A Study of Mindfulness Exercises for Informal Caregivers with Caregiver Strain

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Abstract

Background: Cancer remains the second leading cause of death worldwide (World Health Organization, 2018). Family and friends often find themselves accepting the caregiver role with little or no training. Caregivers may experience both positive and negative effects of caregiving. The consequence of providing this care creates a strain on many caregivers. Increased physical and emotional stress may be detrimental to a caregiver and may lead to a decreased lifespan. Studies have shown the positive effects mindfulness can have on one's emotional and physical well-being.

Purpose: The purpose of this quality improvement project was to identify caregiver strain in informal caregivers of oncology patients and reduce strain thru the implementation and practice of mindfulness exercises.

Methods: Convenience sampling was used to recruit participants. Participants were asked to complete a demographic survey and baseline Modified Caregiver Strain Index (MCSI) via Qualtrics. The MCSI consists of 13 questions to measure strain related to providing care. Participants were instructed to practice a 10-minute guided mindfulness exercise daily for 14 days. After 14 days, participants retook the MCSI. The results were analyzed to assess if mindfulness helped to decrease caregiver strain.

Findings: Seven participants completed the pre-mindfulness exercise survey, while nine completed the post mindfulness exercise survey. However, only four sets of data could be utilized for data analysis because only four individuals correctly utilized the same unique identifier for both the pre- and post- tests. Due to the pre- and post- measurements of caregiver strain, a paired *t*-test was conducted to analyze the effectiveness of mindfulness exercises in decreasing caregiver strain. The *p*-value for the MCSI was not less than 0.05. However, a decrease in the mean indicated a decrease in caregiver strain. A total of seven of the questions which fall within three domains resulted in positive improvements in decreasing caregiver strain. The implementation of mindfulness exercises positively improved caregiver strain.

Conclusion: A quality improvement project to assist in decreasing caregiver strain was implemented for informal caregivers caring for a loved one with cancer. The project explored the concept of practicing a simple, brief, and convenient online mindfulness exercise to improve caregivers' well-being. Although, the project had a small sample size which was difficult to showcase statistically significant results, improvements were seen in three of the five domains measured within the MCSI. Overall benefits from practicing mindfulness align with the promotion of psychosocial and physical well being.

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Chapter 1: Introduction

Background and Significance

Cancer remains the second leading cause of death worldwide. In 2018, approximately 9.6 million deaths occurred due to cancer complications (World Health Organization, 2018). As a result, from advances in medical technology and medical treatment of cancer, many individuals have lengthened prognoses (Choi & Seo, 2019). Park and Look (2019) reported the expected number of cancer survivors to increase to 19 million by 2024 due to both the United States' aging population and advances in technology. Cancer not only affects the patient, but also informal caregivers. An informal caregiver is an unpaid individual who cares for a family member or friend (Young & Snowden, 2016). According to the National Alliance for Caregiving (NAC) (2019), approximately 2.8 million Americans care for a family member or friend with cancer (Wyatt et al., 2019). Choi and Seo (2019) reported that informal caregivers of cancer have an increased burden of caring for a family member for an extended period of time. Caregiving is associated with an increased risk for the development of somatic symptoms, such as, insomnia, fatigue, gastric problems, loss of appetite, headache, and dizziness (Zavagli et al., 2016). Wyatt et al. (2019) reported that providing care for a loved one diagnosed with cancer is more emotionally stressful than other types of caregiving. In fact, as many as 50% of informal caregivers of cancer report being "highly stressed." (Wyatt et al., 2019). The strain and negative impact from caregiving affects a caregiver's lifestyle and may result in lifestyle changes (Or & Kartal, 2019).

The significant, economic impact of cancer on society continues to rise. The Agency for Healthcare Research and Quality (AHRQ) estimated that in 2017, the direct medical costs for cancer, including all health care expenditures, in the United States was $105.5 billion (U.S. Department of Health and Human Services and Centers for Disease Control and Prevention and National Cancer Institute, 2020). The projected total cost of cancer in the United States is expected to increase to $458 billion in 2030 (“Our Aging Population,” 2015). Acute care utilization is the single largest driver of spending in oncology care. Reimbursement from commercial insurance companies and Centers for Medicare and Medicaid Services (CMS) has diminished over recent decades due to changes in health care policy. The reduction of unplanned acute care admissions during chemotherapy treatment is vital in proposed changes to CMS reimbursement (Handley et al., 2018). Cancer treatment costs have greatly increased over the past two decades resulting in financial challenges for patients, families, governments, and society as a whole. The overall economic financial burden of cancer care on the United States health care system not only effects patients, but also informal caregivers (Park & Look, 2019). The financial strain of caregiving may result in depleting long-term savings or accruing more debt. Short-term savings may also be used as 2 in 10 persons have left bills unpaid or late (American Association of Retired Persons & National Alliance for Caregiving, 2020). Financial struggles have made basic needs, such as, food problematic to obtain (American Association of Retired Persons & National Alliance for Caregiving, 2020).

The downsizing of acute care hospitals, increasing expectations for more care being provided at home, results in increased pressure of informal caregivers (Ferrell & Wittenberg, 2017; Zavagli et al., 2016). As reported by Swartz and Collins (2019), one in five adults will be 65 years or older by 2030 and will require assistance of daily living resulting in an increased demand for informal caregivers. Increased risk factors for caregiver strain include around-the-clock care, high or increasing care needs, and care transitions (Frederick, 2018). This gap in health-related needs falls to family members to assist their loved ones to obtain aid with ADL's (activities of daily living) care they require, such as: bathing, feeding, dressing and IADL (instrumental activities of daily living); managing finances, transportation to medical appointments, meal preparation, administering medications, and home maintenance (McIntyre & Song, 2019). According to American Association of Retired Persons (AARP) and the NAC's report, *Caregiving in the U.S. 2020,* 99% of caregivers assisted with IADLs and 60% assisted with ADLs. Often, family members abruptly fulfill the caregiver role with little or no training and are required to be an extension of the health care team (Zavagli et al., 2016). Furthermore, cancer caregivers are 72% more likely to perform medical and nursing tasks than non-cancer caregivers (Wyatt et al., 2019). Taking on this new role, many may not feel adequately prepared, be overwhelmed, or nervous about what is expected of them. Unfamiliar tasks, such as, administering medications, assisting with bathing and meals, and performing medical and nursing procedures may bring about an array of mixed emotions including anxiety, anger, and sadness (Zavagli et al., 2016). According to Berry et al. (2017), caregivers who feel unprepared to assume the role, have a lower sense of self-efficacy which increases the perceived strain. Improving caregiver strain awareness and increasing support and interventions is critical to refining a caregiver's self-confidence (Berry et al., 2017).

According to AARP and NAC (2020), approximately 53.0 million adults, or one in five Americans are caregivers in the United States. This total has increased from the total number of caregivers in 2015, which was estimated to be 43.5 million. In 2020, the prevalence of caregiving increased to 19.2% from 16.6% in 2015 due to the aging Baby Boomer population. Wyatt, Lehto, and Sender's (2019) research identified cancer caregivers as unpaid women who are 53 years old in average and have a high school diploma. The median household income is less than $75,000 for cancer caregivers. On average, 32.9 hours per week of complex care is delivered to the care recipient (Wyatt et al., 2019).

Healthcare and functional demands of care recipients have increased since 2015 (Wyatt et al., 2019). Care recipients have reported needing more care due to long-term physical conditions, mental health issues, and memory problems (American Association of Retired Persons & National Alliance for Caregiving, 2020). The impact from caregiving does not only affect a caregiver's physical health, but also psychological well-being (Zavagli et al., 2016). According to Li et al. (2016), caregivers suffer from social isolation, loneliness, chronic stress, anxiety, and depression. The consequences of abysmal well-being may result in poor care received for the care recipient. Li et al. (2016) identified a direct correlation between caregiver depression and patient depression. Informal caregivers with depression may affect one's emotions and aptitude to function efficiently in the caregiver role. These increased demands reduce caregivers' time to constructively manage stress and promote positive psychological well-being. Tkatch et al. (2017) reported care recipients have more frequent hospitalizations, lower quality of life, and higher levels of mortality when their caregivers struggle with higher levels of strain. Due to a lack of resources, time, transportation issues and stigma, many caregivers refuse to reach out for assistance and support (Stjernswärd & Hansson, 2020). The increased prevalence of caregiver strain is not effectively studied. Even though public awareness campaigns have increased over the past decade to bring awareness of the importance of caregivers' needs, the true magnitude is unknown (Frederick, 2018).

Studies have shown the positive and negative impacts of caregiving (Gray et al., 2016; Tao & McRoy, 2015). Positive effects include adaptation, resilience, a deepening of the relationship between the caregiver and the patient and affection (Young & Snowden, 2017).

Geng et al. (2019) reported when caregivers acknowledge the caregiving experience as more satisfying, better care was provided to the care recipient allowing for a deeper affection. In return, the caregiver was able to provide better care for the care recipient. Life expectancy has proven to be decreased as much as 10 years as a negative result of caregiving (Tao & McRoy, 2015). Li et al. (2016) stated "caregivers are hidden patients who have undergone both substantial physical and emotional stress" (p. 292). The responsibility of caregiving can contribute to physical and mental strains of the caregiving role. Caregiving can also have negative impacts. Caregivers may suffer from depression, anxiety, insomnia, financial strain, time constraints, and missed hours worked (Tao & McRoy, 2015). The physical impacts of caregiving, such as, insomnia, fatigue, loss of appetite, and weight loss, place a high level of stress and decreased quality of life in caregivers (Daken & Ahmad, 2018). According to Bien et al. (2007), female caregivers are more likely to be depressed and unsatisfied in the role of caregiving. A caregiver's age can influence the positive and negative effects of caregiving, as elderly caregivers have been statistically shown to have higher levels of burden (Prevo et al., 2018).

According to Kim et al. (2007), positive effects of caregiving are higher in less educated caregivers. Opposingly, Bien et al. (2007), concluded caregivers with a higher level of education reported more positive impacts related to caring. Additionally, financial strain related to caregiving reduces the number of employed hours worked and increased absenteeism from work. Caregivers are instrumental in providing the daily needs of oncology patients; however, a caregiver's health can significantly impact the care recipient (Li et al., 2016).

Caregivers face many challenges when providing care for a loved one diagnosed with cancer. It is estimated that 80% of this population expressed a desire to remain in their home as long as possible, but only one third attain their request to end of life (Mitchell et al., 2010; Tao & McRoy, 2015). Providing care during end-of-life increased anxiety for many informal caregivers which resulted in increased caregiver strain. This becomes a challenge for caregivers who try to meet the requests of the care recipient (Mitchell et al., 2010). As incidences of cancer continue to rise worldwide, informal caregivers accept the demands required to provide assistance to their loved ones (Dionne-Odom et al., 2018). Although some caregivers find a higher meaning and purpose when fulfilling the caregiver role, strain and stress coexist. AARP and NAC (2020) reported one in four caregivers found it difficult to care for their own health as caregiving had made their own health of poorer quality. As a result of caregivers' declining health, this could impact an already strained system and jeopardize larger system goals to improve health care. On average, caregivers provide care for approximately 4.5 years (American Association of Retired Persons & National Alliance for Caregiving, 2020).

The strain and stress of caregiving suggests caregivers may benefit from professional or peer counseling, support groups, and respite care. According to Dionne-Odom et al., (2018), the use of mental health services is low. However, studies show that caregivers use of mental health services is less than 25% and 16-32% of cancer caregivers are diagnosed with depression and 40-50% have anxiety symptoms (Dionne-Odom et al., 2018). Chronic stress and negative impacts from caregiving will require an intervention to improve health-related quality of life for caregivers. The lack of mental health utilization has brought an awareness to the need of developing and increasing access to hassle-free interventions (Dionne-Odom et al., 2018). Providing support and advocating for informal caregivers, (including medical benefits and payment for care provided) impacts legislators, health care providers, researchers, and both formal and informal caregivers assisting this population (Colby & Ortman, 2014). Little is known as to how cancer caregivers personally manage stress (Wyatt et al., 2019). One such intervention that has shown to have positive results and is easy to implement is mindfulness exercises (Li et al., 2016).

Complementary and integrative health (CIH) therapies, such as, mindfulness, are becoming more popular in the United States. Wyatt, Lehto, and Sender (2019) studied CIH therapies and the positive effects on informal cancer caregivers. CIH therapies have shown to improve mood and sleep, reduce stress, and promote relaxation (Wyatt et al., 2019). Tkatch et al. (2017) identified that many older adults are comfortable utilizing technology as a resource to help improve their mental health. Feasibility from practicing online meditation demonstrated that online interventions have been successful in improving social isolation and loneliness (Tkatch et al., 2017).

Problem Statement

For loved ones diagnosed with cancer, family caregivers provide the essential health-care support needed on a daily basis while at home. The changing dynamics of the health care system, reimbursement regulations, and the increase incidences in cancer rates impacts caregivers of all ages. Although caregiving has several positive effects, such as, psychological satisfaction and growth, assessing a caregiver’s well-being is imperative to ensure the needs of caregivers are met. A caregiver may not be able to provide care appropriately or may not have all of the emotional or physical skills needed (Berry et al., 2017). The addition of mindfulness exercises may reduce caregiver strain in informal caregivers of oncology patients.

Project Goals/Objectives

This quality improvement project was proposed to reduce caregiver strain in informal caregivers of oncology patients through the implementation of practicing mindfulness exercises.

The Modified Caregiver Strain Index (MCSI) was utilized in this project and it consists of 13 questions to measure strain related to providing care (Onega, 2018). The goal of this quality improvement project was to engage caregivers in active participation of mindfulness exercises and decrease caregiver strain. Consented caregivers were instructed to complete a 10-minute guided mindfulness exercise and encouraged to practice daily for 14 days. Pakenham and Samios (2013), proposed mindfulness nurtures acceptance of feelings and is effective on improving several physical symptoms, including chronic pain, depression, psoriasis, and fibromyalgia. Caregivers completed the MCSI before and after the implementation of the mindfulness exercise, to assess the impact of the mindfulness intervention. Appraisal and dissemination of the results of this quality improvement project aided in recommending that mindfulness exercise information be made available to caregivers. Improving caregiver burden with effective stress reduction modalities can reduce physical and emotional well-being and improve care provided to the care recipient. This project was essential to promote and support informal caregivers during the caregiving role.

The clinical psychologist at the cancer center of the large Northeast health care system where the quality improvement project occurred, recognized the need to improve current informal caregiver support. This project brought an awareness of informal caregiver strain by implementing the MCSI for caregiver strain assessment. Furthermore, the amount of caregiver strain experienced was highlighted by the caregivers of their oncology patients. This project determined if mindfulness was an effective intervention to reduce caregiver strain. The PICO question guiding this quality improvement project was: In informal caregivers of oncology patients, does the addition of mindfulness exercises reduce caregiver strain?

As an essential change agent, the DNP prepared APRN recognized the drive for transformation while instilling values and empowering others to use their knowledge to help lead change. To achieve stakeholder buy-in, open communication utilizing a feedback loop was important to ensure effective communication amongst all stakeholders (Porter-O'Grady & Malloch, 2018). All key stakeholders were included in the feedback loop with a clear and concise overview of the project, timeline, individuals' responsibilities, and results.

Caregivers required support and interventions to promote emotional and physical health. If left unassisted, caregivers may experience increased health complications and even mortality. Often, diagnoses are abrupt, and an informal caregiver may not be ready to accept the responsibilities of caring for an ill-loved one (Zavagli et al., 2016). The MSCI assessment enlightened caregivers as well as the staff at the oncology clinic to the amount of strain experienced, and the use of mindfulness exercises were evaluated as a means of reducing the strain.

Definition of Terms

The following theoretical definitions were used to guide this quality improvement project:

Caregiver strain: the perception of persistent problems and a feeling of decreased well-being that results from providing prolonged care (Onega, 2018).

Care recipient: individual receiving care (Li et al., 2016).

Informal caregiver: a person who provides physical, practical, and emotional care and/or support to a relative or a friend without financial reimbursement (Frederick, 2018).

Mindfulness: awareness that emerges through paying attention on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment by moment (Stjernswärd and Hansson, 2020).

Conclusion

In chapter one, the background and significance of informal caregivers was introduced. The awareness for identifying caregiver strain and providing caregivers with quick, easily accessible interventions to promote well-being has been emphasized. The results were used to improve current informal caregiver support and to build a program to benefit informal caregivers. Chapter two provides a detailed literature review of caregiver strain.

Chapter II: Review of Literature

In this chapter, a review of existing literature on the topics of informal caregiving and mindfulness was offered. This chapter explored the positive and negative effects of caregiving. Informal caregivers accept the role, but often are unaware of the strain resulting from caregiving (Zavagli et al., 2016). Literature related to caregiving was reviewed and found that there are some identified positive aspects of caregiving, but there are more negative factors that lead to caregiver strain. Literature related to the effects of mindfulness on reducing caregiver strain was also reviewed and found mindfulness is a convenient intervention to help reduce caregiver strain.

Methodology

Electronic databases utilized for obtaining evidence was obtained through both the University and organization's Health System Libraries. Health science and psychology databases included databases: Ovid Medline, APA PsycInfo (Ovid), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Database of Systematic Reviews, and Agency for Healthcare Research and Quality (AHRQ) were reviewed. MESH headings were composed of *caregivers, family, well-being,* and *mindfulness.* Keywords utilized in the search include *caregivers, carers, family members, mindfulness, mindful awareness, oncology, cancer, positive aspects,* and *negative aspects.* After applying limiters of English language, scholarly peer-reviewed journals, all geography, deduplication, and published between 2015 to present, 231 articles were retrieved. Abstracts and titles were reviewed to identify the suitability of the article. Additional references were obtained and reviewed through relevant articles' bibliographies. Ten articles were selected, and an evaluation of evidence was completed to review data studied, methodology utilized, strengths and weaknesses of the studies, and outcomes identified. The studies reviewed identified the importance of practicing self-care when assuming the caregiver role. The conclusion of these studies identified a need for further exploration of what interventions benefit caregivers in decreasing strain and the appropriate time to begin an intervention.

Findings

The review of literature on informal caregivers found not all caregivers experience negative effects of caregiving. Palacio and Limonero (2020) identified caregiving may result in personal growth of informal caregivers of oncology patients. In contrast, a number of caregivers may experience negative aspects of caregiving including psychological distress, poor health, and unmet social needs (Grover et al., 2018). Mahmood et al. (2016), discovered brief, online mindfulness interventions allowed caregivers to practice in the comfort of one's home and at a convenient time. Feasibility of mindfulness interventions aided in decreasing anxiety, depression, and improving the caregiver's quality of life and well-being (Tkatch et al., 2017).

Positive Aspects of Caregiving. Cobb et al. (2016) explored the positive and negative aspects of informal oncological caregivers and non-oncological caregivers and evaluated if gender was a factor in caregiver strain. A descriptive, correlational design was used for this study with a sample of 111 informal caregivers. Participants were identified through a cancer center and a community hospital on the same campus of the same academic health system. A majority of informal non-oncological caregivers (38.5%) were 50-59 years of age and informal oncological caregivers (29.2%) were 60-69 years of age. The greater part of informal non-oncological caregivers (82.1%) and oncological caregivers (68.1%) were female. Participants were primarily Caucasian, 92.3% for informal non-oncological caregivers and 90.3% for informal oncological caregivers. Both groups of caregivers held a high school degree; informal non-oncological caregivers (20.5%) and informal oncological caregivers (26.4%). The majority of caregivers' current state of health was rated as good; informal non-oncological caregivers (66.7%) and informal oncological caregivers (63.4%). Surveys were distributed via paper or online method and included additional demographic variables included age, gender, ethnicity, and race.

Positive aspects of caregiving identified included caregiver esteem resulted in satisfaction in caring, feeling privileged to care for a loved one, and the importance of providing care. Study instruments utilized were the Caregiver Reaction Assessment instrument (CRA) and the Positive Aspects of Caregiving scale (PAC). The majority of caregivers were in the caregiver role for more than one year and were unpaid. Caregiver esteem was perceived to be higher in caregivers who reported working longer hours outside of the home and caregivers who did not live with the care recipient. For most caregivers, this was their first experience in the caregiver role (Cobb et al., 2016).

Race, age, and ethnicity impacted positive aspects of informal caregiving. Cobb et al. (2016) identified male caregivers were less likely than women to report their physical health was impacted by caregiving and older caregivers reported higher levels of family support. Non-whites were found to have a more positive caregiving experience overall, higher caregiver esteem and less physical health impacts than white caregivers. However, no identified differences were found between informal oncological caregivers and non-oncological caregivers with respect to impact on finance, health schedule, or caregiver esteem (Cobb et al., 2016).

Mosher et al. (2017) explored self-reported positive changes within the patient-caregiver dyads. Individual, semi-structured qualitative interviews with 23 patients with advanced colorectal cancer and 23 informal caregivers were conducted. The caregiver's relationship to the care recipient was spouse/partner (78%) and other family member was 22%. The majority of caregivers were female (87%) and caregiver race was primarily Caucasian (91%). Ninety-six percent of caregivers were married, and the average caregiver was 56 years old. Caregivers possessed an average of 16 years of education and the caregiver's annual household income was >$50,000. The average time since the patient's colorectal cancer diagnosis was 25 months. Seventy-four percent of patients had stage IV colon cancer and were treated with both surgery (100%) and chemotherapy (100%) (Mosher et al., 2017).

Five positive themes were found and included, closer relationships with others, greater appreciation of life, clarifying life priorities, increased faith, and empathy for others. Caregivers reported closer relationships and support from others resulted in a greater emotional closeness within their relationship. A greater appreciation of life was recognized that resulted from a greater awareness of life's conciseness. A cancer diagnosis brought an awareness of life's priorities, such as, focusing on meaningful relationships. Some participants recognized a greater sense of increased faith, renewed church attendance, and regular devotional time. Increased empathy for others was identified with a stronger connection to other individuals who were diagnosed. Caregivers recognized the need to implement better health habits after a loved one's cancer diagnosis, including increased exercise, healthier eating, and preventative health screenings (Mosher et al., 2017).

Grover et al. (2018) studied 30 caregivers of patients with acute myeloblastic leukemia (AML). The average age of caregivers was 42.37 years, and more than half of the caregivers were male (56.7%) and were married (86.7%). Caregivers allocated a daily average of 14.5 hours in providing care to the care recipient (Grove et al., 2018).

Grover et al. (2018) discovered that caregiving was associated with positive aspects and included motivation for the caregiving role and caregiving personal gains. A negative correlation was identified between financial burden, disruption of routine family activities and family interaction, motivation for caregiving role, and caregiver satisfaction. Caregivers with lower levels of caregiver strain had a more positive and appreciative attitude in the caregiver role. A limitation of this study involved a small sample size of caregivers. In general, caregivers of AML care recipients experienced both positive and negative aspects of caregiving. The importance of decreasing strain and improving caregiving satisfaction had a greater impact on the overall well-being of caregivers (Grove et al., 2018).

Palacio and Limonero (2020) found caregiving resulted in personal growth of informal caregivers of oncology patients. This quantitative study with a transversal design of one hundred informal caregivers completed questionnaires pertaining to resilience, aspects of care, emotional distress, spirituality, and posttraumatic growth. The majority of caregivers were women (86%), with an average age of 46.52 years, married (54%), had a high school education (100%) and lived in an urban area (89%). Most of these caregivers lived with their families (99%), were housewives (39%), and were daughters of the care recipient (48%). Seventy-nine percent of the caregivers were practicing Catholics and 32% had two children. A total of 66% of the sample was active in the caregiving role for at least 12 months. The care recipients included the following diagnoses: breast cancer (19%), lung and gastric cancer respectively 15% (Palacio & Limonero, 2020).

Palacio and Limonero (2020) identified that informal caregivers of oncological care recipients often encounter stress experiences due to increased responsibilities. Increased stress may lead to anxiety, depression, and loss of control. However, positive relations were identified between resilience, positive aspects of care, spirituality, and posttraumatic growth. Resilience had a positive effect on posttraumatic growth and an appreciation for life. It had been defined as a natural coping style in times of trauma and stress. A positive relationship endured between improved self-esteem, self-efficacy, and a more positive attitude towards life. Personal growth increased a caregiver's personal strength allowing for new possibilities to emerge. An increase in personal strength enabled personal growth to develop and had been identified as a protective factor for quality of life and emotional self-regulation. These positive relations influenced the reduction of caregiver strain and allowed for the enhancement to the caregiver role (Palacio & Limonero, 2020).

Several studies identified the positive aspects of caregiving (Cobb et al., 2017; Grover et al., 2018; Mosher et al., 2018; Palacio & Limonero, 2020). Cobb et al. (2017) acknowledged caregivers had both positive and negative aspects of caregiving. Caregiving experiences differed between individual demographic factors, race, and ethnicity. Grover et al. (2018) found motivation for the caregiving role to be a positive aspect of informal oncological caregivers. Similarly, challenges faced in the caregiver role may have been a catalyst for personal growth (Mosher et al., 2017). Any endeavor to decrease caregiver strain greatly impacted the overall positive experience of caregiving. Palacio and Limonero (2020) distinguished the importance of relating a meaning to the illness with the intention of developing protective factors in preserving psychological health. Empowering caregivers to recognize one's challenges within the role benefitted caregivers in promoting self-growth and enhanced self-esteem. Moreover, Grover et al. (2018) identified caregiving personal gains and caregiver satisfaction to be related to positive aspects of the caregiving role.

Negative Aspects of Caregiving. Caregivers often experience unmet needs when caring for a loved one. According to Sklenarova et al. (2015), unmet needs were defined as the "requirement for some desirable, necessary, or useful action to be taken or some resources to be provided, to attain optimal well-being” (p. 1513). Several domains of unmet needs transpired into emotional, psychological, comprehensive cancer care, and information. A diagnosis of cancer was a challenging time for both the care recipient and caregivers. Raised emotions included anxiety and depression initiating caregiver strain. Sklenarova et al. (2015) led a cross-sectional study to assess the unmet needs of cancer caregivers that included anxiety, depression, and identify probable predictors of their supportive care needs. A total of 193 pairs of patients and caregivers agreed to complete the survey. Survey response rate was 72.3%. Questionnaires were excluded from the analysis if less than 60% of the items were completed. A total of 188 questionnaire pairs (97.5%) were subject to analysis. The average age of caregivers were 57.8 years, and 136 subjects were female (72.3%). Most caregivers living with the care recipient were a spouse or partner (156 caregivers; 83%) and 77 caregivers (41.0%) were working (Sklenarova et al., 2015).

A total of 43.6% of caregivers reported having less than 10 unmet needs disseminated over four domains included, health care service, information needs, and emotional and psychological needs. The highest unmet need of caregivers was addressing fears about the care recipient’s physical or mental deterioration (52.7%). Likewise, other high-ranking unmet needs encompassed managing concerns about the cancer coming back (44.6%) and working through the caregiver’s feelings about death and dying (40.8%). Unmet needs of caregivers incorporated the whole psychophysical aspect of the care recipient whereas the caregiver was not concerned of one’s own emotional or physical state of health. Poignantly, every fifth caregiver reported having a moderate or high unmet need in receiving emotional support for oneself (22.0%). Moreover, the last ranked unmet caregiver needs were looking after one’s own health, including eating a balanced diet and adequate hours of sleep (20.4%). Sklenarova et al. (2015) identified 48.3% of cancer caregivers would accept psychological support if it were offered.

Caregivers were screened for distress, anxiety, and depression. Results found caregivers to have significantly higher scores compared to patients. Positive screens for caregiver distress were 69.1%, depression was 26.5%, and 34.9% for anxiety. Patients' levels of distress were 54.1%, depression was 28.4%, and 26.3% for anxiety. There was no significant correlation between sociodemographic variables including age, sex, and type of relationship. Sklenarova et al. (2015) suggested that caregiver-tailored screening tools may benefit professionals in order to offer caregiver-tailored help to this invaluable group (Sklenarova et al., 2015).

Caregiving is both emotionally and physically strenuous on the caregiver. A sense of unmet needs in communication, information, and available support services was expressed by informal caregivers (Frederick, 2018; Mitchell et al., 2010; Tao et al., 2015). Zavagli et al. (2016) conducted a study utilizing self-report questionnaires focusing on domains of worry, somatic symptoms, depressive and anxious symptoms, and strain. Domains of worry included relationships, self-confidence, future, work, and financial. One hundred participants who were enrolled in Bologna, Italy's National Tumors Association (ANT), a free medical, nursing, psychological, and social home care for cancer patients, participated in the study. The study population's average age was 49.8 years, and 73 participants were female. The majority of caregivers were care recipient's children (74%). Caregivers were in the caregiving role for an average of 17.5 months and 86% were employed. The average years of education of the caregivers was 13 years (54%) (Zavagli et al., 2016).

Zavagli et al. (2016) found a moderate, positive correlation between domains of worry and physical symptomatology, including depressive and anxious symptoms, and increased strain levels. Worry was a critical variable for caregivers' health and led to increased physical ailments including, cardiovascular, immune, endocrine, and neurovisceral systems. Caregivers frequently experienced worry in the caregiving role and daily life. A main factor in the domains of worry was work, where caregivers felt they do not work hard enough or stress about making mistakes at work. Balancing full-time work and caregiving increased strain. Many caregivers worried about their occupation, fear of losing their jobs, and their future (Zavagli et al., 2016).

Literature aligns that the negative effects of caregiving do not change as a result of the ailments of the care recipient. Caregivers of older adults are at risk for increased caregiver burden and decreased well-being (Or & Kartal, 2019). Not all informal caregivers have the skills, knowledge, and abilities to provide complex medical and nursing care to a care recipient. Complex medical and nursing tasks are required, and more than half of all caregivers provide this care (Tao et al., 2015).

Or and Kartal (2019) studied the effects of care burden on the well-being of family members rendering care to older adults. The study was conducted in the Denizli urban region of west Turkey. A cross-sectional design was used for this study, included a sample of 363 family caregivers of older adults, and data was collected via in-person interviews. Demographic characteristics of family caregivers were 71.6% female, a mean age of 48-54, and 60.3% had an education status of primary school. The majority of the monthly income status was $250-499 (48.8%). The main relationship of caregivers to the elderly person was a daughter or daughter-in-law (30.8%). A total of 51.0% caregivers denied having a chronic disease. A majority of caregivers allocated at least one to six hours of daily care (44.9%) and received social support (62.8%). Caregivers' self-perceived health status was reported as good (57.6%).

Or and Kartal (2019) identified a negative correlation between caregiver burden and the well-being of the caregiver. As caregiver burden increased, caregiver well-being decreased. Caregiver burden indicated to be a robust predictor of the caregiver’s well-being. Moderate levels of caregiver burden were identified in this study and caregivers’ well-being was at a respectable level. Non-caregivers reported higher levels of well-being. The importance of lessening the caregiver burden to increase the caregiver’s well-being and effectiveness in the caregiver role was essential. Caregivers who reported poorer health had increased caregiver burden. Increased caregiver well-being demonstrated a significant relationship between a social support system and perceived health status of the caregiver. Single, older caregivers were identified as having increased well-being for the reason of having more time to care for themselves and the care recipient. A strong social support system was vital in strengthening the well-being and decreasing caregiver burden of caregivers (Or & Kartal, 2019).

Various studies showed the negative aspects of caregiving which effected many caregivers (Or and Kartal, 2019; Sklenarova et al., 2015; Zavagli et al., 2016). Cobb et al. (2016) acknowledged emotional and psychological support as the most challenging aspect of caregiving and daughters of care recipients reported the highest effect impacted schedule and lack of family support. Furthermore, Sklenarova et al. (2015) highlighted the heightened need of support for the caregiver. Or and Kartal (2019) reported lower caregiver burden was identified in Turkey due to a strong support system. This outcome may be due to the Turkish tradition of respecting and protecting older adults. The demands of caregiving permitted caregivers to focus on the care recipient rather than one’s own health and emotional needs. Sklenarova et al. (2015) discussed caregivers neglected their own health due to worrying about the care recipient and future fears. Consistent research showed worry, anxiety, and depression to be main factors that contributed to decreased caregiver well-being and increased caregiver strain. Zavagli et al. (2016) recognized strain levels to be highest in correlation with caregivers' psychophysical health and worry levels. Further research is needed to investigate what are the specific worriers of family caregivers to endorse one's physical and emotional well-being.

Mindfulness: A State of One's Inner Harmony. The concept of mindfulness was grounded in Buddhist philosophies, nonetheless, it has been gaining more popularity in the Western culture (Li et al., 2016). Mindfulness focuses on purpose in a non-judgmental way of the present moment. In mindfulness, one is trained to consciously calm their mind to enjoy the inner peace and connectedness to the present feelings and environment. Mindfulness may be as simple as focusing on one's breathing in order to decrease anxiety and can be practiced anywhere as the ease of access makes its approach favorable (Li et al., 2016). Practicing mindfulness exercises provides effective self-care and stress reduction from the aims of caregiving. The effects from mindfulness have shown to help decrease physical symptoms from depression. The benefits of practicing mindfulness prove to increase health and psychological well-being, while improving cognitive functioning, and resilience (De Frias & Whyne, 2015).

Outcomes from practicing mindfulness have contributed to increased self-esteem, well-being, self-affirmation, and value while providing care. Stress and negative thoughts are decreased while self-regulation is increased. Mindfulness teaches one to explore and compare the differences between the past and present. Thus, increasing caregivers' ability to cope with challenges from caregiving, at the same time enhancing the ability to accept their current feelings. The practice of mindfulness endorses positive thinking and changes the brain's mechanism to shield the negative effects from caregiving. Such protective factors promote mastery control of their current situation and allow positive thoughts to be produced. Long term effects of practicing mindfulness may benefit both the care recipient and caregiver (Geng et al., 2019).

There are several different types of mindfulness programs including mindfulness-based stress reduction (MBSR), mindfulness-based cognitive therapy (MBCT), and brief mindfulness sessions. Although MBSR and MBCT have been proven to be beneficial, both programs are lengthy in time, run over eight weeks, and required in-person sessions (Mahmood et al., 2016). Caregivers desire easy access interventions while limiting their time away from the care recipient. A single session of brief mindfulness has been implemented outside of the clinical setting and has shown to reduce aggressive responses to social threat and reduce the likelihood of producing bias when judging other people's behavior. Mindfulness may have significant effects beyond the clinical setting and health psychology (Mahmood et al., 2016).

Mahmood et al. (2016) investigated the significance of a brief, five-minute, computer-based mindfulness session to assess its benefits. The findings of a brief, single-session, session was successful in creating an increased state of mindfulness. Moreover, a five-minute mindfulness session could easily be incorporated into everyday life, anywhere, and at any given moment when needed. This study included three different randomized studies. Each study utilized the Toronto Mindfulness Scale (TMS) before and after the mindfulness practice. The TMS is a tool utilized to measure one's level of mindfulness at a single point in time. All three studies utilized the same five-minute mindfulness body scan audio file which focused on the sensations of their bodies from foot to head. The audio file purposefully did not mention mindfulness and was administered via a computer (Mahmood et al., 2016).

Study one consisted of 54 high school students, 51 females, two males, and one unidentified ranging from 16 to 18 years. The average age of participants was 17 years.

Participants were randomly placed into either the mindfulness (N = 27) or the control (N = 27) group and the study was conducted in a large computer room. The control group was asked to take a few deep breaths, wait four minutes, instructions were repeated and then participants were allowed to complete the TMS via paper format. There were no significant differences noted between groups. This study included limitations of the post TMS was completed immediately after the mindfulness session. Participants may have possibly remembered their answers from the pre-TMS and used the same answers post-TMS. Furthermore, the computer lab did not have any dividers and participants may have distracted each other (Mahmood et al., 2016).

Study two consisted of 90 participants who were recruited from Amazon’s Mechanical Turk (MTurk) and were randomly placed into either the mindfulness (N = 51) or control (N = 39) group. Participants were able to login from any location to complete the pre-TMS, mindfulness session, and post TMS at any time. The same five-minute mindfulness audio file was used, and the mindfulness group had a significantly higher TMS score post intervention (Mahmood et al., 2016).

Lastly, study three consisted of 61 participants (37 male and 24 female) ranging from 18 to 70 years were recruited from Amazon’s MTurk. The average age was 33.56 years. The mindfulness group had 27 participants and 28 participants in the control group. Participants were able to complete the intervention via computer at any time. Similarly, to study one, participants completed the TMS before and immediately after the mindfulness session, but like study two, it was delivered entirely online. Again, the mindfulness group reported significantly high TMS scores than the control group. Mahmood et al. (2016) highlighted the value of implementing an online, five-minute mindfulness session to obtain the benefits of mindfulness in a non-clinical setting and at the caregiver’s own time. Participants may be more inclined to practice online mindfulness programs in the comfort of their own environments to increase the effectiveness of the intervention. In return, this saved the caregiver time, costly expert training, and the commitment to participate in lengthy courses.

Attendance and attrition may be a challenge in committing to in-person mindfulness sessions. Tkatch et al. (2017) evaluated the feasibility of an online mindfulness intervention to decrease caregiver burden and improve psychological well-being. This study also focused on evaluating the intervention's impact in relation to caregiver burden, quality of life (QOL), psychological well-being, including stress, loneliness, anxiety, and social support. The intervention was eight weeks in length and consisted of online mindfulness meditation, education of self-care focusing on self-compassion. Online sessions were delivered twice weekly via Smartphone or computer and three in-person sessions were offered. These sessions were offered at the beginning, middle, and end of the study. Tkatch et al. (2017) focused on community-dwelling older adult caregivers in South Florida. Community-dwelling referred to older adults who are living independently (Tkatch et al., 2017).

A total of 40 participants completed the program, however, only 22 completed the pre- and post-surveys. Analysis was based upon the 22 completed pre- and post-surveys. The average age of participants was 71 years and ranged from 60-69 years (N = 6) to 80 plus years (N = 3). The majority were female (80%), married (83%), lived with a family member (72%), and 85% were retired/homemakers. While over 50% of participants attended more than half of the in-person sessions, the preferred method of delivery was online (Tkatch et al., 2017).

Positive correlations were seen between increased levels of attendance and positive changes in social support and mental health. Overall, significant correlations were identified between decreased stress, anxiety, and improved mental health. The online mindfulness sessions presented a positive correlation between caregiver burden, quality of life, and psychological well-being. Quality of life was important to consider within the context of practicing mindfulness with the intention of improving anxiety and depression. The outcomes exemplified the noteworthy effects the online mindfulness sessions had of positively impacting caregivers. Tkatch et al. (2017) confirmed the feasibility of primarily online mindfulness sessions of community-dwelling older adult caregivers with the implementation of lower levels of intensity. This type of delivery for mindfulness may be ideal for older adult caregivers who lack resources to transportation or ability to leave the care recipient.

Caregiver strain is a risk for all caregivers. Hearn et al. (2019) conducted a randomized controlled feasibility study with three-month follow-up to investigate the feasibility and efficacy of web-based mindfulness training for caregivers of individuals with spinal cord injuries (SCI). The design utilized a single center randomized controlled trial assessing the intervention at baseline, postintervention, and three-month follow-up. Groups were blinded and placed either into the mindfulness training group or the psychoeducational control group. Individuals were allowed to complete the mindfulness training anytime and at the participants' location of choice. The web-based mindfulness training offered two prerecorded, 10-minute audio-guided mindfulness sessions each day. Participants were asked to practice two times a day, six days a week for a total of eight weeks. The mindfulness sessions focused on topics including breath awareness and assimilation of mindfulness in daily life (Hearn et al, 2019).

Hearn et al. (2019) conducted the study in a community setting with 55 participants. The intervention group had 28 participants and 27 participants in the control group. Most participants were men (52.7%) with a mean age of 44 years, 51% were married and 29% were living together. Mainly, the participants were employed full-time (54.5%) or part-time (32.7%). Many participants were Caucasian, British, Irish, or European (85.5%).

The psychoeducational control group received a weekly email for eight weeks which included psychoeducational materials on SCI and chronic pain to augment one's related care needs. This attention control offered hypothetically significant meaningful interventions. Participants were instructed to read the materials at times and locations fitting for them.

Significant group differences were seen at post-intervention and three-month follow-up. Mindfulness training demonstrated positive changes in caregivers' well-being related to severity of depression, anxiety symptoms, psychological and social quality of life. The psychoeducation control group also experienced positive effects from the psychoeducational training. However, more significant results were discovered within the mindfulness training group. The mindfulness training group incorporated a skills-based training which resulted in enhanced improvements in psychological and social quality of life. Mindfulness encourages nonjudgmental observational skills resulting in caregivers accepting time for self-care. The efficacy of online-based mindfulness training has shown to be beneficial for SCI caregivers and decreased travel and time commitment (Hearn et al., 2019).

Numerous studies researched the positive effects mindfulness intervention had on decreasing stress, anxiety, and improving one's self-growth and self-esteem (Hearn et al., 2019; Mahmood et al., 2016; Tkatch et al., 2017). Mindfulness has been utilized and shown to be effective in both clinical and non-clinical settings. Various studies showed the feasibility and efficacy of delivering mindfulness interventions via online (Hearn et al., 2019; Mahmood et al., 2016; Tkatch et al., s2017). Furthermore, Mahmood et al. (2016) highlighted the benefit of a brief, online five-minute mindfulness session may have on one's well-being. Brief, online mindfulness sessions are highly effective as lengthy mindfulness programs. Caregivers may have increased peace of mind knowing there is no time commitment. Additionally, online programs are valuable for caregivers who have lack of transportation. The research highlights that mindfulness is a proven intervention to help both caregivers and care recipients.

Theoretical/Conceptual Framework

According to Chokkanathan and Mohanty (2017), the social determinants of caregiver well-being had been elucidated by stress theories, contributing to additional improvements in combating caregiver strain. Pearlin's Stress Process Theory aligned with the framework for the proposed implementation of mindfulness exercise to aid in decreasing caregiver strain. Pearlin's Stress Process Theory identified the impact different stressors may have on stress propagation. Often, stressors do not occur alone, but rather in groups which may have a chain reaction that may directly or indirectly impact a caregiver's well-being (Chokkanathan & Mohanty, 2017).

Aneshensel (2015), conveyed Pearlin's Stress Process theory pursued to explain the effects stressors had on mental health. First, stressors injured mental help by devaluing personal and social support resources. Second, these resources reduced the effects of revelation to stressors. Two functions, such as, mediation and moderation demonstrated effects of stressors. Mediation referred to indirect resources including, social resources and personal resources. These indirect resources increased chronic stressors and as a result decrease resources. Moderation denotes the impact resources may have on one's mental health and the strength of the association (Appendix A). These two factors clarify how stressors destruct mental health and why some individuals are affected more by stressors than others. When individuals are in most need of resources, stress has eroded these resources away. Pearlin discussed the effects of everyday chronic stressors debilitate one's mental health. Chronic stressors slowly develop, are taxing for a lengthy period of time and have uncertain endings. Conversely, major life events explode sharply, quickly arise and define when they start and end (Aneshensel, 2015).

Bluestein and Bach (2007) described objective and subjective stressors of caregiver strain are credited to demographic attributes. Objective stressors included the physical demands of caregiving while subjective stressors incorporated the emotional strains of caregiving. Levels of strain are predisposed by modifiers which may include family support, social interactions, community support, and financial demands (Bluestein & Bach, 2007).

Informal caregivers encounter many stressors while providing care for a care recipient. Pearlin's Stress Process Theory identified why stressors may impact some caregivers more than others. Informal caregivers who experience positive effects from caregiving allowed a wider variety of available resources. These individuals support healthy coping skills, such as, seeking support from others. In return, stress levels decreased for these informal caregivers. The emotional and physical ailments from increased caregiving stress depleted the acceptance of available resources, including family support. The effects of high stress levels become cyclic and affect one's physical and mental health, finances, and work (Aneshensel, 2015). Decreasing stressors during the caregiver role through mindfulness may provide enough support to allow more positive resources to become available.

The conceptual framework, Plan, Do, Study, Act (PDSA) cycle was utilized in the proposed DNP project to guide how the problem was best explored and the relationship between variables (Appendix B). The PDSA cycle is a four-stage process which includes the plan for change and observation, trialing the change on a small scale, analyzing the data to determine what was learned, and refining the change according to what was learned (Melnyk & Fineout-Overholt, 2019). The theoretical concepts of Pearlin's Stress Process Theory and the conceptual framework of the PDSA cycle provided an important lens through which the evaluation of stress and reaction were interconnected and formulated the foundation for the DNP project.

Conclusion

This chapter provided an overview of literature on both the positive and negative aspects of caregiving and the benefits of online mindfulness exercises. The need for caregivers will continue to rise as the world's aging population increases (Frederick, 2018). The persistent challenges in informal caregiving may manifest as health care continues transforming (Zavagli et al., 2016). The magnitude of identifying caregiver strain with the aim of allowing caregivers to fulfill the responsibilities of the caregiving role is vital. Practicing mindfulness may effortlessly be incorporated into a caregiver's daily routine. Thus, decreasing anxiety, depression, physical ailments and increasing a caregiver's quality of life and well-being. The DNP project was supported by the theoretical framework of Pearlin's Stress Process Theory and conceptualized through the PDSA model. Identification of caregiver strain may be related to chronic and sudden stressors as detailed by Pearlin's Stress Process Theory in linking factors as to why some caregivers are impacted more by stress than others. In the next chapter, the DNP project's methodology is reviewed.

Chapter III: Methodology

Project Plan

The quality improvement (QI) project offered the implementation of mindfulness exercises to assist in decreasing caregiver strain in a cancer center of a large health care system located in Northeast Pennsylvania. According to Melnyk and Fineout-Overholt (2019), QI projects utilize a systematic approach for problem solving with the goal of improving outcomes. Practice-based evidence and QI have become rigorous and require a framework to determine and understand the desired outcome (Melnyk & Fineout-Overholt, 2019). The Plan, Do, Study, Act cycle (Appendix B) was utilized in guiding the QI project.

The PDSA cycle is a scientific method that follows a four-stage process to test and learn about changes on a small scale. Primarily, a change is planned on a small-trial and cumulatively builds knowledge about change in a structured way. External evidence was needed to support the improvement in addition to refining the change based on what was learned and repeating the testing. While small trials are used within the PDSA cycle, a greater chance of success stands on a broader scale (Melnyk & Fineout-Overholt, 2019).

Plan

Informal caregivers may suffer both detrimental physical and emotional effects resulting from the caregiving role. This identified the foundation for the QI project with the goal of improving caregivers' well-being through practicing a daily, guided mindfulness exercise. The proposal to focus on the implementation of a quality improvement initiative to optimize caregiver support using mindfulness exercises was supported by clinical observations and experiential knowledge, a critical appraisal of research, and formal education.

Do

The cancer center of a large health care system in Northeast Pennsylvania agreed and welcomed the QI project. A longitudinal design was used for the foundation of the project in which repeated measures were assessed over a three-month period. The QI project instructed participants to practice a daily, 10-minute guided mindfulness practice in the comfort of one's own environment and at a convenient time that works best for the caregiver. Due to the recent changes in the health system's visitor policy, very few caregivers attended appointments with loved ones attributable to the current novel pandemic, Covid-19. Enrollment and participation in this study solely relied on promoting the project via flyers displayed in the cancer center and placed in patient folders for patients to take home. Flyers were developed, approved, and implemented (Appendix B). Informal caregivers had an opportunity to participate in the QI study between September thru December 2020.

Study

The participants were chosen from a convenience sample of informal caregivers of established clinic patients. Participants needed access to either a computer or Smartphone to complete the demographic form, pre-Modified Caregiver Strain Index (MCSI) tool and the mindfulness exercise video. The MCSI is a practical tool used to quickly screen for caregiver strain. Immediately after completing 14 days of practicing the guided, 10-minute mindfulness exercise, participants completed the post-MCSI tool. Data from participants was analyzed upon conclusion of the study. The outcomes of the study were analyzed to explore the effectiveness of the mindfulness exercise on caregiver strain. The goal of the QI project was to decrease caregiver strain through mindfulness exercises. Following the conclusion of data collection, results were assessed, measured, and evaluated. According to Melnyk and Fineout-Overholt (2019), data analysis should be systematic, consistent, and thorough.

Act

The magnitude of disseminating the findings to both researchers and clinicians who can use the evidence in formulating practice guidelines or decisions regarding patient care is essential (Melnyk & Fineout-Overholt, 2019). Analysis of the data was used as the foundation to support changes for current caregiver resources and develop a policy. Long term, the mindfulness practice would routinely be offered to all informal caregivers of established patients of the cancer center. The project results were used to improve existing informal caregiver support and foster a program to benefit informal caregivers. The clinical psychologist of the cancer center and the researcher utilized the results to formulate changes and implement routine mindfulness practices for caregivers.

Organizational Setting

The project occurred in the cancer center of a large health care system in Northeast Pennsylvania. The cancer center provides northeast Pennsylvania with the largest team of fellowship trained cancer specialists. Clinical trials and genetic testing are offered at the cancer center. The health care system supports a culture of evidence-based practice and clinical practice guidelines. A multidisciplinary team composed of hematologists, radiation oncologists, surgical oncologists, specialty trained oncology nurses, and a clinical psychologist provide individualized care plans incorporating, consultation, diagnosis, and treatment. Additionally, a weekly cancer support group was available for patients and informal caregivers. These meetings provided emotional support during difficult times and established a network for patients and informal caregivers. Even though these initiatives have been established, further caregiver support was desired.

Patient Participation/ Selection

The anticipated patient population included informal caregivers who were 18 years of age, caring for a loved one diagnosed with cancer, and who could read and speak English. The caregiver either lived with or without the care recipient and assisted daily or provided total care. Exclusion criteria for caregivers was less than 18 years of age and non-English speaking. Participants enrolled anonymously in the QI project via a project link through Qualtrics. The project link provided access to a consent form (Appendix D), demographics survey (Appendix E), and the MCSI.

Project Implementation

The cancer center acknowledged the need to improve present caregiver support resources, even though a cancer support group was already established. Convenience sampling was used in the QI project. A flyer was displayed in the cancer center to promote the project, and patients also received a flyer in the patient's folder of important paperwork distributed at the end of the clinic visit (Appendix C). The health care system's visitation policy had changed due to Covid-19 and it was recommended that patients attended appointments alone. If informal caregivers of patients from the cancer center chose to enroll in the QI project, participants were asked to complete a demographic survey and baseline Modified Caregiver Strain Index (MCSI) via Qualtrics. The MCSI consists of 13 questions to measure strain related to providing care (Onega, 2018). Participants were instructed to practice a 10-minute guided mindfulness exercise daily for 14 days. After 14 days, participants retook the MCSI. The results were analyzed to assess if mindfulness helped to decrease caregiver strain.

Barriers affecting the QI project included Covid-19, changes to the current visitor policy, cancelation of the weekly cancer support group, and a lack of caregivers attending appointments with loved ones.

Ethical Considerations

Collaborative Institutional Training Initiative (CITI) training was completed with a certification obtained in June 2020. An application was submitted to the educational institution's Internal Review Board (IRB) for approval of the QI project in August 2020. IRB approval was obtained from the educational institution and the health care system. Informed consent was based on a 5th grade reading level and obtained through Qualtrics prior to commencing the DNP project.

Compliance to maintain confidentiality followed through the Health Insurance Probability and Accountability Act of 1996 (HIPAA). Participants were deidentified and coded using an individual identification number. Data was collected through Qualtrics, a data collection platform used for projects involving human subjects. An informed consent was provided online and when the participant clicked on accept, it moved to the survey. To protect anonymity due to electronic data, IP addresses were not stored. All data was recorded, stored, and protected in electronic files via a data collection platform on a password protected computer. Strict adherence of HIPAA was preserved to avert unacceptable disclosures.

Four basic ethical principles of health care included, beneficence, nonmaleficence, autonomy, and justice which encompassed this project. Participants' autonomy was respected as the individual had the right to choose whether to participate in the project. The QI project carried low risk of harming others or nonmaleficence. Beneficence was practiced with the goal of improving one's well-being and decreasing caregiver strain. Any informal caregiver who was eligible to participate in the project had a fair and equal chance to do so. Ethical principles guided the significance of assessing the influence of evidence on participants and the way in which evaluations were directed (Melnyk & Fineout-Overholt, 2019).

Timeline of Activities

An in-depth discussion occurred with the cancer center's social worker on March 10, 2020, which comprised of current caregiver resources available at the cancer center. Upon identifying a limited amount of informal caregiver resources available at the cancer center, the idea of the QI project was discussed with the clinical psychologist and the operations manager of the cancer center on March 27, 2020. Both supported the need to increase available caregiver resources. An agreement for increased caregiver resources available at the cancer center was identified and buy-in was obtained. A literature review was performed in June 2020 and a detailed project plan was developed. CITI training was completed on June 7, 2020. The DNP project oral defense occurred on August 4, 2020. IRB approval was received by the educational institution in August 2020 and the health system organization in September 2020. The timeframe for participants to partake in the study was from September-December 2020. Data was collected through an online platform used for projects involving human subjects and analyzed. DNP project goals were evaluated upon completion of the project. Defending the project is anticipated in May 2021.

Stakeholders Involved

Upon identification of the problem, stakeholders were recognized to gain insight of the proposed QI project. The proposed project was discussed with the clinical psychologist, social worker, and operations manager of the cancer center to develop a project plan for implementation and to identify possible barriers. Moreover, the informal caregivers of care recipients were the primary stakeholders in this QI project. The recognition of caregiver strain was key for participation and enrollment. This was accomplished through multidisciplinary meetings at the cancer center and via telemedicine appointments with patients and informal caregivers.

Measurement Instruments

Data from the DNP project measured pre-post mindfulness exercise intervention. The outcomes were measured using the Modified Caregiver Strain Index (MCSI). The MCSI consists of 13 questions to measure strain related to providing care (Appendix F). Major domains measured in this tool include financial, physical, psychological, social, and personal. In 1983, the Caregiver Strain Index (CSI) tool was developed. The MCSI was created in 2003 as it clarifies and updates many of the items on the CSI. Scoring is two points for each ‘yes’, one point for each ‘sometimes’, and zero for each ‘no’ response. Scoring spans from 26 to 0. A higher score implies a higher level of caregiver strain (Onega, 2018).

The MCSI has an internal reliability coefficient of .90 compared to the CSI’s coefficient of .86 in 1983. The MCSI is brief, convenient, self-administered, and easy to score. Recognizing the effects of caregiver strain may specify more individualized strategies for reducing caregiver strain. Professional judgement may be needed to evaluate the level of caregiver strain because the tool does not distinguish between low, moderate, or high levels of caregiver strain (Onega, 2018).

Data Collection Procedures

Participants were informal caregivers of patients who sought treatment at the cancer center. The informal caregivers enrolled anonymously in the project via an online study link. Enrollment was from September-December 2020. Contact information was given to participants if any questions or concerns arose. Participants were directed to complete a demographic form and a baseline MCSI assessment. All participants were instructed to watch a 10-minute guided mindfulness video daily for 14 days via YouTube which had been specifically developed for this QI project. The video link was provided on the flyer. Subsequently, participants were instructed to complete the MCSI post-mindfulness intervention after 14 days.

Data Analysis

The evaluation of results studied the effectiveness of mindfulness exercise to decrease caregiver strain. Central tendency, or a descriptive summary of a dataset through a single value that reflects the center of the data distribution, was used to compare the pre- and post-MCSI scores. Indices of central tendency include the mode, median, and mean (Polit & Beck, 2017). Interpretation of the frequency distributions and central tendency of the data could determine patterns and was accomplished using descriptive statistical analysis. A paired *t*-test was used to analyze the dependent groups of pre- and post-MCSI scores to determine if the mindfulness exercises lead to a significant difference in MCSI scores between the groups. Additional data analyzed included the number, age, gender of participants. Descriptive statistics were utilized to organize and summarize the data to identify if the mindfulness exercise facilitated in decreasing caregiver strain and increasing well-being.

Resources Used for Project Completion

Resources necessary for the completion of the project included buy-in from the operations manager and clinical psychologist of the cancer center. Education and awareness of caregiver strain on informal caregivers was positively received by stakeholders. Related costs for the implementation included the production of the guided mindfulness video and distribution of flyers. The information technology department of the educational institution was contacted to access Qualtrics. Qualtrics was free of charge to use through the educational institution. The project did not acquire any additional time or other duties from staff at the cancer center or additional work hour related costs.

Conclusion

This chapter reviewed the methodology for the proposed QI project. An overview of the project plan including the conceptual framework of PDSA were discussed. Other considerations to the methodology included the project setting, participants, project implementation, ethical considerations, timeline of activities, stakeholders, measurement instruments, data collection procedures, data analysis, and resources used for project completion. The next chapter discusses the results of implementation of mindfulness exercises to decrease caregiver strain.

Chapter IV: Results

Informal caregivers often experience somatic symptoms, financial strain, and lifestyle changes as a result of caring for those with cancer. Simple, brief, and convenient online meditation exercises have been successful in decreasing caregiver strain and increasing health and well-being of informal caregivers (De Frias & Whyne, 2015). The overall purpose of this quality improvement project was to reduce caregiver strain in informal caregivers of oncology patients through the implementation of practicing mindfulness exercises. The following are the results.

Sampling Procedure

Seven participants completed the pre-mindfulness exercise survey, while nine completed the post mindfulness exercise survey. However, only four sets of data could be utilized for data analysis. This was due to the fact that many participants failed to properly create and utilize their unique participant identification codes, therefore comparing pre and post intervention scores was possible for only 4 participants. Participants were 18 years of age and older and were recently caring for a loved one diagnosed with cancer. Non-English-speaking individuals were excluded from the project.

The number of participants in this project was greatly impacted by the COVID-19 pandemic. Due to the pandemic, the healthcare system changed visitation policies and encouraged patients to attend appointments alone. Cancer support groups and caregiver support groups were also cancelled. This greatly impacted the ability to recruit caregivers for this study. Flyers were posted in the clinic and information was handed to the patients, but caregivers were not directly told about this study.

Informal caregivers enrolled anonymously in the project via an online study link through Qualtrics from September until December 2020. Participants were instructed to complete a demographic form and a baseline MCSI assessment prior to initiating mindfulness exercises. The intervention of a 10-minute daily mindfulness exercise was encouraged for the participants to practice at one's own convenience. Upon completion of practicing the mindfulness exercise, participants were instructed to complete the post- MCSI tool. Pre- and post- MCSI scores were further analyzed to assess the benefits of a mindfulness exercise in decreasing caregiver strain.

Descriptive statistics were utilized to identify the outcome of mindfulness exercise in decreasing caregiver strain. Central tendency, or a descriptive summary of a dataset through a single value that reflects the center of the data distribution, was used to compare the pre- and post- MCSI scores. Indices of central tendency include the mode, median, and mean (Polit & Beck, 2017).

Qualtrics provided a spreadsheet of the data collected. Each participant was de-identified and coded with a unique numeric code during the enrollment process. Data analysis began in February 2021 and participant demographics were analyzed for central tendency. A paired *t*-test analyzed the effectiveness of the intervention in decreasing caregiver strain. Statistical Package for the Social Sciences (SPSS) software was utilized for data analysis.

Study Sample

Characteristics of the study participants (n=4) included 75% female (n=3) and 25% male (n=1). The age range of 25-35 years was 25% (n=1), 45-54 years was 25% (n=1), and 65 years or above was 50% (n=2). Informal caregivers living with the care recipient was 25% (n=1) and 75% (n=3) did not live with the care recipient. Most participants were divorced at 50% (n=2) and 75% (n=3) were employed full time at least 40 or more hours per week. The majority of informal caregivers had a college level education and held a Bachelor’s degree (n=2) or a Master’s degree (n=1). Participants who described themselves as White/Caucasian was 75% (n=3) and Asian was 25% (n=1).

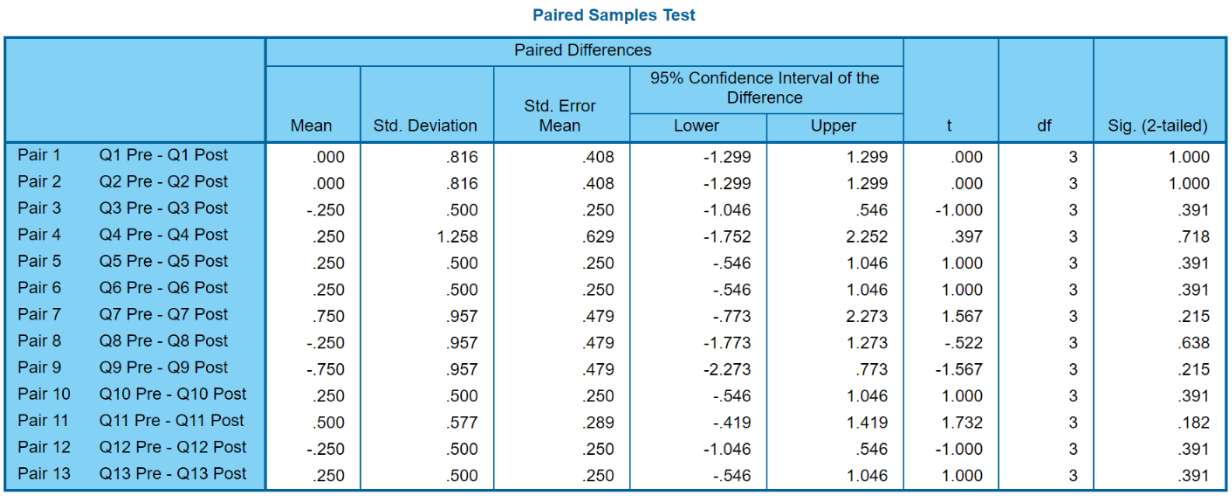
Post Intervention Scores

Data interpretation for the MCSI was analyzed using SPSS. Due to the pre- and post-measurements of caregiver strain, a paired *t*-test was conducted to analyze the effectiveness of mindfulness exercises in decreasing caregiver strain. P-value of less than 0.05 is regarded as statistically significant for the paired *t*-test (Kim & Mallory, 2017). The *p*-value for the MCSI was not less than 0.05 and was not considered statistically significant.

Due to a small sample size, individual questions were analyzed to assess improvements in caregiver well-being pertaining to major domains; financial, physical, psychological, social, and personal (Table 1). The mean scores for each question were analyzed. A decrease in the mean indicated a decrease in caregiver strain. A total of seven of the questions which fall within three domains resulted in positive improvements in decreasing caregiver strain. Those questions assessed time restrictions, family adjustments, changes in personal plans, increased demands on time, emotional challenges, work adjustments, and feeling overwhelmed.

Table 1

Paired Samples t-test



Paired Samples Test

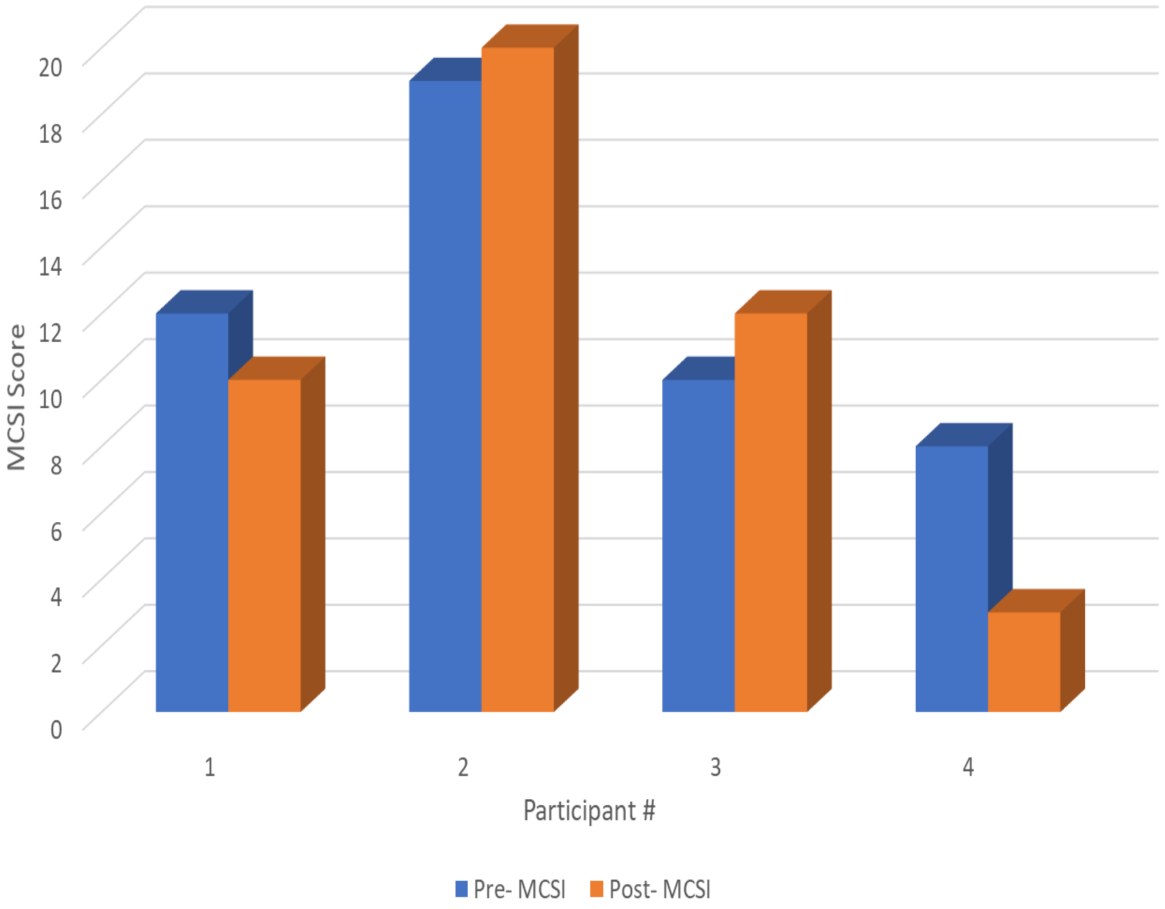
		Paired Differences					t	df	Sig. (2-tailed)
					95% Confidence Interval of the Difference				
		Mean	Std. Deviation	Std. Error Mean	Lower	Upper			
Pair 1	Q1 Pre - Q1 Post	.000	.816	.408	-1.299	1.299	.000	3	1.000
Pair 2	Q2 Pre - Q2 Post	.000	.816	.408	-1.299	1.299	.000	3	1.000
Pair 3	Q3 Pre - Q3 Post	-.250	.500	.250	-1.046	.546	-1.000	3	.391
Pair 4	Q4 Pre - Q4 Post	.250	1.258	.629	-1.752	2.252	.397	3	.718
Pair 5	Q5 Pre - Q5 Post	.250	.500	.250	-.546	1.046	1.000	3	.391
Pair 6	Q6 Pre - Q6 Post	.250	.500	.250	-.546	1.046	1.000	3	.391
Pair 7	Q7 Pre - Q7 Post	.750	.957	.479	-.773	2.273	1.567	3	.215
Pair 8	Q8 Pre - Q8 Post	-.250	.957	.479	-1.773	1.273	-.522	3	.638
Pair 9	Q9 Pre - Q9 Post	-.750	.957	.479	-2.273	.773	-1.567	3	.215
Pair 10	Q10 Pre - Q10 Post	.250	.500	.250	-.546	1.046	1.000	3	.391
Pair 11	Q11 Pre - Q11 Post	.500	.577	.289	-.419	1.419	1.732	3	.182
Pair 12	Q12 Pre - Q12 Post	-.250	.500	.250	-1.046	.546	-1.000	3	.391
Pair 13	Q13 Pre - Q13 Post	.250	.500	.250	-.546	1.046	1.000	3	.391

Many questions that showed improvements fell within the psychological domain (Figure 1). Personal time restrictions had a pre- MCSI mean of 1.00 and a post- MCSI mean of 0.75. The impact caregiving had placed on caring for a person who has changed so much from his/her former self had a pre- MCSI mean of 1.25 regarding and a post- MCSI mean of 1.00. This displayed an improvement in the caregivers' well-being. Additional demands placed on the caregiver from other family members had a pre- MCSI mean of 1.50 and a post- MCSI of .75. This presented a positive outcome from the implementation of mindfulness exercises. Further areas of improvement focused on social and personal domains. Family adjustments had a pre- MCSI mean of 1.00 and a post- MCSI mean of .75. Job requirements were significantly impacted with a pre- MCSI of 1.00 and a post- MCSI of .50. This presented a positive improvement from practicing mindfulness exercises.

Other domains of improvement for caregivers' well-being were social and personal. Adjustments to family routines showed a pre- MCSI mean of 1.00 and a post- MCSI mean of .75. Furthermore, work adjustments had the most significant improvement with a pre- MCSI mean of 1.00 and a post- MCSI mean of .50. Questions regarding changes to personal plans and feeling completely overwhelmed both had a pre- MCSI mean of 1.25 and a post- MCSI mean of 1.00. The implementation of mindfulness exercises positively improved caregiver strain.

Figure 1

Comparison of Pre- Post- MCSI Scores



Conclusion

In chapter four, a summary of the findings for the quality improvement project was analyzed. The data answered the project question, “In informal caregivers of oncology patients, does the addition of mindfulness exercises reduce caregiver strain?” Although, the results were not statistically significant, participants did have a decrease in caregiver strain in the domains of psychological, social, and personal. Descriptive statistics were presented to conclude the effectiveness of mindfulness exercises to reduce caregiver strain. Chapter five will discuss implications, findings, and recommendations to clinical practice.

Chapter V: Conclusion

The number of cancer survivors is expected to increase to 19 million individuals by 2024 due to advances in technology and the United States' aging population (Park & Look, 2019). By 2030, one in five adults will be 65 years or older and will require assistance of daily living. The need for increased informal caregivers has been identified as the structure of health care is incessantly changing. Family members often take on the role of informal caregiver abruptly and may not feel effectively prepared, be overwhelmed, or unsure of expectations (Zavagli et al., 2016). Zavagli et al., (2016) reported the impact from caregiving not only affects the caregiver's physical health, but also affects psychological well-being. Mindfulness, or the ability to focus on purpose in a non-judgmental way of the present moment, has proven to be beneficial in decreasing anxiety, improving cognitive functioning, and resilience (De Frias & Whyne, 2015).

Chapter five contains a summary of the findings with recommendations and conclusions of the findings. The goal of this quality improvement project was to engage caregivers in active participation of mindfulness exercises to decrease caregiver strain. This project was essential to promote and support informal caregivers during the caregiving role. Additional actions and recommendations for nursing practice are given and suggestions for future research are provided.

Implications

This quality improvement project supports previous research of the benefits and significance of practicing mindfulness exercises in decreasing caregiver strain. Although the results were not statistically significant, improvements were seen in three of the five domains measured within the MCSI. A decrease in the mean indicated a decrease in caregiver strain. Half or 50% (n=2) of the sample had a decrease in caregiver strain while the other 50% (n=2) had an increase in caregiver strain. A total of seven of the questions that fall within three domains resulted in positive improvements in decreasing caregiver strain. Areas of improvement included time restrictions, family adjustments, changes in personal plans, increased demands on time, emotional challenges, work adjustments, and feeling overwhelmed. Mindfulness exercises allotted participants to improve areas of well-being, such as, psychologically, socially, and personally. Participants uncovered improvements in accepting whom the care recipient once was, to whom the care recipient has become after a cancer diagnosis. Personal time restraints and additional demands placed on the caregiver improved as a result of practicing the mindfulness exercise. Family adjustments, routines, and job requirements displayed an improvement in the well-being of caregivers. Participants had the most positive impact in work adjustments, personal plans, and feeling completely overwhelmed. These recognized benefits from practicing mindfulness exercises have the possibility to improve the well-being of an immeasurable number of informal caregivers of cancer patients. Nurses and other health care providers should provide informal caregivers with information regarding the benefits of incorporating mindfulness exercises into one's daily routine. This information could be provided during appointments when caregivers accompany patients.

Implications for future research include a replication of the study with a larger sample size. This will assist in identifying the significance of benefits mindfulness exercises offer in improving well-being. Changes to promoting and recruitment of the project would benefit from face-to-face interaction with possible participants. This would not only increase the sample size, but also help to clarify any questions. Research confirms the positive outcomes from mindfulness exercises as it supports individuals of all ages. Recommendations are given to conduct future research in informal caregivers of palliative patients.

Sustainability

Although the results were not statistically significant, the findings align with the efficacy of practicing mindfulness exercises in decreasing caregiver strain. The implementation of mindfulness exercises in informal caregivers with caregiver strain has the ability to improve one's well-being, cognitive functioning, and resilience (De Frias & Whyne, 2015). Practicing mindfulness exercises is sensible, feasible, and convenient for caregivers. The benefits from practicing mindfulness have been reported to decrease depression and somatic symptoms (Daken & Ahmad, 2018). The approach is ideal for caregivers with time restrictions, transportation issues, and physical limitations. When caregiver strain is decreased, caregivers have more satisfaction in caring, feel privileged to care for a loved one, and understand the importance of providing care. Caregivers demonstrated a higher level of self-esteem and aligned with positive aspects of caregiving when strain was decreased (Cobb et al., 2016).

The results from this quality improvement project will be presented to the clinical psychologist and operations manager at the cancer center. Discussion can occur with the social worker to disseminate the findings and to assist in providing mindfulness exercises as an additional resource in decreasing caregiver strain. A brochure can be provided to caregivers explaining the benefits mindfulness exercises provide. The social worker can practice a simple mindfulness exercise with caregivers during a meeting to explore its simplicity. The clinic nurse can discuss the benefits of mindfulness exercises with the patient and caregiver during office visits. Educational pamphlets with the mindfulness exercise link can be made available as a resource for both patients and caregivers in the clinic. Dissemination of findings will also be discussed with the healthcare providers at the clinic during a monthly staff meeting. Providers can encourage caregivers to practice mindfulness as part of one's daily routine. A plan to disseminate the findings during a poster presentation at an oncology conference has been identified.

The results of this project provide evidence to support mindfulness as an effective way to promote the well-being of informal caregivers while decreasing caregiver strain. This study aligns with previous studies that support the feasibility and noteworthy benefits of practicing online mindfulness sessions to decrease anxiety and depression related to caregiver strain (Hearn et al., 2019; Mahmood, 2019; Tkatch et al., 2017).

Limitations

Several limiting factors were identified with the design and implementation of this project. The novel Covid-19 pandemic had a major impact with obtaining a large number of participants for this project. Potential participants were unable to meet face-to-face with the author of this project. This barrier may have resulted in a lack of promotion for this project, communication, and clarity of participant expectations. Instructions may have been unclear when participants were required to create a unique, individual identification number which was used to de-identify participants. Only four sets of data could be analyzed at the end of the data collection period due to incomplete data sets. A small sample size made it difficult to show results as statistically significant in mindfulness exercises assisting to decrease caregiver strain.

Conclusion

A quality improvement project to assist in decreasing caregiver strain was implemented for informal caregivers caring for a loved one with cancer. The project explored the concept of practicing a simple, brief, and convenient online mindfulness exercise to improve caregivers' well-being. Although, the project had a small sample size which was difficult to showcase statistically significant results, improvements were seen in three of the five domains measured within the MCSI. This project aligns with past research regarding the benefits from practicing mindfulness to promote psychosocial and physical well-being of informal caregivers.

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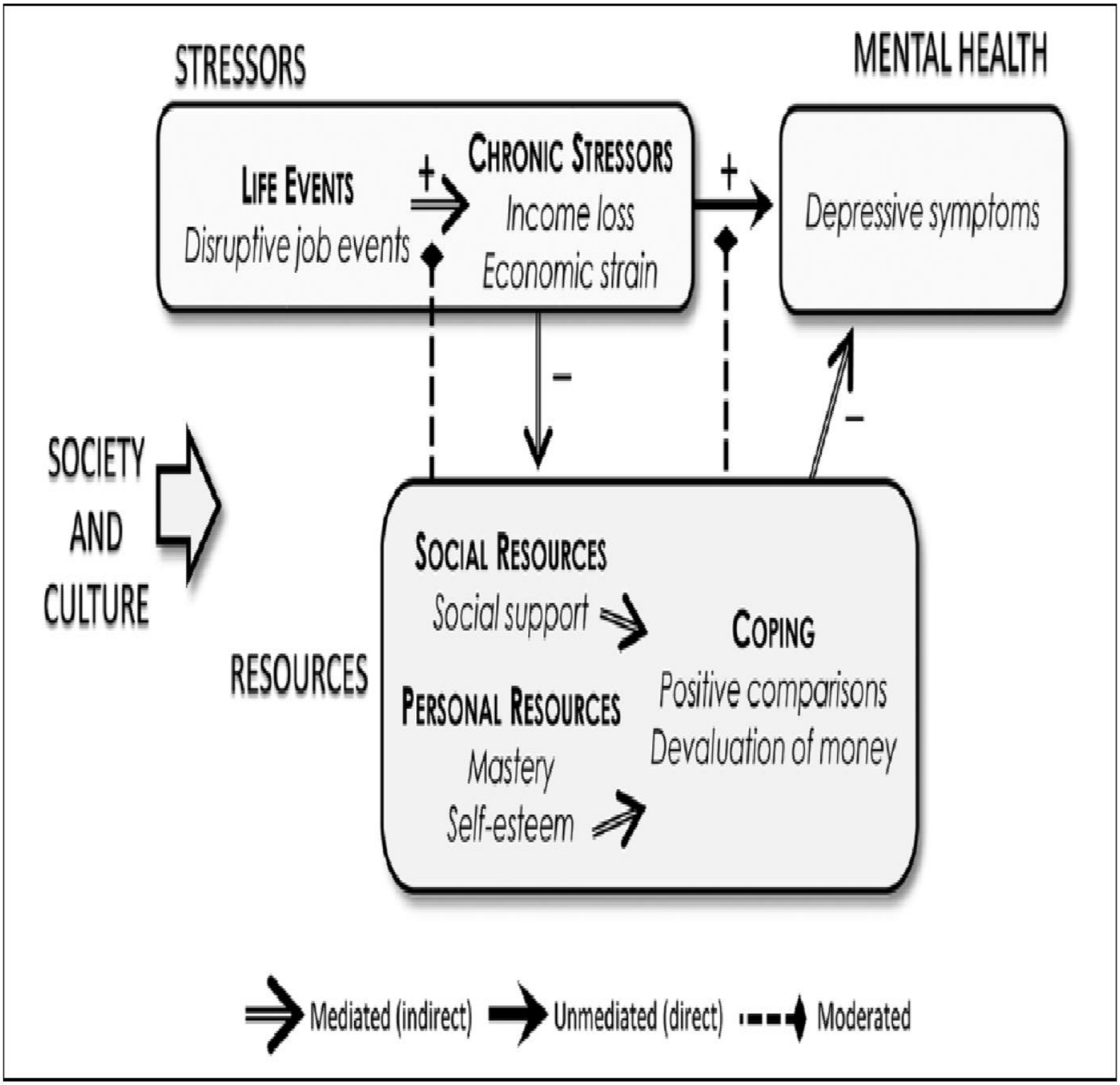
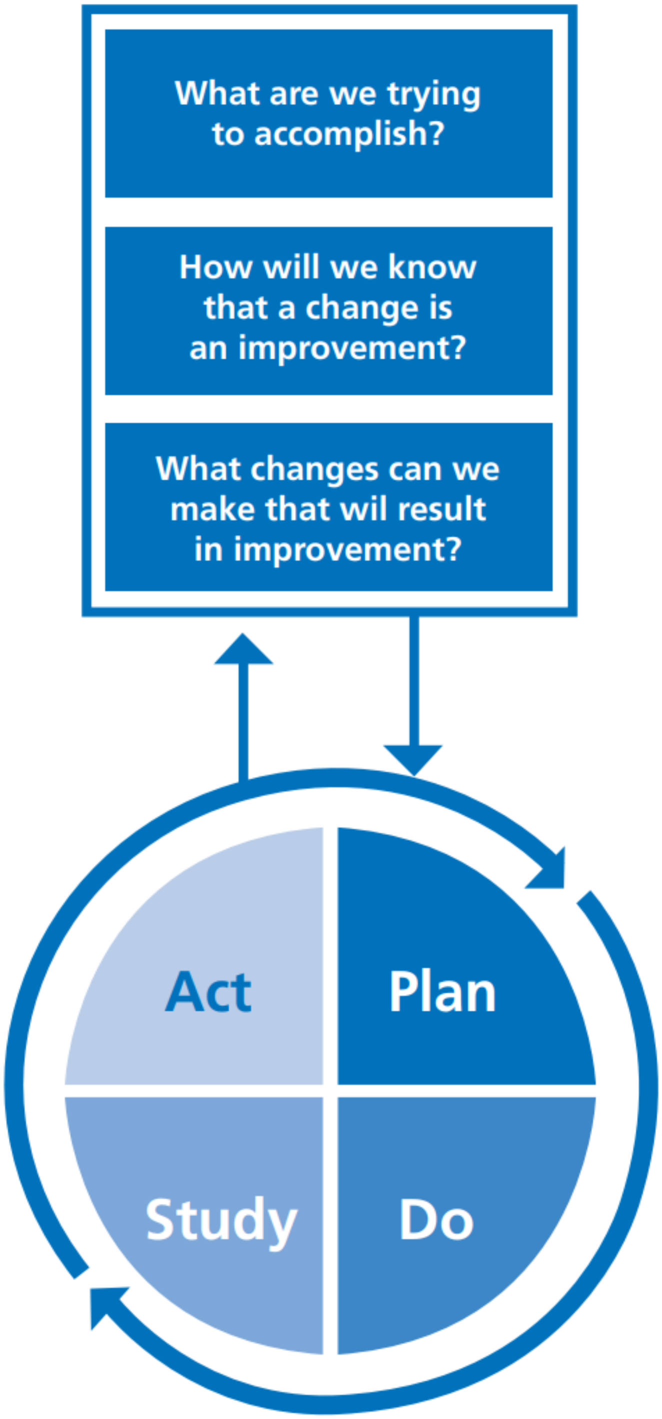
Appendix A

Pearlin's Stress Process Model



Appendix B

Plan-Do-Study Act Cycle



Appendix C

Participant Recruitment Flyer

CARING FOR A LOVED ONE WITH CANCER?

Are you a caregiver that suffers from any of the following: anxiety, increased stress, insomnia, fatigue, loss of appetite, headache, social isolation, loneliness, or depression?

ENROLL IN OUR STUDY TO HELP DECREASE CAREGIVER STRAIN THROUGH MINDFULNESS

Caregivers are needed who are:

- 18 years and older
- Currently caring for a loved one with cancer
- English speaking

Caregivers will be encouraged to watch a 10-minute guided mindfulness video daily via YouTube for two weeks. Participants will be asked to answer a 13-item questionnaire before and after the completion of the mindfulness intervention. Participation is anonymous.

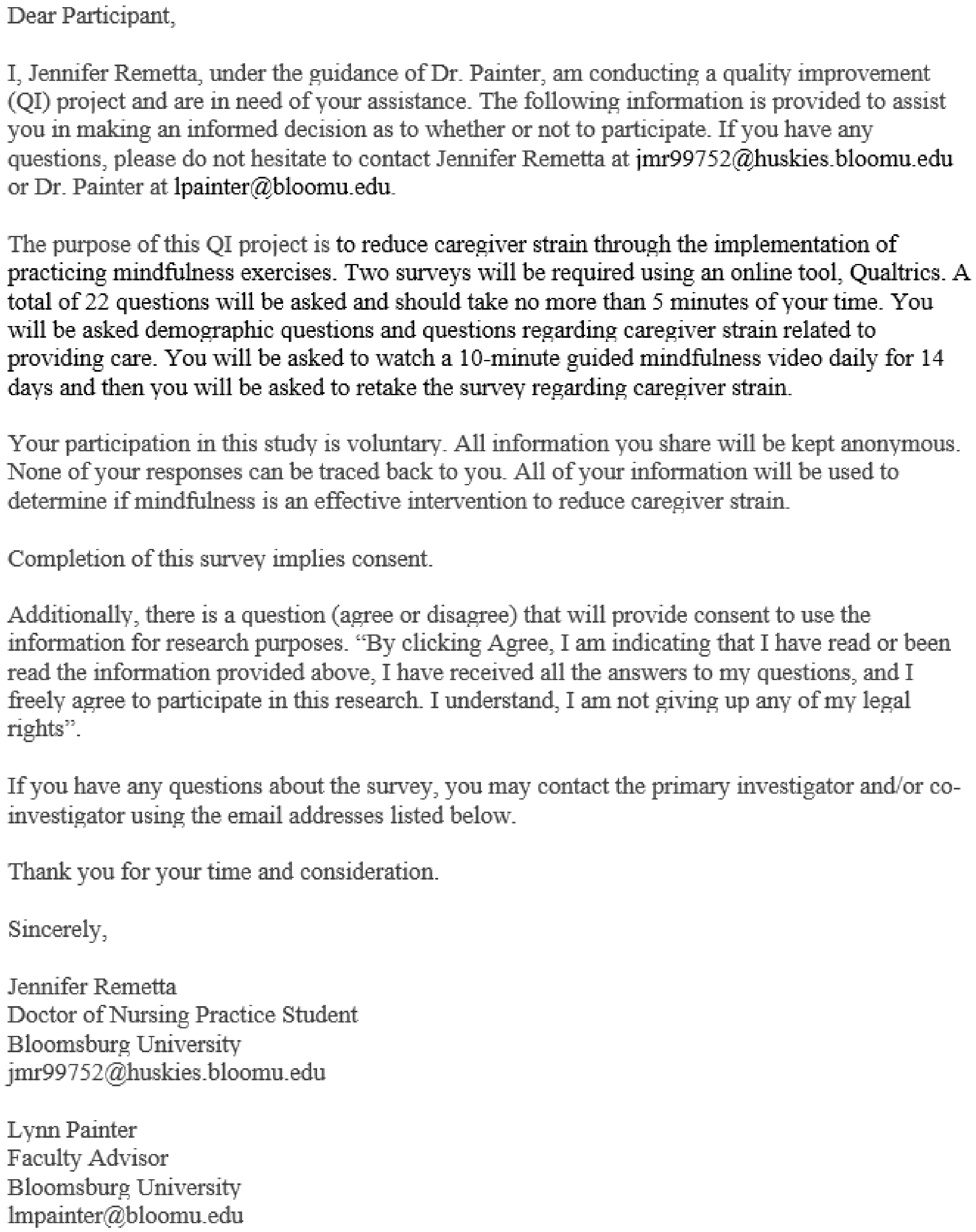
If you chose to participate in this study, you will help determine if mindfulness is an effective intervention to reduce caregiver strain.

ENROLL AT:
https://bloomu.az1.qualtrics.com/jfe/form/SV_bpi8Agv3KhXMVsV

Questions: Contact Jennifer at 570-430-1750 -or- jmr99752@huskies.bloomu.edu

Appendix D

Consent Form



Dear Participant,

I, Jennifer Remetta, under the guidance of Dr. Painter, am conducting a quality improvement (QI) project and are in need of your assistance. The following information is provided to assist you in making an informed decision as to whether or not to participate. If you have any questions, please do not hesitate to contact Jennifer Remetta at jmr99752@huskies.bloomu.edu or Dr. Painter at lpainter@bloomu.edu.

The purpose of this QI project is to reduce caregiver strain through the implementation of practicing mindfulness exercises. Two surveys will be required using an online tool, Qualtrics. A total of 22 questions will be asked and should take no more than 5 minutes of your time. You will be asked demographic questions and questions regarding caregiver strain related to providing care. You will be asked to watch a 10-minute guided mindfulness video daily for 14 days and then you will be asked to retake the survey regarding caregiver strain.

Your participation in this study is voluntary. All information you share will be kept anonymous. None of your responses can be traced back to you. All of your information will be used to determine if mindfulness is an effective intervention to reduce caregiver strain.

Completion of this survey implies consent.

Additionally, there is a question (agree or disagree) that will provide consent to use the information for research purposes. "By clicking Agree, I am indicating that I have read or been read the information provided above, I have received all the answers to my questions, and I freely agree to participate in this research. I understand, I am not giving up any of my legal rights".

If you have any questions about the survey, you may contact the primary investigator and/or co-investigator using the email addresses listed below.

Thank you for your time and consideration.

Sincerely,

Jennifer Remetta
Doctor of Nursing Practice Student
Bloomsburg University
jmr99752@huskies.bloomu.edu

Lynn Painter
Faculty Advisor
Bloomsburg University
lmpainter@bloomu.edu

Appendix E

Demographic Survey

Please answer the following questions.

1. Please indicate your gender.

___ Male
___ Female
___ Other

2. Please select the category that includes your age.

___ 18-24
___ 25-34
___ 35-44
___ 45-54
___ 55-64
___ 65 or Above

3. Do you currently live with the care recipient?

___ Yes
___ No

4. What best describes your marital status?

___ Single
___ Married, or in a domestic partnership
___ Separated
___ Divorced
___ Widowed
___ Prefer not to answer
___ Unemployed

5. What best describes your employment status?

___ Employed full time (40 or more hours per week)
___ Employed part time (up to 39 hours per week)
___ Unemployed
___ Retired
___ Self-employed

6. What is our highest level of education?

___ Less than high school diploma
___ Graduated high school
___ Some college, no degree
___ Associate degree
___ Bachelor’s degree
___ Master’s degree
___ Doctorate

7. What is your household income?

___ $0 - $24, 999
___ $25,000 - $49,000
___ $50,000 - $74,999
___ $75,000 - $99,999
___ $100,00 - $149,999
___ $150,000 or more

8. Are you of Hispanic, Latino, or of Spanish origin?

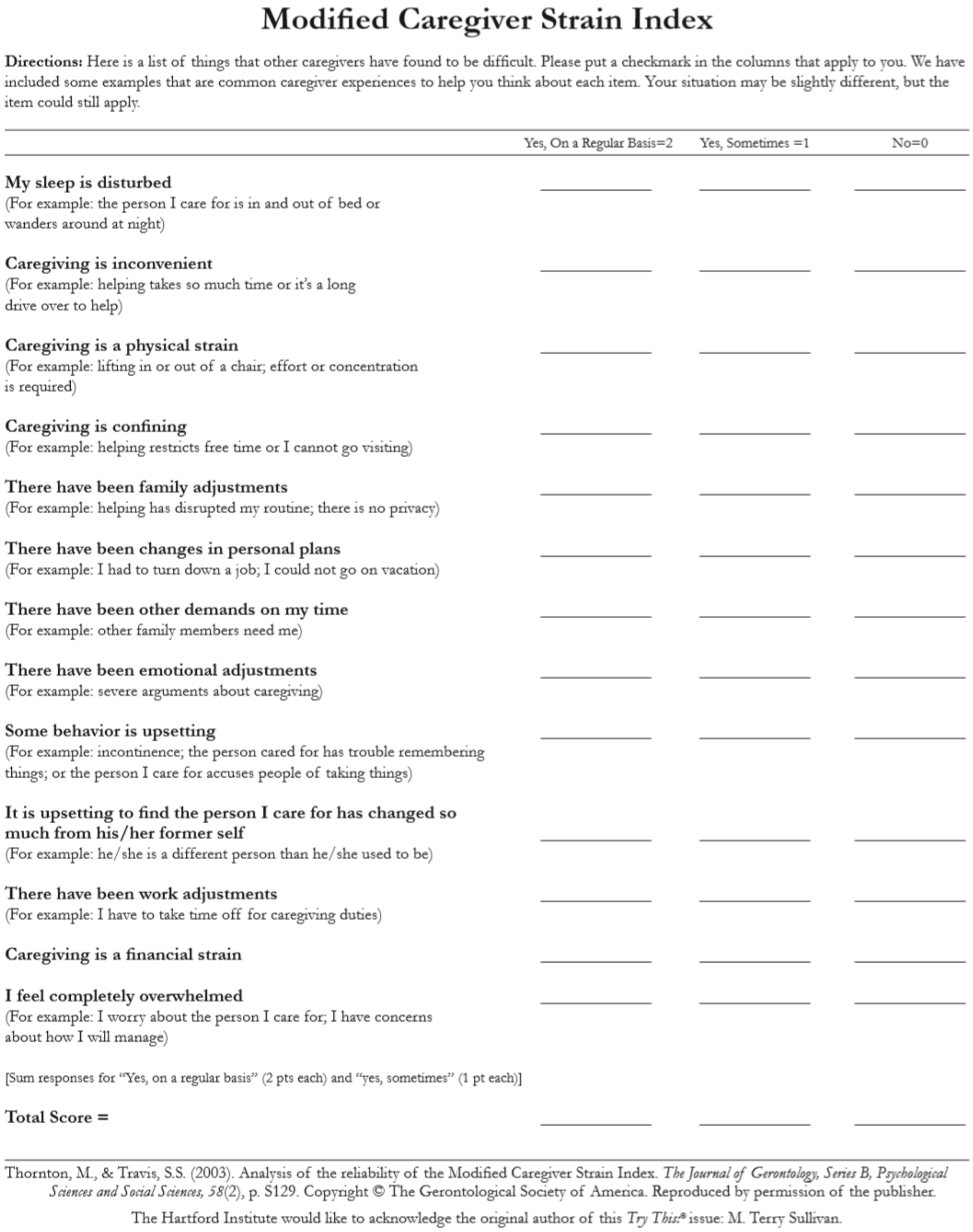
___ Yes
___ No

9. How would you describe yourself?

___ America Indian or Alaska Native
___ Asian
___ Black or African American
___ Native Hawaiian or Other Pacific Islander
___ White

Appendix F

Modified Caregiver Strain Index



Modified Caregiver Strain Index

Directions: Here is a list of things that other caregivers have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes, On a Regular Basis=2	Yes, Sometimes =1	No=0
My sleep is disturbed (For example: the person I care for is in and out of bed or wanders around at night)			
Caregiving is inconvenient (For example: helping takes so much time or it's a long drive over to help)			
Caregiving is a physical strain (For example: lifting in or out of a chair; effort or concentration is required)			
Caregiving is confining (For example: helping restricts free time or I cannot go visiting)			
There have been family adjustments (For example: helping has disrupted my routine; there is no privacy)			
There have been changes in personal plans (For example: I had to turn down a job; I could not go on vacation)			
There have been other demands on my time (For example: other family members need me)			
There have been emotional adjustments (For example: severe arguments about caregiving)			
Some behavior is upsetting (For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)			
It is upsetting to find the person I care for has changed so much from his/her former self (For example: he/she is a different person than he/she used to be)			
There have been work adjustments (For example: I have to take time off for caregiving duties)			
Caregiving is a financial strain			
I feel completely overwhelmed (For example: I worry about the person I care for; I have concerns about how I will manage)			

[Sum responses for "Yes, on a regular basis" (2 pts each) and "yes, sometimes" (1 pt each)]

Total Score =			

Thornton, M., & Travis, S.S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. *The Journal of Gerontology, Series B, Psychological Sciences and Social Sciences, 58*(2), p. S129. Copyright © The Gerontological Society of America. Reproduced by permission of the publisher.

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