et al., 2012). Depression and anxiety were found to be increasingly high in individuals suffering from chronic fatigue; however, more research was warranted to understand the factors concerning fatigue and future therapies (Kettenbach et al., 2021). Anxiety was not one of the factors that was studied in relation to sarcoidosis mental health, but anxiety was indicated in a few studies.

Although social isolation was identified with feeling lonely, there was a lack of

research that had sustained feeling lonely as a mental health aspect of sarcoidosis. Strategies for patient well-being need to be established for patient support success in relation to health-related quality of life for sarcoidosis patients (Saketkoo et al., 2021). This study addressed the gap in the literature by identifying the lack of knowledge pertaining to the relationship between the mental health aspects of sarcoidosis and how doctors, diagnosed patients, and caregivers were able to describe depression, anxiousness, and feeling lonely in relation to the disease through narrative. This study also addressed sarcoidosis legislation in relation to mental health legislation.

### **Summary and Transition**

This chapter introduced the literature review, the literature search strategy, two theoretical frameworks, and an extensive literature review of sarcoidosis and sarcoidosis mental health. Also discussed were sarcoidosis legislation, mental health legislation, the instruments utilized for this study, and the gap in the literature pertaining to this research had also been discussed. Next, in Chapter 3, the methodology of this study is discussed.

### Chapter 3: Research Method

The purpose of this general qualitative study with narrative techniques was to gather secondary data of firsthand descriptions based on the impacts of sarcoidosis within three facets of mental health: depression, anxiousness, and feeling lonely. To do so, I reviewed secondary data—the stories of three primary populations for contextual and thematic content. In extending the purpose of this research, legislation related to the disease was also explored and compared narratively to the Bipartisan Safer Communities Act of 2022, which proposed mental health measures. Online website stories told by doctors, diagnosed patients, and caregivers from YouTube, FSR, and Life and Breath Foundation for Sarcoidosis were reviewed along with a few others. A contextual and thematic approach was used to explore the words used in context and then identify themes that might reveal significant phenomena in relation to sarcoidosis mental health.

This chapter includes a discussion of the research design, the rationale for selecting the design, and the researcher's role. Also included in this section is the research methodology, which discusses the logic behind the population selection, the data instrument, how secondary data were selected and collected, and how the secondary data were analyzed. Issues of trustworthiness conceptualizing credibility, transferability, dependability, confirmability, and intra- and intercoder reliability are also discussed in this chapter. Ethical procedures pertaining to how secondary data were utilized and how the individuals in the web stories' identities remained anonymous based on any necessary permissions, copyrights, privacy, and legal stipulations conclude the methodology section of this chapter. Then, a summary of Chapter 3 follows.

## Research Design and Rationale

### Research Design

The research questions for this study were as follows:

- RQ 1: How do sarcoidosis stories from doctors, diagnosed patients, and caregivers impact mental health inclusion within sarcoidosis legislation based on depression, anxiousness, and feeling lonely?
- RQ 2: How does current sarcoidosis legislation compare to the Bipartisan Safer Communities Act of 2022?

The purpose of this general qualitative study, with narrative techniques, was to gather secondary data of firsthand descriptions based on the impacts of sarcoidosis within three facets of mental health: depression, anxiousness, and feeling lonely. Legislation related to the disease was also explored and compared narratively to the Bipartisan Safer Communities Act of 2022, which proposed mental health measures. Stories are considered life, conveying the experience narratively (Clandinn & Connelly, 2000). Consequently, this study could create a narrative that includes sarcoidosis mental health from a public policy perspective. A general qualitative study design with narrative techniques was selected for this study because there was a story to tell.

Qualitative research allows for analyzing what was human or personal and showing expressions of what was sometimes lost within the numerical aspects of clinical investigation (Patton, 2015). Qualitative studies are also utilized as a platform for the voiceless to be heard and reduce the dynamic of authority the researcher displayed over the participant (Creswell, 2013). Although narrative research is intended to relay the

human experience through story (Bryda, 2020), researchers must also be aware of what was not conveyed in the expressed account (Andrews, 2021).

This research could be conducted using other research methods, but the narrative approach needed to be added to this field of study pertaining to sarcoidosis. For instance, this study did not implement a phenomenological approach because the research was not to provide personal experiences of living with sarcoidosis. Additionally, not all population sets within the study will have personally experienced the phenomenon being explored. Phenomenological research allows for the elucidation of existence through communicated events (Creswell, 2013). No individual interviews or focus groups of participants were conducted, reducing the ethical concerns in relation to mental health.

### **Rationale**

My study was a general qualitative study with narrative techniques. This study focused on sarcoidosis mental health stories from doctors, diagnosed patients, and caregivers. I used a general qualitative study with narrative techniques to allow for a content linguistic approach to qualitative data—exploring the words used in context and then identifying trends that might reveal significant phenomena. The reasoning for utilizing narrative techniques was based on collecting stories about a particular phenomenon. Narrative study designs combine stories among individuals (Creswell, 2013).

Narrative research collects lived interactions through interviewing and reviewing of documents, photos, memorabilia, artifacts, and the numerous available mediums (Clandinin & Connelly, 2000). Digital open-source data resources along with social

media were used in this study, which equated to secondary data. Social media sites, such as YouTube, have allowed for the study of cancer patient survivors through their online posts of personal stories on the site (Chou et al., 2011). Even public health departments within the U.S. have used social media to educate and warn individuals through narratives during the COVID-19 pandemic (Caine et al., 2022). With the advancement of technology, I utilized secondary data that included stories from public domain sources provided on the internet. Using actual participants of the selected population sets were not conducted to eliminate potential ethical issues and researcher biases. Social media in research also allows the researcher to engage with unlimited data instantly (Rogers, 2019). Utilizing digital stories and text from social media sites come with issues. Inaccurate data and unauthorized data usage pose obstacles when using social media for research (Li et al., 2021). However, online data from social media sites provide plausible comprehension of lived experiences that pertain to specific medical issues (McDonald et al., 2019). With online video and text, this information had already been captured. This information could be reviewed countless times, and the collected data is considered public domain secondary data with no particular permissions needed for use.

### **Role of the Researcher**

This general qualitative study used narrative techniques to review secondary data, including videos, transcripts, and text from digital data sources. Field observations have changed over time, and it is up to the researcher to explore new options for observing and collecting data (Miles et al., 2014). Utilizing these resources excluded possible biases that would have occurred involving actual individual participants from each population set. I



did not have any direct or experienced association with the individuals utilized from the digital data sources, and this also negated any influence over participant data. Using digital secondary data sources, internet websites, allows the topic to be narrowed down promptly without creating biases between the researcher and the participant. To eliminate any other potential biases, I utilized analytic memoing, which allowed me to capture personal notes and other themes or concepts that showed connections not already accounted for in the study. Memoing the researcher's thoughts when analyzing data provides perceptive unification of the information being explored (Miles et al., 2014). Additionally, I did not institute any distinctive expectations as they pertained to the stories collected for this study.

## **Methodology**

### **Participant Selection Logic**

Qualitative research does not limit the researcher to conducting interviews or taking notes in the field. Assessing text, viewing videos, and scanning transcripts are some approaches to qualitative data collection (Creswell, 2013). Interacting with actual participants for this study was unnecessary since stories were gathered from public domain data sources and examined. The population for this study consisted of doctors, diagnosed patients, and caregivers who had provided stories from secondary data sources concerning the disease sarcoidosis. Doctors were composed of physicians who had treated patients with the disease or who had researched the illness. Patients were individuals who had been diagnosed with sarcoidosis, and caregivers were consistent with individuals who were not medical professionals and cared for the diagnosed patient

in the patient's home. Purposeful random sampling was utilized to perceive participants who were intentionally suitable for the study's purpose. When utilizing purposeful sampling, the researcher can explore the area of concern and the unique occurrence the study intended to investigate (Creswell, 2014). Doctors had to have treated a sarcoidosis patient or had done prior research on the disease to qualify for this population set.

Patients were selected for the sample based on having a diagnosis of the disease.

Caregivers were selected for the caregiver population set based on not being considered professionals within the medical field, and the caregiver lived with the patient or visited the sarcoidosis patient in the patient's home. The doctors were able to provide the medical perspective of the disease, diagnosed patients allowed for an individual perspective of sarcoidosis, and caregivers were able to support the perspective of assisting someone with the disease.

The stories were only specified in the fact that the story was about sarcoidosis. All stories were about sarcoidosis, with the mental health aspect discovered during analysis and not before. Some stories relayed the mental health aspects of the disease in the narrative title. These stories were not considered applicable to the study or part of the bulk of the secondary data. This study was to review 25 videos and transcripts from YouTube, along with 25 sarcoidosis stories ( $N = 50$ ) relayed in text versions from FSR and Life and Breath Foundation for Sarcoidosis. Other possible reputable sarcoidosis websites containing stories about the illness were also utilized. If saturation could not be met with the provided number, then 50 videos and transcripts, along with 50 text relayed stories, were to be reviewed not to exceed 100 stories. The protocols for collecting the

secondary data from websites for the population sets are listed under the Data Analysis Plan section, and legislation is discussed under the Instrumentation section of this chapter.

A saturation method in research was when data became redundant, and no new impressions were pinpointed (Hennink & Kaiser, 2022). Although FSR (2022) reported that 10% of sarcoidosis patients who developed the disease had a poorer quality of health, this study aimed to show that more individuals have dealt with one or more of the mental health aspects of sarcoidosis. The researched literature implied that fatigue, neurosarcoidosis, and chronic sarcoidosis were all related to one or more of the mental health aspects of sarcoidosis, as well as a poorer quality of life. This study reached data saturation when 25% of the collected stories relayed one or more of the mental health aspects of sarcoidosis based on depression, anxiousness, and feeling lonely.

### **Instrumentation**

This general qualitative study, using narrative techniques, used researcher-developed data collection instruments and a published data analysis template for coding based on the story. Although this study utilized secondary data, it was necessary to provide the difference between primary and secondary data. Primary data pertained to original data collected for the first time from an actual source; secondary data was the primary data stored and then utilized within other research after the initial study (Hox & Boeije, 2005). The basis for a researcher-developed instrument for data collection was instituted due to the accumulation of secondary data. Secondary data was structured and practical for researchers with time constraints and budgets (Johnson & Sylvia (2018).

Content validity was established by allowing the data collection templates to answer the research questions generated for this study specifically. Also, the templates were reviewed by one outside faculty member, Dr. Nicole Hayes from Walden University, in order to obtain content validity for the researcher-developed instrument. A template was created for research question one concerning sarcoidosis mental health and research question two referencing sarcoidosis legislation. In searching for secondary data protocols and data collection templates, nothing was found that directly related to the protocols and data collection the researcher had intended for the study. The data collection protocols are found in this chapter's Data Analysis Plan section, while data collection templates for this study are found in Appendices A and B.

Secondary data was analyzed utilizing Creswell's (2013) Template for Coding a Narrative Study. In reviewing the coding template used for this study, the template was established as a content-driven coding concept for analyzing data. The Template for Coding a Narrative Study was based on the plot structure approach or the three-dimensional model (Creswell, 2013). This study utilized the plot structure approach. Researchers should establish the necessary approach by applying the concepts within the Template for Coding a Narrative Study (Creswell, 2013). Dr. Creswell and SAGE Publications were contacted about copyright permissions for the electronic reprinting of Creswell's narrative coding template. This researcher was then directed to contact the Copyright Clearance Center and completed a request for permission form about utilizing the coding template within this study. The request for use was denied based on the fact that no permissions were necessary to utilize the Template for Coding a Narrative Study

because SAGE Publication allowed for the use of the template due to SAGE's Pre-Approved Permissions Policy use for dissertations. Due to possible copyright permissions and fees for modifying the template, no new illustration of the coding template, which excluded the three-dimensional bracketed section, was available for this study.

Most of the videos that were uploaded to YouTube usually came with an entirely written transcript of the video. These transcripts and text from the other posted web stories were assessed with the Template for Coding a Narrative Study. If any videos from public domain data sources did not have a transcript, then these videos would have had to be transcribed manually. If manual transcription had to be performed, this study would have applied VLC Media Player and Google Transcribe Audio to Text, a free transcription service by Google. Using more than one method of accumulating data was one of the many ways for the researcher to circumvent bias (Miles et al., 2014).

### **Data Collection and Analysis Instruments**

I created the data collection protocols listed in this chapter and the data collection templates in Appendices A and B. The protocols pertained directly to the procedures for collecting secondary data, and the templates correspond to both research questions based on data collection for this study. In utilizing the researcher-developed protocols and templates designed for this study, these instructions and forms were equivalent to interviewing the data, as if one were interviewing an actual person. Delve software was utilized to store the collected data for this study.

The Template for Coding a Narrative Study was published as a method of data analysis when conducting research with a narrative design (Creswell, 2013). Although

there were several ways to code qualitative data for a general qualitative study, no prior studies were found utilizing Creswell's template. No instructions on how to use the template were located, and the format seemed self-explanatory based on the presented concepts of the form. It is warranted that the researcher gathers as much data as possible from the story based on time, the central theme, and individual and collective viewpoints of the phenomenon (Creswell, 2013). A thematic narrative coding structure was also included in Creswell's template. This study focused on the template structure based on plot, chronology, and themes. Once completed, the manually coded narratives for each transcript and text were stored on a 2Terabite drive along with coded legislation.

Since the template had yet to be identified with any particular study, the reliability and validity of the instrument became questionable. Several other narrative coding templates have been used in research. Researchers developed many ways of data analysis by designing guides for what information would be pertinent to the study being conducted with the assistance of technological software (Creswell, 2013). Delve qualitative coding software was utilized to recreate Creswell's template for digital use of data analysis and memoing to increase the reliability and validity of the narratives collected. Utilizing computer software for coding data allows for consistency and credibility of systematically arranged information that was amassed for inquiry (Creswell, 2013).

### **Procedures for Recruitment, Participation, and Data Collection**

This study was to include a purposeful random sample of 50 stories from doctors, diagnosed patients, and caregivers in relation to sarcoidosis mental health. These stories

were in the format of videos and transcripts, along with posted narratives in text from digital open-source data resources with public domain permissions. The secondary data was collected by me. Secondary data was collected by viewing videos, reading transcripts, and overlooking text from YouTube, FSR, the Breath and Life Foundation, and other potential websites. Secondary data was to be collected for 40 days, with 20 days to meet saturation and 20 days more if saturation was not met within the first 20 days. Secondary data was not to exceed 100 stories. Secondary data was collected utilizing the interview protocols and data collection templates created by me, along with memoing and visual and readable observations. The secondary data was analyzed using the Template for Coding a Narrative Study. If my recruitment plan culminated in having an insufficient population sample, then I would have to rely on secondary data from other reputable digital open-source data resources that pertained to sarcoidosis showcasing the population sets as my sources of reliable information for this research to continue.

This study also reviewed sarcoidosis legislation and compared the legislation to the Bipartisan Safer Communities Act of 2022. Secondary data collection for sarcoidosis legislation was from the U.S. Congress's website, which housed many different pieces of sarcoidosis legislation. Congress' website was also a known digital open-source data resource with public domain permissions. I also collected this secondary data. Secondary data was to be collected by reviewing the text of all presented legislation concerning sarcoidosis for 15 days and notetaking through memoing and readable observations. Secondary data was analyzed using the Template for Coding a Narrative Study. Reviewing narratives concerning sarcoidosis legislation provided insight into the social

viewpoint of the disease.

Since this study utilized collected secondary data, which had already been created and was located within the digital open-sourced public domain, this study did not have to have a withdrawal plan for participant participation. The stories of doctors, diagnosed patients, and caregivers pertaining to sarcoidosis were researched. The mental health elements of the disease that were analyzed are depression, anxiousness, and feeling lonely. Also, no plan for exiting the study was necessary, or any debriefing procedures were established. There were no follow-up procedures for this study. Since digital open-source data resources were collected, this study did not utilize any demographic information from the stories, such as name, age, gender, race, employment, income level, and so forth. Utilizing digital open-source data resources allowed for the reduction of researcher bias and any ethical concerns.

### **Data Analysis Plan**

Researchers need to consider how data is analyzed (Maxwell, 2013). This study collected secondary data from the provided digital open-source data resources, which yielded insight into the mental health aspects of sarcoidosis pertaining to depression, anxiousness, and feeling lonely. These stories were collected from three population sets: doctors, diagnosed patients, and caregivers. Stories were collected from digital open-source data resources that have public domain permissions. Other pertinent secondary data pertaining to the plot of the narrative, chronology, and associated themes also provided rich descriptive data, which allowed for an understanding of the topic. Also, secondary data from the U.S. Congress's website provided insight into the current



legislation passed and pending legislation about sarcoidosis. Reviewing legislation about sarcoidosis and comparing it to mental health legislation allowed for the development of a narrative about sarcoidosis and mental health.

Discovering and organizing data for inquiry purposes was necessary within qualitative research (Patton, 2015). Coding words and phrases was one of the many methods utilized within narrative studies. Provisional coding and emotion coding were utilized, and the labels of depression, anxiousness, and feeling lonely were employed as the main themes. The rich, thick text was utilized to provide data for the plot and the chronology of the reviewed narratives. In Vivo coding was also utilized for memoing purposes to capture any additional themes presented during secondary data analysis. Memoing was also used to identify any personal notes during data analysis.

The protocol for analyzing digital secondary data for this study was as follows:

- Become familiar with websites being utilized for the study
- Locate necessary secondary data pertaining to sarcoidosis in narrative format
- Review videos and take notes (transcribe if no transcript is available)
- Review transcripts/text and take notes
- Create Word documents for transcripts/text (Once all steps are completed, come back to this step, upload Word documents into Delve software, and follow the remaining steps again for computerized analysis)
- Read through Word documents and look for meanings, themes, and patterns

- Decide what to code and apply codes already created based on the Template for Coding a Narrative Study
- Add new codes as needed
- Collate codes with secondary data excerpt
- Adjust and revise codes as needed
- Group new codes into the themes based on the Template for Coding a Narrative Study
- Evaluate and revise themes
- Conclude analysis

The procedure for coding followed the Template for Coding a Narrative Study.

The story was first identified. This information included the name of the digital open-source data resource, the title of the video, transcript, or text, and data citation. Next, the plot was identified with the following codes and values applied: Character = population set; setting = issue of sarcoidosis; problem = sarcoidosis issue in relation to mental health based on fatigue, systemic or chronic sarcoidosis, and neurosarcoidosis; action = what was done in relation to the problem; and resolution = the results of the action taken. Next, the story's chronology and the events concerning sarcoidosis were reviewed based on epiphanies = the issues that occurred in relation to sarcoidosis, and events = when these epiphanies took place. The last coding section of the template discussed was the thematic section. This section identified the mental health aspects of sarcoidosis based on depression, anxiousness, and feeling lonely. Discerning experiences accounted for the basis of narrative inquiry (Patton, 2015).

The procedures for coding the legislation were similar to utilizing the Template for Coding a Narrative Study. Under the section on plot structure, the character = the population being discussed; setting = the department bringing about the proposed legislation; problem = sarcoidosis issues listed within the legislative narrative; action = the idea being presented within the legislation about sarcoidosis; and resolution = the actions which have taken place since the legislation's introduction. The themes section of the template was utilized to analyze other concepts within the legislation.

Delve qualitative software was utilized to capture, store, and identify secondary data based on the narratives selected to review for this study. IBM SPSS was not necessary for any calculated secondary data that pertained to data analysis. Also, VLC Media Player and Google Transcribe were not used to relay any videos lacking a transcript to text suitable for review. Discrepant cases were coded accordingly to show that the collected secondary data was compatible.

### **Issues of Trustworthiness**

#### **Credibility, Transferability, Dependability, Confirmability**

Trustworthiness within research has been achieved through methods of validation and evaluation (Creswell, 2013). This study utilized validation methods relating to trustworthiness revolving around credibility, transferability, dependability, and confirmability. The evaluation method selected for this study pertained to memoing. Credibility was achieved through unrestricted thinking and an organized method of inquiry, which produced distinctive discoveries (Patton, 2013). Credibility for this study was determined through descriptive and interpretive text that relayed the mental health

aspects of sarcoidosis. The credibility of the collected secondary data also came from triangulation based on the three different population sets, which provided insight into the phenomenon from three perspectives. These perspectives were considered collective and did not display contrast.

Transferability was possible when research could be generalized (Miles et al., 2014). This study displayed transferability by allowing the research to be conducted further by seeking additional narratives from other social media platforms. This study allows for research on other illnesses to be conducted in such a manner. Dependability for a study had been achieved when data became corresponding (Miles et al., 2014). Additional strategies to establish credibility, transferability, and dependability included comparing the literature and secondary data collected along with manual and computerized analysis. Thick, rich descriptions from the literature compared with the collected secondary data provided a connection between the secondary data and theory-based research. Confirmability within a study was established through the applicability of the research methodology utilized (Miles et al., 2014). In order to gain control over the confirmability of this study, it was necessary to provide a detailed process of how secondary data was accumulated, examined, and construed, which can be found in the Procedures for Recruitment section of this study. Also, memoing was provided as a method of confirmability, allowing for any personal notes and any additional themes not mentioned to be collected.

### **Ethical Procedures**

This study was conducted according to Walden University's International Review

Board. Moral apprehensions were a significant element that needed to be considered at the onset of a study (Creswell, 2013). Since this study related to mental health, there were many concerns about recruitment materials and the overall methodological process. Consent involving mental health data from digital sources was noted to be an issue (Nichols et al., 2020). Data that was contributed with full knowledge of the participant would assist in resolving future consent concerns based on mental health and social media posted publicly displayed narratives. Ethical concerns pertaining to this study were minimal since the research utilized digital open-source data resources with public domain permissions. The stories that were collected about sarcoidosis from YouTube, FSR, and the Breath and Life Foundation were easily accessible to any individual who may visit these websites. There were no ethical concerns in collecting secondary data since the data collected from internet websites had public domain permissions on the information provided within a public forum space. With the secondary data being collected from digital open-source data resources with public domain permissions, ethical concerns about using secondary data were diminished. Ethical considerations should be well-thought-out according to the different units of the study that were combined in the research (Creswell, 2013). Demographic data was not considered since face-to-face interviews were not utilized. Secondary data was stored on an external 2Terabyte drive for five years. I am the only one to have access to the secondary data. After five years, the secondary data will be destroyed. I have sarcoidosis, and I eliminated bias by not interviewing actual participants and by gathering secondary data, which were stories from the internet concerning the mental health aspects of the disease. Memoing was also

instituted during secondary data collection and analysis to prevent possible researcher bias and identify additional themes that were not previously recorded. Also, the International Review Board (IRB) for Walden University was contacted by email about using internet data from social media and public websites. The International Review Board responded by email, relaying that no permission was needed due to the secondary data being collected from sources with public domain permissions.

### **Summary and Transition**

This chapter introduced the methodology for this study, which discussed how the general qualitative design with narrative techniques was utilized and the rationale for the design. Also discussed in Chapter 3 was the role the researcher partook in the study, along with the methodology of the study, which included the logic for participant selection, the instrument for data collection, the procedures for recruitment, participation, and secondary data collection, as well as the data analysis plan. This chapter ended with the issues of trustworthiness based on credibility, transferability, dependability, confirmability, and intra and intercoder reliability. Although digital open-source data resources with public domain permissions were utilized for this study, ethical procedures based on demographic data were still implemented to allow for participant anonymity. Next, Chapter 4 discusses the results based on the utilization of the presented methodology.

## Chapter 4: Results

The purpose of this general qualitative study with narrative techniques was to gather secondary data of firsthand descriptions based on the impacts of sarcoidosis within three facets of mental health: depression, anxiousness, and feeling lonely. In doing so, I reviewed the stories of three primary populations for contextual and thematic content. Legislation related to the disease was also explored and compared narratively to the Bipartisan Safer Communities Act of 2022, which proposed mental health measures. The research questions for this study were as follows:

- RQ 1: How do sarcoidosis stories from doctors, diagnosed patients, and caregivers impact mental health inclusion within sarcoidosis legislation based on depression, anxiousness, and feeling lonely?
- RQ 2: How does current sarcoidosis legislation compare to the Bipartisan Safer Communities Act?

Chapter 4 displays the results of this study utilizing text and numerical values, along with tables and figures to assist in explaining what was observable within the collected secondary data. These results were based on the preselected and discovered themes, which allowed for the coding of the secondary data and additional categories to be uncovered. This chapter includes pertinent information in relation to the setting of the study, demographics, data collection, data analysis, evidence of trustworthiness, and the study's results, along with a summary of the chapter.

### **Setting**

Since secondary data were utilized for this study, I established the setting for

collecting and analyzing the data. A review of the secondary data collection instruments was conducted to ensure no changes were needed before utilizing the documents for data collection. Only after all items needed for secondary data collection were set up and made readily available, along with IRB approval, did data collection and analysis begin. My home office was the primary setting for data collection and analysis. No personal or organizational conditions influenced the collection of secondary data or any experiences that influenced the interpretation of the study results.

### **Demographics**

Secondary data pertained to the stories of sarcoidosis doctors, patients, and caregivers. These stories were based on videos, transcripts, and text stories collected from various websites. Legislation that pertained to sarcoidosis was collected from the U.S. congressional website. The original number of stories to be collected was 50, but due to some of the stories containing more than one population set, the total number of stories obtained for the study was 54. The secondary data based on narratives had a chronological timeline based on the population sets. Narratives from sarcoidosis doctors ranged in dates from 2013 to 2023, sarcoidosis patients narratives from 2016 to 2023, and sarcoidosis caregivers narratives from 2008 to 2023. In relation to legislation, the chronological timeline ranged from the 85<sup>th</sup> Congress of 1957 to 1958 to the 117<sup>th</sup> Congress of 2021 to 2022.

Demographic data were not considered since I did not have the opportunity to question participants in face-to-face interviews. Further, the population sets pertaining to sarcoidosis legislation was the general public, which included doctors, patients,



caregivers, and family members. Military personnel and veterans were considered separate populations due to legislation specific to the armed forces for current and former personnel. There was no predetermined number for the collection of sarcoidosis legislation.

### **Data Collection**

The secondary data collected for the study consisted of stories from 11 doctors, 38 patients, five caregivers, and three stories that did not pertain to any population set. Secondary data pertaining to sarcoidosis stories for each population set were collected from various online websites, including the following: Youtube.com, Stopsarcoidosis.org, LifeandBreath.org, CleavlandClinic.org, PennMedicine.org, Lung.org, TempleHealth.org, SarcoidosisNews.com, and Inspire.com. The search terms utilized on the internet and at each website were *sarcoidosis*, *sarcoidosis stories*, *sarcoidosis doctor stories*, *sarcoidosis patient stories*, and *sarcoidosis caregiver stories*. No stories were searched using the terms *depression*, *anxiousness*, or *feeling lonely* to avoid skewing the study results.

Legislation in relation to sarcoidosis was numbered at 42. The website utilized for sarcoidosis legislation was Congress.gov. The search term for sarcoidosis legislation was *sarcoidosis*, along with filtering the search for legislation only, all congressional sessions, and relevancy of oldest to newest based on the date of introduction.

I collected data within 18-days. Each secondary data collection instrument related to each research question took approximately 9 days each to find, review, and collect the necessary secondary data. Secondary data were collected manually utilizing the

secondary data collection instruments, which I created and were approved by the IRB at Walden University (IRB approval #12-18-23-0316069). Videos were viewed, transcripts and text were read, and secondary data were captured from this process and entered manually by me. Stories and legislation were kept in separate digital folders and then later reviewed to establish the consistency of the data collected. The only variation in the data collection from the presented plan in Chapter 3 was that the data collection took less time than the predicted 40 days (20 days for each research question). The unusual circumstance during data collection was the lack of secondary data pertaining to doctor and caregiver stories.

### **Data Analysis**

Data analysis lasted approximately 10 days (6 days for stories and 4 days for legislation). Some themes were already preselected based on the research questions provided for the study. The themes utilized within this study were depression, anxiousness, and feeling lonely. The categorization of the population sets was also predetermined. No preset themes were utilized for the legislation, so themes were created based on the legislation type: laws, bills, amendments, resolutions, joint resolutions, and concurrent resolutions. All stories and legislation either had a transcript provided or were written in text format on the website, so transcription of stories was not necessary for this study.

A total of 27 video stories, 27 text stories, and 42 pieces of legislation were reviewed for this study. Each story transcription/text and piece of legislation text was copied and pasted into a Word document, and stories were separated from legislation in

electronic files. Once data were manually collected, these files were transferred digitally to the secondary data collection instruments and filed electronically. All collected secondary data were saved on a 2Terabyte drive, and then the completed secondary data collection instruments were again saved digitally into Delve software. Narratives were separated as sarcoidosis stories (VS for video stories and TS for text stories) and sarcoidosis legislation (LT for legislation text).

### **Process for Data Coding and Analysis**

Delve software was also utilized to code the collected secondary data. The coding methods utilized within this study were provisional, emotion, and In Vivo coding. Provisional coding was utilized for the mental health aspects of sarcoidosis, which were depression, anxiousness, and feeling lonely. These codes were created based on the foundational inquiry anticipated within the secondary data before analysis. Emotion coding was utilized to capture rich, thick descriptions within the stories and legislation related to the contributed emotive states. In Vivo coding was utilized to maintain researcher notes, along with the negative impacts, a categorized code added due to the many participants' explained involvements of adverse effects in relation to sarcoidosis.

Coding and analysis for both research questions were based on the Template for Coding a Narrative Study, found in Appendix C. Utilization of the template for this study can be found in Appendix D. Table 2 contains the preset and found themes, along with the codes and categories that emerged from the stories for the first research question secondary data collection instrument. The themes, codes, and categories created for the second research question for the secondary data collection instrument are in Table 3.

**Table 2***Sarcoidosis Stories Secondary Data*

THEMES	CODES	CATEGORIES
Depression	Psychological burdens	Doctors
Anxiousness	Negative impacts	Patients
Feeling lonely	Neurological manifestations	Caregivers
		Population
		Death
		One organ
		Systemic
		Researcher notes

**Table 3***Sarcoidosis Legislation Secondary Data*

THEMES	CODES	CATEGORIES
Public law	Mental health military	Population military
Bill	Sarcoidosis mental health	Population general public
Amendment	Sarcoidosis relation chronic disease	One organ
Resolution	Sarcoidosis relation environmental exposures	Systemic
Joint Resolution	Sarcoidosis autoimmune condition	
Concurrent Resolution	Sarcoidosis relation misc.	
	Sarcoidosis rare disease	
	Sarcoidosis awareness	
	National Sarcoidosis Awareness	

**Descriptive Text in Relation to Themes for RQ 1**

Under the theme of depression, VS7, told by a doctor, described how “Patients may be affected by symptoms that are more difficult to quantify, such as fatigue or a sense of hopelessness or depression.” A patient, TS21, listed under the theme of anxiousness, conveyed, “Sometimes when I awake in the morning, I’m afraid of what my day may bring.” Patient TS11 expressed the theme of feeling lonely by stating, “The thing that I have troubles with is because you get bedridden, you get isolated.” More

information pertaining to sarcoidosis stories based on narrative expressions can be seen in Table 4 of the Results section of this chapter.

Psychological burdens described by VS5, a patient, indicated, “I have learned to manage and live with the physical changes; it’s not that bad. Perhaps more of a challenge is living with the emotional scars.” Negative impacts related to VS18, a patient who shared, “I didn’t have income. I didn’t have no way to pay my rent, my bills, get my medication, pay to see the doctors.” Neurological manifestations were mentioned by TS25, a patient who stated, “I explained to him that breathing affects what your body can and cannot do, and that includes a lot of motor skills.”

### ***Discrepant Cases***

Three discrepant cases did not qualify under any population set: VS25, VS26, and VS27. These video stories pertained to sarcoidosis but were mainly informational videos versus someone telling a story. More information on the discrepant cases can be found in the Results section of this chapter.

### **Descriptive Text in Relation to Themes for RQ 2**

The themes created for the discovered sarcoidosis legislation related to the type of legislation associated with the disease sarcoidosis. Regarding actual public laws, LT3 and LT5 approved bills supporting “Designating August 29, 1990, as "National Sarcoidosis Awareness Day.” Neither of these pieces of legislation included any mention of sarcoidosis mental health, depression, anxiousness, or feeling lonely. There were no discrepant cases in relation to sarcoidosis legislation. The comparison of sarcoidosis legislation to the Bipartisan Safer Communities Act of 2022 appears in the Results

section of this chapter. More information in relation to sarcoidosis legislation can also be found in the Results section of this chapter.

### **Evidence of Trustworthiness**

This study utilized validation methods related to trustworthiness, including credibility, transferability, dependability, and confirmability. The evaluation method selected for this study was memoing based on researcher notes.

#### **Credibility**

The credibility of this study was determined through descriptive and interpretive text relaying the mental health aspects of sarcoidosis. The credibility of the collected secondary data came from triangulation based on the three different population sets, which provided insight into the phenomenon from three perspectives.

#### **Transferability**

This study displayed transferability by allowing the research to be conducted using additional narratives that were provided by other websites. Additional strategies utilized to establish credibility, transferability, and dependability were the observed comparisons of the literature and secondary data, which had been collected manually and digitally, and then analyzed digitally. Thick, rich descriptions from the literature compared with the collected secondary data provided a connection between the secondary data and theory-based research.

#### **Dependability**

The study's dependability was achieved through triangulation based on the collected secondary data of stories from three different population sets, the review of

legislation pertaining to sarcoidosis, and the peer-reviewed literature found within Chapter 2 of this study.

### **Confirmability**

The detailed process of how secondary data was accumulated, examined, and construed confirmed this study. I used memoing as a method of confirmability, which allowed for personal notes to be collected and any additional themes that may not have been mentioned.

## **Results**

The results of this study were applied to each research question and significant data pertaining to sarcoidosis mental health was provided to support the study's purpose. The purpose of this general qualitative study with narrative techniques was to gather secondary data of firsthand descriptions based on the impacts of sarcoidosis within three facets of mental health: depression, anxiousness, and feeling lonely. Secondary data, the stories of three primary populations, were reviewed for contextual and thematic content. In extending the purpose of this research, legislation related to the disease was also explored and compared narratively to the Bipartisan Safer Communities Act of 2022, which proposed mental health measures.

### **Results RQ 1**

The first research question was, "How do sarcoidosis stories from doctors, diagnosed patients, and caregivers impact mental health inclusion within sarcoidosis legislation based on depression, anxiousness, and feeling lonely?" The collected stories from the three population sets revealed four stories and seven instances that included

depression, five stories that reported anxiousness, and five stories that relayed feeling lonely. Two stories overlapped with depression and anxiousness, while another story overlapped with depression and feeling lonely, which can be seen in Table 4.

With a total of 54 stories, 25% needed to contain at least one of the main themes pertaining to sarcoidosis mental health aspects to reach data saturation. Only 13.5 of the stories needed at least one of the themes present, and there was a total of 14 that contained at least one of the themes, meeting data saturation. Some of the secondary data collected relayed information, such as TS14, a patient, discussing having “mood swings” and “depression,” and how TS19, a doctor who talked about “anxiety.” A detailed account of the collected data for RQ 1 can be seen in Table 4.

## **Results RQ 2**

The second research question was, “How does current sarcoidosis legislation compare to the Bipartisan Safer Communities Act of 2022? The collected legislation was reviewed and compared to the mental health sections of the Bipartisan Safer Communities Act (2022), which related to mental and behavioral health services for children and families. Fifteen pieces of legislation referenced mental health measures, but nine were exclusive to military personnel, veterans, and their families. Five pieces of legislation referenced sarcoidosis mental health inclusion based on depression and one piece of legislation related to emotional support resources. Some of the secondary data relayed information, such as LT17 discussing “environmental sarcoidosis” in relation to “medical research programs.” Also, in LT1, sarcoidosis is listed as a “chronic disease,” or LT19 about how sarcoidosis is related to “autoimmune diseases” and considered, as



listed in LT30, one of the many “rare diseases” or as in LT39, one of the few “rare disorders.” A detailed account of the collected data for RQ2 can be seen in Table 5.

In comparing sarcoidosis legislation to the Bipartisan Safer Communities Act (2022), there were several texts with no mental health inclusion in legislation pertaining to the disease. Although six pieces of legislation referenced some mental health aspects (LT19, LT21, LT23, LT24, LT25, & LT27), there was no mention of mental health services and nothing about mental health for children or any association with schools. Also, no federal departments were enlisted to help those with sarcoidosis, unlike the Bipartisan Safer Communities Act of 2022. Funding for research on the disease was mentioned. However, no suicide prevention for sarcoidosis patients and no training for those within the medical field in treating those with mental health issues in relation to the disease were found.

### **Discrepant Cases**

As discussed earlier, three descript cases, VS25, VS26, and VS27, did not qualify under any population sets. Although the videos relayed information about sarcoidosis, VS25 and VS27 did not present the preset themes of depression, anxiousness, and feeling lonely. All these video stories did qualify for the study under the coding for negative impacts and neurological manifestations.

In revealing the negative impacts on the quality of life caused by sarcoidosis, VS25 discussed how the disease “may last for years” and “cause organ damage.” VS27 discussed the development of “restrictive lung disease because sarcoidosis causes interstitial lung fibrosis.” Neurological manifestations revealed, such as from VS25, an

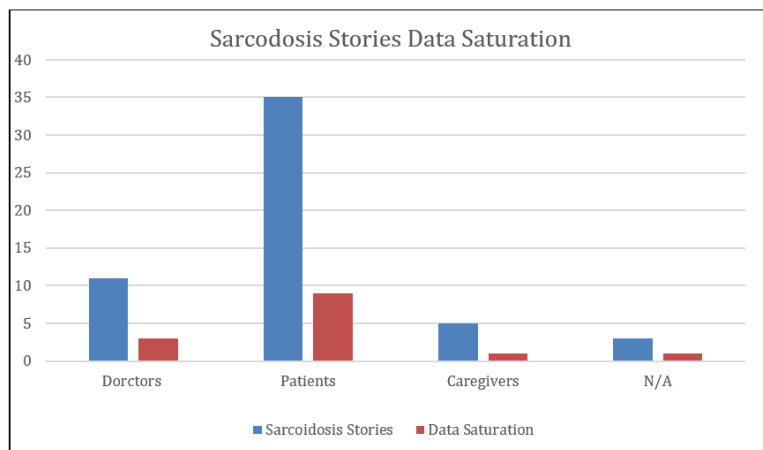
issue of the “brain,” and VS27 discussed “facial muscle” complications.

### **Gap in Research**

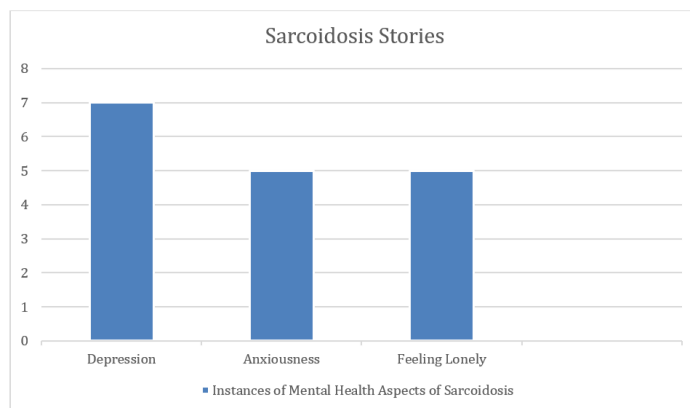
The gap in research, as addressed in Chapter 2, referenced the lack of research pertaining to sarcoidosis mental health based on depression, anxiousness, and feeling lonely. Several stories described bouts of depression, anxiousness, and feeling lonely, and the literature review reported the lack of research based on these mental health aspects. Even a few pieces of legislation called for more research on the disease and support for sarcoidosis patients and their families, similar to the available studies in Chapter 2.

### **Results Table RQ 1**

Basic tables with numerical values and text were utilized to support the collected secondary data based on reviewing the data, collating the results of the collected information, and providing the preset and created themes, codes, and categories. IBM SPSS was not utilized for this study. In relation to RQ1, sarcoidosis stories, Figure 1, which displays numerical data, is based on the tally of the represented population based on the three mental health aspects in relation to sarcoidosis. Figure 1 displays a sample population configuration based on the preset themes of depression, anxiousness, and feeling lonely and accounts for the met saturation of the study based on 54 selected sarcoidosis stories.

**Figure 1***Sarcoidosis Stories Data Saturation*

The saturation that needed to be met was 13.5 stories. Fourteen stories provided the necessary data to obtain data saturation for this study, along with 17 instances of the mental health aspects of sarcoidosis being mentioned, as seen in Figure 2.

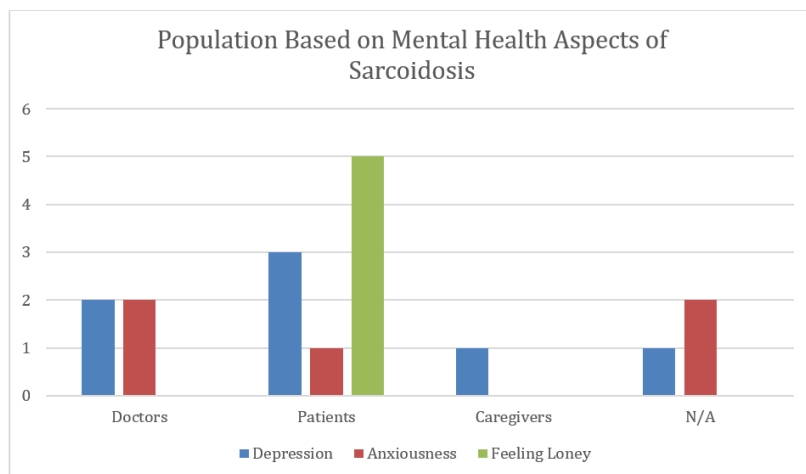
**Figure 2***Instances of Mental Health Aspects of Sarcoidosis*

Among doctors, patients, and caregivers, depression was mentioned more than any other mental health aspect in relation to sarcoidosis, with seven instances totaled.

Anxiousness and feeling lonely tied for second, having five stories each relating to sarcoidosis mental health. Patients also reported more incidences of depression, anxiousness, and feeling lonely than any other population set. Doctors did not discuss feeling lonely in dealing with sarcoidosis, and caregivers described depression as an issue pertaining to the illness. The discrepant population set noted depression and anxiousness, which can be seen in Figure 3. Table 4 displays texts of the stories based on codes, themes, and narrative expressions in relation to the mental health aspects of sarcoidosis.

**Figure 3**

*Population Based on Mental Health Aspects of Sarcoidosis*



**Table 4***Sarcoidosis Stories in Relation to Codes, Themes, and Narrative Expressions*

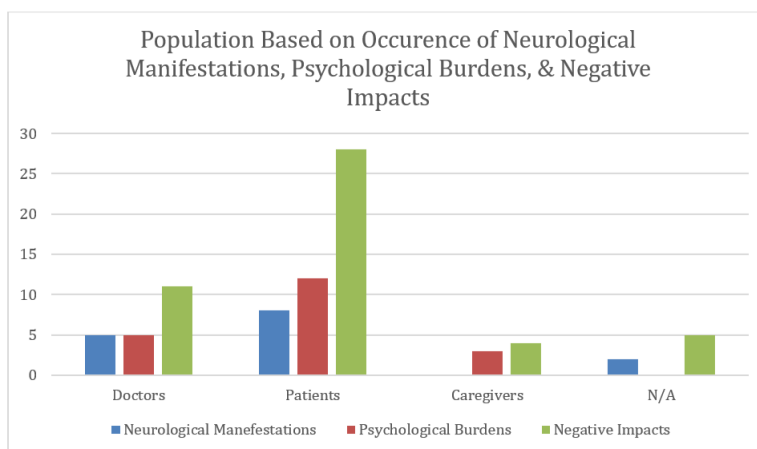
Sarcoidosis Stories	Population Set	Themes	Narrative Expressions
VS7	Doctor	Depression/Anxiousness	Depression hard to spot, sense of hopelessness
VS8	Patient	Depression	Depressed
VS18	Patient	Depression/Feeling lonely	Stressful dealing with abusive caregiver/not around people for a long time
VS26	N/A	Anxiousness	Depression hard to spot, sense of hopelessness
TS1	Patient	Anxiousness	Depressed
TS4	Patient	Feeling lonely	Stressful dealing with abusive caregiver/not around people for a long time May be challenging to live with
TS8	Patient	Feeling lonely	Bodily stress caused by a combination of issues
TS10	Patient	Feeling lonely	Isolation from family and friends, lonely disease, feeling different, alone
TS11	Patient	Feeling lonely	Patients think they are alone
TS14	Patient	Depression	Tired, crying
TS17	Patient	Feeling lonely	Isolated from being bedridden, does not socialize
TS19	Doctor	Depression, anxiousness	Mood swings, depression
TS21	Patient	Anxiousness	Sad, feeling alone
TS23	Caregiver	Depression	Depression, anxiety Anxiousness Manic depression

The occurrences that may arise due to the mental health aspects of sarcoidosis are also conveyed. A sample configuration of characteristics based on occurrences related to sarcoidosis was made available for this study to show the connection between neurological manifestations, psychological burdens, and negative impacts related to the disease. There were more negative impacts with sarcoidosis than any other occurrence,

tabulating 46 stories. Psychological burdens were emphasized in at least 20 of the collected stories, while neurological manifestations were pinpointed in 15, as shown in Figure 4.

#### Figure 4

##### *Population Based on Occurrence*



Some of the neurological manifestations described were mobility and motor function issues (VS6, TS25), neurosarcoidosis (VS20, VS26, TS4, TS7), brain fog (VS18), the brain (VS11, VS17), and the nervous system (VS11, VS13). Psychological burdens were labeled as in TS3 reporting “frustration,” while TS19 expressed “mood change.” The negative impacts emphasized from the secondary data were identified in VS7, where sarcoidosis was “difficult to diagnose,” and VS9, and how “sarcoidosis can affect almost every part of the body.” TS19 reflected, “For some patients, it may take several months to years before a diagnosis is determined.”

#### Results Table RQ 2

In relation to RQ2, sarcoidosis legislation, Table 5 displays the legislation specific

to sarcoidosis. There are two laws pertaining to sarcoidosis: LT3 and LT5. LT3 and LT5 designated August 29, 1990, as National Sarcoidosis Awareness Day. LT4 is an amendment to LT3, and LT4 designated August 29, 1990, as National Sarcoidosis Awareness Day as well. All other sarcoidosis legislation was either introduced or agreed to in the House.

Although there were no discrepant cases in relation to legislation, there was a typographical error in its online congressional listing. LT3, which is House Joint Resolution 519 designating April 16, 1990, as National Sarcoidosis Awareness Day, the actual statute read as Designating August 29, 1990, as National Sarcoidosis Awareness Day. The Committee Discharged Senate text, Engrossed in-House text, the Referred in Senate text, and the Enrolled Bill text all read as the statute.

The error came in the Introduced to House text, which called for the designated awareness day as April 16, 1990. I could not locate any data that pertained to the reasoning behind the change in designation dates for this actual law. Legislation specific to sarcoidosis can be seen in Table 5.

**Table 5***Legislation Specific to Sarcoidosis*

Sarcoidosis Legislation	Themes	Legislation Name/Description	Legislation Status
LT3	Law	H.J. Res. 519 - Designating April 29, 1990 as “National Sarcoidosis Awareness Day.”	Became law
LT4	Amendment	H. Amdt. 706 to H.J. Res. 519 - Amending H.J. Res. 519 designating Aug. 29, 1990 “National Sarcoidosis Awareness Day.”	Agreed to w/o objection
LT5	Law	H.J. Res. 309 – Designating Aug. 29, 1991, as “National Sarcoidosis Awareness Day.”	Became law
LT6	Joint Resolution	H.J. Res. 399 – Designating Aug. 29, 1994, as “National Sarcoidosis Awareness Day.”	Introduced
LT7	Concurrent Resolution	H. Con. Res. 429 – Expressing the sense of the Congress that there should be established a National Sarcoidosis Awareness Day, and for other purposes.	Introduced
LT20	Resolution	H. Res. 1149 – Expressing support for the designation of April 2008 as National Sarcoidosis Awareness Month, and supporting the effects to devote new resources to research the causes of disease, environmental and otherwise, along with treatments and workforce strategies to support individuals with sarcoidosis.	Agree to in House
LT26	Concurrent resolution	H. Con. Res. 262 – Supporting the goals and ideals of National Sarcoidosis Awareness Month in April 2010 and supporting efforts to devote new resources to research the causes of the disease, environmental and otherwise, along with treatments and workforce strategies to support individuals with sarcoidosis and their families	Introduced
LT27	Resolution	S.R. 443 - A resolution designating April 2016 as “National Sarcoidosis Awareness Month.”	Introduced

In giving more insight into the sarcoidosis legislation, LT3, LT5, LT6, and LT7 all described sarcoidosis, discussed who is affected, the number of individuals who may be affected, the need for research, the support needed for individuals with the disease, and the need for a cure, treatments, and awareness. LT4 pertains to amending House Joint Resolution 519, designating Aug. 29, 1990, as National Sarcoidosis Awareness Day.

LT20 and LT26 explain sarcoidosis, the organs affected by the disease, and what can happen while living with the condition. These two pieces of legislation also convey



how the disease can be disabling, become fatal, affect numerous people, list the population most affected by the illness, and show that there may be no symptoms. Also discussed is how sarcoidosis is troublesome to detect, has no explained origin, and how a cure is unidentified. Also found within LT20 and LT26 was how sarcoidosis has been around for more than 100 years and was the cause of death of those working in fluorescent light factories in the 1940s.

Rescue workers from the September 11<sup>th</sup> disaster who ended up with diagnoses of sarcoidosis were also referenced in both pieces of legislation, along with factory workers and navy deckgrinders. LT20 and LT26 also encouraged more research on ecological and work-related interactions pertaining to sarcoidosis. There was also a designation for making April 2010 National Sarcoidosis Awareness Month and supporting the goals of the proposed designation. The two pieces of legislation also call for understanding sarcoidosis and how it has affected the nation's workforce, specific vocations, and awareness of the disease being relayed through committed organizations.

LT27 provided similarities to LT20 and LT26, with the following exceptions. There was a discussion of how sarcoidosis could affect multiple organs, was considered a rare disease, how the illness was "undertreated or misdiagnosed," and how there was minimal information in relation to the illness. The legislation also discusses sarcoidosis taking years to diagnose, how patients have a difficult time locating doctors who are familiar with the disease, and inadequate therapeutics. The advocating of making April National Sarcoidosis Awareness Month for 2016 was also included. Other pieces of legislation included sarcoidosis but were not specific to the disease. Please see Table 6

for non-specific sarcoidosis legislation.

**Table 6**

*Legislation Including Sarcoidosis But Not Specific*

Sarcoidosis Legislation	Themes	Legislation Name/Description	Legislation Status
LT17	Bill	S. 1873 – Biodefense and Pandemic Vaccine and Drug Development Act of 2005.	Introduced
LT18	Bill	S. 1880 -National Biodefense and Pandemic Preparedness Act of 2005.	Introduced
LT19	Bill	H.R. 6214 – Prevention, Awareness, and Research of Autoimmune Disease Act of 2006.	Introduced
LT21	Bill	H.R. 7078 - Prevention, Awareness, and Research of Autoimmune Diseases Act of 2008.	Introduced
LT23	Bill	H.R. 2084 – Prevention, Awareness, and Research of Autoimmune Diseases Act of 2009.	Introduced
LT24	Resolution	H. Res. 1122- Supporting the goals and ideals of the Year of the Lung 2010.	Introduced
LT25	Resolution	S. Res. 432 - A bill supporting the goals and ideals of the Year of the Lung 2010.	Agreed to in Senate
LT30	Resolution	S. Res. 74 – A resolution designating February 28, 2021, as “Rare Disease Day.”	Agreed to in Senate
LT39	Resolution	H. Res. 948 – Recognizing the extraordinary challenges faced by patients of color with rare diseases and the need to identify and promote evidence-based solutions to alleviate the disproportionate burden of rare diseases on these communities and supporting the recognition of the last day in February as “Rare Diseases Day.”	Introduced

In providing more insight into the legislation in Table 6, LT17 and LT18 wanted to provide insight into “environmental sarcoidosis” in relation to “medical research programs.” LT19 and LT23 discuss sarcoidosis in relation to being an autoimmune disease and explain the disease, where the disease can be found in the body, who is at risk for the disease, and the age range for the illness. LT21 speaks on awareness and research of autoimmune diseases and their relation to sarcoidosis, provides examples of autoimmune diseases, including sarcoidosis, and explains the illness, how it affects the body, the number of people affected by the disease, whom it affects, and the age.

LT24 and LT25 explain sarcoidosis, the organ in which it occurs the most, how the disease affects people of a certain age, and how the illness is unknown. LT30 considers sarcoidosis one of the many listed rare diseases, while LT39 lists sarcoidosis with a few rare disorders within the legislation. There was also legislation that pertained to mental health and depression in relation to sarcoidosis, which can be seen in Table 7.

**Table 7**

*Legislation Pertaining to Sarcoidosis Mental Health and Depression*

Sarcoidosis Legislation	Themes	Legislation Name/Description	Legislation Status	Mental Health/Depression
LT19	Bill	H.R. 6214 – Prevention, Awareness, and Research of Autoimmune Disease Act of 2006.	Introduced	Relationship between Autoimmune diseases and mental health, depression
LT21	Bill	H.R. 7078 – Prevention, Awareness, and Research of Autoimmune Diseases Act of 2008.	Introduced	Relationship between Autoimmune diseases and mental health, depression
LT23	Bill	H.R. 2084 – Prevention, Awareness, and Research of Autoimmune Diseases Act of 2009.	Introduced	Relationship between Autoimmune diseases and mental health, depression
LT24	Bill	H. Res. 1122- Supporting the goals and ideals of the Year of the Lung 2010.	Introduced	Relationship between Autoimmune diseases and mental health, depression
LT25	Resolution	S. Res. 432 - A bill supporting the goals and ideals of the Year of the Lung 2010.	Agreed to in Senate	Insufficient sleep and its relationship to depression
LT27	Resolution	S. Res. 443 – A resolution designating April 2016 as “National Sarcoidosis Awareness Day.”	Introduced	Emotional support resources are a struggle to find

LT19, LT21, and LT23 describe how autoimmune diseases “can have a devastating impact on a patient’s mental state” and calls for funding to be made available for research pertaining to autoimmune diseases and mental health, with depression listed as “cognitive and mood disorders.” Sarcoidosis is categorized as an autoimmune disease within these pieces of legislation. In LT24 and LT25, depression is listed as a chronic disease in relation to insufficient sleep. This legislation relates to sarcoidosis being listed as a disease associated with the lungs. LT27 is slated to designate April 2016 National

Sarcoidosis Awareness Month, but this legislation mentions how

“many sarcoidosis patients struggle to find knowledgeable physicians and emotional support resources relating to sarcoidosis.”

### **Summary**

In summarizing this chapter, both research questions were explored, and data was reviewed in relation to each question. RQ1: How do sarcoidosis stories from doctors, diagnosed patients, and caregivers impact mental health inclusion within sarcoidosis legislation based on depression, anxiousness, and feeling lonely? With 25% of the collected stories having some form of mental health aspect in relation to sarcoidosis, saturation was met for the study.

RQ2: How does current sarcoidosis legislation compare to the Bipartisan Safer Communities Act of 2022? The comparison of sarcoidosis legislation to the Bipartisan Safer Communities Act of 2022 had no similarities beyond making funding available for research. Chapter 5 will conclude this research.

## Chapter 5: Discussion, Conclusions, and Recommendations

### **Findings**

The purpose of this general qualitative study with narrative techniques was to gather secondary data of firsthand descriptions based on the impacts of sarcoidosis within three facets of mental health: depression, anxiousness, and feeling lonely. In doing so, I reviewed the stories of three primary populations for contextual and thematic content. In extending the purpose of this research, legislation related to the disease was also explored and compared narratively to the Bipartisan Safer Communities Act of 2022, which proposed mental health measures. The study was conducted to raise awareness of the disease sarcoidosis and to bring about change within sarcoidosis legislation including, mental health measures within the narrative of the proposed public policy. The gap in the literature identified was the lack of knowledge that pertained to the relationship between the mental health aspects of sarcoidosis and how doctors, diagnosed patients, and caregivers were able to describe depression, anxiousness, and feeling lonely in relation to the disease through narrative.

The results of this study confirmed that doctors, patients, and caregivers have knowledge of and have experienced the mental health aspects of sarcoidosis based on depression, anxiousness, and feeling lonely. There were 14 (25%) out of 54 stories that identified at least one of the mental health aspects of sarcoidosis within the presented narratives. Depression, anxiousness, and feeling lonely were the predetermined themes used for the narratives of the three population sets.

Additionally, this study presented legislation in relation to sarcoidosis and showed

an association between sarcoidosis and the lack of mental health inclusion within current legislation pertaining to the disease. The comparison of sarcoidosis legislation to the Bipartisan Safer Communities Act of 2022 showed only funding as a similar factor between the assessment. Out of the 42 pieces of legislation in relation to sarcoidosis that were reviewed, only five pieces of legislation provided mental health inclusion based on depression in relation to sarcoidosis. Although the pieces of legislation had some relation to sarcoidosis, the disease was not the main topic of the legislation. The themes discovered during the review of the legislation were based on the legislation type: public law, bill, amendment, resolution, joint resolution, and concurrent resolution. Chapter 5 follows with an interpretation of the findings, limitations within the study, recommendations for future research, implications for positive social change, and concluding thoughts.

### **Interpretations**

The results of this study were able to answer each research question, substantiate the lack of research pertaining to sarcoidosis mental health, and provide data supporting the study's purpose. Although the study results maintained a higher percentage of patient narratives, these perspectives were collective in nature, and no display of contrast was observed. Sarcoidosis narratives bring about an understanding of how depression, anxiousness, and feeling lonely could affect mental health in relation to the illness. Doctors and caregivers could become more aware of these mental health aspects when caring for sarcoidosis patients. Patients need to understand that sarcoidosis mental health could be an issue when dealing with the disease.

In comparing sarcoidosis legislation to the Bipartisan Safer Communities Act of 2022, several indications publicized the lack of mental health inclusion in legislation pertaining to the disease. Additionally, what is mentioned in the stories versus what is contained in the legislation is analogous. It is clear that the stories from the population sets need to be considered when discussing and creating future sarcoidosis legislation. There needs to be more insight within sarcoidosis legislation as it pertains to the inclusion of mental health based on depression, anxiousness, and feeling lonely. Sarcoidosis legislation, which was provided for this study, shows that there is a national concern that pertains to the illness.

### **Relationship to Literature**

In discussing the literature found in Chapter 2 pertaining to the mental health aspects of sarcoidosis in relation to depression, anxiousness, and feeling lonely, an association between neurosarcoidosis and depression has been identified (Byg et al., 2022). There were 15 stories in relation to neurological manifestations, but only five stories where neurosarcoidosis was mentioned. Out of those five stories, four related to all the mental health aspects of sarcoidosis, while one story indicated depression in association with neurosarcoidosis. There is also an association between psychological symptoms and sarcoidosis (Goracci et al., 2008). Twenty stories reported psychological burdens pertaining to sarcoidosis. Out of those 20 stories, five were related to depression and psychological burdens, showing an enhanced likelihood of the relationship. The literature also discussed social isolation in relation to sarcoidosis (Flavin, 2015), and five stories pertained to feeling lonely. Depression was found within the literature in Chapter

2 to be the predominant mental health aspect, which was also found in the collected stories.

The narratives presented in the stories and the narratives presented in the legislation both displayed a connection to the studies in Chapter 2, showing the applicability of the research topic. Depression, anxiousness, and feeling lonely were described by each population set, which gave insight into a disease that has not been studied extensively from the mental health perspective. Demographic data were not being considered since I did not have the opportunity to question participants in face-to-face interviews.

### **Relationship to Theoretical Frameworks**

In relation to the selected theories for this study, the ACF, the shared ideology found within the secondary data, was understanding the disease sarcoidosis. From the stories based on the disease, the population sets utilized for this study can be seen as the actors, while the legislation pertaining to sarcoidosis is the solution to be advocated. All the actors maintained the same issue while allowing for the mental health aspects of sarcoidosis to be the connection between the actors besides the disease itself.

In relation to the NPF, the setting was characterized as the issue, or sarcoidosis mental health, while the characters were the actors, similar to the ACF. The connection between the actors was the mental health aspects of sarcoidosis as well as the disease. The moral or solution was maintained as the legislation that pertained to sarcoidosis.

### **Limitations of the Study**

There were four limitations pertaining to this study. The first limitation was



population sampling. Purposeful random sampling was utilized for this study, and the population sample reflected the general population that the study deemed to identify. Although the study was able to extract the necessary population sets, doctor and caregiver stories were lacking. Patient stories comprised more than half of the collected stories, resulting in a higher population count of patients and the mental health aspects of sarcoidosis.

The second limitation of this study was the sample size. However, the sample size was large enough to indicate an actual representation of individuals living with sarcoidosis, especially since more patient stories were collected than any other population set. The third limitation pertained to the use of secondary data. Despite this potential limitation, secondary data was essential in capturing sarcoidosis stories and finding legislation. The secondary data for this study came from reputable databases that were accessed online. The quality of the information is accurate based on comparing the collected data to the peer-reviewed research found in Chapter 2.

The final limitation of this study pertained to researcher bias. However, I was able to set aside my biases by not including my personal experience of living with sarcoidosis, which was accomplished through memoing. I captured my thoughts about several of the provided stories, which may have triggered me in any way. A trigger for me in this case was how similar some of the patient experiences were to my own. However, I could not fully understand the topic since I have sarcoidosis. I have also increased my knowledge of the disease while bringing awareness to the illness. This study can be likened to advocacy for sarcoidosis.

## **Recommendations**

Some of the recommendations are linked mainly with the population sets employed in this study. Future researchers may want to utilize actual human participants to ensure an equal number of individuals for each population set. Additionally, the number of participants could be increased to cover a more extensive diversity of the population sets. The study could be conducted for an extended period to bring about more stability to the study.

Another recommendation for this study would be to focus more on the relationship between fatigue and the mental health aspects of sarcoidosis. Fatigue was found to be a significant contributor in relation to the mental health aspects of sarcoidosis, according to the research found in Chapter 2. Although fatigue was relayed in some of the stories under the category coded negative impacts, this symptom was not a key element in this study. There is also a recommendation for this study to be conducted utilizing one population set and one mental health aspect at a time instead of including all within one study. Breaking down the population sets and the mental health aspects would provide for a more detailed review of sarcoidosis in relation to depression, anxiousness, and feeling lonely.

In relation to sarcoidosis legislation, it is recommended that current organizations that provide research and outreach contact the legislators who have created sarcoidosis legislation and work on including sarcoidosis mental health in future political narratives in relation to the disease. Also, more state and federal dollars must be appropriated for sarcoidosis research and other funding related to the disease.

To conclude my recommendations, I would like to add one of the main things I would have done differently in conducting this study. I would have utilized software different from Delve. I found it challenging to gather the correct basic computations within the formatted Excel output spreadsheets provided when reviewing material. There was also a limit on the amount of data that could be stored, so legislation could not be downloaded and coded using the software because the files were too large, so manual coding was conducted for the legislation.

### **Implications**

Based on the results of this study, the plausible outcomes for adequate societal progress can be perceived from the perspective of the individual, family, organization, and societal/policy. Awareness of sarcoidosis and the mental health aspects of the disease are essential for all groups. The narratives bring about a better understanding of the disease, while the legislation intends to expound on the illness through awareness, research, and funding. This study would be best if conducted using empirical research based on the NPF and narrative techniques. Those who treat sarcoidosis patients and research the disease may find it necessary to duplicate or continue this study.

### **Conclusion**

Sarcoidosis is a rare disease/disorder that mainly affects the lungs and heart but can also affect any organ within the body. This disease has an array of symptoms that could devastate the individual. Neurological and psychological manifestations need to be considered when diagnosing sarcoidosis. The mental health aspects of sarcoidosis need to be included when bringing about awareness of the disease. Anyone could be affected by

sarcoidosis, but those working in industrial occupations or interacting with toxic airborne hazards need to be aware of the potential of this disease. Because sarcoidosis already has two laws that pertain to the illness, there is a need for awareness programs, research prospects, and funding.

To conclude, the collected stories and the legislation pertaining to the illness captured the lack of awareness of sarcoidosis. This study established the need for more research on the mental health aspects of sarcoidosis, and the need for mental health measures within sarcoidosis legislation. This study can shed some light on what future legislation could do to help those with this disease.

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## Appendix A: Secondary Data Protocol and Collection Template RQ 1

## Sarcoidosis Mental Health Secondary Data Protocol and Data Collection Template

Title of Study:\_\_\_\_\_

IRB Approval of Data Collection Protocol and Collection:\_\_\_\_\_

Principal Researcher:\_\_\_\_\_

Statement of Compliance: This study will be conducted in accordance with International Review Board for Walden University. Dorothy Michelle Kemp, who is solely responsible for the research within this study, has completed the Human Subjects Protection and ICH GCP Training, although human subjects will not be utilized for this study. A copy of the completed training is as follows:

\*Certificate of Completion\*

The National Institutes of Health (NIH) Office of Extramural Research certifies that \*Dorothy Kemp\* successfully completed the NIH Web-based training course “Protecting Human Research Participants”.

Date of completion: 09/19/2015

Certification Number: 1861175

**Secondary Data Protocol Summary**

Title of Study

Problem Statement:

Purpose of the Study:

Study Population:

Secondary Data Sources:

**Protocol for Secondary Data Collection**

Got to website

Distinguish data to be collected as video, transcript, or text from website

Gather necessary data according to secondary data collection protocol

Enter data into Delve software

Summarize data collected

**Secondary Data Collection Template**

Date of Secondary Data

Collection:\_\_\_\_\_

Time of Secondary Data

Collection:\_\_\_\_\_

Website:\_\_\_\_\_

Type of secondary data Video\_\_\_\_ Transcript\_\_\_\_ Text\_\_\_\_

URL for video/transcript/text:\_\_\_\_\_

Title of video/transcript/text: \_\_\_\_\_

Indicate population set (doctor, diagnosed patient, or caregiver): \_\_\_\_\_

Type of sarcoidosis being discussed (one organ or systemic): \_\_\_\_\_

Symptoms of sarcoidosis being discussed or described (write out symptoms according to lit review): \_\_\_\_\_

How does info relate to sarcoidosis mental health (depression, anxiousness, feeling lonely): \_\_\_\_\_

What neurological manifestations were described: \_\_\_\_\_

What psychological burdens were discussed: \_\_\_\_\_

What negative impacts on the quality of life were discussed: \_\_\_\_\_

Researcher Notes:

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## Appendix B: Secondary Data Protocol and Collection Template RQ 2

## Sarcoidosis Legislation Secondary Data Protocol and Data Collection Template

Title of Study:\_\_\_\_\_

IRB Approval of Data Collection Protocol and Collection:\_\_\_\_\_

Principal Researcher:\_\_\_\_\_

Statement of Compliance: This study will be conducted in accordance with International Review Board for Walden University. Dorothy Michelle Kemp, who is solely responsible for the research within this study, has completed the Human Subjects Protection and ICH GCP Training, although human subjects will not be utilized for this study. A copy of the completed training is as follows:

\*Certificate of Completion\*

The National Institutes of Health (NIH) Office of Extramural Research certifies that \*Dorothy Kemp\* successfully completed the NIH Web-based training course "Protecting Human Research Participants".

Date of completion: 09/19/2015

Certification Number: 1861175

## Secondary Data Protocol Summary

Title of Study

Problem Statement:

Purpose of the Study:

Study Population:

Secondary Data Sources:

**Protocol for Secondary Data Collection**

Got to website

Distinguish legislation to be by searching legislative websites, databases

Gather necessary data according to secondary data collection protocol

Enter collected data into Delve software

Summarize data collected

**Secondary Data Collection Template**

Date of Secondary Data

Collection:\_\_\_\_\_

Time of Secondary Data

Collection:\_\_\_\_\_

Website:\_\_\_\_\_

Type of secondary data: Video\_\_\_\_ Transcript\_\_\_\_ Text\_\_\_\_

URL for

video/transcript/text:\_\_\_\_\_

Type of legislation: Local\_\_\_\_ State\_\_\_\_ Federal\_\_\_\_

Title of legislative:\_\_\_\_\_

Indicate population set according to provided legislation:\_\_\_\_\_

Type of sarcoidosis being discussed (one organ or systemic):\_\_\_\_\_

Where is sarcoidosis found in the legislation:\_\_\_\_\_

What does the legislation state about sarcoidosis?\_\_\_\_\_

\_\_\_\_\_

based on depression, anxiousness, feeling lonely):\_\_\_\_\_

\_\_\_\_\_

Researcher Notes:

\_\_\_\_\_

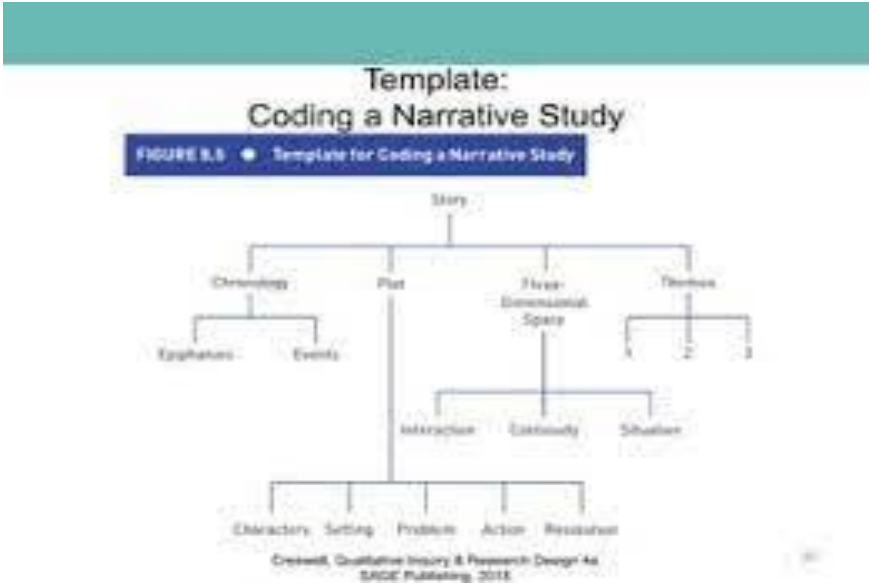
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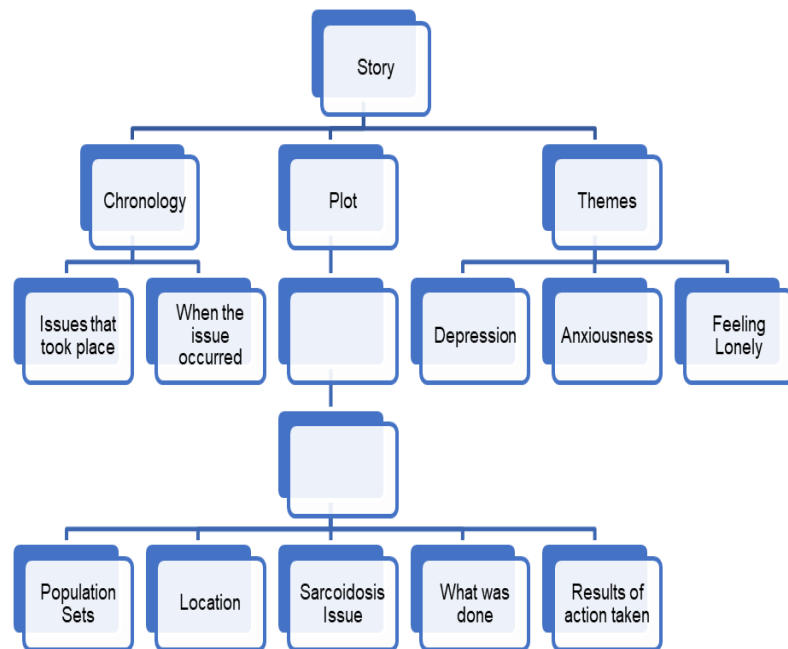
Appendix C: Template for Coding a Narrative Study





Appendix D: Template for Coding a Narrative Study

RQ 1



RQ 2

