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## Interventions to Reduce Role Strain of Informal Adult Caregivers of Individuals with Neurocognitive and Mental Disorders

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**Interventions to Reduce Role Strain of Informal Adult Caregivers of Individuals with  
Neurocognitive and Mental Disorders**

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### Abstract

**Purpose:** This project sought to determine if a combination of stress reduction, self-guided bibliotherapy, and health literacy training is an effective way to reduce stress and role strain of informal caregivers and improve their quality of life.

**Background:** The value of the unpaid labor performed by caregivers is estimated to be at least \$306 billion annually that is nearly double the combined costs of \$43 billion in home health care and \$115 billion in nursing home care. Numerous studies posit caregivers are at risk of developing high levels of physical, emotional, and mental strain, which can negatively impact their role, quality of life, and increase medical costs.

**Methods:** A mix-method design was employed focusing on the role strain and quality of life of relatives and friends assisting individuals with neurocognitive or mental health disorders. A pretest-posttest survey design and an educational intervention was used. Subjects were recruited from family support groups, social media, and different organizations in Georgia. The subjects engaged in weekly online self-guided activities for eight-weeks and responded to survey questions regarding demographics, depression, anxiety, and stress levels. Eligible subjects were English-speaking adults from 18 years and older with or without comorbid conditions who assisted with daily living activities for a relative or friend for more than one month. The intervention included an educational resource kit with information on self-guided bibliotherapy and psychiatric medications for participants who scored high on the depression, anxiety, and stress scales.

**Results:** Four women completed the project. Descriptive statistics and qualitative data from surveys and emails were employed for the data analysis due to the small sample size. A non-parametric test was used given small sample size (Kruskal-Wallis tests for variables with 3 response categories and Mann-Whitney tests for variables with 2 response categories). The non-parametric test showed no statistical significance between the pre and post-test with a p-value of 0.05. We did not identify significant differences in DASS-21 scores based on any of the variables assessed.

**Conclusion:** The project's findings indicated decreasing caregiver stress may lead to improved quality of life and fewer stress-related health problems. The findings strongly imply interventions to reduce the negative impact of caregiving may be effective if participants fully engage and adhere to the directions given by the researcher. All the participants reported their care recipient's ill-health affected their social lives and ability to engage in self-care activities.

**Keywords:** informal caregiver, role strain, adult caregivers, caregiver stress, education intervention, health literacy.

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## **Interventions to Reduce Role Strain of Informal Caregivers of Patients with Neurocognitive and Mental Disorders**

One in five people living in American are classified as informal caregivers (Gérain & Zech, 2019). Studies show they are in worse physical, emotional, and mental health now than five years ago (Gérain & Zech, 2019). An informal caregiver is widely defined as an individual who cares for a relative or friend with a chronic or disabling condition without formal training or compensation (Collins & Swartz, 2011). In Collins and Swartz's (2011) study, eight percent of adults needing long-term care who were living at home received 90 percent of their care from uncompensated family members. The National Family Caregivers Association and Family Caregiver Alliance (2006) reported unpaid caregivers gave an estimated \$375 billion in cost savings nationwide. The National Alliance for Caregiving and the American Association of Retired Persons (AARP) in 2020 calculated 53.0 million U.S. people above the age of 18 gave uncompensated care to disabled individuals living in their communities. Caregivers save the U.S. \$306 billion yearly in care costs, which is close to double the combined costs of home health care \$43 billion and nursing home care that was estimated to be \$115 billion (The National Family Caregivers Association & Family Caregiver Alliance, 2006).

It is evident that neurocognitive and mental health disorders place burden on the person affected and present a substantial challenge to their caregivers (Trautmann et al., 2016). The caregivers of psychiatric patients who cannot navigate the caregiving role may suffer poor health consequences such as mental health disorders, high blood pressure, and other health problems (Tucci & Moukaddam, 2017). Gérain and Zech (2019) stress that the strain experienced by informal care providers in attending to their mentally ill care recipients can be overwhelming for the caregivers. Still, few studies have been conducted on interventions to reduce caregivers'

stress. The informal caregiver role strain initially gained attention by researchers in 1986 but was not given much scholarly attention (Gérain & Zech, 2019). In their 2019 study, Gérain and Zech noted an increased number of studies using burnout measures to assess informal caregiver role strain since it was first acknowledged in 1986. The authors suggest until recent times, research and interventions focused only on formal caregivers. However, newer studies have applied the same burnout measures to examine the adverse health effects on chronically ill patients (Gérain & Zech, 2019).

Stress from caregiving can manifest in various ways but mainly presents as physical, emotional, mental exhaustion, and distress consisting of depressive and anxious symptoms (Gérain & Zech, 2019). The impact of caregiving on people who provide care for their relatives and friends needs to be addressed because stress increases one's risk of developing mental illness (World Health Organization [WHO], 2019). More work about interventions to improve informal caregiver strain is of great importance since both the caregiver and care receiver's quality of life suffers (Melnik et al., 2011). Strain from caregiving increases the caregivers' risk for health-related problems and loss of interest in the social activities they once enjoyed. Developing educational and self-care interventions to help informal caretakers is vital now more than ever as caregiving demand rises with the increase in mental illness cases worldwide (Berkman et al., 2015). According to Berkman et al. (2015), educational interventions have decreased caregiving's adverse effects and increased optimal outcomes for caregivers and care receivers.

### **Background and Significance**

It is estimated that 165 million individuals in the European Union are impacted by mental illness annually (Trautmann et al., 2016). Additionally, it has been calculated that half of the world's population of adults in the middle- and high-income nations, including the United

States, will suffer from at least one mental illness in their lifetime (Trautmann et al., 2016; Tucci & Moukaddam, 2017). In 2017, Tucci and Moukaddam reported that twenty-six percent or approximately 264 million globally of individuals impacted by mental disorders have depression. The global mental health problem makes depression the leading cause of disability worldwide and suicide second-highest cause of death among 15-29-year-olds (Trautmann et al., 2016; Tucci & Moukaddam, 2017). According to information from WHO (2019), 15-29 years old make up twenty percent of those suffering from mental disorders globally. However, depression and anxiety are most common disorders costing the global economy one trillion annually (WHO, 2019). The research also showed the age-adjusted rate of people committing suicide from 1999 through 2014 increased by twenty-four percent from 10.5 to 13.0 per 100,000 individuals (Tucci & Moukaddam, 2017).

According to Trautmann et al. (2016), estimating actual costs is complicated because of inadequate data and studies but reported that the cost of mental health illness is higher than the cost of cancer, diabetes, and other somatic diseases. Information from 2010 projected indirect costs to be \$1.7 trillion and the direct cost at \$0.8 trillion (Trautmann et al., 2016). The authors reported the combined direct and indirect costs of mental illness to be 2.5 trillion dollars. Irrespective of the standards that authorities use to estimate the costs of mental health disorders, all research shows substantial increase in the expense of psychiatric disorders over the past ten years that is expected to continue globally (Tucci & Moukaddam, 2017). Tucci and Moukaddam (2017) stated mental disorders' economic impact does not show a total picture of psychiatric disorders' stress on patients and their caregivers.

Trautmann et al. (2016) state the effects of psychiatric disorders are not limited to a small portion of the predisposed individuals in the population but are a substantial public health issue

with clear consequences for the world. Mental disorders have various consequences for the sick individual and their families, especially their primary caregiver (American Psychiatric Association [APA], 2013). These psychiatric disorders can detrimentally affect the economy and caretakers or loved ones of those with mental disorders. Numerous studies show informal caregivers providing care to relatives who are chronically disabled are themselves at risk of developing health problems (National Alliance for Caregiving & AARP, 2020).

### **Clinical Question**

Will non-pharmacological interventions including bibliotherapy, stress reduction, and improving health literacy reduce role strain of informal adult caregivers' providing care for individuals with neurocognitive or mental disorders?

### **Purpose of the Project**

The purpose of this qualitative and quantitative mix-method quality improvement project was to discover how participating in weekly self-care activities would impact informal caregivers' health. There is sufficient research that show the caregiving can be stressful. Studies also show that educational interventions and health literacy training may decrease stress and improve caregivers' quality of life. Therefore, it was imperative to search and critically evaluate the literature for an evidence-based framework for developing the program.

### **Review of Literature**

A vast search was conducted to elicit journals to support this current DNP project. Studies on the project topic were identified by conducting complete searches using the following databases: CINAHL (EBSCOHost), Google Scholar, and Cochrane Library. Further research was conducted on national and international databases. Reference lists of studies meeting inclusion criteria were reviewed to determine if any references met the standards for inclusion in

this project. Searches were done using a combination of the following terms: caregiver stress, caregiver role strain, and caregivers of people with mental disorders. With some exceptions on authorities on this subject, there was a five-year limit on the published research considered for this project. The search included studies published between 2015 and 2020. Studies were incorporated if they were published in a peer-reviewed journal or government website.

Participants were caregivers of people with mental disorders and cognitive problems like dementia, depression, bipolar disorder, and schizophrenia. The articles had to be printed in English, and those articles printed in other languages were excluded. Studies with only abstracts provided were also excluded. Research on caregivers of patients in long-term care facilities and studies on compensated caregivers were rejected because they did not fit the project's inclusion criteria. Furthermore, domestic, and international internet database were reviewed for information related to caregiver role strain and the effects on quality of life.

In the beginning, searches yielded thousands of articles, which required filtering the desired year period and full-text articles to decrease the number of articles. Limiting studies further to those conducted in the last five years generated 208 studies. Forty-three of the articles were scanned thoroughly, and 18 articles met the inclusion criteria. The 18 articles were evaluated using the Grade of Recommendation, Assessment, Development, and Evaluation (GRADE) scale (McCaffrey, 2012).

GRADE is among many tools used to rate evidence, but it has an advantage over the other rating systems. In 2008, Guyatt et al. emphasized one great advantage of using the GRADE criteria is that it was created by a group of international representatives who develop guidelines. According to Guyatt et al. (2008), organizations worldwide prefer this rating system over others because it is explicit, comprehensive, transparent, and pragmatic in providing a scale for

assessing the quality and strength of recommendation. The quality of evidence is categorized in the GRADE system as high, moderate, low, or very low (Guyatt et al., 2008).

According to Schmidt and Brown (2017), most nursing practice evidence has been derived from tradition, authority, trial and error, personal experiences, intuition, borrowed evidence, and scientific research to guide practice. The authors also stated nurses could not rely solely on borrowed evidence because nursing offers a unique perspective on patient care. The process of this current DNP project shows how to build one's own body of evidence using scientific research (Schmidt & Brown, 2017).

Several studies confirm family caregivers and the services they render are essential to their care recipients (Karadağ-Saygı, 2020). According to Karadağ-Saygı (2020), caretakers should also be recognized as vital to healthcare and seen as partners by healthcare providers. Furthermore, family caregivers should be supported with supplementary resources (Roth et al., 2015). All reviewed literature supports this project's importance, which evaluated present studies on interventions to assist informal caregivers.

Brown et al. (2015) conducted a randomized study to investigate the effectiveness of mindfulness-based interventions that target the caregiver burden. Their study reported individuals with Alzheimer's Disease (AD) receive about 80 percent of family caregivers' care. Some of these patients required at least 36 hours of care daily (Mace & Rabins, 2011). According to Brown et al. (2015), interventions intended to preserve caregiver well-being are advantageous in significant ways. First, reducing family caregiver stress can effectively delay patient institutionalization by enabling family members to give home care longer (Mace & Rabins, 2011). Additionally, interventions that aid in sustaining the psychological and physical well-being of family caregivers may decrease healthcare costs and improve life quality

(Mittelman, 2005). Lastly, Brown et al. (2015) supported interventions to reduce caregiver burden to maintain and improve their mental and physical functioning.

Identifying the need for caregiver support, scholars have created numerous interventions for caregivers who tend to individuals with AD/dementia and other related mental illnesses. These interventions include psycho-educational programs, support groups, behavioral management programs, individual or family counseling, and multicomponent interventions (Mittelman, 2005). According to Brown et al. (2015) such interventions have shown to reduce caregiver distress and psychological morbidity and improve the caregiver's overall psychological well-being.

A qualitative study conducted by Stanley et al. (2015) investigated the extent of burden experienced by 50 spouses of patients with psychotic disorders and noted that caregivers of people with severe mental illness experience mental health issues themselves. The Depression, Anxiety, and Stress Scale and Burden Assessment Schedule were used to measure caregivers' mental health. A 2014 systematic review study carried out by Van der Lee et al. also reviewed determinant models of caregiver and patient burden in dementia caregivers. Van der Lee et al. (2014) reviewed a total of 56 publications. It included 32 studies on burden models and 24 on depression and mental health models, and this study found neuroticism to have the most potent effect on caregiver burden. The results also showed that caregivers who felt competent or enjoyed high self-efficacy decreased in caregiver burden.

A second randomized controlled study by Zoladl et al. (2020) intended to determine the outcome of utilizing the participatory care model on the caregiver burden and resilience of home-based caregivers of individuals with mental illness. In the study, 66 families with mentally ill patients hospitalized at Shahid Rajaei Psychiatric Hospital in Yasuj between 2014 to 2015 were

included. The participants were placed in two groups, experimental and interventional groups, based on convenience and simple random sampling. A Chi-squared test revealed caregiver burden was significantly lower in the experimental group than the control group after the intervention ( $P=0.0001$ ). The findings also showed an increase in the experimental group's resilience versus the control group after the intervention.

A systematic review and meta-analysis study along with Randomized Controlled Trials (RCTs) and quasi-experiments were conducted by Wang et al. in 2020 on informal caregivers caring for dementia patients. They examined nine articles on diverse bibliotherapy methods used to enhance informal caregivers' mental health and the impact on health outcomes. The preferred reporting items for systematic reviews and meta-analysis checklist was utilized to direct the research. Self-help bibliotherapy was the primary intervention administered to the 1,030 participants aged 18 years and older. Wang et al. (2020) included past studies suggesting bibliotherapy may strengthen caregivers' health outcomes in their research. This study added three additional bibliotherapy types from previously studied, including written, video, and web-based therapy. The researchers implemented self-guided bibliotherapy as the chief intervention and evaluated its efficacy. Wang et al. (2020) employed the Population Intervention, Comparator, Outcomes, and Setting (PICOS) model to construct their research. Two reviewers used the Cochrane collaboration risk of bias instrument for RCTs to evaluate the quality of studies separately. The Cochrane collaboration risk of bias tool appraised the risk of bias from seven aspects: random sequence generation, allocation concealment, blinding of participants, personal blinding of outcome assessment, incomplete outcome data, selective reporting, and other biases. Each component was rated as "low risk," "unclean risk," or "high risk" accordingly. An Evaluation Manager 5.3 was used to examine the information, standardized mean difference

(SMD), and 95% confidence interval (CI). The Evaluation Manager 5.3 was also used to estimate the pooled treatment effects.

In 2020, Wang et al. concluded that bibliotherapy may be sustained over three to six months and has beneficial effects on reducing depression, improving self-efficacy for dealing with problem behaviors, and decreasing anxiety among informal caregivers. The authors noted that some samples were small and of low quality. The researchers reported possible biases since all the mental well-being outcomes were measured subjectively. The variables such as age, ethnicity, culture, educational level, environment, and individual conditions may also impact the results of the research. The effects on various mental health outcomes were inconclusive due to the limited number of studies and prompted further studies on this topic. A single-blinded randomized controlled study conducted by Gaugler et al. (2015), and a systematic meta-synthesis of qualitative studies conducted by Cross et al. (2018) showed a similar outcome.

A randomized controlled study was undertaken by Behrouian et al. (2020) to explore the effects of emotional regulation education on stress, anxiety, and depression. The study consisted of 70 family caregivers of individuals with schizophrenia sent to mental health facilities in Kerman, Iran, from 2016 to 2017. Those who participated in the study were placed in two groups, an intervention, and a control group. The intervention group received eight 90-minute emotional regulation teaching sessions. The participants also completed the Depression, Anxiety, and Stress scales-21, and it was found those in the intervention group had a reduction in stress, anxiety, and depression versus the control group, who did not show any change. A study conducted by McCann et al. (2015) showed that emotional regulation education maybe effective in reducing stress, anxiety, and depression. Corry et al. (2019) completed a similar study that validated the findings.

Correspondingly, Chan et al. (2018; 2019) conducted a cross-sectional study to see if increasing the level of mastery or caregiving competence will guard caretakers against poor mental health outcomes. It was concluded high mastery and caregiving competence were linked to a decrease in depression levels. Another cohort study was completed by Chan et al. in 2019 and, this time, they sought to report the development of a caregiver-centric screening tool to detect the risk of depression on admission to a healthcare facility. The screening tool was also designed to predict the three-month risk of depression as well as the quality of life among 274 family care providers of older adults who had an unplanned admission. The results revealed the caregiver-centric instrument is a new, self-administered, and practical tool, and caregivers can quickly test if they are at risk for depression.

In 2016, Chien et al. conducted an RCT across two early psychosis clinics in Hong Kong. The study conductors sought to examine the effects of a five-month clinician-supported problem-solving bibliotherapy for Chinese family caregivers of people with first-episode psychosis. They also wanted to improve family burden, caregivers' problem-solving skills, and the caregiving experience as well as reduce psychotic symptoms and duration of re-hospitalizations. The group who received clinician-supported problem-solving bibliotherapy reported significant improvement in family burden and the caregiving experience as well as reductions in the severity of psychotic symptoms of the care recipients and decreased the duration of re-hospitalizations compared to the other groups.

Furthermore, the study conducted by Chien et al. (2016) implies bibliotherapy has significant benefits for caregivers' burden of care. For instance, families in the study demonstrated significant improvements 12 months after the study in their family burden on finances, social activities, relationships, and general well-being compared to their counterparts

who did not receive the intervention. The care recipients with first-episode psychosis also showed positive effects after the intervention. The positive effects included reductions in the severity of psychotic symptoms, improved functioning, and decreased readmissions. These promising results warrant further research on interventions such as this, which includes family caregivers (Chien et al., 2016). Chien et al. (2016) said past and present bodies of research point to the fact that high levels of mastery or caretakers' competence and additional caregiving support may buffer against poor mental health outcomes and improve quality of life. Studies also reveal the positive effects of the interventions against stressors and negative well-being (Chien et al., 2016). The only limitation is there are only a few studies conducted on interventions for support caregivers.

Conversely, Keniş-Coşkun et al. (2020) carried out a correlational cross-sectional study to determine the effect of caregiver burden, resilience, and quality of life of the parents of individuals seen in an outpatient pediatric rehab health center. The study included a total of 107 patients and caregivers. The study showed caregiver burden was more elevated in parents of children who could not walk than children who could walk. The correlation between caregiver burden and resilience was moderate. The authors noted that it was unclear what was influencing caregiver burden and resilience. A descriptive, cross-sectional, and correlation study conducted by (Özkan et al., 2019) gave similar conclusions. A study conducted by Wingrove and Rickwood (2017) and Yu et al. (2015) validated the study conducted by Keniş-Coşkun et al. (2020).

Lorig et al. (2017) did a longitudinal design study to examine how effective Building Better Caregivers (BBC), a small-group, six-week community-based, and peer-led intervention, is when used on 128 family care providers of individuals with mental disabilities. Participants showed a considerable improvement in caregiver strain and depression (Lorig et al., 2017). In 2017, Ng et

al. also conducted a qualitative and quantitative study on 126 family caregivers to observe the effects of a Community Mental Health Intervention Project (CoMHIP) on the burden of caregivers who have relatives with suspected mental illness. In the end, caregivers subjectively experienced a substantial decrease in stress concerning the caregiving subscales, supervision, tension, worrying, and urging after looking for CoMHIP service. Another qualitative study was carried out in 2015 by Roth et al. which re-evaluated existing evidence on the impact of caregiving on caregivers' health. The study focused mainly on one frequently cited claim that family caregiving is associated with an increased risk for mortality (Roth et al., 2015). The authors concluded more rigorous methods must be used in studies on the health effects of caregiving.

All the evidence obtained through the review of literature suggests informal caregivers are essential in the health system, and interventions are needed to support them (Van der Lee et al., 2014). The reviewed studies also support the importance of the current project, which will investigate and evaluate existing interventions if they are effective. All the literature reviewed so far also shows a need for further research to determine how best to intervene to benefit caregiver well-being. There is also a demand for interventions that address the family's needs before severe disease progression, and more stressful caregiver conditions occur (Brown et al., 2015).

### **Theoretical and Conceptual Frameworks**

McCaffrey (2012) states that the purpose of theory is to clarify observable phenomena, aid nurses in making sense of what is occurring, and offer frameworks for attending to patients in any situation. According to Bonnel and Smith (2014), theoretical and conceptual frameworks guide organizational projects and stand as a practice resource. Bonnel and Smith also noted that frameworks serve as a building block for clinical projects and establish the range of its scope.

Middle-range theories like Roy's adaptation model and the caregiver stress theory may be more suitable to guide topics dealing with educating patients and quality of life issues like this project (Bonnel & Smith, 2014).

McCaffrey, in 2012 gave credit to Florence Nightingale as a trailblazer in developing theoretical nursing care plans, which means theory has been the building block of the nursing discipline. Many contemporary theorists speak of knowing and understanding patients through pattern recognition, intuition, and reflection (McCaffrey, 2012): "This knowing challenge existing structures within the framework of theoretical knowledge to create new and limitless opportunities for nurses to change structures and organizations to meet the health and wellness needs of persons" (McCaffrey, 2012, p. 61). McCaffrey (2012) suggests while there has been a significant development in theory and its use in building a substantial body of knowledge in the nursing discipline, there is still a disconnect in linking ideas, research, and nursing practice. She also said many nurses who are more focused on practice do not see the importance of theory in day-to-day practice. Moreover, practice-focused nurses do not recognize the dynamic and harmonizing relationship between theory, research, and practice and how theory offers a belief system to steer practice on the organizational level (Schmidt & Brown, 2017).

According to Schmidt and Brown (2017), theories and evidence acquired from research create an essential foundation for practice, and it is the element on which organizations can thrive. The use of change theory and models in the Doctor of Nursing Practice (DNP) project can help overcome obstacles to translating it into practice (Schmidt & Brown, 2017). Schmidt and Brown (2017) also indicate the use of theory and models in the DNP project will bring structure, understanding, and guidance to practice change. Likewise, improvement will become readily accepted within the organization and by other disciplines because it will be based on sound

evidence that has been evaluated through the interprofessional Evidence-Based Practice (EBP) process (Aarons et al., 2009).

Furthermore, models and theories will be needed to guide the current DNP project's implementation process and guide practice decisions built on the best existing research evidence (Melnik et al., 2011). According to Melnyk et al. (2011), theories and models are essential if nursing professionals want to alter practice to be evidence-based, used on the organizational level, and not just on the individual practice level. Additionally, models and theories can assist as a corporate guide in the application phase of the EBP project to incorporate the most recent evidence into practice and facilitate implementation of the project (Christenbery, 2019).

### **Roy's Adaptation Model**

Tsai (2003) described the Roy Adaptation Model (RAM) as a nursing theory that has been vastly employed for studies. Sister Callista Roy constructed it in 1970 and included adaptation, adaptation level, stimuli, and coping mechanisms (Roy, 2014). The model was revised in 1976 to incorporate the four adaptive modes and again in 1984 (Tsai, 2003). RAM was modified in 1979 where Roy stated that everyone has a level of adaption or different abilities to survive various circumstances (Turan & Canli, 2020). The authors also noted the goal of RAM is to help in promoting adaptation in the four adaptive modes, contribute to health, quality of life and dying with dignity through counseling. Tsai (2003) noted only some researchers had adopted it in the context of caregiving for people with chronic illnesses.

A middle-range theory of caregiver stress was used for this project to build on the RAM and gain insight into its suitability in the context of stress in caregivers (Tsai, 2003). Roy (2014) included four constructs to the finished model that included: input, control, process, effectors, and output. In 2003, Tsai outlined the input, which consists of the focal stimuli, contextual

stimuli, and residual stimuli. He also stated the focal stimuli has to do with the caregivers' objective burden, and the contextual stimulus as the caregiver's social support, societal roles, and events in the caregivers' life, causing them stress. Tsai (2003) further described residual stimuli as race, age, gender, and the relationship between the caregivers and their care recipients. The four constructs were added to reflect an integrated view of the mind, body, and spirit. Individuals and groups are bio-psycho-social beings who are in continual contact with their surroundings (Tsai, 2003). In describing Roy's model, Tsai (2003) said the goal of a person in RAM was a positive adaptation, and the role of the nurse was to help the person with the process. Roy's model also proposes that individuals use innate and learned mechanisms to survive (Roy, 2014).

### **The Caregiver Stress Theory**

In 2003, Tsai said the caregiver stress theory, which he formulated, was based on Roy's 1984 framework, which included four adaptive modes. The 1984 conceptualized version of the theory was used in this project because of the uncomplicated relationship between the constructs and presents four assumptions (Tsai, 2003). The first assumption is caregivers can respond to changes in the environment (Roy, 2014). In 2014, Roy described the second assumption as the caregivers' perceptions affect how they answer environmental stimuli. Roy (2014) also outlined the third assumption: caregivers' adaptation is a function of their environmental stimuli and adaptation level. According to Roy (2014), the last premise involves perceptions about caregiver effectors such as physical function, self-confidence, pleasure in the role, and happiness in marriage, which result from chronic caregiving. Furthermore, the caregiver stress theory suggests stressful situations in a persons' life add to their perceived stress beyond the impact of responsibilities or duties (Tsai, 2003). In other words, Tsai believes caregivers with stressful life

situations may have an increased stress level than their counterparts who do not have stressful life situations.

Tsai (2003) also proposed in his theory that a robust social support system from friends and family members can decrease the stress caregiver's encounter. According to Tsai (2003), social support is the caregiver's resources needed to improve their welfare. Therefore, caregivers with more social support are expected to show less stress than those without strong social support (Tsai, 2003). He also states this is because social support is a buffer against caregiving strain and helps the caregiver cope or change how they think about the caregiving experience. Tsai's theory also posited the more social roles a caregiver has, the better they feel because the rewards from the various roles will exceed the adverse effects of having all those roles and thus enhance caregivers' well-being (Tsai, 2003). Other variables necessary in the caregiver stress theory by Tsai (2003) are age, social function, adaptation level, and the skills they possess to handle life.

### **Application of the Theoretical Framework**

In the caregiver stress theory, Tsai (2003) suggests caregiving's objective burden serves as the most critical stimulus experienced by caretakers that, creates the need for adaptation. The burden can be the obligations or tasks related to chronic disease caregiving, disturbing the caregivers' life regarding finances and other social roles (Tsai, 2003). He also said ineffective coping responses result in health problems such as depression that result from caregivers' perceived stress. Severe symptoms such as depression, anxiety, and other health issues may occur if there is a lack of understanding or attention to health problems (American Psychiatric Association [APA], 2013). According to Tsai (2003), knowledge deficit of health issues impacts four modes of the human system and positive adaptation of the family and individuals.

The connection between the theory of caregiver stress and the DNP project is the emphasis on adaptation and the holistic aspect of individuals (Roy, 2014). RAM and the theory of caregiver stress focus on the human adaptive system responses and environmental stimuli, which constantly change (Fawcett & Susan, 2013). According to the theory, the nurses' responsibility is to help individuals and groups adapt to the four adaptive modes (Fawcett & Susan, 2013).

Another goal of nursing, as noted by Fawcett and Susan (2013), is to contribute to the health, quality of life, and dignity of persons who are dying by evaluating behaviors and other things that impact adaptive mastery. Additionally, nurses intervene to increase individuals' adaptive skills to enhance environmental interaction (Fawcett & Susan, 2013). According to Tsai (2003), caregivers' inability to adapt to their role can impede the care they provide to their patients. He also states that giving care to individuals with mental illnesses may be long-term; therefore, adaptation is needed consistently.

In 2013, the American Psychiatric Association reported that some individuals with mental illness never go back to their previous level of functioning and require long term care from others. The unpredictability of mental disorders is because the symptoms of mental illness can be severe and unpredictable (APA, 2013). The severity of the mental disorder of care recipients also affects the caregivers' level of functioning and influences the four modes of the human system described by Roy (2014). Adaptation is most often necessary for the family to meet the demands of care receivers and prevent health problems that may develop due to ineffective adaptation (Tsai, 2003).

### **Methodology**

This DNP project is a quality improvement project that employed a mix-method design focusing on the role strain and quality of life of relatives and friends assisting individuals with

neurocognitive or mental health disorders. The project captures the essential principles of the DNP Essential VII because it sought to give informal caregivers interventions that will avert their future health challenges and improve the caregiving experience (American Nurses Association [ANA], 2015). Chow et al. (2010) defines mixed-method study designs as a compilation of evaluations and analyses of qualitative and quantitative data. A sequential rather than concurrent approach was employed to help with the organization and flow of the project (Creswell & Plano Clark; Vicki L., 2017).

### **Subjects**

This projects' prospective cohort was unpaid adult family or friend caregivers ages 18 to 89. Caregivers were responsible for the decision-making and caregiving of individuals with neurocognitive and/or mental health disorders. The SI and the project team members emailed recruitment letters and flyers to their contacts and prospective subjects. The flyer and recruitment letter included contact information for the project chair and SI. The targeted number of participants was 50. The preferred setting was a local outpatient mental health facility; however, the search had to be expanded to include community family support groups and anyone who met the inclusion criteria. The DNP project team recommended I join the National Alliance on Mental Illness (NAMI) family support group and email personal contacts.

Care recipients could be children, adolescents, or adults under 65. The project included all genders, all marital, racial, educational, socioeconomic, and ethnic backgrounds.

Additionally, eligible caregivers must have aided with daily living activities for recipients for at least one month (Chien et al., 2016). Subjects were high functioning adults, able to communicate in written and conversational English and be male or female from 18 to 89 years old with or without comorbid conditions. Exclusion criteria were non-English speakers, individuals with debilitating disease, are deaf or blind, or are younger than 18 years. Also, those who had not provided caregiving services for at least one month were excluded.

### **Implementation/Evaluation**

#### **Setting**

The project team used a multi-site approach that included online support groups for family caregivers and local suburban outpatient facilities. An outpatient clinic that provides care for adolescents and young adults with different psychiatric disorders was the first choice for the DNP project setting. However, the scope of the project implementation had to be broadened due to COVID-19 restrictions and insufficient enrollment. Many clinics closed their doors due to the pandemic and others saw patients virtually. In addition, the preferred site had to be a practice that gave comprehensive psychiatric care including assessment, evaluation, and medication management. The practice also had to offer treatment for various mental health problems, have had no less than five spacious exam rooms, and the number of established patients should have been more than 20. We focused on suburban healthcare organizations located in Atlanta,

Georgia, or within 50 miles from Atlanta. A practice that takes private, Medicare, and Medicaid patients was preferred.

### **Instrument/Tools**

The two questionnaires were used to gather information about participants. The first questionnaire found in Appendix F was a Microsoft Word document used to collect caregivers' demographic data. The socio-demographic data collected included age, gender, education level, primary language, relationship to the care recipient, duration of care, and economic status (Behrouian et al., 2020). The second questionnaire was the Depression, Anxiety, and Stress Scale (DASS) found in Appendix E. DASS is a self-report tool used in measuring anxiety, depression, and stress which has been employed in various settings (Siamak & Bahram, 2007)). The assessment and results reflect the past seven days (Basha & Kaya, 2016). There are two versions of the DASS scale, 42-items and a shorter version which has 21-items. Numerous evidence and researchers have reported the reliability and validity of the DASS (Mennella & Avital, 2017; Le et al., 2017)). According to Behrouian et al. (2020), the DASS-21 measuring tool contains 21 items and three subscales that can be broadly used to evaluate depression, anxiety, and stress. In addition, the scale can also be used to assess patient reaction to psychiatric treatment (Behrouian et al., 2020).

Each item on the DASS-21 scale scores items from 0 (never) to 3 (always) on a 4-point Likert-type scale (Behrouian et al., 2020). The subscale of DASS-21 includes expressions that measure a person's unhappiness, lack of self-esteem, despair, the worthlessness of life, lack of interest in engaging in daily affairs, lack of life enjoyment, and lack of power and energy (Mennella & Avital, 2017). The anxiety subscale of the DASS-21 contains expressions that

assess physiological arousal, fears, and situational anxiety. The DASS-21 subscale of stress, however, includes expressions such as difficulty in achieving relations, nervous tension, irritability, and restlessness (Mennella & Avital, 2017).

According to Behrouian et al. (2020), the DASS-21 is a tool that can be administered and interpreted in outpatient and inpatient care settings. Behrouian et al. (2020) reported in their study that the DASS scale's validity and reliability were confirmed in Iran. The DASS-21 scale was completed electronically by participants who selected their answers to all corresponding statements in each of the three subscales. Each item on the questionnaire were scored from zero to three with high scores signifying elevated levels of depression, anxiety, and/or stress (Mennella & Avital, 2017). The original DASS questionnaire contains 42 items. Therefore, the final score obtained from DASS-21 was multiplied as instructed by the author of the tool. Behrouian et al. (2020) suggest that healthcare professionals outside of psychology can administer the DASS-21 scale. However, treatment decisions based on the score profile should be made by experienced providers including nursing professionals, primary and acute care clinicians, and mental health providers.

### **Recruitment**

Recruitment for the project started after approval from the Georgia State University's (GSU) Institutional Review Board (IRB) on June 19, 2021 (see Appendix H). The Alter Dementia's August newsletter advertised the project. Dr. Nelson who is the President of the

United Advanced Practice Registered Nurses of Georgia (UAPRN) also announced the project on the UAPRN website which helped enroll two of the participants. Recruitment flyers were distributed at national and local organization sites and family support groups, such as NAMI, Alzheimer's, and dementia. Some recruitment flyers were emailed to personal contacts of the DNP team. It was also shared on all social media platforms, newsletters, magazines, instructional videos, and conferences. In addition, flyers were also presented at the Georgia State Counseling Centers' weekly case study conference, where attendants were encouraged to share with their family, friends, and social media platforms. Project team members were also encouraged to share the flyers and study information with their family members, friends, co-workers, professional organizations, and communities. Furthermore, I contacted local hospitals, colleges, businesses, and other community organizations and shared the flyers with their directors. Those interested in the study were directed to the student.

### **Data Collection**

The socio-demographic characteristics of caregivers were collected electronically using the Georgia State University Qualtrics program (Behrouian et al., 2020). The study utilized a pretest-posttest survey design with education intervention to examine if self-guided bibliotherapy, stress reduction, and psychopharmacological educational interventions can effectively reduce caregiving's negative impacts. There was a pretest questionnaire utilizing DASS-21 to assess the baseline functioning of caregivers. A post-test questionnaire utilizing the

DASS-21 was administered after the interventions to measure any caregiving functioning level changes. The SI sent an email with a link to the informed consent and the pre-post-tests to all participants. The interventions were administered electronically using Microsoft PowerPoint and safely stored on a portable flash drive. Only those who scored very high on the DASS-21 scale received additional resources on common psychiatric medication and information on mental health providers in their communities.

### **Intervention**

Caregivers engaged in weekly self-guided activities that included different types of meditation, bibliotherapy, physical exercise, and stress reduction activities. Participants walked for at least 15 minutes per week. Additionally, caregivers watched a 3–5-minute YouTube video on deep breathing exercises, bibliotherapy, or mindfulness meditation. Caregivers who reported that they were stressed on the DASS-21 scale at the end of the intervention received additional educational resources kits to teach them about patients' medications, diagnosis, and side effects. All participants were invited to join the National Alliance on Mental Health (NAMI) weekly family support meetings. Only one participant joined the NAMI meetings. The participant reported the NAMI meetings were very helpful because group members gave her information on free community services. All educational kits were disseminated as electronic documents.

### **Components of Analysis/Statistical Tests**

The project was measured using pretest and post-test questionnaires. The individuals who assisted in the data analysis included an expert statistician and data services specialist. The data was exported from Qualtrics into the IBM statistical package for the social sciences (SPSS) where descriptive statistics (counts, percentages, means, and standard deviation) were performed. The data analysis team used the SPSS software irrespective of the small sample size. The statistical significance was set at  $p < 0.05$ . Two subjects did not complete the post-test, so the analysis team did not count the missing data.

### **Results**

There was a total of seven individuals who enrolled in the project, but only four participated and completed the project. All participants were female. Two were African Americans, one Caucasian, and one Hispanic. All four participants completed the pre-test, demographic questionnaire, and intervention with only two completing the post-test questionnaire. One participant completed the pre-test and post-test on the same day. Descriptive statistics were employed for the data analysis due to the small sample size. A non-parametric test was used given small sample size (Kruskal-Wallis tests for variables with 3 response categories and Mann-Whitney tests for variables with 2 response categories). We did not identify significant differences in DASS-21 scores based on any of the variables assessed. Furthermore, the test did not show any statistical significance between the variables in the pre-and post-test DASS-21 after the intervention. Subjects reported the project intervention was “helpful.” Another participant said she could not fully engage in the interventions because of family obligations. Still, she enjoyed the resources, such as the weekly NAMI family support group

meetings given by the SI. The pre-test found in Appendix C represents the DASS-21 mean score for N=3 was 26 and standard deviation was 15.62. The mean and standard deviation was not computed for the post test. The data analysis team decided to describe the post test result in a table which can be found in Appendix D.

All participants (n=4, 100%) identified as female, and all were college educated. 50% of the sample (n=2) reported being married, while 25% (n=1) were divorced and 25% (n=1) were single. The pretest DASS-21 score was used for the three participants because one participant completed the pre and posttest on the same day which was at the end of the project. The reason why the DASS-21 score mean was 35 is because we multiplied by two as instructed by the author of the instrument. This makes it comparable to the score on the full 42 item questionnaire. Two reported difficulties winding down with increase in their heart rate. The caregiving experiences communicated the participants highlights their everyday challenges in their role as caregivers.

### **Discussion**

The findings strongly imply interventions to reduce the negative impact of caregiving may be effective if participants fully engage and adhere to the directions given by the researcher. All the participants reported their care recipient's ill-health affected their social lives and ability to engage in self-care activities. This shows the considerable impact caregiving has on caregivers' social and leisure activities, which may lead to poor outcomes (Wingrove & Rickwood, 2017). According Wingrove and Rickwood (2017), caregivers may experience decreased access to social support, resulting in reduced social networks and increased isolation. This may lead to mental health-related problems for the caregiver.

Several reminders were sent before participants completed the pre and post-tests. Subjects reported their busy schedules as an obstacle to fully engaging in the project. One participant stated the weekly self-care activities were helpful but found the resources like joining NAMI most beneficial. The subject further reported it was a very turbulent time for her and her family because her care recipient was unstable and had to be admitted into an inpatient behavioral facility during the project. She also stated that she could not participate fully due to being in crisis mode. The participant said, "I know in my head I have to take care of myself so I can help my daughter, so I am working on that, and I'm glad I found your project."

Overall, both the qualitative and quantitative results show that informal caregivers were mostly stressed in their role. Seven individuals enrolled in the study, but only four participated, with two not completing the post-test. Additionally, not all participants completed their pretest in the first week of the project as instructed. Only three seemed to actively engage in the weekly interventions, with only two completing the post-test. The findings suggest they experience some emotional stress because of the difficult caregiving responsibilities they endure individually.

### **Practice Implications**

This DNP project shows that there is a crucial need to recognize the impact caring for individuals with neurocognitive and mental illness has on caregivers. The project also demonstrated that using self-guided such as meditation, physical exercise, and educational interventions maybe effective in reducing the stress associated with the caregiving experience.

Using readily accessible educational tools and resources from AARP, Alzheimer's Association, NAMI, and other organizations will give caregivers reference materials to guide them in their caregiving role. In addition, tailoring the interventions to the individual caregiver may improve their interest and engagement. Healthcare providers should consider including caregivers in their patient care plan. Including caregivers might improve the patient adherence to their treatment plan and outcome.

Wingrove and Rickwood (2017) suggested health promotion among informal caregivers may improve understanding of how their mental health impacts their ability to care for their care recipient. Even though the sample size was small, and participants did not engage in the project as desired, it still gave some insight into the challenges caregivers face in supporting their loved ones, especially during the current pandemic. Optimistically, more understanding of their experience will encourage informed interventions and strategies to safeguard caregivers' mental health and well-being and better position them to support their care receivers (Wingrove & Rickwood, 2017). This project added to the literature in that it validates what previous studies have indicated about the need for more caregiver support.

### **Limitations**

Although, this DNP project results clearly support the benefits of interventions to support informal caregivers, some limitations should be addressed in future research. For example, there should be more diversity in the sample. Second, the time of recruitment should be considered.

This DNP project recruitment took place during the holiday season when people are busy with traveling and preparations for celebration. Individuals' business of the holiday season and COVID-19 restrictions may have contributed to the low enrollment and participation. Lastly, most of the participants did not follow directions as they were given and did not fully engage in the weekly interventions. Nonetheless, the present project represents a step in addressing the limited research on resources that support informal caregivers.

### **Conclusion**

The COVID-19 led to an increase in mental health issues. According to Ramírez-Ortiz et al. (2020), individuals who have little to no contact with others and are isolated from socializing are susceptible to developing psychological complications ranging from isolated symptoms to common mental illnesses such as depression anxiety, and insomnia. The overwhelming increase in mental health cases caused many individuals with mental health problems to be turned away from receiving treatment and services. The decrease in the availability of mental health providers due to the COVID-19 restrictions led to an increased need for informal caregivers. Mental health providers closed their doors and saw most of their patients virtually to decrease the spread of COVID-19. However, several studies show caregivers are at risk of developing high levels of physical, emotional, and mental strain, which can have a negative effect on their quality of life.

Studies consistently indicate that caregivers are instrumental to the healthcare system and care recipients (National Alliance for Caregiving & AARP, 2020). Studies also show informal

caregivers of patients with neurocognitive disorders or mental illness are at significant risk of poor physical health (Brown et al., 2015). According to Brown et al. (2015), psychiatric health challenges such as depression and anxiety are common amongst these family caregivers. The authors suggest stress from caregiving can negatively affect the health of caregivers and result in loss of work productivity.

In 2015, Brown et al. stated that non-pharmacological self-help interventions such as bibliotherapy, stress-reduction techniques, and health literacy training could improve caregivers' health. More resources such as financial relief, care networks, and training like formal care providers receive are needed to support informal caregivers (Moran et al., 2017). These authors reported that the use of stress reduction techniques might decrease caregiver stress that can reduce stress-related health problems. Stress reduction interventions may improve health perception, reduce the loss of days from work, and improve the care of patients (Moran et al., 2017). According to Brown et al. (2016), stress-reducing interventions and techniques are not being used by informal caregivers because most measures are focused on formal caregivers. The author notes that caregivers may practice stress reduction techniques more often if healthcare providers introduce and encourage their use. Clinicians tailor care to only their patients and do not include family members in the care plan. Most clinicians do not realize that including family caregivers will improve their patient's outcome.

Research indicates that high levels of mastery, competence, and additional caregiving support may buffer against poor mental health outcomes and improve caregiver quality of life (Chien et al., 2016). Studies also reveal the positive effects of caregiver competence against stressors and negative well-being (Karadağ-Saygı, 2020). According to Karadağ-Saygı (2020), the main limitation to the past and present studies is the limited number of high levels of research on effective interventions to support caregivers. A limitation of this project is that most of the literature reviewed focused mainly on the negative impact of caregiving rather than finding ways to solve the problem (Behrouian et al., 2020). As the need for more informal caregivers increases, there will also be a need for robust evidence on quality interventions that will support caregivers (Wingrove et al., 2017).

The purpose of this quality improvement project was to determine if participation in weekly self-care activities for eight weeks would reduce caregiver role strain, enhance the caregiving experience, and improve their quality of life. This project also explored how caregiver self-care and support may decrease depression, anxiety, and stress. This goal was achieved because the project provides insight into the experiences of uncompensated adult family and friend caregivers of children, adolescents, or adults under 65. Most studies reviewed for this project shows additional support such as financial relief, care networks, and training in caregiving to support caregivers may also be beneficial.

The research reviewed supports the importance of self-guided interventions to assist informal caregivers. Tsai (2003) proposes that having strong social support may be a buffer against stress in caregivers. According to Tsai (2003), social support can be given in the form of information to caregivers to make them feel loved, respected, and appreciated. The DNP project provided information on available self-care interventions to support informal caregivers. As suggested by Tsai, the additional education tools provided to family caregivers who exhibited high-stress levels will help them adapt to mental disorders changing nature. Despite the limitations previously noted, this DNP project provided caregivers with initial support to ease the burden during caregiving and may help more than just informal caregivers. Although the generalization of the findings may be validated by future studies, this DNP project has provided clear support for self-care interventions to help caregivers.

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## Appendix A

### *Search Strategy*

Search Criteria	Keywords
Key Search Terms Used	Medical Subject Headings (MeSH) terms were extracted from Pubmed resulting in the following keywords: Caregiver strain ( <b>CS</b> ); Caregiver role strain ( <b>CRS</b> ); informal caregiver ( <b>IC</b> ); Patients with Mental Illness ( <b>PMI</b> ). The following keywords were added during the search process: Caregiver Burnout ( <b>CB</b> ); Informal caregiver and mental illness ( <b>IC+MI</b> ); Caregiver role strain and mental illness ( <b>CRS + PMI</b> ); Caregiver Burnout and Patients with Mental illness ( <b>CB+PMI</b> ). <b>Note: Bolded abbreviations are used in Table 2.</b>
Years/Language	10 years/English
Age of Subjects	Children, adolescents, adults, geriatrics
Search Engines	Google, Google Scholar
Database	CINAHL(EBSCOHost), Google Scholar, Cochrane Library, Pubmed
Professional Organizations	The National Alliance for Caregiving ( <a href="https://www.caregiver.org">https://www.caregiver.org</a> )
Government & Regulator Agencies	World Health Organization ( <a href="https://www.who.int">https://www.who.int</a> )Centers for Disease Control and Prevention( <a href="https://www.cdc.gov">https://www.cdc.gov</a> )
Others	Bibliographies

**Appendix B***Search Results*

Database	Search Terms	Results (Number & type of Studies Located)	Dates Searched
CINHAL/EBSCO	CS* CRS ICCB (IC+MI) (CRS + PMI) (CB+PMI) =2,912	14 articles accepted	08/27/20- 10/22/2020
PubMed	(CB+PMI) =180 CRS =56	No articles accepted	08/27/20- 10/22/2020
Google Scholar	CRS + =79,600	No articles accepted	08/27/20- 10/22/2020
Cochrane Library	IC+CRS=2	1 article accepted	08/27/20- 10/22/2020
Professional Organizations	MI	1 article accepted Level V	08/27/20- 10/22/2020
Government & Regulatory Agencies	MI	1 article accepted Level V	08/27/20- 10/22/2020
Bibliography	By Citation Link	5 articles accepted	08/27/20- 10/22/2020

Note. Search terms in Appendix B can be found in Appendix A bolded and abbreviated and can be used in interpretation.

## Appendix C

Table 1: Demographics and Pre-test score.

	n	%
Gender		
Male	0	0
Female	4	100
Age		
25-49 year	2	50
50-64 years	2	50
Marital Status		
Divorced	1	25
Married	2	50
Single	1	25
Language		
English	4	100
Education		
College	4	100
Employment status		
Employed	2	50
Unemployed	2	50
Do you care for someone with special needs/mental illness/neurocognitive disorder?		
Yes	4	100
No	0	0
Care recipient		
Child	3	75
Family member	1	25
Length of Caregiving		

More than 1 year	4	100
Work hours lost		
Yes	3	75
No	1	25
Number of work hours lost		
10-20	1	25
≥25	2	50
<10	1	25
Which describes You?		
Stressed	4	100
Do You Have Any of The Following?		
Anxiety	1	25
Stress	1	25
Other	2	50
Was Your Diagnosis Before or After Providing Care?		
After Caregiving	2	50
Not Sure	2	50
Have You Tried Any of The Following?		
Deep breathing exercises	1	25
Mindfulness therapy	2	50
Physical exercise	0	0
Self-guided bibliotherapy	1	25
	Mean	Std. Deviation
Pre- Test DASS Score (N=3)	26	15.62

## Appendix D

ITEM	N
<b>Stress Scale</b>	
I found it hard to wind down	1
I found it difficult to relax	1
I found it hard to wind down	1
I tended to over-react to situations	1
I found myself getting agitated	1
<b>Depression Scale</b>	
I was unable to become enthusiastic about anything	1
I felt downhearted and blue	1
I found it difficult to work up the initiative to do things	1
<b>Anxiety Scale</b>	
I was aware of the action of my heart in the absence of physical exertion	2
I experienced trembling (e.g., in the hands)	1
I felt scared without any good reason	1
I was aware of dryness of my mouth	1

## Appendix E

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### DASS–21 Stress scale

I was intolerant of anything that kept me from getting on with what I was doing (14).  
I felt I was rather touchy (18).  
I found it difficult to relax (12).  
I found myself getting agitated (11).  
I felt that I was using a lot of nervous energy (8).  
I found it hard to wind down (1).  
I tended to over-react to situations (6).

---

### DASS–21 Depression scale

I felt that life was meaningless (21).  
I felt that I had nothing to look forward to (10).  
I couldn't seem to experience any positive feeling at all (3).  
I was unable to become enthusiastic about anything (16).  
I felt that I wasn't worth much as a person (17).  
I felt downhearted and blue (13).  
I found it difficult to work up the initiative to do things (5).

---

### DASS–21 Anxiety scale

I was aware of the action of my heart in the absence of physical exertion (19).  
I experienced breathing difficulty (4).  
I experienced trembling (e.g., in the hands) (7).  
I felt I was close to panic (15).  
I felt scared without any good reason (20).  
I was worried about situations in which I might panic and make a fool of myself (9).  
I was aware of dryness of my mouth (2).

---

**Appendix F**

**DEMOGRAPHIC SURVEY**

**Name (initials):**

**Gender:**

**Phone Number:**

**Email:**

How old are you? (*circle one*)

What is your marital status? (*circle one*)

- Under 18
- 18-24
- 25-34
- 35-49
- 50-64
- 65+

- Never Married
- Married
- Widowed
- Divorced
- Separated
- engaged

What is your household income? (*circle one*)  
***one***

What is your highest level of education? (*circle*

- Under \$29,999
- \$30,000-\$49,999
- \$50,000-74,999
- \$75,000 -\$199,999
- \$200,000 or more

- Elementary School
- High School
- Vocational
- College

Do you speak, write, read in English? (circle one)

- Yes
- No

What is your employment status? (*circle one*)

Which describes you?(*circle one*)

- I am employed
- I am unemployed
- I am disabled

- Black
- Hispanic
- White
- Mixed

Which sentence describes you? (circle one)

- I am disabled
- I am NOT disabled

Which one of the statements below best describes your personal responsibilities regarding care recipients with mental illness? (*circle one*)

I am not a carer for anyone with mental illness

I am a carer of a someone with mental illness but someone else is the primary carer

I am the primary carer of someone with mental illness

I equally share the care of someone with mental illness.

Which one of the statements below best describes your relationship with your care recipient? (circle one)

Child(ren)

Family Member

Friend

How old is the person you give care? (circle one)

Under 13 years

13- 18 years

19-65 years

65+

How long have you been caring for your loved one? (circle one)

Less than 1 month

1 month

1-12 months

1-2 years

3-5 years

5 years or more

Have you lost work hours because you were taking care of your dependent? (circle One)

Yes No

If yes, please specify the number of hours

25 hours or more

20-25 hours

10-20 hours

Less than 10 hours

Which of the following describes you?

I enjoy being a caregiver

I do not enjoy being a caregiver

I am stressed from caregiving

Do you have any of the following? (circle one)

Depression

Body Aches

Anxiety

Other (please list):

Stress

Was your diagnosis before or after providing care? (circle one)

Before

After

What have you tried any of the following? (circle one)

Mindfulness therapy

Self-guided bibliotherapy (self-help books, written materials)

Deep breathing exercises

Meditation

Physical exercise

## Appendix G

### Informed Consent

**Title:** Interventions to Reduce Role Strain of Informal Adult Caregivers of individuals with Neurocognitive and Mental Disorders

**Principal Investigator:** Dr. Traci Sims

**Co-Investigator:** Dr. Michelle Nelson

**Co-Investigator:** Dr. Miranda Hawks

**Student Principal Investigator:** Diana Awuah

#### **Introduction and Key Information**

- You are invited to take part in a research study. It is up to you to decide if you would like to take part in the study.
- The goal of this study is to see if learning about how lower stress and information on common mental health drugs is helpful in lowering stress of caregivers.
- Your role in the study will last eight weeks.
- You will be asked to do the following: Read information about how to lower your stress and practice ways you can bring your stress down. You will also be asked to work on surveys. The surveys will take about one hour to finish.
- The risks of being in this study include Taking part in this study will not put you in any danger than you would experience on a typical day.
- This study may or may not benefit you. Overall, we hope to gain information about the impact of these interventions.

#### **Purpose**

- The reason for this study is to see if education on self-guided bibliotherapy, stress reduction, and health literacy is an effective way to decrease family caregivers' stress and role strain.
- You are invited to take part in this research study because you are a friend or family caregiver of an individual with mental illness. No more than 50 people will be invited to take part in this study.

#### **Procedures**

- If you decide to take part, you will be given a Microsoft Word and PowerPoint document on self-guided bibliotherapy, stress reduction, and common mental disorder drugs.
- You will be asked to fill out surveys, one before and after you have completed the program.
- You will be responsible for studying the documents and performing the exercises at your own pace every week for six weeks.
- The whole study will take eight-weeks. You will have four weeks to review all documents.
- Most of the information will be shared though email but you may also receive calls.

#### **Future Research**

Researchers will not use or distribute your data for future research studies even if identifiers are removed.

**Risks**

In this study, you will not have any more risks than you would in a typical day of life. No injury is expected from this study, but if you believe you have been harmed, contact the research team as soon as possible. Georgia State University and the research team have not set aside funds to compensate for any injury.

**Benefits**

This study may or may not benefit you. You may learn skills and understanding that will help you. Overall, we hope to gain information about the impact of these interventions that will benefit society.

**Alternatives**

The alternative to taking part in this study is not to take part in the study.

**Compensation**

You will receive a \$5 Amazon gift card through your email for taking part in this study.

**Voluntary Participation and Withdrawal**

You do not have to be in this study. If you decide to be in the study and change your mind, you have the right to drop out at any time. You may skip questions or stop participating at any time. You may refuse to take part in the study or stop at any time. This will not cause you to lose any benefits to which you are otherwise entitled.

**Confidentiality**

We will keep your records private to the extent allowed by law. The following people and entities will have access to the information you provide: • Dr. Michelle Nelson, Dr. Traci Sims, Diana Awuah • GSU Institutional Review Board • Dr. Miranda Hawks, Office for Human Research Protection (OHRP) We will use a study number rather than your name on study records. The information you give will be kept on a password-protected flash drive. The code sheet that connects your study number with your name and contact information will be stored separately from the data to protect privacy. When we present or publish the results, we will not use your name or other information that may identify you. Researchers do not have total control of privacy of the data. Information sent over the internet may not be secure so encryption will be used to protect your information as best as possible. All information on the flash drive will be deleted after the completion of the project.

**Contact Information**

PI- Dr. Traci Sims, [tsims8@gsu.edu](mailto:tsims8@gsu.edu), 404-413-1157

Student PI-Diana Awuah, [dawuah@gsu.edu](mailto:dawuah@gsu.edu), 404-643-2818

- If you have questions about the study or your part in it
- If you have questions, concerns, or complaints about the study.

The IRB at Georgia State University reviews all research that involves human participants. You can contact the IRB if you would like to speak to someone who is not involved directly with the study. You can contact the IRB for questions, concerns, problems, information, input, or questions about your rights as a research participant. Contact the IRB at 404-413-3500 or [irb@gsu.edu](mailto:irb@gsu.edu).

**Consent**

If you wish to keep a copy of this consent form, please print a copy.

If you are willing to take part in this research, a link to a survey will be sent to through your email where you will click a button saying you agree.

**Appendix H**

## INSTITUTIONAL REVIEW BOARD

Mail: P.O. Box 3999  
 Atlanta, Georgia 30302-3999  
 Phone: 404/413-3500

In Person: 3rd Floor  
 58 Edgewood  
 FWA: 00000129

September 13, 2021

Principal Investigator: Traci Sims

Key Personnel: Awuah, Diana M; Hawks, Miranda R; Nelson, Michelle; Sims, Traci

Study Department: College-Nursing/Health Prof

Study Title: Interventions to Reduce Role Strain of Adult Informal Caregivers of Individuals with Neurocognitive and Mental Disorders

Review Type: Expedited Amendment

IRB Number: H21630 Reference Number: 366950

Approval Date: 06/19/2021

Status Check Due By: 06/18/2024

Amendment Effective Date: 09/08/2021

The Georgia State University Institutional Review Board reviewed and **approved** the amendment to your above-referenced Study.

This amendment is approved for the following modification(s):

- Dr. Nelson was replaced with Traci Sims on flyers as study contact.
- Expand the places where flyers, consent forms, and information about the study will be distributed to increase the chance of getting more participants.

The amendment does not alter the approval period, which is listed above, and the study must be renewed at least 30 days before the due date if research is to continue beyond that time frame. Any unanticipated events or problems resulting from this investigation must be reported immediately to the University Institutional Review Board.

For more information visit our website at [www.gsu.edu/irb](http://www.gsu.edu/irb).

Sincerely,

A handwritten signature in black ink, appearing to read "Cynthia A. Hoffner". The signature is written in a cursive style with a long horizontal flourish at the end.

Cynthia A. Hoffner, IRB Chair