

AFRICAN AMERICAN CAREGIVER EXPERIENCES ASSOCIATED WITH INDIVIDUALS  
DIAGNOSED WITH SEVERE RETT SYNDROME

By

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### **Abstract**

This dissertation explores the unique challenges and needs of African American caregivers of individuals diagnosed with Rett Syndrome (RTT). Despite the International Rett Syndrome Foundation (IRSF) providing significant support resources, gaps persist, especially in addressing specific needs of African American caregivers. This study will use qualitative research methods to explore socio-economic status, family support structures, and caregiving resources available for African American caregivers of individuals with RTT. The study will also seek to identify and close gaps witnessed in previous studies regarding physical, emotional, and financial impact of caregiving on African American families. The investigation's findings are intended to inform IRSF strategies for improving resource allocation and support structures, thereby enhancing the quality of life for African American caregivers of individuals with RTT syndrome. The research emphasizes the need for tailored support strategies that address ethnic, socio-economic, and cultural nuances within caregiving communities. Despite the study being site-specific, and its results not readily generalizable, the findings provide critical insights that highlight the urgent need for more inclusive and diverse support resources. By addressing these unmet needs, this research makes a significant contribution to enhancing the well-being and quality of life for African American caregivers, ultimately fostering more equitable caregiving support structures.

**Keywords:** *Quality of life, Rett syndrome, socio-economic factors, caregiving impact, African American caregivers, International Rett Syndrome Foundation (IRSF), caregiver burden, cultural sensitivity, caregiver experiences; and Health disparities.*

## Executive Summary

African American caregivers caring for individuals with chronic disorders experiences. This project aims to improve QOL for African American caregivers caring for individuals with RTT syndrome and to have IRSF bring more awareness for the need within the minority population so that their caregiver's role could improve. The research focuses on African American caregivers' coping strategies, access to financial resources, and adapting to changes in the family dynamic.

*Methods:* This qualitative study of 12 African American caregivers caring for individuals with RTT daily. The in-depth interview allowed the caregivers to share their challenges of caring for individuals with RTT syndrome. A focus group was completed by 5 IRSF State Representatives who shared relevant information about caregivers' challenges. An observation was implemented through social media activity with the families sharing their experiences of having an individual with RTT. *Results:* The experience of being an African American caregiver of a child with Rett syndrome was expressed as being an "unexpected lifestyle" and was described via three main themes. The primary themes that emerged from the data were: (a) the importance of support, (b) the challenges of caregiving, and (c) balancing work and caregiving responsibilities.

*Conclusions:* Rett syndrome dramatically impacts the lives of the caregivers involved, especially with not much awareness being recognized among the IRSF organization. The care provided played a significant role, and caregivers highlighted the lack of resources. These findings have important implications for identifying the need for IRSF to bring more awareness of coping strategies, access to financial resources, and adapting to changes in the family dynamic.

**Keywords:** *Africa American, Rett syndrome, caregivers, rare disease, qualitative research, adaptation, family functioning, quality of life; and Rett syndrome.*

### **Dedication**

This dissertation is dedicated to my family, whose experience with a RTT Syndrome patient inspired and motivated me to undertake this research. I have a special gratitude to my parents, Mr. & Mrs. XXX, for the support and encouragement that made this journey achievable and worth every effort. A special dedication of this dissertation to my close family friends, XXX for the unwavering support and love during this journey.

I would also like to dedicate this study to all African American caregivers of individuals with RTT Syndrome who continue to face daunting challenges in their duty of caregiving.

## Acknowledgement

I first want to give thanks and praise to Almighty God for His grace and blessings throughout this new chapter in my life. I also want to give special appreciation to all groups and individuals who contributed to my success in completing this dissertation. I also want to appreciate my family and close friends for their support through encouragement and resources that they have offered me throughout the journey.

A special gratitude I give to our final year project manager, XXX, whose contribution in stimulating suggestions and encouragement, helped me to coordinate my project, especially in writing this dissertation. A special thanks to staff from my faculty at Oxford University. The staff created an enabling environment by availing all required equipment and materials critical for the completion of this dissertation project.

I am heartily thankful to my supervisor, XXXX, whose encouragement, guidance, and support from the initial to the final level enabled me to develop an understanding of the subject. His advice on both research as well as on my career have been priceless. I am also grateful to the participants and the International Rett Syndrome Foundation (IRSF) who, despite any impediment that came their way, helped me in numerous ways and made this study possible.

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## **List of Abbreviations**

|                |   |
|----------------|---|
| <b>(RTT)</b>   | The Rett syndrome                                   |
| <b>(QOL)</b>   | Quality of Life                                     |
| <b>(MECP2)</b> | mutation of coding for methyl-CpG-binding protein 2 |
| <b>(CSS)</b>   | Clinical Severity Scale                             |
| <b>(CDC)</b>   | Centers for Disease Control and Prevention          |
| <b>(PCS)</b>   | Physical Component Scores                           |
| <b>(MCS)</b>   | Mental Component Scores                             |

## CHAPTER ONE: INTRODUCTION

### Overview

The purpose of this project was to improve QOL for African American caregivers caring for individuals with RTT syndrome. The focus of the current project is to bring awareness to issues experienced by African American caregivers of individuals with RTT syndrome and provide the IRSF with insights to better serve this population. The International RTT Syndrome Foundation is an organization that is designed to cater to families with individuals with RTT, therefore, it is fundamental to identify the lack among the African American population for IRSF to improve the QOL. The study's purpose is to explore and present coping methods, self-efficacy, family functioning, and adaptation through which African American caregivers of individuals diagnosed with RTT syndrome are capable of sustainably maintaining positive QOL. African American caregivers of individuals diagnosed with RTT syndrome experience challenges associated with limited awareness, support, and resources that lead to difficulties balancing caregiving responsibilities and their personal and professional roles. This is why it is important to create awareness about the issues that they face and to also find means of improving the methods they use in coping, self-efficacy, family functioning, and adaptation so that they can experience positive QOL.

### The Public Administration Setting and Background

The IRSF headquarters is in the United States at 4500 Cooper Road, Suite 204, Cincinnati, Ohio. The IRSF is an international organization, and its members are comprised of caregivers of individuals diagnosed with RTT syndrome. The purpose of the organization is to identify a cure for RTT syndrome by partnering with physicians, community members, and families to invest in groundbreaking research, establish treatment pipelines, and eliminate

barriers that prohibit the success of clinical trials. Throughout the past 15 years, the IRSF has collaborated with a panel of over 15 expert neurologists who have treated over 1,000 individuals from the RTT community. Their research efforts have provided significant insights leading to an increase in recommended areas for future research.

Melissa Kennedy serves as the chief executive officer and oversees the leaders within the organization. Leaders with the IRSF are multidisciplinary and have backgrounds in science, research, advocacy, medical advisory, marketing, and family and community engagement. They serve as advocates and scientists to provide resources, empirical data, and in hopes of identifying a cure for the disorder. Researchers with the IRSF have found that treatment development is most effective when the needs of the family are prioritized. Family needs are essential in treatment development due to the ongoing need for community support, clinical networks, and physicians throughout the United States. Efforts made by the organization to find a cure are driven by the goal to find a cure and empower families with information, knowledge, and connectivity (IRSF, 2023).

Despite all the efforts of the IRSF, no cure for RTT syndrome has been identified. As a result, caregivers continue to experience significant challenges associated with caring for individuals with RTT syndrome. This problem is exacerbated especially for African Americans considering factors relative to their experience related to race, limitations in resources, and coping strategies. This project will specifically focus on the experiences of African American IRSF caregivers who reside in Virginia and Georgia and provide the IRSF with additional insight on how to support African American caregivers.

### **Introduction to the Problem**

According to Fu et al. (2020), RTT syndrome is a condition that is currently recognized as being among the leading causes of intellectual and physical disability among females. This

disorder compromises their ability to walk, talk, and meet age-appropriate milestones. It is unclear what causes RTT syndrome to be more severe in some individuals than others (Ehrhart et al., 2016). Fu et al. (2020) noted that RTT syndrome is also linked to a host of related comorbidities, including epilepsy, scoliosis, malnutrition, sporadic episodes of gastrointestinal problems, onset osteoporosis, bruxism, screaming spells, and respiratory issues (Rozensztrauch et al., 2021). Most of the symptoms typically occur during the second stage of RTT syndrome (Palacios-Ceña et al., 2018). According to Kyle et al. (2018), this is the stage where microcephaly worsens, and many individuals experience seizures and breathing irregularities. In the third stage, many individuals experience stagnated symptoms, and some even experience mild recovery (Palacios-Ceña et al., 2018). However, suppression of symptoms is usually short-lived as motor deterioration increases. RTT is a lifelong condition requiring individuals to rely on a wheelchair and other assistive devices for communication (Downs et al., 2020). In addition, almost all individuals with RTT lose their hands' functioning and require considerable assistance.

Individuals with this disorder typically require 24-hour care from a caregiver. The burden on caregivers of individuals with RTT syndrome can be overwhelming due to the unexpected life changes affecting their overall personal and professional life. Studies on RTT syndrome suggested that there are limited resources available to help caregivers cope with stressors (Güeita-Rodríguez et al, 2020). This is particularly evident for African American caregivers partly due to their coping strategies, financial barriers, and access to limited resources.

The National Alliance for Caregiving (2020) found that 47.7 was the average age of African American caregivers. These caregivers are less likely to be married when compared to other racial/ethnic groups. African American caregivers report having a lower household income than Hispanic, White, and Asian caregivers (National Alliance for Caregiving, 2020). The financial impact for African American caregivers is also greater when compared to other races.

African Americans are more likely to have a difficult time managing financial expenses, establishing a savings account, pay outstanding expenses and more likely to acquire debt (National Alliance for Caregiving, 2020). In addition, African American caregivers experience a greater level of health impairments and an overall lower quality of life. They face significant barriers that disrupt family dynamics and require additional support and resources to help them to adequately care for individuals with RTT syndrome. Hence, the purpose of this study is to highlight the unique experiences of African American caregivers associated with implementing coping strategies, access to financial resources, and adapting to changes in the family dynamic. In addition, information gained from this project will be used to support the IRSF with providing tools and resources to African American caregivers to improve their quality of life and the overall caregiving experience.

The IRSF played an integral role in the Omnibus Fiscal Year 2022 (FY22) appropriations bill passed by Congress in early March to request federal funding for research on RTT syndrome. The organizations efforts were essential in pushing RTT syndrome to become a topic of legislation for research funding through the U.S. Department of Defense Peer-Reviewed Medical Research Program (DOD PRMRP). The approval allowed researchers to apply for federal grants to further study RTT syndrome (IRSF, 2023). This significant achievement marked year-long advocacy efforts by the IRSF that were initiated with written letters to members of Congress to seek federal funding. The IRSF educated policymakers on RTT syndrome, its impact on families, and for federal funds to advance research in April 2021. Securing additional funds and federal support has been a critical step in identifying treatments and a possible cure for RTT syndrome. Unfortunately, requests for additional funds often exceed the funding levels previously provided through private foundations. Despite efforts to raise awareness by the IRSF, it does not specifically highlight the needs of African American caregivers of individuals diagnosed with

RTT syndrome. Research on this population will provide the IRSF with additional information to develop tools and resources to support these families.

### **Significance of the Problem**

The focus of the current project is to bring awareness to issues experienced by African American caregivers of individual's with RTT syndrome and provide the IRSF with insights to better serve this population. African Americans caregivers require support with implementing effective coping strategies, accessing financial resources, and adapting to changes in the family dynamic as a result of their caregiver role (Algood & Davis, 2019). Several studies have revealed that caring for individuals with RTT can be demanding. Caregivers are required to devote time and effort to adapting to the individual's evolving needs. These needs are relative to decreased coordination or mobility, repetitive hand movements, reduced eye contact, loss of interest in usual activities, loss of speech, seizures, breathing irregularities, and slow growth. Caregivers often experience isolation from society, family, and friends and find it extremely hard to balance outside relationships and employment. Palacios-Ceña et al. (2019) noted that these problems occur because RTT syndrome usually affects individuals in infancy and is known as a lifelong condition with no cure.

The experience between caregivers and professionals differs significantly. Professionals are more likely to be knowledgeable of the specific needs of individuals diagnosed with RTT syndrome. On the other hand, caregivers require a greater level of support to aid them in caring for individuals with RTT syndrome (Güeita-Rodríguez et al., 2020). For instance, many caregivers become easily overwhelmed and may require therapy to cope with the challenges of caring for an individual with RTT syndrome. Caregivers struggle with accepting that the disorder is life altering and lifelong (Cardinali et al., 2019). Since most primary caregivers of RTT

individuals are the parents, they blame themselves for the individual's condition due to unknown causes of the disorder, leading to symptoms of depression. Therefore, caregivers would benefit from resources and support to improve the quality of their life.

According to Palacios-Ceña et al. (2019) caring for an individual with RTT syndrome is like an obstacle course. Caregivers reported having difficulty with responding to the rapid changes associated with individuals with RTT syndrome. They experience significant levels of emotional stress, interrupting their lives to assume the role of a caregiver. Coping with emotional stressors and understanding their symptoms, managing daily routines with limited support and available treatment options, and scarce financial resources further diminish the quality of life for caregivers (Cardinali et al., 2019). These factors also take a toll on their physical health and mental well-being.

Lane et al. (2017) specifically examined the experiences of African American caregivers in relation to how they cope with caring for the individual with RTT. According to their findings, African American caregivers experience far more significant challenges than their Caucasian counterparts. It is evident that individuals diagnosed with RTT syndrome require an intense level of support. Even more critical is the level of support required by African Americans as they are more predisposed to physical and emotional health risks. For instance, low economic and health statuses are associated with ethnicity.

### **Purpose Statement**

The purpose of this project was to improve QOL for African American caregivers caring for individuals with RTT syndrome. The focus is to bring more awareness about RTT syndrome to the healthcare community to design professional development opportunities to increase effective coping strategies, provide support and resources, and secure financial assistance for

African American caregivers. It is important to solve this problem to improve the QOL for African American caregivers who care for individuals diagnosed with RTT syndrome. The first approach regarding data collection will be structured interviews with African American caregivers of individuals with RTT syndrome who are members of the IRSF. The second approach regarding data collection will be a focus group with five IRSF state representatives via telephone conference sharing RTT caregivers' challenges that revolve around everyday care. The third approach regarding data collection will be an observation fulfilled through social media activities on Facebook in the RTT Families Forum revealing their experiences of having an individual with RTT with other families.

## **CHAPTER TWO: LITERATURE REVIEW**

### **Overview**

This chapter presents a well-detailed overview and critical evaluation of the literature published on the research topic. This section starts with an introduction to the topic, followed by several key subtopics that dissects the nature of the RTT syndrome to expound on the measures that have so far been undertaken to ensure proper caregiving. The flow of the content in this chapter is focused on analysis of research conducted on the topic and this will touch on the findings and developments on the topic.

### **About the International RTT Syndrome Foundation (IRSF)**

The International RTT Syndrome Foundation (IRSF) and the legacy foundation's investments have changed the view of RTT syndrome throughout the years. Their research has contributed to discovering that the methyl-CPG-binding protein 2 (MECP2) gene is associated with the cause RTT syndrome. While a majority of RTT individuals have MECP2 mutations (Classical RTT), Pejhan and Rastergar (2021) shared that a small percentage of the RTT was caused by the cyclin-dependent kinase-kinase-like 5 (CDKL5) and FOXP1. In both cases, the genetic mutation leads to abnormal brain function and development impairment.

RTT individuals with classical RTT experience neurodevelopment progression that over the first six to eight months of life appears normal, but rapidly start regressing thereafter. The individual has symptoms of muscle hypotonia and deceleration of head growth (Pejhan & Rastergar, 2021). Also, there are delays, stagnation, or regressions in motor skills, and weak posture, which leads to scoliosis (Pejhan & Rastergar, 2021). Depending on the type of MECP2 gene located on the X chromosome determines the lifespan of the individual with RTT. In contrast, CDKL5 genes are associated with RTT-like symptoms in males (Pejhan & Rastergar, 2021).

In addition, IRSF appraises the nature and characteristics of RTT and points out that it is the majority of females affected rather than males due to the MECP2 gene (IRSF, 2023). The MECP2 is mainly found on the X chromosome, and while males have only one X chromosome, females have two X which allows them to live longer with unexpected complications. Caffarelli et al. (2020) indicated that regardless of how much of the genetic mutation of RTT manifests in the mutation of coding for MECP2, even a single mutation in one gene can cause the RTT condition to transpire. MECP2 plays a major role in brain cells, causing loss or gain of the function of the mutation, which causes neurodevelopment disorders with RTT individuals (Liyanage et al., 2019), and also increases the risk of fragility fractures due to the decrease in bone mass caused by the MECP2 (Caffarelli et al., 2020).

Over the years scientists have successfully discovered the reversibility of RTT syndrome in mice (IRSF, 2023). However, no dependable neurophysiological biomarkers correlated towards the pathophysiology of the syndrome have been resolved (Smirnov et al., 2021). Therefore, there is no cure for RTT as of today. Other advancements reported by the IRSF included detecting early gene therapy work in RTT syndrome, the initial trial for RTT syndrome on individuals with RTT, and the development of the first Phase 3 clinical trial (IRSF, 2023). This information has been published in the RTT Syndrome Handbook for RTT caregivers, health professionals, and researchers' benefit.

### **Life with RTT Syndrome**

According to Palacios-Ceña et al. (2019), overall characteristics of RTT include that infants usually seem healthy and grow and develop normally during infancy. Vessoayan et al., (2018) explains that over time, the individual tends to lose coordination of their hands as well as speech, and this loss of coordination commonly occurs very rapidly. Patel et al., (2022) further

states that it is important to note that RTT affects everyone differently; for some RTT individuals, their degeneration can be stabilized for some years depending on the severity. It is also important to note that there is no known cure for RTT. Still, individuals with RTT can receive some medication as well as speech, nutritional, and physical support to ensure that their symptoms are well managed to improve their Quality of Life (QOL) and mitigate further complications from occurring (Vashi & Justice, 2019). Recently, IRSF announced a drug called DAYBUE (trofinetide) was approved by the FDA to treat some of the symptoms caused by RTT. However, because the drug is new and there has not been much groundbreaking news on the results of the drug's benefit, it still leaves families with uncertainty.

Many authors have presented that RTT syndrome can have many varied symptoms. Normally, the symptoms and severity often differ at different stages of an individual's life as they grow. However, over time, some of the most common symptoms have been identified as having slow development, loss of hand motion, loss of mobility, reduced head growth, seizures, loss of speech, breathing irregularities, and intellectual disability (Kriemer, 2019). Zuckerman et al. (2018) revealed that RTT syndrome is not a well-known disorder as many individuals have not heard of it. In fact, research on RTT syndrome is limited due to the lack of awareness of the syndrome. Ak et al. (2022) offered a summarized description of RTT by stating that it is a condition that is unordinary and that it usually emerges abruptly. RTT syndrome takes advantage of an individual's projected life interrupting developmental growth. Strugnell et al. (2019) point out that even though RTT mostly affects females, the condition is sporadic and is known to occur in about 1 out of every 10,000 to 15,000 live female births.

Unfortunately, it is quite difficult for caregivers of an individual with RTT syndrome to make informative decisions due to the limited resources available. In addition, with RTT affecting individuals in different ways, it makes it difficult to know what type of treatment is

required. This mysterious disorder leads caregivers to a disparity in trying to figure out what works best for the individual's needs preceding depression and frustration. Ambiguity the right care plan is not in place for the caregiver, it could cause more impairment and complication for the individual with RTT.

However, it is important to note that some studies have revealed links between demographics and self-efficacy, family functioning, adaptation, and coping methods of different families caring for someone with a disorder play a major factor in the type of care provided (Jon-Ubabuco & Dimmitt, 2019). For instance, Jon-Ubabuco and Dimmitt (2019) distinguished that African Americans often deny seeking medical professional assistance because of shame, stigma, and cultural distrust. African Americans are more subjected to relying on their religion or faith, rather than seeking medical assistance (Algood & Davis, 2020).

However, vulnerable populations, including ethnic minorities and low-income earning families, are more adversely affected when developing ideal coping methods, self-efficacy, family functioning, and adaptation (Hastert et al., 2022). Bolbocean et al. (2021) perceived in their study, that African American caregivers usually work more and earn less, which triggers mental and physical issues making it difficult for them to have what society considers a normal lifestyle (Hastert et al., 2022), and that it is more common for African American caregivers to live in a single-family home or one person income. As a result, African American caregivers face issues of not having the finances to get equipment or supplies for the individual with RTT.

This research will explain what RTT is, and the challenges individuals and their families encounter. However, the research focuses on African American caregivers providing care for individuals with RTT belonging to middle and low-income categories. The paper offers details pertaining to the link between demographic factors and the challenges of life for families having a member with RTT, as well as obstacles that caregivers face because of the intuitive attention

required. The research also details terms the physical and mental issues that African American caregivers experience during their service delivery. Indeed, their experiences will shape the perceptions they develop linked to the services they provide daily. Also, it will explore the measures taken or support needed for African American caregivers to care for individuals with RTT to have a balanced life and subsequently experience positive QOL.

It is important to understand RTT syndrome and its effects on caregivers. According to Kyle et al. (2018), RTT was first described as a genetic neurological disorder that mainly affects females and can lead to considerable impairments that adversely affect all aspects of functioning or life. Kyle et al. (2018) explained that some factors resulting in the differences in the RTT symptoms in the individual include the environment and the kind of support they are provided throughout their development. For instance, their social and physical experiences, including how they communicate with those close to them, affect the severity of their symptoms (Cook et al, 2018). These are factors that also affect how they engage in social interactions and activities. Early intervention pertaining to medical attention and therapy also impacts the mitigation of their symptoms during their stages of development.

Treatment for RTT syndrome includes disability services and developmental therapies that focus on gross motor functioning. Ongoing investigations on medication trials that target growth factors and glutamate modulators to manage the symptoms of RTT syndrome were found to be effective treatment methods (Ak et al., 2022). Another critical factor is that the condition usually shortens the lifespan of individuals however, its specific impacts on an individual's lifespan are yet to be fully understood. The overall life expectancy of people with RTT syndrome depends on the onset of symptoms. Ordinary individuals with RTT syndrome often survive until their 40s or 50s (Singh et al., 2021).

According to Fu et al. (2020), RTT syndrome is a condition that is currently recognized as being among the leading causes of intellectual and physical disability among women. The disorder can cause severe intellectual disability in individuals. It is unclear what causes RTT to be more severe in some individuals than others (Ehrhart et al., 2016), however, RTT is linked to a host of related comorbidities, the key ones include epilepsy, scoliosis, malnutrition, sporadic episodes of gastrointestinal problems, onset osteoporosis, bruxism, screaming spells, and respiratory issues (Fu et al., 2020; Rozensztrauch et al., 2021). Most of the symptoms listed above along with comorbidity commonly occur during the second stage of the development of RTT syndrome. This is the stage where microcephaly worsens, and many individuals begin to experience seizures and breathing irregularities (Kyle et al., 2018). The third stage is where many individuals experience stagnated symptoms, and some even experience mild recovery. However, suppression of symptoms is usually short-lived as motor deterioration increases; RTT is a life-long condition (Kyle et al., 2018). According to Fu et al. (2020), later studies found that a genetic mutation causes RTT but is rarely inherited.

According to Kyle et al. (2018), it was Andreas Rett, an Austrian pediatric neurologist, who first described RTT after observing two female individuals with identical hand-wringing stereotypies in his clinic waiting room. Andreas Rett examined the two young girls and realized they had a similar history regarding the fact that they both experienced early normal development but later experienced a period of regression that was succeeded by loss of purposeful hand movements. Andreas believed that the condition was caused by a metabolic disorder and first termed it as ‘cerebroatrophic hyperammonemia’ in a German article in 1966 (Pereira et al, 2019). It was about 17 years later that the medical fraternity developed greater insight and understanding of the progressive neurological disorder. Caring for individuals with

RTT requires considerable commitment from both the primary caregiver and the families of the individuals with RTT. Also of note is that the level and the nature of attention and support accorded to individuals with RTT depends on the severity of the individual's symptoms. It can sometimes be daunting to offer care services to individuals with severe RTT.

### **The International RTT Syndrome Foundation (IRSF)**

The purpose of the IRSF organization is to identify a cure for RTT syndrome by partnering with physicians, community members, and families. Over the years IRSF has reported over 80 grants investing in groundbreaking research, establishing treatment pipelines, and eliminating barriers that prohibit the success of clinical trials. Throughout the past 15 years, the IRSF has collaborated with a panel of over 15 expert neurologists who have treated over 1,000 individuals from the RTT community (IRSF, 2023). The IRSF continues to focus on getting a cure for RTT syndrome.

### ***Benefits of the Organization***

The International RTT Syndrome Foundation (IRSF) has positively impacted the lives of individuals with RTT and their caregivers through its various programs. Advocacy is one of the IRSF's efforts to help create awareness about RTT and support the well-being of individuals with the syndrome (Romano et al., 2019). In addition, IRSF works with various organizations to promote policies that enhance the well-being of individuals with disabilities. One such policy is the Americans with Disabilities Act (ADA), designed to offer protection for individuals with disabilities and promote equality in workplaces, learning institutions, and transportation (Romano et al., 2019). Through its efforts to create awareness in society about RTT, the IRSF has ensured that individuals with RTT can access healthcare services and that the needs of individuals with the syndrome are widely known to healthcare providers.

The IRSF offers support services to families of individuals with RTT syndrome and their caregivers in various ways. The foundation has published many reading materials about RTT syndrome for families and caregivers to read and understand the nature of the syndrome, its impact, and the kind of support they should provide for the individual with RTT. In addition, regional representatives of each state are in place to support families of individuals with the syndrome and share experiences.

The IRSF has a community of caregivers, individuals, and families affected by RTT. This community helps sensitize society about the syndrome and supports families. The foundation organizes events and conferences where caregivers, healthcare providers, and families can connect and engage one another in sharing and learning new information about caring for RTT individuals. IRSF offers a space for the formation of local support groups for caregivers and families of individuals with RTT to get the support and information they need to improve the quality of caregiving.

### ***Research Advancements***

The IRSF has invested heavily in research in efforts to find an effective treatment for RTT Syndrome. The organization's funding of research has led to an advanced mainstream understanding of RTT and the introduction of new and improved treatments. One of the milestones achieved by IRSF is its support of gene therapy research, which has shown significant progress in animal models of RTT syndrome (Vashi & Justice, 2019). Liu et al. (2020) reported in their article that high-frequency fornix stimulation in an RTT mouse model improves individual cognitive deficits in correlation to the neural circuits involved in memory and learning development.

The organization has also contributed to various clinical trials undertaken by pharmaceutical companies for RTT treatment, such as the Trofinetide drug trial, which has shown improved healthcare in treating breathing patterns and motor functions in RTT syndrome individuals (IRSF, 2023). Through its research funding program, the IRSF has greatly contributed to the research field and moved closer to finding a cure for RTT syndrome.

### **African American Caregiver**

African American caregivers experience unique challenges when caring for individuals with RTT syndrome. Lack of support is one of the major challenges that African American caregivers of individuals with RTT syndrome face. Many are isolated and lack access to support groups, respite care, and other critical resources that help them adequately manage and administer their caregivers' responsibilities. Many African American caregivers lack awareness about available resources for individuals with RTT. Such harsh experiences make caregiving more difficult and stressful since caregivers must dedicate themselves to giving the best care for RTT individuals as they manage the many different symptoms. According to Hansen (2018), African American caregivers suffer from emotional stress whereby extreme caregiving responsibilities exert more pressure on their mental well-being leading to increased levels of stress, anxiety, and depression. African American caregivers are also reported to experience guilt and shame as they feel incapable of providing adequate care for RTT individuals under their care and prioritizing their personal well-being (Mthombeni & Nwoye, 2017).

Siler et al. (2021) believed in their study that African American often rely on their spirituality to cope with medical conditions. African American caregivers responded to the study by reigning that by being engaged to one's spirituality affluences people decisions on healthcare decisions and promote well-being while caring for someone with a disability (Siler et al. 2021).

A caregiver possibly manages psychological distress such as feeling hopelessness, anger, and depression, by trusting in God or a higher power. Siler et al. (2021) added that there are four general styles used in their article that identify that African American caregivers merely depend on spirituality to help cope with medical conditions. The four styles consist of: self-directing styles necessitates the relationship with God or what is sacred to them, deferring styles is when a person depends on God for strength to cope with the medical conditions, collaborative approach is when a person connects with the divine, and surrender styles is when an individual accede the will of God by learning to live with life crisis.

### ***Coping Strategies***

The RTT syndrome coping strategies are designed to help individuals suffering from the disorder and their families manage the challenges of the disorder. The first coping strategy for RTT, as explained by the IRSF, is building a support network. Family members, healthcare professionals, support groups, and community members at large comprise the basic units of the support network for caregivers of individuals with RTT disorder. A support network helps the family of the individual with RTT syndrome and the caregiver by offering emotional support, tangible assistance, and important information to support individuals with RTT symptoms. Support groups and healthcare professionals as part of the support network are valuable resources for families and caregivers of individuals with RTT as they present opportunities to connect families with similar predicaments to share their experiences.

Establishing a daily routine is another coping strategy that helps individuals with RTT to experience a sense of security and contentment. According to the IRSF, establishing a routine helps caregivers to give the individual a better life by managing the symptoms and the disorder. The designed routine entails activities that are fulfilling to the individual, stimulating, and

promoting relaxation. In addition, the environment for the RTT individual should be safe and comfortable, as well as help the individual keep away from sensory overload.

Physical therapy and communication are highly considered coping strategies for individuals with RTT. Physical activities help to manage motor symptoms, including stiffness and weakness, boosting the mobility of individuals with RTT syndrome (Gold et al., 2017). Physical therapists must understand the needs of individuals with RTT, and their guidance on the best physical activities for them is highly sought after to help improve mobility and the best assistive technologies to improve the individual's daily lifestyle. In addition, many RTT individuals have difficulty with verbal communication. However, Amoako & Hare (2019) state with the right guidance from speech therapists, alternative methods of communication, such as assistive devices and sign language, can be used to help individuals with RTT learn to express their needs and facilitate social engagements and interactions with family members and caregivers.

It is pivotal to have support groups for caregivers of individuals with RTT. The lifestyle becomes overwhelming and quite draining for the family or caregiver. The IRSF state representatives provide encouragement, comfort, and resources, and, more so, share their own life experiences with having an individual with RTT to care for. It is important to bring awareness so that all ethnicities will have the same opportunity for coping strategies to deal with an individual with RTT. However, eating healthy, exercising, and getting the proper sleep will also help deal with the anxiety and stress of being a caregiver. Still, it is important to have someone to talk to who can help with controlling stress, depression, and feeling alone. IRSF designates state representatives to have an individual with RTT or the experience of being around someone with RTT before being chosen to advocate for RTT families with support and encouragement.

### ***Financial Resources***

Caregivers from lower socioeconomic backgrounds may have a limited understanding of developmental needs associated with an individual diagnosed with a developmental disability. Moreover, knowledge of developmental milestones and needs may be limited. The research found that Caucasian mothers are more knowledgeable of developmental needs when compared to other ethnic groups. Unfortunately, African American caregivers are less knowledgeable and report being unfamiliar with other caregivers in their community (Zuckerman et al., 2018).

### ***Adapting to Changes in Family Dynamics***

People suffering from RTT usually require specialized care and support from their families to meet their daily needs. Navigation of daily challenges is difficult when they do not get the help they need to live comfortably with the condition. Adapting to changes in family dynamics for individuals with RTT syndrome demands a high degree of flexibility and communication (Hartshorne & Schafer, 2018). Thus, establishing a support network that connects family members, friends, and healthcare professionals is highly required to enable individuals with RTT, their caregivers, and immediate family members access to emotional support, needed assistance, and knowledge to manage the challenges they experience.

Communication is important in helping the caregiver, individual with RTT, and family members adapt to family dynamics changes. Family discussions are thus essential to engage each other to understand expectations and responsibilities in catering to the individual with RTT. According to McGee et al. (2022), clear and effective communication helps reduce stress and anxiety and keeps the family united to offer care for the individual with RTT. In addition, communication helps the family and the caregiver to adjust to new routines, seek additional support, and modify the physical environment to support the new needs of the RTT individual.

Adapting to change can be challenging, and it takes considerable time to embrace new circumstances, but it only requires the support network and willingness of family members to navigate the challenges posed by RTT.

### **Narrative Review**

African American caregivers of individuals with RTT syndrome face various challenges when delivering individual care. This narrative review focuses on three specific areas of research about African American caregivers of individuals with RTT syndrome: coping strategies, adapting to changes in family dynamics, and access to financial resources. African American caregivers use a variety of coping strategies to overcome stress and meet caregiving demands. African American caregivers of individuals with RTT syndrome rely on strategies such as social support from friends and family, participating in spiritual activities, and reading more publications about RTT syndrome (McGee et al., 2022). However, some caregivers opt for alternative ways of coping by using maladaptive coping strategies, which include denial or avoidance, which have negative impacts as they lead to stress and deterioration in health outcomes (Salehi-tali et al., 2017).

Inadequate financial resources are another challenge that African American caregivers' experiences in their line of duty. Most of them have lower incomes and struggle to settle their medical bills, buy prescription drugs, and other healthcare expenses connected to individual care (Wilks et al., 2018). The financial strain increases stress levels and hinders the caregiver from providing adequate care. IRSF has sponsored several conferences to explore ways to improve care for individuals with RTT and to keep the caregiver updated on research.

Adapting to changes in the family dynamic is a necessary strategy for coping that African American caregivers of individuals with RTT disorder adopt. When a family member develops a

disorder, it alters the family dynamic; hence, caregivers must adapt to new roles and responsibilities. In addition, more behavioral and psychological changes are experienced among family members and friends; accordingly, caregivers must learn how to navigate such changes. Whereas some studies suggest that caregiving can strengthen family relationships, others suggest that caregiving roles and responsibilities can lead to strained family relationships. According to Heffer & Willoughby (2017), coping strategies developed from caregivers' cultural beliefs are essential in their commitment to care; hence, healthcare professionals should encourage African American caregivers to utilize such strategies to uphold physical and psychological health in their line of duty.

### ***Impacts of Race & Ethnicity on Resources***

IRSF, through its support network, provides interactive sessions and conferences between caregivers and families of individuals with RTT syndrome to discuss and understand the best ways to overcome cultural barriers in the sphere of care for individuals with RTT syndrome. Cultural barriers such as racism and ethnicity hinder the effectiveness of caregiving in various ways. A case where the caregiver does not have financial support or family support puts a burden on the caregiver's mental health (Salehi-tai et al., 2017). A caregiver from a minority ethnic group or low economic status would feel uncomfortable discussing health concerns with their individual as they would feel unequal to discuss cultural background due to existing prejudiced attitudes based on ethnicity. Cultural barriers affect the caregiver's ability to understand the individual's health needs, which disrupts the provision of appropriate care (Heffer & Willoughby, 2017). Different cultures have different beliefs regarding health and illness, affecting how individuals reflect on their illness and manage their treatment. When the caregiver

is unfamiliar with such cultural beliefs and practices, providing adequate care tailored for the individual with RTT syndrome becomes difficult.

### ***Organizational Approaches for Racial Consideration***

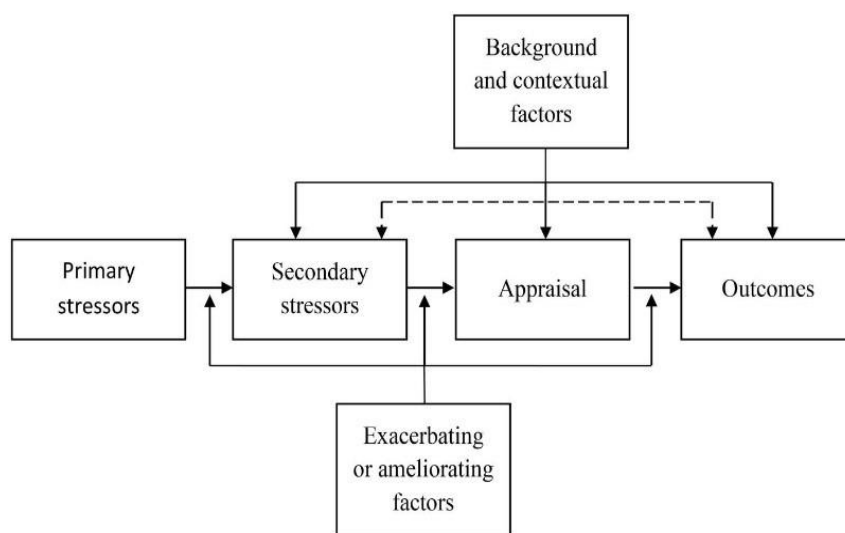
The International RTT Syndrome Foundation (IRSF) has several organizational approaches that promote racial consideration and boost caregiving for individuals with RTT syndrome. The Diversity, Equity, and Inclusion (DEI) Committee is one of the approaches to ensuring that the policies and practices of IRSF are inclusive and equitable for all people seeking help with RTT syndrome, regardless of race or ethnicity (IRSF, 2023). The DEI committee operates by a well-designed strategic plan containing goals and action plans for enhancing diversity and inclusion within the organization's operations and the wider RTT syndrome community network (Garelnabi et al., 2022). Another approach promoted by the IRSF is the development of educational resources and training conferences to boost cultural competence among caregivers, community groups, and healthcare providers. The organization has various webinars and training modules that educate care providers on cultural diversity, implicit bias, and effective communication when offering care services to multicultural individual populations.

### **Theoretical Review**

Theories utilized in this research study to dissect and explain the research objective include the model of carer stress and burden, social structural theory, and the health disparities theory. Each of the listed theories presents key factors that contribute to the understanding of caregiver challenges. The use of these theories in the current study will provide insightful information to improve services for African American caregivers with the IRSF.

### *The Model of Carer Stress and Burden*

The model of carer stress (MCSB) and the burden are utilized in this research study to help in understanding how caregiving stress occurs and affects African American caregivers of individuals with RTT syndrome. This theory integrates two models, the stress process model and the appraisal model to investigate caregiver stress in neurodegenerative disorders (Mori et al. 2019). The model breaks down the process into six different interacting elements including communication difficulties, medication management and attending regular doctor visits, treatments, and therapies, and managing the physical care needs of the individuals. Difficulties associated with managing caregiver needs can result in emotional stress.



**Figure 1.** The Model of Carer Stress and Burden.

The first element of the MCSB is primary stressors which involve objective elements in the caregiving setting and include the types of tasks performed and the intensity of symptoms associated with the time spent in the caregiver role. Primary stressors trigger secondary stressors such as reduced leisure time, family feuds, and financial stress. The third appraisal element is the subjective, self-assessment of a caregiver's situation surrounding their evaluation of the balance between demands and resources. The fourth appraisal element involves psychological and

behavioral issues such as individual well-being and depression while behavioral outcomes entail substance abuse (Mori et al., 2019). The fifth element is exacerbating and mitigating factors that influence relational dynamics and are distinct from primary and secondary stressors. Some key factors that modify relationships involve coping strategies, personality facades, and other helpful resources.

### ***Social Structural Theory***

One of the main theories explaining the challenges faced by African American caregivers with individuals diagnosed with RTT syndrome is the social structural theory (SST). This theory suggests that larger societal factors such as poverty, discrimination, and racism play a significant role in shaping the experiences and outcomes of African American caregivers. Cook et al. (2018) explained that African American caregivers of individuals diagnosed with RTT syndrome face several demographic factors, affecting their QOL. Bulgarelli et al. (2017) found that although the income of African Americans can be comparable to Caucasians and Hispanics, many of them are predisposed to factors that characterize them as having a low socioeconomic status. These factors are associated with challenges of limited access to resources and support, financial assistance, respite care, and educational programs.

SST asserts that demographic factors can have a significant impact on the QOL of African American caregivers, influencing their experiences, resources, and outcomes in complex and multifaceted ways. These factors include race, socioeconomic status, and cultural attitudes. According to Palacios-Ceña, et al. (2019) and Bamba (2019), ethnicity contributes to caregiver stress as evidenced by the unique challenges faced by African American caregivers including limited access to resources and support, socio-economic barriers, and cultural stigma surrounding disabilities. African American caregivers of individuals with RTT syndrome are faced with

increased stress and burdens and must navigate complex medical and educational systems while managing the daily care of their loved ones.

Experiences of caregivers of individuals with RTT syndrome can be further explained based on a caregiver's background and ethnic, cultural, and sociodemographic factors. Research has revealed that race and ethnicity have direct and profound impacts on the challenges that caregivers experience when caring for individuals with RTT syndrome. Jon-Ubabuco et al., (2019) explained that regardless of race, some of the challenges experienced by caregivers include communication difficulties, managing medications, accessing routine medical appointments, treatment, and financial stressors. These factors are exacerbated for African Americans due to limited access to resources and support, financial assistance, respite care, and educational programs.

SST can be used to provide insight into challenges associated with socioeconomic status. For example, families who have a low socioeconomic status face greater challenges than families belonging to a higher economic level status. Olson et al. (2021) found that there was a correlation between demographic variables such as socioeconomic status and parental stressors associated with managing individuals with degenerative conditions. Socioeconomic, developmental indicators and parental stress influenced the quality of life for individuals. The lack of relevant resources decreased the quality of life for individuals diagnosed with RTT syndrome. Moreover, socioeconomic variables extensively impacted the socialization, communication, and externalizing behaviors of individuals with RTT syndrome. For instance, families characterized by a low socioeconomic status often strive to provide for themselves, which means that many spend a lot of time at work trying to earn a living.

### ***Health Disparities Theory***

The Health Disparities Theory (HDT) is beneficial in examining how and why demographic factors such as ethnicity and socioeconomic status impact the QOL of African American caregivers. The theory highlights the unequal distribution of resources and access to health care that African American caregivers may face, leading to increased psychological, emotional, and physical challenges (Palacios-Ceña, et al., 2019). Increased work hours with limited time to manage their private life can result in emotional and psychological issues associated with fatigue. Based on HDT, these challenges are further compounded because African Americans face greater challenges with accessing quality healthcare. Limited access to quality healthcare may be attributed to historical systematic discrimination faced by African Americans. Countless research studies have found that many African American caregivers have developed stigmas surrounding discrimination. In addition, stigmas surrounding disabilities and race have also increased stress levels for African American caregivers. These findings reflect the ongoing need for public health agencies, healthcare providers, and support systems to remain aware of these barriers (Slaboda et al., 2021). Recognizing these challenges should also prompt organizations to identify strategies and resources to improve the quality of life for African American caregivers (Zuckerman et al., 2018).

### **Summary**

African American caregivers of individuals diagnosed with RTT syndrome face unique challenges. These barriers are associated with the intersection of race along with implementing effective coping strategies, accessing financial resources, and adapting to changes in the family dynamic. Some of the key adverse experiences that have been highlighted in the chapter include health disparities. The chapter has shown that African American caregivers are more exposed to

challenges when administering care to RTT compared to other ethnic groups. This disparity is part of a broader pattern of health disparities faced by African Americans in the US due to various forms of discrimination. Another concern is limited access to resources increases barriers for African American caregivers in accessing health care knowledge, skills, and support services. The model of carer stress and burden suggested that caregivers must balance the demands of caregiving with other responsibilities, such as taking more than one job, enjoying leisure time, and caring for other family members. Imbalances in the role of caregivers have been associated with stress and burnout. African American caregivers of individuals with RTT syndrome often demonstrate resilience and strength in the face of adversity. Fundamentally, it is important to recognize the unique experiences and challenges faced by African American caregivers, leading to increased access to resources and support and equity in care, treatment, and research opportunities as provided by the IRSF and other related organizations.

## CHAPTER THREE: RESEARCH METHODOLOGY

### Overview

The IRSF provides resources to professionals and caregivers of individuals diagnosed with RTT syndrome. However, needs related specifically to African American caregivers remain unmet although the research indicates that they require support with implementing effective coping strategies, accessing financial resources, and adapting to changes in the family dynamic. Thus, it is pertinent that the IRSF expand its understanding of the need's relative to African Americans. The purpose of this project is to provide the IRSF with strategies to improve the QOL for African American caregivers caring for individuals with RTT syndrome. Increased awareness of these differences will ensure that African American caregivers are provided with essential resources needed to improve their overall QOL. This section will present the project permissions, methodology, qualitative research, research design, research philosophy, sampling techniques and data collection, role of the investigator, ethical considerations, project questions, procedures, data collection, and analysis for the evidence-based project.

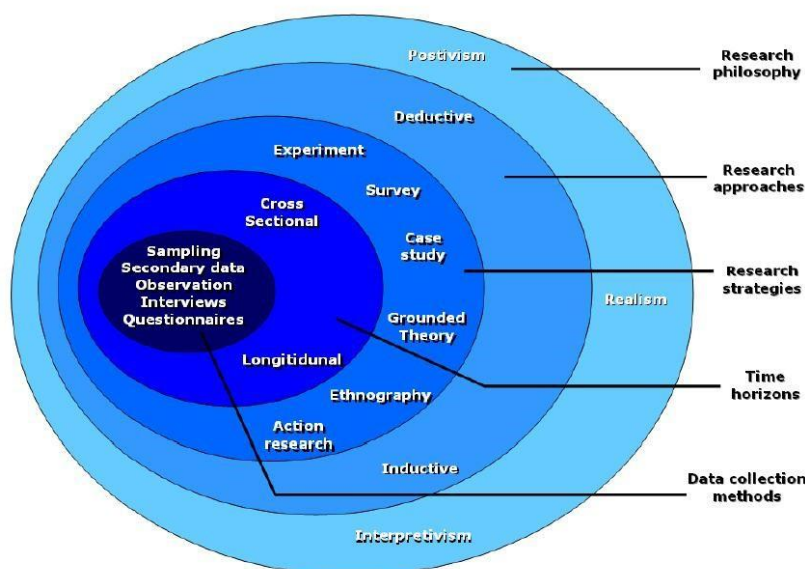


Figure 2: Research Onion (Phair, & Warren, 2021)

**Figure 2** is a research onion and it represents a conceptual framework relied on organizing the current research study. The key stages involved in undertaking the research are represented on the research onion as it contains several layers, each layer unfolding a definite stage of the research. The layers include a research philosophy, approach, strategy, time schedule, data collection, data analysis, and research findings.

Due to the lack of attention and research on Rett syndrome, there was a gap in information about the disorder. To fill this gap, this qualitative research study will provide insight into caregivers' experiences for individuals with Rett syndrome. Detailed information from interviews will provide data for analysis, while secondary research, including scholarly journals and articles, will offer insight. A meta-analysis will be done to ascertain the best source for use. A sample of 10 secondary sources will be used for this study. Qualitative research methods are more natural and nurturing than quantitative since they are conducted by speaking to caregivers' face to face instead of over the phone or online (Weyant, 2022). Since caregivers are uniquely positioned to understand their disabled individual's experiences due to their proximity to their life, qualitative methods are more likely to elicit honest responses from caregivers (Brown, 2022). Qualitative methods allow caregivers to share their experiences without needing professional support or assistance. using qualitative research methods will be beneficial when gathering data on rare experiences such as caring for children with Rett syndrome (Kreutzmann, 2022). Caregiver interviews provide useful information on how the individual experience being diagnosed with this rare neurological disorder and living with it day by day. Detailed information gathered through these interviews will help caregivers support their individuals affected by RTT and provide them with basic needs such as medical supplies, special home modifications, accessible transportation, and homecare assistance while in care homes.

## **Methodology**

The research topic for the current study is “*African American Caregiver Experiences Associated with Individuals Diagnosed with Severe Rett Syndrome.*” Research objective of the study is to research and establish the plight of African American caregiver experiences with individuals with Rett Syndrome by uncovering their daily work experiences, their needs, expectations, and hinderances as they tend to RTT individuals. The main research question being explored is “What are the physical and mental health impacts African American caregivers experience from offering caregiving services to individuals living with RTT?” This research study will be conducted using a qualitative research method. In selecting the methods, the research variables were highly considered. From that perspective, the independent variable is caregivers of individuals with Rett Syndrome, while dependent variable is physical and mental health impacts on African American caregivers.

## **Qualitative Research**

Qualitative research is a research methodology that examines subjective, non-numerical data to develop an understanding of complicated processes (Weyant, 2022). It employs methods such as interviews, focus groups, observation, and content analysis to investigate and comprehend people's experiences, beliefs, attitudes, and perceptions. Concerning this research study, African American caregivers experience unique challenges when caregiving to individuals with Rett Syndrome. Past research studies failed to establish a clear pattern of events that contribute to such outcomes; hence, the current study seeks to close that gap using a qualitative research methodology. Although there are some downsides to qualitative research methods compared to quantitative ones, using qualitative research methods will be beneficial when gathering data on rare experiences such as caring for children with Rett syndrome (Kreutzmann,

2022). Caregiver interviews provide useful information on how the individual experience being diagnosed with this rare neurological disorder and living with it day by day. Detailed information gathered through these interviews will help caregivers support their individuals affected by RTT and provide them with basic needs such as medical supplies, special home modifications, accessible transportation, and homecare assistance while in care homes.

### ***Research Design***

The entire approach or plan for performing a research study is referred to as the research design. According to Weyant (2022), research design describes the methodology, methods, procedures, and techniques to be utilized in collecting and analyzing data to answer research questions or test research hypotheses. A research design acts as a roadmap for the whole research process, ensuring that the study is well-structured and organized (Weyant, 2022). It comprises crucial decisions on the sampling strategy, data gathering methods, data analysis methodologies, and the general framework for interpreting the results. The research design is an essential component of every research project because it ensures that the data obtained is trustworthy, valid, and widely applicable to the target group (McBeath, 2023). It also helps to guarantee that the study is done ethically and in accordance with accepted research practices.

Narrative research design is selected for the current research study. A narrative research design is a qualitative research technique that involves gathering, evaluating, and interpreting personal accounts or narratives of events (Weyant, 2022). Rather than objective or measurable occurrences, the major emphasis of narrative research is on the individual's viewpoint and understanding of their experiences. According to McBeath (2023), life histories, personal tales, and cultural narratives are examples of narrative research designs used to investigate complicated

and subjective experiences. In-depth interviews, focus groups, or textual narratives are commonly used in research to find patterns, themes, and meanings.

The selected research design is focused on answering questions what, how, and why in connection to the main research question. The research design investigates the plight of African American caregivers of children with Severe Rett Syndrome on what they experience during the care, the challenges that hinder their care delivery, and what they need to feel comfortable in their line of work. The design is selected to ensure enough data is collected to shed light on the nature of services offered by African American caregivers of RTT individuals and to identify challenges they face.

### **Research Philosophy**

In carrying out a research study, the set of assumptions, beliefs, and ideals that influence the research process is referred to as research philosophy (McBeath, 2023). It is a structure that researchers use to organize their research questions, design their investigations, and analyze their findings. The researcher's worldview is shaped by research philosophy, which impacts research topics and hypotheses and directs the selection of research methodologies and data processing procedures. In this research study, interpretivism research philosophy is selected to help in exploring and understanding the experiences of African American caregivers of individuals with Severe Rett Syndrome. The study philosophy of interpretivism stresses the relevance of subjective experience and interpretation in human action (McBeath, 2023). It implies that individuals build and interpret social reality depending on their own experiences, ethnic background, and social environment.

The positivist idea that there is an objective world that can be explored and evaluated through scientific means is rejected by interpretivism. Instead, it contends that the researcher's

responsibility is to comprehend and interpret the significance of human acts and behavior. The use of qualitative research methods which include interviews, observations, and case studies, which permit researchers to investigate complicated and nuanced phenomena, is emphasized by interpretivism (McBeath, 2023). The relevance of the researcher's subjectivity in the research project is also recognized by interpretivism. Researchers must be conscious of their own preconceptions and assumptions, as well as how they may affect study findings. They must also build rapport and trust with study participants in order to collect rich and thorough information about their backgrounds and viewpoints. The research phenomena being explored in the current study is “*African American Caregiver Experiences Associated with Individuals Diagnosed with Severe Rett Syndrome*” and interpretivism philosophy is relevant to the study as it reveals the experiences and perspectives of the affected parties which are African American caregivers and individuals with RTT condition.

## **Sampling Techniques and Data Collection Methods**

### ***Data Collection***

Non-numerical data, such as words, images, and observations, are collected using qualitative data gathering methods to acquire a better understanding of a phenomena (McBeath, 2023). Structured interviews, focus groups, and surveys forms the primary data collection methods while published books, journals, healthcare industry reports, and health magazines forms the secondary data collection methods.

### ***Primary Data Collection***

The practice of gathering data directly from the originator, which might be persons, organizations, or events, is referred to as primary data collection (McBeath, 2023). This information may be gathered using a variety of ways, including surveys, interviews,

observations, and experiments. In this research study, structured interviews, focus groups, and surveys form the primary data collection methods. The affected population include African American caregivers, their immediate families, and the RTT individuals under their care. Key stakeholders in the department of health regarding the improvement of healthcare outcomes for patients with Severe Rett Syndrome are also an interest group in the investigation of the research phenomena.

### **Population and Sample Size**

The target population for this study is African American caregivers of individuals with Severe Rett Syndrome. Selection of target participants from the defined population will be done on the merits of their knowledge on the research topic and their past and current experiences with individuals with RTT condition. Identification of such participants will be through referrals, inquiries from local healthcare facilities, and through personal connections. Unbalanced procedures and random sample size will be employed to define the sample size.

### ***Sampling Technique and Sample Size***

Purposeful sampling is the sampling technique used in this research study. It is a sampling technique that entails selection of participants who bear specific characteristics or experiences considered relevant to the research question. The emphasis on the use of purposeful sampling is to gain an in-depth knowledge regarding the experiences of African American caregivers of individuals with Severe Rett Syndrome. Homogenous sampling in this research study is selected as participants are chosen based on similarities in traits such as employment or ethnicity. This form of sampling is frequently employed in research to investigate the experiences of a certain population.

**Permissions**

At the commencement of this project, written permission will be obtained from the IRSF gatekeeper to conduct the capstone project with members of the organization. Permission provided will allow the researcher to conduct interviews with members and focus groups with state representatives from the organization. The permission request forms are in Appendix 1 below. The project does not require IRB approval because the capstone project is site-specific, the results and solution to the problem are not generalizable beyond the site, and the project will not be published or disseminated beyond the site. The participants will be asked for consent before including their information in the study. Also, permission was obtained from the primary supervisor of Oxford University to conduct the study.

**Investigator's Role**

The investigator's role is critical in this research based on my personal experience as an African American caregiver of an individual diagnosed with RTT syndrome. The investigator is knowledgeable of the potential for bias due to observing challenges related to African American caregivers who provide care to individuals with RTT syndrome. The investor is familiar with financial limitations and lack of necessary support.

African American caregivers lack financial support, rather it is because of single-family homes or only one member is able to work and meet all the needs in the home. African American caregivers are burdened with not having accessible transportation, Hoyer to lift the individual in the home, and adaptive communication devices. While on the other hand, other ethnic groups have more family support, more financial support, and the necessary equipment and modifications required for the individual with RTT in their home.

My family were faced with challenges through the years for not having enough resources to provide what was needed in our home to care for someone with RTT syndrome. The IRSF provided information on how to cope with having an individual with RTT syndrome. However, no funds were provided to families to help subsidize the burden of missed work to pay bills because of the many appointments or sick days encountered. Fortunately, I was able educate myself by asking multiple questions of other families with RTT individual, and by doing research. If it had not been from my ambition and knowledge, my family would probably be in the same situation. Therefore, I cannot express enough how important it is to bring awareness to help African American caregivers reach a positive QOL. The investigator can collaboratively collect information to report also by the experience of being a member of the IRSF and serving as one of the state representatives. Therefore, the role of the investigator in the current research study on African American caregivers' roles and challenges in caring for individuals with RTT include designing the study. The investigator is responsible for developing the study design, including selecting the appropriate research methods and participants. The researcher is again responsible for recruiting the participants in this study. The researcher oversees communicating with the African American caregivers of the individuals living with RTT as well as the caregivers of the individuals living with RTT. After recruiting the participants, the researcher gets to collect information from the participants through interviews. Thereafter, the investigator gets to engage in data analysis to determine the experience and impacts of African American caregivers' roles in caring for individuals with RTT. The investigator then disseminates and reports the findings of the research.

## **Ethical Considerations**

When conducting research on the topic "African American Caregiver Experiences Associated with Individuals Diagnosed with RTT Syndrome," the researcher gets to make various ethical considerations to ensure the well-being and protection of the participants. Some of the key ethical considerations that a researcher may make in this study include getting informed consent. The researcher obtained informed consent from all participants in the study, ensuring that they fully understand the purpose and procedures of the research, and that they voluntarily agree to participate. Additionally, the researcher maintains confidentiality and anonymity. The researcher has taken measures to protect the confidentiality and anonymity of the participants, such as using pseudonyms or removing identifying information from the data. The researcher also ensures that steps are taken to minimize any potential harm or discomfort that may result from participation in the study, such as providing participants with resources for support or debriefing them after the study. Additionally, the researcher also ensures that there is cultural sensitivity in the study. This is important because the study is focused on investigating the impacts on caregiving to individuals living with RTT, by African American caregivers. The researcher also ensures that power dynamics are addressed between the researcher and the participants, such as the researcher's role as an authority figure, and takes steps to minimize these dynamics. The Institutional Review Board (IRB) approval is not deemed necessary in the study, and the researcher ensures that the study has received confirmation and approval from an Institutional Review Board (IRB), which is responsible for evaluating and approving research projects to ensure that they are ethical and meet legal and regulatory requirements.

## Questions

**Central Question:** What opportunities exist to educate the IRSF on the needs and resources available for African American caregivers of individuals with RTT syndrome to improve their QOL?

**Sub-question 1:** What are the physical and mental health impacts on African American caregivers of individuals living with RTT syndrome?

**Sub-question 2:** How do demographic factors (ethnicity and socioeconomic factors) impact the QOL of caregivers?

**Sub-question 3:** What are the unmet needs of African American caregivers of individuals **diagnosed with RTT Syndrome?**

## Data Collection and Analysis

This study will identify and describe the coping strategies used by African American caregivers of individuals with RTT syndrome. A total of 12 caregivers will be interviewed, and the data will be analyzed using constant comparative methods. The primary themes that emerged from the data will be (a) the importance of support, (b) the challenges of caregiving, and (c) balancing work and caregiving responsibilities.

This qualitative project will use interviews, a focus group, and observation to obtain information that can be used to enhance services and resources offered through the IRSF. In-depth interviews with 12 African American caregivers caring for individuals with RTT syndrome residing in Virginia and Georgia will be conducted. The researcher will use Zoom or telephone to interview participants using 10 open-ended questions regarding their experiences as a caregiver. The researcher will also develop a focus group with six IRSF regional representatives

who will complete a survey at the conclusion of the focus group. Lastly, an observation will be conducted using the RTT Syndrome Family Support Forum Facebook page.

There is a lack of information on African American caregivers' experiences with RTT Syndrome. To address the gap, a literature analysis will be conducted. The following databases will be searched: CINAHL, PubMed, PsycINFO, Jerry Farwell, Wiley Online Library, and Web of Science. The keywords to be used are *Africa American, RTT Syndrome-RTT, caregivers, qualitative research, and quality of life*. The search will be limited to English-language articles published between the 1<sup>st</sup> of January 2017 and the 20<sup>th</sup> of September 2023. A total of 78 articles will be identified and analyzed.

Many authors believe that RTT is a neurodegenerative disorder that progresses over time, resulting in the affected individual's adolescent part of life causing total impairment. Rozensztrauch et al. (2021) conducted research that revealed that roughly 44% of individuals by the time of two years old had lost their motor abilities and capacity for independence. These findings are consistent with those of numerous previous studies where most instances, between the ages of one and two years, previously acquired skills began to deteriorate. The QOL assessment enables treatment to be modified to meet the needs of all individuals aiming to increase the individual's life expectancy, independence, and well-being through regular activities.

An interdisciplinary approach and constant collaboration should be used with the individual's family for RTT-affected adolescents to receive rehabilitation. In light of this, Rozensztrauch et al., (2021) presented that it is unsurprising that kids who spent more than 10 hours of physical QOL were considerably higher ( $p = 0.044$ ) over the week in rehabilitation programs compared to individuals who receive 5 to 10 hours of rehabilitation therapy every

week. This study's limitations must be considered while analyzing its results. First, only correlations between predictors and QOL ratings, not other relationships, were shown by the cross-sectional approach. Second, a general questionnaire was used to conduct the study, and a special questionnaire for individuals with RTT is necessary for disease in later research. Lastly, only 23 children participated in the study, with a small number of participants thus the findings were likely to bias (Rozensztrauch et al., 2021).

The QOL of individuals with RTT, according to Rozensztrauch et al. (2021), is better understood as explained in various studies that have explored this topic. Individuals with RTT significantly reduced QOL across all instrument parameters, particularly social well-being. Factors such as epilepsy, breathing issues, and scoliosis had no discernible impact on how well the family was operating (Rozensztrauch et al., 2021). Measurement of QOL identifies areas where an individual and their family need critical assistance from practitioners to make the best choices for their care.

In support of the above-presented information, Palacios-Ceña, et al. (2019) summarize in their research article that caring for individuals with RTT can be both rewarding and challenging. The rewards of caring for individuals with RTT include fulfillment that caregivers experience after getting positively improving the health, well-being, and overall QOL of individuals with RTT, along with that of their family members. Many caregivers report a deep sense of fulfillment from caring for their individual with RTT. They often describe the experience as an opportunity to learn, grow, and deepen their relationships with their individual. Quite the opposite, the challenges can be more than the benefits because RTT is a neurodevelopmental disorder that is commonly linked to adverse impacts on the communication, mobility, and daily living skills of those that it affects. Some of the issues that most caregivers experience when

caring for the needs of RTT individuals include that they experience difficulties in managing the physical and emotional demands of the individual with RTT.

Most individuals with RTT usually need assistance with feeding, dressing, and even using the bathroom, and maintaining proper hygiene. Meeting these needs requires that the caregivers offer round-the-clock care services. This is proving to be challenging since due to the existing shortage of caregivers, including communal-based caregivers who offer home-based care services, many caregivers find themselves working long hours. This leaves limited time for them to work on their personal needs and wants, which may also require commitment. In most cases, this includes the caregivers having limited time to take care of their social needs, relationships, and even activities such as higher education for caregivers who are keen on expanding their academic qualifications (Mendoza et al., 2020). In support of this but from a different perspective, Zhang, et al. (2018) emphasize that caring for individuals with RTT is essentially the full-time responsibility of caregivers.

Individuals with RTT have social and communication difficulties, and this compounds the challenges that caregivers experience in ensuring that they offer quality care services. As previously mentioned, it is usually prudent to ensure that augmentative communication tools are used so that individuals and older individuals living with RTT are able to express and interact with others more efficiently (Banerjee et al., 2022). Notably, at times even with the use of assistive tools, it is at times still difficult to understand the needs and wants of the individual with RTT. The impact that this has on the caregivers, as well as the individual, is that it can result in frustration and feelings of isolation. Such challenges can be compounded by the difficulties that individuals with RTT face regarding being able to adapt to changes. It is natural that as individuals grow and develop, they experience changes; hence, it is usually imperative, yet

difficult for the caregivers to adapt to the changes of the individual, as changes mean that their needs also change (Zhang et al., 2018). Caregivers for children living with RTT face the challenge of lack of adequate support and lack of resources. According to (Banerjee et al., 2022), there is limited information and support available for caregivers and families caring for individual with RTT which make it difficult for caregivers to find resources and connect with others who understand their situation.

The project goal is to have the IRSF organization bring more awareness to African American caregivers of an individual with RTT by sharing how it affects the caregiver's QOL, causing their mental and physical health to alter. Additionally, demographic factors such as ethnicity and socioeconomic factors have been found to impact the level of QOL of African American caregivers. The vivacity of having QOL was described in an article by World Health Organization (ScienceDirect, 2023). It entails how people are viewed by their mental health, physical health, spirituality, socioeconomic factors, personal belief, and individual environment. And if not maintained a positive QOL, a caregiver could encounter financial, physical, and emotional strain (Starks et al., 2018).

## **Interviews**

This study's qualitative research interview questions are based on qualitative principles. Interviews become the key strategy for acquiring primary data for this study since the researcher will select the sample and the questions to be asked. To eliminate bias, each respondent in this dissertation is asked to answer the identical sequence of questions. Through caregiver interviews, the researcher will better understand the patient's experience. This is particularly useful when trying to gather information about a rare disorder that is not well-known or studied. Additionally, since most patients with Rett syndrome are institutionalized, the targeted participant group of

participants will be highly accessible (Banerjee et al., 2022). Through caregiver interviews, the researcher will better understand how the disorder affects the patient's daily life and relationships. Interviews will also be used to gather information about how caregivers find support and coping mechanisms to deal with their daily pattern of care and how it impacts their lives (Mthombeni & Nwoye, 2017). Conducting caregiver interviews allows researchers to learn about this disorder and gather information from those who have experienced it firsthand.

The first sub-question for this project will explore the physical and mental health impacts on African American caregivers of individuals living with RTT syndrome. The interviews will consist of 12 African American caregivers who reside in Virginia and Georgia. Scheduled, structured interviews will be conducted via Zoom and are expected to last up to 30 minutes. Each interview will be recorded for accuracy with the interviewee's permission. Data collected from the interviews will be transcribed for analysis.

Interviews help the researcher to gain more insight into the experience of the participants. This is particularly useful when gathering information about a rare disorder that is not well-known or studied. Caregiver interviews are ideal because they are more accessible to the researcher as most individuals with RTT syndrome are institutionalized (Banerjee et al., 2022). Through caregiver interviews, researchers will better understand how the disorder affects the individual's daily life and relationships. Interviews will also gather information on how caregivers identify support and coping mechanisms to deal with their situation. Using focused research questions, caregivers will help to answer the research questions related to individuals with RTT syndrome (Mthombeni & Nwoye, 2017).

RTT syndrome is a rare disorder and there is a lack of insight regarding the care needs of individuals. Therefore, conducting caregiver interviews allows researchers to learn about this

disorder and gather information based on lived experiences. Additionally, this method allows them to understand how individuals with RTT syndrome and their families feel about the disorder. This information will be beneficial in generating new resources and raising awareness for individuals and families affected by RTT syndrome (Mthombeni & Nwoye, 2017).

1. How has being a caregiver affected your physical health?

Question one was designed to obtain insight from caregivers regarding changes in their health due to responsibilities related to the caregiver role. Cardinali et al., (2019) found that the absence of resources has a significant impact on physical health outcomes for caregivers. Limited resources and a lack of knowledge regarding proper caregiving techniques used by professional staff may have a significant impact on the health of informal caregivers for individuals diagnosed with RTT syndrome. Learning more about physical health impacts is necessary to provide researchers with insight into health impairments that extend beyond the individual with RTT syndrome. This information can also provide organizations with greater insights into health disparities that are experienced by African American caregivers.

2. How do you maintain a quality of life while caring for your individual with RTT syndrome?

This question is vital to achieving evidence from the caregiver challenge encountered on a daily basis when caring for an RTT individual. Slaboda et al. (2021) implied that the role of caring for someone else that is disabled is difficult and can depressingly affect the person's QOL.

Acquiring more information from the caregiver will allow healthcare providers to understand how to conserve the measurements to help African Americans have a positive QOL. However, Slaboda et al. (2021) argued that lacking these resources from healthcare providers will cause the caregiver's own personal health to decline and become detrimental to caring for the individual.

Hence, caregivers often felt more emotionally and physically drained from the care causing them to lack self-care even more (Slaboda et al., 2021). Therefore, this question will provide insight into the critical needs of self-care while caring for an individual with RTT. Also, it will bring awareness to the demands that evolve around daily care.

3. How much has being an RTT caregiver impacted your mental health?

This question is necessary to bring awareness about the strain that African American caregivers faced when caring for individuals with RTT. Baji et al. (2019) state that the problem with indirect care leads to stress, fear, loneliness, hopelessness, and anxiety about what the future holds. The caregiver's physical health is subjected to decline because they become overwhelmed from providing the care (Baji et al., 2019). Allowing caregivers to respond to the questions will enable more insight into why it is important to get support and prevent mental health issues.

4. Can you describe any symptoms of stress, anxiety, or depression that you have experienced because of caregiving?

This question will provide insight into how the African American caregiver adapts to life and manage to care for the individual with RTT altogether. It will allow more awareness of the different experiences African American encounter compared to other races. According to Williams (2018), African American caregivers suffer responsibilities that lead to exhaustion and emotional stress causing their mental well-being to increased levels of stress, anxiety, and depression. This question will explain the different levels of stress, anxiety, or depression and the indicators that affect mental well-being. It will allow African American caregivers caring for an individual with RTT syndrome to express their need for support from IRSF and healthcare providers.

5. Describe the level of support you receive from healthcare professionals being knowledgeable about the care of an RTT individual?

This question is asked to determine the lack of support provided by healthcare professionals and public administration for African American while caring for the individual with RTT syndrome. It is essential to acquire a precise sense of perspective to understand the solution to caregiving responsibilities. Not only will it bring more awareness for healthcare providers, but possibly allow the African American caregiver the opportunity to vent about their need to have a better QOL. It was shared in an article written by Williamson (2018) that caregivers of RTT syndrome individuals have a difficult time finding quality professional care and are barred by local rehabilitation centers because of the severity of the individual with RTT needs. This question is asked in hopes to close some of the gaps and bring more awareness.

6. What coping strategies do you implement to handle your mental and emotional needs as a caregiver?

This question is inquired to bring awareness of the emotional stress that African American caregiver experience differently from other ethnic groups. Not having suitable resources for the caregiver's needs can result in emotional stress. Also, learning how to cope with emotional stressors and understanding their symptoms, could manage daily routines. Cardinali et al. (2019) presumed by saying that limited support, lack of treatment options, and scarce financial resources further diminish the quality of life for caregivers which makes it difficult to cope with stress. This information could also bring more insight to IRSF on how to bring more awareness to this situation.

7. Explain your experiences of receiving care (e.g., equipment, supplies, modification, homecare) as a caregiver compared to other race caregivers of other ethnicities?

Question seven was anticipated to get the understanding of African American caregiver experience in relation to other ethnic groups. Algood and Davis (2019), believed that there are disparities in healthcare, housing, employment, finances, and education that influence the QOL among African American caregivers. And that the United States has partialities toward the class base and gender-based approaches to social oppression rather than considering race as a factor (Algood & Davis, 2019). This question will help identify some of the issues that are downsized as an African American caregiver in hopes that they will receive the same opportunities as other ethnic groups.

8. Describe moments where you felt disparity among healthcare professionals when seeking assistance for your individual with RTT?

This question is important to identify the barriers that African American caregivers face when caring for individuals with RTT. Cohen et al. (2019) discovered in their research that even though African Americans and White caregivers uphold the same responsibilities, African American caregivers are the sole provider, while whites have more support for the care they provide. This question will bring more rationale as to why it is like that, and also help healthcare professionals to reach out more to the African American population. It helps healthcare professionals understand what approach to take to resolve the issue or at least make improvements in the future.

9. What types of support do you lack as an African American caregiver of an individual with RTT syndrome?

This question provides information about African Americans' QOL while providing care for individuals with RTT. It will help identify what coping strategies if any or use, access to financial resources, and how they adapt to changes in the family dynamic. Without having these three under control it makes it difficult to have a positive QOL. Algood and Davis (2019)

revealed that African American caregivers have a difficult time caring for their disabled individuals which leads to a poor quality of life. Having more awareness brought about for these issues will hopefully help African American caregivers improve QOL. Even though IRSF is designed to bring awareness for RTT, there is still a need to recognize the setbacks related to African American caregivers of individuals diagnosed with RTT syndrome. This question will assist the IRSF with additional information to develop tools and resources to support these families.

10. Is there anything else you would like to share about how caregiving has impacted your physical or mental health as an African American caregiver for someone with RTT syndrome?

This question will give the participants an opportunity to share things that were not asked in the interview. It would allow them to feel more engaged and cared for in regard to their need for care. Having the participants add their own personal experiences will give them a chance to open up more about how their QOL is affecting them while caring for the individual with RTT. In doing so, this will allow the researcher to be open-minded about circumstances that need to be addressed. In addition, it will facilitate IRSF and healthcare professionals to understand the standpoint of the African American caregiver experience and the critical needs.

Thematic analysis will be used in this qualitative data when conducting the interviews. This method will allow the researcher to identify, analyze, and interpret themes within qualitative data. The researcher will illustrate the data to identify common themes to be coded and transcribed through a six-step process of familiarization, coding, generating themes reviewing themes, defining, naming, and writing up (Scharp & Sanders, 2018). Clarke and Braun (2017) stated that codes are essential to organizing the themes into the smallest units of analysis to summarize the data. The thematic analysis is arranged in a pattern to identify a salient

characteristic of the research (Scharp & Sanders, 2018). Therefore, researchers can ask more personal questions to help close the gaps in the research.

### **Focus Group**

The second sub-question for this project explored how demographic factors (ethnicity and socioeconomic factors) impact the QOL of caregivers. The focus groups will consist of 5 IRSF State Representatives that agreed to participate in the group. The participants will have ten questions asked by the researchers. The focus group will take place via conference call. This focus group will allow everyone to have an open discussion and clarity on how the IRSF will better serve members of all nationalities.

In conducting the current study, it is important to note that the population of African American carers commonly lack adequate resources to provide individuals with RTT needs. African Americans according to Rozensztrauch, Sebzda, & Śmigiel, (2021) face considerable challenges when it comes to getting by their regular lives. Studies have shown that African Americans currently make up the highest population of individuals living in poor neighbourhoods, yet they belong to minority population groups in terms of their numbers. Additionally, the African Americans face considerable predisposed factor which have been institutionalized over the years. This includes facing discriminations and barriers when it comes to access to education and quality health care services. All of these are factors that according to Rozensztrauch, Sebzda, & Śmigiel, (2021) show that the African Americans are exposed to greater risks of having poor quality of health and quality of lives. Such issues are compounded when they have to cope with caring for children living with RTT. For the current project, a total of 6 African American caregivers, all of who are African Americans will be interviewed.

1. How has a role as a state representative influenced caregivers with individuals with RTT?

This question is enquired to see if the role of a state representative is necessary for families. It will provide insight into what they do to help the families overall. According to the IRSF (2022), the state representative is supposed to provide families with resources such as medical attention, therapies, Medicaid, and other funding, as well as educational support. Thus, state representatives must be knowledgeable in all capacities of what is going on within the IRSF to better serve the members. If lacking that knowledge, it would be impossible to fully execute their role. This question is necessary because it allows the researcher to be knowledgeable of the specific responsibilities.

2. How would you describe the QOL for American African caregivers in relation to other ethnic groups associated with the IRSF organization?

This question was designed to see if the QOL for African American caregivers was identified by the state representative. From my own personal perspective, I find that most African American distance away from organizations for help and instead lean more towards their religion for their inner strength. Como et al. (2019) stated that African American are categorized as having the highest risk factors, incidence, morbidity, and other chronic diseases compared to other races. Therefore, the importance of solving these issues is to improve the QOL for African American caregivers who care for individuals diagnosed with RTT syndrome. Not only will it enhance the QOL for the African American caregiver, but it will also bring more awareness to their personal needs as the caregiver.

3. What are the main issues that caregivers face when seeking assistance from IRSF representatives?

This question was asked to bring insight from the representative on a personal continuum. It allows the representative to take part in sharing their opinion (s) about their experience. Asking this open-ended question helps the researcher to see the standpoint from different demographics' needs. RTT caregivers are faced with similar needs, however, depending on the race the need and support could be different. However, in an article presented by Palacios-Ceña et al. (2019), states that RTT caregivers describe their individual with RTT care as being unexpected from day to day (e.g., seizures, nutritional problems, bowel problems, sleeping disorders, respiratory disorders, and stereotypical movement). This question would provide insights that could help identify the main stressor faced by RTT carers.

4. As a state representative how do you feel about the way IRSF distribute the funds provided by investors, events fundraiser, and private donors?

Question four is essential to the research to see if there are any complaints about how IRSF allocates the funds being raised each year. Especially, since the state representatives are unpaid (volunteers). State representatives are committed to donating their time to caregivers of RTT syndrome to support them with resources to improve their care. It will allow them to provide input on how to distribute grants to families in need of adaptive devices, modifications, or supplies to alleviate some of the financial stress. Not only financial stress, but it will also help with mental and physical stress as well. This question is vital to help realize why event fundraisers made by the local community of those states should go towards families in need within that state. In 2021, IRSF reported that \$4.13 M was raised through sponsorship, grants, fundraising events, investments, and other income (IRSF, 2022). The \$4.10 of the funds were allocated towards family empowerment, research, advocacy, and administration (IRSF, 2022).

None were given to the RTT families in need of improving their care at home. This question could benefit caregivers of all ethnicities and demographic areas.

5. How often do you assist with African American caregivers caring for individuals RTT?

This question is asked in this project to discover if African American take advantage of the resources and information provided by the state representative. Obtaining this information would allow the researcher to record pertinent data comprehending the difference between race and need. According to National Alliance for Caring (2020), blacks have a greater impact on financial burden than any other race. This could make the African American carer to become depressed and not be willing to seek additional resources. National Alliance for Caring (2020) revealed that the depression of care for African Americans is deeply rooted in the past, and considered to be uncompensated slave labor, labeling caregiving as women's work. This question will help identify the lack of support that African American caregivers need to have a QOL.

6. Do you think there is a difference in ethnicity support level when talking to the caregiver?

Question six was designed to determine if there was an explicit disparity among the ethnicity groups documented by the state reps. This information is vital to the research to see if African Americans have more physical and mental stress than other races. An article written by Wilks et al. (2018) disclosed that African American caregivers handle their stress levels by relying more on spiritual appraisal and higher levels of religiosity as opposed to another race. The divergent standpoints provided by the reps can support the gap that African American caregivers have a

different approach on being a caregiver. This question will help the IRSF to increase more programs to support all ethnic groups.

7. What is the most challenging part of being a state representative?

Question seven is designed to gain knowledge from the state representative's role. It will provide clarity on the pros and cons of being a state representative. Also, it will bring awareness to the IRSF on what the lack is, if any, and how to better prepare their state representatives in the future. It is vital for state representatives to be competent, compassionate, and great listeners to serve the IRSF families. This question will provide insight into the challenges encountered by the state representatives and improve the IRSF program.

8. What improvement could be made to better serve caregivers with RTT individuals?

This question is important to gain insight into the caregiver's stressors. Donnellan et al. (2018) believed resilient carers are more likely to be optimistic and have a positive QOL while caring for a disabled individual. On the other hand, Humphrey et al. (2021) emphasized that carers become drained while caring for the disabled individual leading to mental health issues and interrupting QOL. This question would provide the IRSF organization with more insight shared by the state representative on the caregiver stressors beyond the RTT disorder that they have experienced. Also, it would make it more salient to the caregiver's personal struggle. By doing so, hopefully, the IRSF state representative will identify the needs of the caregivers and respond to them directly.

9. Describe how the IRSF is beneficial to serving all ethnic groups.

This question is asked to identify whether there are any racial differences among demographics. The purpose is to bring awareness to the IRSF organization whose purpose is to advocate for families with RTT individuals and reach all nationalities. This will give IRSF more insight into

the gaps needed to be filled. The state representative's information could enhance the research data by providing prevalent information. This question is asked to determine how African Americans and other races could be served in a beneficial way by the IRSF.

10. In what ways do you believe that the IRSF organization could better serve the RTT families who are members of their organization?

Question ten was asked to gain insight into how the reps feel about the IRSF organization overall. This will allow the reps to discuss areas where they think need to be addressed or challenged. The question will help the researcher have a full description of the role and responsibilities. The rep should be able to display any bias faced while honoring the role as a volunteer and what they think needs to be improved. This question was asked at the end to hopefully close any gaps about the pros and cons of being a state representative that was not addressed in the earlier questions.

### **Observation**

The third sub-question for this project will explore the physical and mental health impacts on African American caregivers of individuals living with RTT syndrome. The researcher will observe activities happening on the RTT Syndrome Family Support Forum social media Facebook page posted by families caring for individuals with RTT syndrome. The researcher will serve as a participant observer to gain subjective data unscheduled. There will be a total of five observations conducted within ten days.

Observations conducted via social media have been beneficial in providing researchers with data for qualitative analysis. In this project, I will use a passive analysis. Expressly, passive analysis is a useful way to observe and explore patterns, information pertaining to a specific topic, and interactions between Facebook group users' modifications. Therefore, having access

to members in the Family of RTT Syndrome Forum Facebook group provides personal insight into the caregiver's everyday life. Facebook is recognized for having a platform that provides massive information on various topics. Over the years, it has multiplied to over 1.2 billion active members (Franz et al., 2019). It is a meaningful source to get pertinent information that would be difficult to obtain in another setting. Franz et al. (2019) state that Facebook is an essential source for qualitative researchers because individuals spend a significant portion of their social lives on it; thus, allowing researchers to view, note, and record. Like everything else involved with social media, Facebook has its pros and cons, depending on the topic and what is being researched.

In this section, I observed Facebook users' interaction with other users in the same group setting (e.g., passive analysis), in a private group available on Facebook (RTT Syndrome Family Forum). I was able to explicitly observe all Facebook data at any time. I was able to join the group, which displayed that it was established in July 2011 and consisted of 9405 members. Becoming a member allowed me to observe and gather as much information as possible. The focus was to see how African American caregivers managed their QOL while caring for an individual with RTT. However, there was a lack of phenomenological to report and observe from African American caregivers caring for individuals with RTT because none were identified during the observation. Therefore, there was a gap in the literacy pose to satisfying the research topic.

Hence, I observed how caregivers struggle with ways to adapt to their individual with RTT behaviors (e.g., a caregiver stated that it is hard to watch her other child play a sport because her individual with RTT makes noise and requires a lot of attention). Many questions were posted about how the caregiver copes with their individual having multiple seizures, constipation, contraction, and screams through the night. It also discussed the need for

modifications and equipment for their homes. The Forum aims to encourage and share informative information to better care for the individual with RTT. However, no African American participated in the post during the five days of observation. There were posts of encouragement, motivation, and praise report from some of the caregivers. This forum was where I observed caregivers discussing their severe seizures and wanting input from other caregivers. Only one caregiver replied to the post. A caregiver inquired about a sleep-safe bed for her individual with RTT. There were 4 likes and 53 comments, posts with pictures of beds, and comments on what works best for their individual. A caregiver questioned the power of attorney and the fees. She has issues getting guardianship for her daughter now that her individual with RTT has reached 21. There were 29 likes and 66 comments. A caregiver asked about spinal fusion surgery, and there were several replies provided that gave suggestions about how to care for an individual after surgery. Lastly, the caregiver posted the news about receiving the new commercial product-Daybue that has been clinically proven to improve the individual with RTT cognitive skills and other medical benefits.

This observation revealed that the caregivers are nervous, overwhelmed, frustrated, and searching for answers on what to do about the unexpected RTT syndrome disorder. The RTT Syndrome Family Support Forum negated the caregiver's pain and strain of not having enough finance or resources to assist with helping them get the required equipment or supplies required to care for their RTT individual. A few members post words of encouragement to try to uplift other group members. In some cases, there were comments about seizures, wheelchair lifts, waking spells, constipation, and DayBue (Trofinetide), a new clinical trial drug approved by the FDA. African American caregivers did not engage in any of the posts during this observation. I have included in the appendices protocol with the description of this observation.

## **Secondary Research**

### ***Secondary Data Collection Techniques***

Instead of gathering data directly from primary sources, secondary data collection approaches entail receiving information that has previously been acquired and processed by someone else. Overall, secondary data collecting strategies can be a cost-effective and time-efficient approach to obtain information, but researchers must exercise caution when evaluating the quality and relevance of the data they use. Scholarly journals and peer review articles are the secondary sources selected for this study. Scholarly journals are foundational sources for obtaining accurate and detailed information on a specific topic. These journals are peer-reviewed by academic professionals who are deemed experts and inspected to maintain academic scientific standards before publication (Ong & Sui Pheng, 2021). A thorough review of each article is essential to ensure the information is well-researched and documented to provide reliable reference material. Journal articles on Rett syndrome may provide insight into how to care for caregivers with severe Rett syndrome. Research on this population will be beneficial in educating others on the severity of Rett syndrome and how it impacts the role of the caregiver. Researching in these journals allows caregivers to understand better how severe Rett Syndrome affects the individual health and well-being so they will better support them at home.

Articles are useful for informing caregivers about the care needed for those with severe forms of Rett syndrome because they provide detailed information about the condition. These articles will give caregivers insight into how other people with this condition cope with daily life tasks like feeding themselves (Banerjee et al., 2022). This helps caregivers better understand how to help their patients and prepare them for daily activities. Additionally, articles inform caregivers about treatment options that may help improve the lives of those with severe forms of

Rett syndrome. This helps caregivers to make better-informed decisions when caring for these patients and prepares them for daily activities such as eating and toileting.

### **Summary**

The purpose of this chapter was to improve the QOL for African American caregivers caring for individuals with RTT syndrome by identifying coping strategies, accessing financial resources, and adapting to changes in the family dynamic. At the inauguration of this project, written permission to conduct the capstone project was obtained from the primary supervisor of Oxford University to conduct the study. The investigator's role explained the biases that are faced in this research due to the opposition of seeing firsthand the challenges faced having an individual with RTT. The research gathered data from participants via interviews, focus groups, and observation. The researcher obtained informed consent from all participants in the study, ensuring that they fully understand the purpose and procedures of the research and that they voluntarily agree to participate.

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