CALMING FOR CAREGIVERS: EFFECTIVENESS OF AROMATHERAPY, MINDFULNESS MEDITATION, VISUAL STIMULATION, AND MUSIC THERAPY ON SELF-PERCEIVED LEVELS OF STRESS FOR CAREGIVERS OF PEOPLE WITH DEMENTIA

A thesis submitted to the faculty at Stanbridge University in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy

by

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Certification of Approval

I certify that I have read Calming for Caregivers: Effectiveness of Aromatherapy, Mindfulness Meditation, Visual Stimulation, and Music Therapy on Self-Perceived Levels of Stress for Caregivers of People With Dementia by Hiu Laam Cheung, Rachael Grant, Sara Miller, and Susan Yi, and in my opinion, this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy at Stanbridge University.

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Abstract

Evidence indicates a lack of occupational therapy strategies and resources to provide supportive services for caregivers to benefit individuals with dementia and their caregivers. 18% of caregivers for people with dementia (CPWD), compared to 6% of caregivers of people without dementia, show an increase in stress or burden when caregiving (Alzheimer's Association, 2015). Nearly 60% of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high (Alzheimer's Impact Movement, 2019). The purpose of this project was to develop a readily accessible and interactive website for CPWD that contains informative evidence-based interventions found to effectively calm and reduce stress and also aim at increasing the confidence of CPWD. The framework used for this project was the Ecology of Human Performance (EHP) model which addresses the person, task, and environment, and these three components were incorporated throughout the project. This study was designed to create and implement a web-based resource containing four sections of different calming strategy interventions: aromatherapy, mindfulness meditation, visual stimulation, and music therapy. All interventions selected had evidence to support their efficacy for calming behaviors. We collaborated with Alzheimer's Orange County to disseminate the web-based resource to recruit participants via email. Pre- and post-test surveys were collected for data analysis. Frequency and percentage analysis revealed participants reported feeling less stressed and had a better understanding of different calming strategies after browsing the website. Implications for occupational therapy include practical application of the four calming strategies as interventions to be used in clinical practice, as well as opportunities for education to reduce perceived levels of caregiver

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stress by method of a web-based resource. Future research should expand on investigating different data collection methods to yield more results for a comprehensive representation of the caregiver community. Due to working with an organization, caregivers might underreport due to the perceived risk of results being revealed to their organization. Furthermore, the web-based resource could also be beneficially utilized with different caregiver populations such as those with Parkinson's disease and patients who have experienced strokes. Conclusively, the use of a web-based resource for CPWD can be beneficial for reducing perceived levels of stress and integrating novel calming strategies into daily life.

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Calming for Caregivers: Effectiveness of Aromatherapy, Mindfulness Meditation, Visual Stimulation, and Music Therapy on Self-Perceived Levels of Stress for Caregivers of

People with Dementia

Dementia is an umbrella term used to describe a number of progressive neurodegenerative diseases of the brain that are related to the loss of memory and other cognitive functions. These deficits impact a person's ability to engage in meaningful occupations (Alzheimer's Association, 2015). Caregivers of people with dementia (CPWD) play a vital role to support the quality of life for people impacted by dementia. Primary CPWD contribute 85% of the total care and are often family members who are unpaid and inadequately trained (Gitlin & Schulz, 2012; Dizazzo-Miller, Winston, Winkler, & Donovan, 2017; Yoo et al., 2019). Compared to any other disease, the level of caregiver burden is greater when caring for people with dementia. Caregiver burden can be expounded by the negative and subjective outcomes of providing care, including extensive hours, psychological distress and feelings of despair, physical health issues, economic (financial) and social problems, and hardships on family relationships (Collins, Given, & Given, 1994; Yigitalp, Surucu, Gumus, & Evinc, 2017; Yoo et al., 2019). Caregiver burden, such as emotional and physical stress, ultimately decreases the overall quality of care that is provided for the person with dementia (Alzheimer's Association, 2015).

Occupational therapy (OT) practitioners offer holistic client-centered care for people with dementia and their caregivers. Occupational therapists (OTs) integrate the environment and the task into the treatment plan, in order to make the treatment relevant to what the person finds meaningful and valuable. Therefore, OTs have an innate ability

understanding of the importance of client-centered care, which makes them a valuable team member when working with CPWD. OTs provide unique services for CPWD through education and development of new skills, which reduces stress and improves the caregiver's ability to participate in meaningful occupations, such as the caregiving of others (Walker, Allen, Koch, Sprehe, & Webber, 2017). According to the Occupational Therapy Practice Framework III (American Occupational Therapy Association [AOTA], 2014), arranging, supervising, and providing care for others is considered an instrumental activity of daily living (IADL). However, the high level of burden experienced by CPWD has the potential to negatively impact the capacity of performance of this occupation. Providing support to address this problem is essential to the quality of life for the CPWD as well as the person with dementia. Walker et al. (2017) have noted the lack of research about effective occupational therapy strategies to support individuals with dementia and their caregivers. In addition, Rosalynn Carter Institute for Caregiving (2012), also identified that there is a need for effective supportive services for caregivers, an important public health concern.

The AOTA and the American Occupational Therapy Foundation (AOTF) Research Agenda, which establish the goals and priorities for occupational therapy research, have defined key components for the development of this research project. The first component is to create novel, theory-based interventions for promoting activity/participation/occupation and improving quality of life. The second component is to design and implement community-based participatory research to "increase the relevance, acceptability, and usefulness of evidence-based scientific findings in improving" occupational therapy (AOTA & AOTF, 2011). Master of Science in Occupational Therapy curricular threads are features of the program that are woven into each course; they will also be tied into this research project. The identified curricular threads include: psychosocial aspects of care, which focuses on the physical and emotional burden of the CPWD; occupation-based focus, which is the IADL of providing care; health care, by developing a community based program educating CPWD on useful calming strategies; and transformative and lifelong learning, through teaching caregivers how to use effective calming strategies they can use for life.

Although there is limited research on specific interventions to effectively support CPWD in care management, several research studies have determined that caregiver education can improve their confidence and care-efficacy when planning to care for the person with dementia (Ducharme et al., 2011; Dizazzo-Miller et al., 2017; Walker et al., 2017). Hence, the purpose of this project was to develop an easily accessible and interactive website for CPWD containing informative evidence-based interventions found to effectively calm and reduce stress. In addition, the materials presented on the webbased resources in regard to these calming strategies offer educational resources for caregivers and in turn can increase the confidence of CPWD while providing care. The target population for this project are unpaid caregivers for people with dementia who are residents of Orange County, California, and are associated with the Alzheimer's Orange County organization. Partnering with a local organization allowed us to reach a larger sample of participants to achieve our goal of developing a community-based intervention.

The website will focus on calming strategies for the caregiver and the patient with dementia. There will be content to focus on reducing stress and anxiety, through the interaction and exploration of pages dedicated to aromatherapy, mindfulness meditation,

visual stimulation, and music therapy. Through the utilization of the website, the caregiver can better care for their own occupational needs, therefore, the caregiver is more likely to have a meaningful experience in providing care to the individual with dementia. In conclusion, we intended to answer the question: will our occupational therapy based website developed for CPWD be an effective calming strategy tool to reduce perceived caregiver's burden and stress?

Literature Review

Several studies have suggested the benefit of using online resources to reduce caregiver burden. Torkamani et al. (2014) studied caregivers who utilized an online platform which included education, communication with other caregivers, questionnaires that assessed the health of themselves and the individual they are caring for, and contact information of health professionals. After six months, the caregivers reported an increased quality of life and decreased burden and depression. In another study, researchers found that a family education program reduced caregiver burden during and after the program (Pahlavanzadeh, Heidari, Maghsudi, Ghazavi, & Samandari, 2010). These studies provided resources for caregivers and their families, however, resources with content for specific strategies intending to calm the caregivers is lacking (Pahlavanzadeh et al., 2010; Torkamani et al., 2014). Based on this finding, the researchers discovered a need for a web-based resource specifically targeting CPWD that intended to calm and reduce caregiver burden. The four calming themes researched and analyzed in this project include aromatherapy, visual stimulation, music therapy, and mindfulness meditation.

Aromatherapy

To manage agitation and depression in individuals with dementia, psychotropic medications are often used, however, these medications have significant side effects, have limited effectiveness, and are often expensive (Yang, Wang, & Wang, 2016). For these reasons, CPWD may choose not to use medications to manage the agitation and depression, but instead seek other methods to manage these emotions. Aromatherapy is a nonpharmacological form of complementary alternative medicine that uses essential plant oils to address psychological and physical health through skin and/or respiratory absorption of the chemical ingredients from the plant (Ballard, O'Brien, Reichelt, & Perry, 2002; Padilla, 2011). A physiological response is produced when the constituents or the aroma of the essential oil enter and combine in the circulatory system (Fu, Moyle, & Cooke, 2013). It is believed that an aromatherapy massage increases the oxygenation and nutrients of cells and tissues that release endorphins and promotes physical and mental relaxation (Clarke, 2008; Yang et al., 2016). Studies completed on aromatherapy revealed that certain essential oils can reduce agitated behaviors, anxiety, and promote relaxation (Padilla, 2011; Fu et al., 2013). In addition to calming the caregivers, individuals with dementia can also benefit from the calming effects of aromatherapy (Padilla, 2011; Fu et al., 2013; Dimitrious et al., 2018).

According to a systematic review by Perry and Howes (2011), Melissa oil (lemon balm) was found to improve memory, enhance sleep, and reduce agitation in young adults; lavender oil was also found to reduce anxiety and aggression when combined with a massage and as a topical application. A systematic review by Padilla (2011) found that lemon balm and lavender oils can potentially induce relaxation and reduce agitation when

applied topically via diffusers and lotions. Yang et al. (2016) also proposed that light massage with lavender oil may alleviate agitation in people with dementia. In a review by Srivastava, Shankar, and Gupta (2010), chamomile oil was found to have a calming effect on the central nervous system (CNS) because the chemicals in the plant bind onto the receptors in the brain to induce sedation and produce hypnotic effects. Wang and Heinbockel (2018) revealed that valerian oil has sedative effects on the CNS, and as a result reduces stress-induced anxiety.

Overall, the benefits of aromatherapy can promote different calming effects such as reducing agitation, enhancing sleep, reducing anxiety, and vary between which essential oils are used or combined. Aromatherapy is a less expensive and less invasive non-pharmacological treatment that has been proven through many studies to offer health benefits for both caregivers and the person with dementia.

Mindfulness Meditation

Caregivers that experience chronic stress are at a higher risk of developing depression (Lavretsky et al., 2013). Due to the associated costs and side effects of medications, some caregivers prefer to use alternative medicine for stress reduction (Lavretsky et al., 2013). Meditation has been studied as a potential technique to reduce stress, anxiety, depression, and to improve a participant's level of attention (Danucalov et al., 2013). Multiple studies have demonstrated that when a CPWD practice some form of mindfulness meditation, their perceived level of stress and anxiety are reduced (Whitebird et al., 2012; Danucalov et al., 2013). Kirtan Kriya (KK) is a brief 12-minute form of yogic meditation that can be used for stress reduction (Lavretsky et al., 2013). In a randomized pilot study performed by Lavretsky et al. (2013) participants were placed in a KK meditation group or a passive relaxation group that listened to instrumental music for 12 minutes each day for eight weeks. Results found improvements in the KK group relating to depressive symptoms, mental health, and cognition when compared to control group (Lavretsky et al., 2013).

An alternative form of meditation is diaphragmatic breathing or deep breathing, in which the individual takes multiple long and deep breaths in an attempt to reduce their level of stress and anxiety. Ma et al. (2017) effectively summarized the mechanism of this breathing technique, "diaphragmatic breathing involves contraction of the diaphragm, expansion of the belly, and deepening of inhalation and exhalation, which consequently decreases the respiration frequency and maximizes the amount of blood gases." Mindfulness breathing exercises allow individuals to focus on a purpose to reduce automatic thoughts, rumination, and excessive worries by focusing on the present moment, and to remove negative evaluation of the current situation (Beng et al., 2016). In the experiment done by Ma et al. (2017), the researchers found that after an 8-week diaphragmatic breathing training, the participants demonstrated greater sustained attention and reported lower negative affect scores. More importantly, the participants showed improvements in sustained attention after only 15 minutes of diaphragmatic breathing.

Visual Stimulation

Visual stimulation is a technique that uses images and videos to promote calming effects. The benefits of visual stimulation include improved quality of sleep, reduce anxiety, stress, and aggression (Lubos, 2008; Dewing, 2009; Minguillon, Lopez-Gordo, Renedo-Criado, Sanchez-Carrion, & Pelayo, 2017). Based on these findings, visual

stimulation is beneficial for individuals who experience a high level of burden, such as caregivers of CPWD. The visual stimulation page of the website provided caregivers an accessible and quick stress-relieving resource.

Three common visual stimulation techniques include color therapy, light therapy, and guided imagery. Color therapy is described as exposing individuals to colors such as blue and pink to produce therapeutic calming effects (Lubos, 2008; Minguillon et al., 2017). Color therapy has been shown to reduce aggression, stress, and increase alertness (Lubos, 2008; Minguillon et al., 2017). Based on these studies, the researchers used blue and pink colors as a theme throughout the website, as well as providing blue and pink stimulating images to implement calming therapy. In addition, light therapy also promotes alertness and quality sleep (Wu & Swaab, 2007; Dewing, 2009). Using highintensity lights, light boxes, or clear, large windows for natural sunlight are all helpful ways to regulate the circadian rhythm, which reduces negative behaviors (Wu & Swaab, 2007; Dewing, 2009). Also, within the visual stimulation section, nature-based images and directions have been provided to perform guided imagery interventions. According to Nguyen and Brymer (2018), nature-based guided imagery interventions are beneficial in reducing anxiety. Grassi, Gaggioli, and Riva (2009) found visual content of a virtual island with sounds of ocean waves playing in the background can reduce anxiety levels and increase relaxation and self-efficacy levels.

Music Therapy

Music has the ability to bring individuals into relaxation and provide sensory stimulation. Music therapy is described as listening to different types of music to bring individuals to a calm state. Five factors that are positively affected by using music

therapy are attention, emotion, cognition, behavior, and communication (Koelsch, 2009). In addition, a study found that the heartbeat will synchronize to the rhythm of a song (Bernardi et al., 2017). Based on these findings, music therapy has positive effects on mood and reducing stress.

With the positive effects of music found, when music therapy is utilized it has been shown to reduce symptoms such as agitation and sundowning in individuals with dementia (Cohen-Mansfield, 2001; Lesta & Petocz, 2006). According to Dimitriou et al. (2018), music therapy is an effective non-pharmacological intervention to reduce agitation and reduce caregiver distress. These studies provide evidence that music therapy has a beneficial effect on symptoms experienced by individuals with dementia. Therefore, the website is targeting the reduction of these symptoms as well as providing a resource of calming strategies for the caregivers to utilize.

There are a variety of genres of music that are utilized for this music intervention, but specific types of music are found to be most effective. According to Craig (2014), the most effective music intervention is to use songs that the individual is familiar with or brings feelings of nostalgia. Other studies found that classical or waltz style music produced similar results (Cohen-Mansfield, 2001; Lesta & Petocz, 2006). Therefore, the web-based resource included popular songs from each decade starting from the 1940s to the 1980s, classical music, and waltz style songs.

Ecology of Human Performance Model

The Ecology of Human Performance (EHP) model addresses three components the person, the task, and the environment. The EHP model has a strong emphasis on the individual and their environment but also takes into account context. Context can be described by the physical qualities of the environment or the cultural background of the individual (Dunn, Brown, & McGuigan, 1994). Similar to how an ecosystem interacts and each organism is linked with its surroundings, a person's performance is directly related to their environment (Dunn et al., 1994). The EHP model also provides five intervention strategies for OTs to build their interventions around: establish/restore, alter, adapt, prevent, and create (Dunn et al., 1994). Each component, within the EHP model is evaluated to provide client-centered intervention strategies.

An OT provides therapeutic interventions that encompass the individual's personal barriers, context, and meaningful occupations. The individual's personal barriers include physical and cognitive capabilities, which are comprised of body functions including psychological systems and body structures (AOTA, 2014). Within the EHP context, the physical environment is considered, in addition to cultural, personal, social, temporal and virtual factors (AOTA, 2014). Occupations are activities that individuals participate in everyday life (AOTA, 2014). A few examples of these occupations are self-care, caring for others, home management, safety, and emergency maintenance (AOTA, 2014). A construct of the EHP framework involves the person, family members, and the OT to ensure maximum performance of the individual (Dunn et al., 1994). Therefore, the development and implementation of the web-based project will be based on evidence identified in the EHP model.

The EHP model provides guidance and the foundation for the web-based resource. The targeted population of caregivers of people with dementia (CPWD) experience stress and decreased emotional well-being because of their occupation of providing care for individuals with dementia (Alzheimer's Association, 2014). The

website provides technology-based strategies to reduce stress of the CPWD population to incorporate the virtual context of the EHP model. Furthermore, the components of the EHP model are vital to the foundation of the caregiver website, as the website utilizes the five intervention strategies to promote caregiver confidence and competence.

The five strategies within the EHP model supports the decision to develop a caregiver resource. The first strategy is to establish or restore an individual's performance skills and coping methods (Dunn et al., 1994). The web-based resource promotes establishing a routine for the caregiver to utilize the website to reduce stress and increase coping skills. The second strategy, alter, focuses on the individual's context where the occupational performance occurs (Dunn et al., 1994). To address this strategy, the website alters the virtual context of the individual, creating a calming environment for the caregiver. Adapt is the third strategy within the EHP model, which is defined as a modification of the individual's context (Dunn et al., 1994). An example of adaptation is the utilization of the website as a technological modification to implement evidencebased strategies within caregiving. The fourth strategy is prevention, which is a strategy that aims to avoid negative performance outcomes (Dunn et al., 1994). The prevention of stress for the caregivers ultimately allows for optimal occupational performance when taking care of a loved one with dementia. The final strategy, create, looks at designing an efficient environment for the caregiver; for example, using the resource will create a positive outlet to reduce caregiver stress (Dunn et al., 1994). These intervention strategies will be applied to the web-based resource to advance the theoretical foundation of the project.

Methodology

The first step in developing our evidence-based project included purchasing the URL domain name for the platform to develop our website, which is www.calmingforcaregivers.com. Next, we designed, developed and tested the content of the website with volunteers from Alzheimer's Orange County prior to the initial data collection phase. Content selection was based on an exhaustive and thorough analysis of literature related to calming strategies, caregiver burden, and caregiving for patients with dementia.

The design of the website was intended to promote a calming and sensory enriching experience on every page. To promote immediate relaxation, the researchers implemented a simple phrase that stated, "take a deep breath" along with a calming image on the home page. Components of the web pages included moving images, flip boxes, and educational videos to enhance the sensory experience. The color blue was chosen as the primary color of the website because research shows that it has calming effects (Lubos, 2008). Large font size was used on the website to increase accessibility (Kort & Hoof, 2014). The researchers used a simplistic design to facilitate navigation through the website.

On the web-based resource, there are four sections each containing different calming strategy interventions. We established resources that educate about aromatherapy, mindfulness meditation, visual stimulation, and music therapy, which all have evidence to support their efficiency for calming behaviors.

The CPWD were informed on how to use aromatherapy to reduce agitation and aggression in the person with dementia and decrease overall stress levels for both parties.

Specific oils, such as lavender oil, lemon balm, chamomile oil, and valerian oil have been shown to have calming properties. The website was designed to help each caregiver understand the effective methods for use, including: vaporization, adding oil to a tissue or cloth for the individual to smell, applying the oil directly to the skin, and creating a spray bottle mixture for application to the chest (Ballard et al., 2002; Padilla, 2011; Perry & Howes, 2011; Fu et al., 2013; Riley-Doucet & Dunn, 2013). There is a disclaimer that informed the CPWD of potential skin allergy risks and the way to perform a skin allergy test.

In the mindfulness meditation section, information regarding meditation practice and deep breathing techniques were presented. KK is a particular type of meditation practice that involves simple repetitions of four sounds: SA TA NA MA, translating to birth, life, death, and rebirth (Newberg, Wintering, Khalsa, Roggenkamp, & Waldman, 2010). While vocalizing these sounds, the person sequentially touches their thumb to their index finger, middle finger, fourth finger, and then fifth finger. First, performed out loud for 2 minutes, then in a whisper for 2 minutes, next in silence for 4 minutes, and then in a whisper for 2 more minutes, and then out loud again for the last 2 minutes. The total time to practice this meditation is 12 minutes (Newberg et al., 2010). According to Lavretsky et al. (2013), KK improved mental health, cognitive functioning, and psychological stress. The study done by Newberg et al. (2010), reported that adults with memory loss found KK enjoyable and beneficial and there were positive results in their neuroimaging and improvement in their cognitive function. Although these strategies are intended for the caregiver, they can also be used for the individual with dementia that they are caring for. Information relating to deep breathing or diaphragmatic breathing

was included, and information was provided to help clients to practice a calming breathing technique. Beng et al. (2016) have stated that deep breathing exercise can promote reduction of negative ruminating thoughts and remove excessive worries. A 5minute instructional video was provided for caregivers to practice deep breathing exercises.

In the visual stimulation section, information was provided about light therapy to help with sundowning and sleep-wake cycles for the individual with dementia (Wu & Swaab, 2007). As mentioned previously, the use of high-intense lights, clear and large windows for natural sunlight, and light boxes can help regulate the circadian rhythm of the person with dementia which reduce negative behaviors (Wu & Swaab, 2007; Dewing, 2009). Also, within the visual stimulation section, nature-based images and directions were provided to perform guided imagery interventions. According to Nguyen and Brymer (2018), nature-based guided imagery interventions can reduce anxiety. Color therapy has also shown to reduce levels of stress. Lubos (2008) found that the color blue has a calming effect due to a decrease in the stimulation of the sympathetic nervous system. Therefore, we incorporated calming blue colors throughout our website.

In the music therapy section, information to reduce agitation and sundowning symptoms that include specific types of music was presented (Cohen-Mansfield, 2001; Lesta & Petocz, 2006). Specific strategies included listening to quiet or waltz music and singing music out loud to encourage relaxation and decrease agitation (Cohen-Mansfield, 2001; Lesta & Petocz, 2006). Based on research done by Craig (2014), on the music therapy page, there is a reminder banner that states "Tip: Find music you prefer that brings you to a happy place."

Once the website content was developed, we disseminated the strategies and collected data through the pre- and post-tests. Alzheimer's Orange County sent out an email to all potential participants that contained an informational flyer providing instructions on how to access the website and participate in the research. The participant typed in the URL of the website and the first page contained the informed consent form, demographic information form, and a pre-test questionnaire. Next, the participant navigated through the website. After viewing the website, the participant completed a post-test questionnaire giving feedback on the effectiveness and usefulness of the content provided by clicking on the "post-survey" tab.

Privacy of the data was held to the highest standard and kept in three ways: 1) The data was encrypted, 2) Only the researchers had access to the encrypted data, and 3) the web developer accessed the data under the direction of the researchers. Once the data was collected from the participants, the researchers performed frequency data testing which provided evidence for answering the identified research question.

Measurement

The pre- and post-test questionnaires were used to collect data regarding the participants' self-perceived levels of stress before and after exploring the content on the website. This was measured by using a clearly labeled 7-point Likert scale, which is more reliable and valid than a 5-point Likert scale according to Joshi, Kale, Chandel, and Pal (2015).

Statistical Analyzing Method

Frequency and percentage analysis were performed on the participants' responses provided by the 7-point Likert scale on the pre- and post-test questionnaires.

Materials

Materials required for this research study included an original informed consent form and pre- and post-test forms. Participants must have access to a computer, tablet, or smartphone to interact with the website. (See Appendix A, Appendix B, and Appendix C)

Ethical and Legal Considerations

The researchers focused on ethical issues throughout the duration of the project by addressing anonymity, informed consent, storage of data and benefits of the project to the participants. All of this was expounded upon in the informed consent and instructions on the webpage. The informed consent was accessed through the website. The informed consent included a description of what the study entailed, the time required to participate in the study, the risks and benefits, information regarding reimbursement, participants' rights, contact information of researchers' advisor, and additional contact information for participants' concerns. The participants signed an informed consent by checking the agreement box. Then, the participants' demographic information was collected such as age, gender, and ethnicity while keeping the participants anonymous. All informed consents, demographic information, and pre- and post-test surveys were stored in a protected location. All data gathered was sent to an encrypted and password protected Stanbridge University email and stored in a password protected server. Only the researchers, research advisor, web developer, and Alzheimer's Orange County organization had access to the data gathered.

The researchers collaborated with the Alzheimer's Orange County organization to develop and gain access to their population of caregivers. The organization disseminated the email that the researchers created to recruit participants. Since the researchers did not have direct contact with the participants, the study had no conflict of interest and remained anonymous.

The researchers addressed copyright issues in the development of the website content. The pictures and videos used for the website content are not copyrighted. The search engine used to find pictures and videos were filtered to only show not copyrighted content. Some of the included videos were instructional videos created by the researchers.

Results

From December 2019 through April 2020, the website gathered 20 responses for the pre-test and post-test questionnaires. Due to the design of the website there is no concrete way to determine the exact number of participants. However, the demographic information gathered revealed that 90% were Caucasian, 80% were female, and 70% were caring for a spouse. All participants were over 56 years old, and the majority of respondents were aged 71 years and older. 70% of the respondents have been providing care for someone with dementia for over 4 years, many for over 10 years. The percentage of respondents who attended a class related to stress reduction was 70%.

The positive findings from the data suggested a 10% decrease of current stress levels from the pre-test to post-test results. Additionally, there was a 20% increase in a good understanding of calming strategies. These results indicate that the four calming strategies may be effective interventions for CPWD to reduce levels of stress.

When asked if the respondents had ways to cope with stress on the pre-test, 90% reported that they agreed, and on the post-test 70% reported they agreed, which shows a 20% decrease in agreement. There was no change in the level of confidence in the respondents' ways to cope with stress. 40% of the respondents disagreed when asked if

they felt calm caring for someone with dementia in the pre-test, while 80% of the respondents disagreed in the post-test. The responses illustrated a 10% increase in agreement regarding having trouble relaxing. Several factors may have contributed to these unfavorable results such as exposure to novel coping strategies, limited computer skills, and the researchers' choice of syntax for the surveys.

Discussion

The planning process involved identifying the gap in the literature to distinguish the needs of accessible resources for unpaid and untrained CPWD. After a thorough literature review, four calming strategy interventions were identified: aromatherapy, mindfulness meditation, visual stimulation, and music therapy. The next step in the process was to identify a specific strategy and method to deliver the resources to the targeted population. The researchers shared a common interest in incorporating modern technology to influence a greater audience, thus a web-based resource was created to fill the identified need. The researchers' partner, Alzheimer's Orange County, identified the average age of the prospective population to be 70 years or older, therefore it was imperative to build a user-friendly web-based resource that can be easily accessed by all individuals regardless of age or computer navigation. We maintained communication with Alzheimer's Orange County throughout the duration of the study to ensure to maximize the potential number of respondents.

The researchers learned how to comprehensively build a website and utilize various intervention strategies when working with CPWD. The project benefited CPWD through an accessible resource because it was shown to reduce their stress levels.

Furthermore, this project provided supplemental information for Alzheimer's Orange County in preparation for their conference on the values of aromatherapy.

Initially, this project intended to encompass fall prevention strategies such as an exercise program and home modifications, as well as calming strategies. However, the undertaking of this proposed idea would have exceeded the time frame allotted to the researchers. Additionally, a phone-based application was the proposed project platform, however, limited finances and resources to aid in the development were unavailable, which changed the project to a web-based platform.

Limitations

A limitation of this research project includes low response rate, and further research needs to be done to confirm the reliability of the results found. Given that the instructions were presented to a third-party source and then distributed to the respondents, the researchers did not have access to how instructions were disseminated. Therefore, the researchers were unable to regulate the dissemination portion of the recruitment process. Additionally, to maintain the anonymity of the participants we were unable to use appropriate measures to identify the ways pre-test to post-test responses correlated due to our inexperience in website development.

Conclusion

Implications

The implications for occupational therapy include support for the four calming strategies to be used in clinical practice, as well as opportunities for education to reduce perceived levels of caregiver stress by using a web-based resource. The project promotes

caregivers to feel more support in their daily occupations and confident in providing care for a loved one.

Recommendations for Future Research

Future researchers can investigate modifications to the existing web-based resource to improve user experience when navigating through the web pages. They can implement additional calming strategies or refine the current content of the web-based resource. Furthermore, researchers may find that presenting the website to small focus groups can ensure an optimal level of understanding and implementation of strategies into daily life. Finally, researchers can add to the pre-test and post-test surveys questions about knowledge regarding the four calming strategies presented on the website and if they feel more confident using the strategies after navigating through the website.

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Appendix A

Informed Consent

STANBRIDGE UNIVERSITY RESEARCH CONSENT FORM

Description: You are invited to participate in a research study on a website that includes different ways to reduce stress for you and the person you are caring for. You will be asked to use the website on your smartphone, tablet, or laptop, then give us feedback on the information within the website, and how easy or hard it is to use. You will not be videotaped or photographed during the session.

Your Time Involvement: Your participation will take about 30 minutes.

Risks and Benefits: The foreseeable risks to you for participating in this study are the potential added stress when learning to use a new website and in understanding the information within the website.

Payment: There will be no payment for participation in this study.

Participant Rights: If you have read and signed this form you are consenting to participate in this study. Participation in this study is voluntary and you have the right to withdraw at any point without penalty. Your alternative is to not participate in this study. You have the right to refuse to answer specific questions. Your identity will not be disclosed at any time. The results of this study may be shared at professional meetings or published in scientific journals.

Contact Information: If you have any questions about this research you may contact <u>caregiverwebsite@my.stanbridge.edu</u> or if you need further assistance you may reach the Faculty Advisor: Denise Miller; dmiller@stanbridge.edu.

I Agree to Participate I Disagree to Participate

Date_____

Appendix B

Demographic Information

- Have you taken this survey before? (If yes, skip to the bottom and press submit) Yes or No
- 2. Age: below 50, 50-55, 56-60, 61-65, 66-70, 71+
- 3. Gender: Male, Female, Non-binary/Third gender, or Prefer not to say
- Ethnicity: African American, Caucasian, Asian/Pacific Islander, American Indian, Hispanic/Latino, Other
- 5. Education level: Some high school, High school/GED, Some college, Bachelors or higher
- 6. Relationship to person you are caring for: spouse, child, sibling, parent, family member, other
- 7. Do you have other dependents that you care for? Yes or No
- 8. Do you read and understand English? Yes or No
- 9. How long have you been a caregiver? <1, 1-3, 4-6, 7-9, 10+ years
- 10. Have you attended any classes related to reducing your stress? Yes or No
- 11. What caregiver resource are you affiliated with? (fill in)

Appendix C

Pre- and Post-Test Questionnaires

Pre-test questions:

I currently feel stressed.

1	2	3	4	5	6	7
Completely	Mostly	Slightly	Neutral	Slightly	Mostly	Completely
Disagree	Disagree	Disagree		Agree	Agree	Agree

I have ways to cope with stress.

1	2	3	4	5	6	7
Completely	Mostly	Slightly	Neutral	Slightly	Mostly	Completely
Disagree	Disagree	Disagree		Agree	Agree	Agree

I feel confident in my ways to cope with stress.

1	2	3	4	5	6	7
Completely	Mostly	Slightly	Neutral	Slightly	Mostly	Completely
Disagree	Disagree	Disagree		Agree	Agree	Agree

I feel calm when caring for someone with dementia.

1	2	3	4	5	6	7
Completely	Mostly	Slightly	Neutral	Slightly	Mostly	Completely
Disagree	Disagree	Disagree		Agree	Agree	Agree

I have trouble relaxing.

1	2	3	4	5	6	7
Completely	Mostly	Slightly	Neutral	Slightly	Mostly	Completely
Disagree	Disagree	Disagree		Agree	Agree	Agree

1	2	3	4	5	6	7
Completely	Mostly	Slightly	Neutral	Slightly	Mostly	Completely
Disagree	Disagree	Disagree		Agree	Agree	Agree

I have a good understanding of calming strategies.

Have you taken this survey before?

Yes 🗆

No 🗆

Post test questions:

I currently feel stressed.

1	2	3	4	5	6	7
Completely	Mostly	Slightly	Neutral	Slightly	Mostly	Completely
Disagree	Disagree	Disagree		Agree	Agree	Agree

I have ways to cope with stress.

1	2	3	4	5	6	7
Completely	Mostly	Slightly	Neutral	Slightly	Mostly	Completely
Disagree	Disagree	Disagree		Agree	Agree	Agree

I feel confident in my ways to cope with stress.

1	2	3	4	5	6	7
Completely	Mostly	Slightly	Neutral	Slightly	Mostly	Completely
Disagree	Disagree	Disagree		Agree	Agree	Agree

I feel calm when caring for someone with dementia.

1	2	3	4	5	6	7
Completely	Mostly	Slightly	Neutral	Slightly	Mostly	Completely
Disagree	Disagree	Disagree		Agree	Agree	Agree

I have trouble relaxing.

1	2	3	4	5	6	7
Completely	Mostly	Slightly	Neutral	Slightly	Mostly	Completely
Disagree	Disagree	Disagree		Agree	Agree	Agree

After using this resource, I have a better understanding of calming strategies.

1	2	3	4	5	6	7
Completely	Mostly	Slightly	Neutral	Slightly	Mostly	Completely
Disagree	Disagree	Disagree		Agree	Agree	Agree

Check all the pages you visited (Click all that apply)

Aromatherapy \Box

Mindfulness Meditation \Box

Visual Stimulation \Box

Music Therapy \Box

Appendix D

Flyer



CALMING THE CAREGIVER

WWW.CALMINGFORCAREGIVERS.COM

If you have any questions, feel free to email us at caregiverwebsite@my.stanbridge.edu



Step by step instructions are provided on the following page

STEPS TO ACCESS

1.GO TO

WWW.CALMINGFORCAREGIVERS.COM

2.COMPLETE THE INFORMED CONSENT, SURVEY QUESTIONS, AND DEMOGRAPHIC INFORMATION

3.EXPLORE ALL PAGES

4.GO TO PAGE LABELED "POST SURVEY" AND COMPLETE

5.THANK YOU FOR YOUR PARTICIPATION!