The Effect of Art Therapy on Caregivers

Fatme Zaiour

University of Detroit Mercy

**Abstract**

**Objective:**  Caregiver strain is associated with high mortality levels. A few interventions have examined the influence of art therapy on caregiver stress or burden. The present study aimed to investigate whether attending six 1-hour art therapy sessions could help reduce strain levels among caregivers of a person with a chronic and disabling illness.

**Methods**: A descriptive pilot study examining the feasibility of conducting a single group, pretest/posttest study, examining the effects of art therapy on strain levels was conducted. Participants were assessed for caregiver strain prior to the intervention (T0) and again after class ended (T1) using the 13 item Modified Caregiver Strain Index (MCSI) tool. Items were summed for a total score. Higher values indicated higher burden/strain. Participants completed satisfaction survey about the experience.

**Results:** Seven caregiver’s who met inclusion criteria were enrolled. A Wilcoxon Rank test utilizing SPSS statistical analysis was used, which determined that art therapy made a statistically significant impact strain scores of caregivers. Highest burden identified by most caregivers were the physical strain: trying to adjust to other responsibilities of family members/work: and having concerns about loved ones and how they will manage. The sample size was too small to run inferential and results could not be generalized.

**Conclusion:** The art-based intervention of knitting and crocheting had a statistically significant impact on caregiver burden. Art therapy interventions are recommended for caregivers. This study serves a starting point to investigate how an art-based intervention, such as knitting and crocheting, can lower strain levels.

**Introduction**

Caregiving is a vital public health issue that influences the quality of life for millions of individuals. Caregiving, in general, refers to services provided to individuals who are unable to care for themselves due to a disability or functional limitation (CMS, 2006). Most individuals living with a chronic and debilitating illness may partially or fully depend on their caregivers depending on the severity of their impairment. In general, caregiving, refers to services provided to individuals who are unable to care for themselves due to a disability or functional limitation

There are Two types of caregivers: formal (paid caregivers) and informal caregivers (unpaid caregivers). Project will focus on the informal caregivers. Currently there is an estimated prevalence of 53 million informal caregivers in the United States, up from the estimated 43.5 million caregivers back in 2015 (FCA, 2020).

Although caring for a loved one is associated with a sense of personal growth and emotional rewards (Lloyd, Patterson, & Muers, 2016), it can also be associated with significant physical, psychological, and financial burden for the caregiver. When the level of burden exceeds the caregiver’s ability to provide care, this can not only affect the caregiver’s overall health, but also the care recipient’s quality of life, and can result in increased hospital visits, and costly institutional placement.

A great amount of published research exists on interventions aimed at improving caregivers’ health and well-being. Various types of caregiver interventions include Psycho-educational interventions, supportive interventions, psychotherapy, respite or adult day care, and multicomponent interventions. However, only a few studies have examined the influence of art therapy on caregiver stress or burden. The present study aimed to investigate whether attending six 1-hour art therapy sessions (offered through the Henry Ford Health System C.A.R.E program) could help reduce strain levels among caregivers of a person with a chronic and disabling illness. In efforts to improve health outcomes of older adults and their caregivers, Henry Ford Health System launched The C.A.R.E (Caregiver, Assistance, Resource, and Education) Program in 2016.

**Background**

**Art Therapy**

Art therapy can be viewed as a self-care technique that utilizes arts and materials in sessions with a psychotherapeutic trained therapist to help address caregiver’s emotional well-being (Art Therapy Association (AATA). In art therapy, the focus is on the process of art making not the art itself. Therefore, it does not matter how good the individual is in making art, it is more about how the art making process makes one feel, and the potential insights that one gains from the creation. It is a language of self-exploration. It can help shift caregivers’ attention away from their worries and alleviate their burden or stress.

Various literature reported on the effectiveness of art therapy in relieving caregiver stress and improving quality of life. One study by Kaimal et., al (2019) examined the differences in outcomes between two visual expressive conditions (coloring and open studio art therapy) of informal caregivers of patients undergoing radiation oncology treatment. Both conditions resulted in significant improvement in the caregivers’ symptoms of stress, anxiety, and mood in a single 45-minute intervention. Other studies also demonstrated that providing art-based interventions to support caregiver’s psychological needs helped reduce stress and increase positive emotions (Tjasink, 2019; Van Lith, 2019; Khan, 2017).

**Significance of the Problem**

The need for informal caregivers is rapidly increasing, and the potential number of informal caregivers is decreasing. According to the Regional Economic Model, Inc (REMI), the United States caregiver support ratio in 2010 was at its peak, at 7 potential caregivers for every person in the high-risk years of 80-plus and has been declining since (Figure 1). The Caregiver ratio is the number of potential caregivers aged 45-64 for individuals aged 80 and older. By 2030 and beyond (2050), the ratio is projected to decline and continue to drift downward, when all the boomers will be aging into the high-risk years of 80-plus (AARP, 2020). In Michigan the caregiver ratio has been declining since 1990 and is projected to decrease from 4.1 to 3.3 between 2030 and 2050 (Table below on page #6). These numbers suggest that the increasing frail older population will have fewer potential family caregivers on whom they can rely. Michigan and other states will face care gaps that will ultimately result in increased hospitalization and earlier long-term placement of care recipients, which can impact healthcare cost.

In 2004, informal caregiving had an estimated national economic value of $306 billion annually, greatly exceeding the combined costs of nursing home care ($103.2 billion) and home health care ($36.1 billion). In 2013, the value of unpaid caregiving was $470 billion, which also exceeded the total value of long-term support services spending at $339 billion (Reinhard, 2015). Clearly, caregivers serve a great economic benefit the U.S. Without informal caregivers, spending for long-term care services would be much higher.





**Purpose Statement**

It is imperative that actions are taken to positively influence caregivers and help alleviate their burden. The CDC highlights several of the actions a community may take to make such a difference. One action is to evaluate caregiver support programs to determine program accessibility, effectiveness, and or impact. A few caregiver programs exist, with the goal of alleviating caregiver burden and other variables associated with the demanding role of caring for an older person with a chronic illness. The project will be designed to answer the following clinical question:

Did the Henry Ford CARE program help informal caregivers of individuals with chronic and disabling disease decrease caregiver burden, by providing informational and emotional support to carry out their caregiver activities?

**Literature Review**

A comprehensive search of the literature on caregiver burden was conducted utilizing PubMed, Cumulative Index of Nursing and Allied Health Literature, MEDLINE, and Psych Info databases. Search terms included caregiver burden, art therapy, outcome measures, caregiver support, support caregiver programs, and interventions alleviating caregiver burden. Inclusion criteria included full text article in English from the past five to ten years. Most research found were around ten years and beyond. This comprehensive review aimed to investigate the current literature regarding the impact of different types of art therapy interventions on caregivers. Only four studies were identified that explored and supported the use of art therapy interventions in caregivers of individuals with various medical diagnosis.

Kaimal et al. (2019) conducted a mixed method pilot study, that offered two art-based interventions (open art studio therapy and coloring) for informal caregivers of patients undergoing radiation oncology treatment (n=9), and oncology professionals (n=25) providing care to the patients. This study aimed to compare the effects of two brief visual arts interventions on measures of stress, anxiety, self-efficacy, and burnout. Participants were randomly assigned to either independent open studio art therapy session and complete all scales and saliva collections immediately before and after the session. The saliva was collected to examine the change in salivary biomarkers, (cortisol, IL-6, and CRP) pre- and post-intervention. Salivary markers are commonly used to measure the activation of the hypothalamic-pituitary-adrenal (HPA) axis. When there are high levels of chronic stress, such as in caregivers, this can contribute to chronic inflammation and activation of the HPA axis. Kaimal et al. (2019) found that both visual expression conditions resulted in significant improvement outcomes in a single 45-min intervention. There was no evidence of change in any of the biomarkers measured. It is important to note that the salivary biomarker data suffered from a smaller sample size due to problems with the data collection for several of the participants who were not able to generate enough saliva to enable analysis. Therefore, little could be determined from these results.

Richard et al. (2013) tested the influence of a Visual Arts Education (VAE) program on self-esteem, caregiver burden, and quality of life (QOL), among 26 pairs of individuals with dementia and their caregivers. This study was a randomized controlled single-blind trial. Pairs were randomized to either the control or VAE (experimental) group. Each group met once a week (1.5 hours) for 8 weeks and were assessed at baseline, 2 months, and 6 months. The VAE group participated in various art activities (hat decoration, collage, painting) and created an art product each week. The control group participated in less complex art activities. The findings from this study showed the experimental group post-test results at 6 months had significantly improved self-esteem for the persons with dementia on the Rosenberg Self-Esteem scale (ROS), and reduced caregiver burden on the Zarit Burden Interview scale. QOL improvements were marginally significant for the person with dementia, at 6 months on the QOL- AD (Alzheimer’s disease) test instrument. Both groups expressed they enjoyed the art activities and were meaningful to them.

Walsh et.al (2007) examined the effects of a two-hour art-making classes (AMC) on reducing anxiety and stress among family caregivers (n=69) of patients with cancer. The study design was a quasi-experimental (pretest/posttest with no control group) study. The AMC contained art-making activities such as watercolor paintings, decorating jewelry boxes, and the making of silk scarves or wall hangings. Participants completed a Beck Anxiety Inventory (BAI) and provided a saliva sample pre and post AMC intervention. The saliva sample was used to measure salivary cortisol, which indicates stress levels. Anxiety and Stress levels were significantly reduced.

Camic et al (2014) conducted a pretest-posttest design study to examine the impact of an art gallery-based intervention on individuals with dementia and their caregivers. Participants completed pre and post intervention questionnaires related to quality and burden. The study also included semi-structured interviews after sessions ended. Burden levels of caregivers were improved, however were not statistically significant. Qualitative results support the continued development of art gallery-based programs for people with dementia and their caregivers.

All studies had a small sample size and most lacked a control group. All studies revealed there is a significant reduction or improvement of caregiver burden post intervention, despite sample size, lack of control group, and length of intervention. Some of the studies included a qualitative component, through open ended surveys or semi structured interviews that revealed support for use of future art therapy interventions, and positive feedback from participants about how they felt about the intervention.

**Organizational Assessment**

***Mission.*** The mission of the Henry Ford Health system is to improve lives through excellence in the science and art of health care and healing. CARE program staff strive to improve quality of life of caregivers by offering support and educational services and providing assistance in identifying resources within their community. The DNP student will be able to utilize the concept of Henry Ford’s mission as a guide throughout the DNP project.

***Vision.*** Henry Ford embraced a new vision in 2018, leading the organization closer to its True North. Henry Ford’s True North is its vision. It is envisioned that Henry Ford will be the trusted partner in health, leading the nation in superior care and value, one person at a time. Focusing on the True North, the CARE program ensures that caregivers are supported so they have a better quality of life and are able to continue providing care for their loved one.

***Values.*** At Henry Ford Health System patient and family centered care is valued and a top priority. Retired Chief Executive Officer (CEO), Nancy Schlichting, recognized the value of supporting caregivers, and thus generously committed a portion of the president’s fund to initiate the CARE program. CARE staff value the support of informal caregivers of all ages and backgrounds.

A SWOT analysis was conducted to assess the Henry Ford CARE program’s situation.

**SWOT Analysis**

***Strengths***

The Henry Ford CARE program offers a variety of services such as support groups, art therapy/creative mindfulness sessions, and self-care classes that are offered at various times and dates for the caregiver. Prior to Covid-19 pandemic, support group sessions were offered at seven locations (Midtown Detroit, Plymouth, St. Clair Shores, West Bloomfield, Wyandotte, HAP Southfield, and Jackson). In addition, CARE program staff have personally presented and met with more than 100 departments and areas within the health system. Meetings concentrated on increasing CARE program awareness, educating employees on how and why to access caregiver services, and encouraging them to refer their patient’s caregivers.

CARE program leaders at Henry Ford are in favor of an evaluation of the CARE program and improving practices within the program. Currently there are sufficient funds available to continue with efforts supporting strategies/components of the program. In addition, there are adequate number of CARE program staff to carry out the proposed intervention of art therapy sessions of informal caregiver participants to explore impact on their quality of life.

***Weaknesses***

Due to Covid-19 pandemic, in person classes were held from January until March 13th, and transitioned to virtual online classes in June 2020. In reference to 2020 Data for CARE program, 128 informal caregivers participated in support group sessions, compared with 203 caregivers that participated in the previous year. With limited support group sessions and being exclusively online, these narrows target population of caregivers to those that only have access to a computer, iPad, and smart phone. Therefore, project intervention may not have as many caregiver participants as desired.

Unfortunately, since in person meetings are not possible, this may present a challenge in attempting to increase awareness of the program and recruit informal caregiver participants for the DNP project. A different strategy or approach will need to be planned.

***Opportunities.***

Henry Ford CARE staff have made connections with various community organizations (Area Agency on Aging, The Alzheimer association, and The Lake House) that support and connect with caregivers. These communications helped promote Henry Ford Health Systems CARE program Services and increase program awareness. With an increase in program awareness, there is a good chance of having a higher number of caregiver referrals. This will provide a more positive outlook on possibly having more informal caregivers that may be willing to participate in Art Therapy sessions and be part of the study. In addition, since the knitting and crocheting art-based course was being offered virtually for the first time through the program, there was a great opportunity to evaluate such course to explore whether this course can have an impact on caregiver burden.

***Threats***

The current Covid-19 pandemic is identified as the major threat impacting the CARE program. During the initial wave of the pandemic, as mentioned, all the in-person sessions were held for several months. CARE leaders continued their efforts and sessions resumed back virtually in June 2020. For the CARE program to continue providing caregiver support services, we must ensure that caregivers continue to participate in program services, regardless of pandemic threat.

The aging population, the increased number of people living longer with chronic disease, and the increased prevalence of caregiver burden are all identified as external factors or threats that may impact informal caregiver participation in CARE services. Caregivers with an increased burden, that feel overwhelmed due to the increased tasks associated with caregiving may not be willing to participate in group sessions/ DNP project.

**Rationale**

Increased prevalence of caregiver burden is associated with various adverse consequences. It is relevant to integrate *effective* evidence-based caregiver support programs into healthcare systems that can assist caregivers manage the challenges faced while providing care. Per CDC, an important step to positively influence caregivers and help alleviate their burden is to evaluate caregiver support programs to determine program effectiveness, and or impact. As discussed in the literature review section, all caregiver interventions have a significant impact on one or more outcome variables, such as burden and depression. In addition, caregiver interventions that include social support, such as supportive groups, promote health sustaining functions improving overall well-being of the caregiver and decreasing burden. Therefore, the DNP student will perform a program evaluation of the Henry Ford CARE program, to determine its effectiveness. More specifically, project will focus on the art therapy intervention and its impact on the caregiver.

**Conceptual framework**

The Transactional Stress Processing Theory (Appendix A), developed by Lazarus and Folkman (1984), is utilized as a theoretical framework for guidance with the DNP project, an evaluation of a caregiver support program. This framework has also been known as the transactional theory of stress and coping, and the appraisal theory. The theory consists of four major constructs, which include stress, appraisal, coping efforts, and health-related outcomes. Following is a discussion of each construct and how they may relate to caregivers.

**Stress**

Theory suggests that stress involves an encounter (transaction) between and individual and an environment. It states that stress results from an imbalance between demands and resources. Thus, individuals become stressed when the pressure (demand) exceeds their ability to cope and mediate stress (resources). Therefore, the interpretation of the stressful situation becomes more important than the situation itself. Caring for a loved one with a chronic and disabling disease, for example, can be highly stressful for the caregiver. When the level of burden or stress exceeds the caregiver’s ability to provide care, this impacts the caregiver’s overall health, their ability to cope, and seek resources to help alleviate their burden.

**Appraisal**

Lazarus and Folkman (1984) define appraisal as an evaluation/assessment of a situation. Two types of appraisals identified in the theory are primary and secondary. The transactional model explains that potentially stressful situations, such as the care demands associated with caregiving, will trigger the primary appraisal process, in which the individual will evaluate degree of threat of the situation in relation to their well-being. The caregiver may appraise the situation as irrelevant or having no significance/impact, a benign/positive encounter, or a stressful. When the situation is perceived/appraised as stressful, the caregiver will then engage in a secondary appraisal process to evaluate whether they have the ability to cope with the situation.

**Coping.**

Coping efforts or strategies are developed in response to the individuals stress appraisal. The purpose of coping is to reduce or avoid stress. Folkman and Lazarus differentiate between two types of coping efforts which include 1) problem-focused; and 2) emotion focused.

Problem-focused coping is defined as “the management of the problem that is causing the distress.” For example, when caregivers feel they have control over the situation, they may act to alleviate the stress encountered, by seeking resources/ caregiver support programs, and participating in pleasant activities. Emotion-focused coping, on the other hand, refers to the “regulation of distress” that can result when individuals feel that they have little control of the situation. Possible emotional coping, as identified by Lazarus and Folkman include denial, avoidance, distraction, and self-blame.

Coping efforts impact caregiver burden. The use of problem focused coping strategies can be associated with more positive outcomes in caregivers than emotion-focused coping. One study examined the use of problem and emotion-focused coping in mothers caring for an adult child with a mental health condition (Kim, 2003). Increased use of problem-focused coping strategies contributed to decreased mother burden. On the other hand, emotion-focused strategies increased burden and contributed to poorer-parent child relations.

**Health-related outcomes.**

A major concern in the Transactional Process Theory is the impact of stress on the individual’s health, and self-care management. Ineffective coping may directly impact one’s physiologic and emotional being, and health related behavior. Individuals under stress may abandon previous health related behaviors such as eating healthy foods and exercising regularly. Individuals may even commit risky behaviors such as consuming alcohol, drug abuse (Lazarus, 1984). Chronic stress can lead to significant health consequences/outcomes. Caregivers, for example, who do not cope well with the caregiving situation are more at risk of increased burden. In summary, The Transactional Processing theory (situation-->primary appraisal--> Secondary appraisal---> Stress---> coping-->health-related outcomes) was selected to guide or support the project.

**Project Purpose**

**Scope**

This Doctor of Nursing Practice (DNP) project is an evaluation of the Henry Ford CARE program focusing on the informal caregiver as the ultimate target. The DNP student will facilitate recruitment of informal caregivers to participate in Art Therapy sessions that will be offered virtually one day a week. Informal caregivers who agree to participate will plan on attending one-hour long sessions once a week for 6 weeks. The virtual sessions will be led by licensed art therapist.

**Goal & Objectives**

The purpose of this project is to explore the impact of an art therapy intervention on a group of informal caregivers in terms of care caregiver burden, and satisfaction. The goal is to improve quality of life for the caregiver. The objectives of the stated goal include the following:

1. By the end of the 6 week virtual art therapy sessions, 50% of participants will report reduced caregiver burden from baseline.
2. By the end of the 6 week virtual art therapy sessions, 100% of the participants will report satisfaction with the CARE program Art therapy sessions and will plan to attend future classes.

**Methods**

**Design**

The study is guided by the Lazarus and Folkman Transactional Process Theory (see appendix A and B).   It is an evaluation of the Henry Ford C.A.R.E program, more specifically on the impact of an art therapy intervention on caregiver strain or burden.  A pretest and post-test design were used to examine changes in caregiver pretest scores (as a baseline measurement) and post-test scores (as the outcome variable) following the art-based intervention (Knitting and crocheting). As the intervention was web-based, all data was collected via telephone by the researcher, except for the survey which was sent via survey monkey after the course sessions ended.

**Intervention**

The intervention consisted of a virtual six-week session of an art-based activity, knitting and crocheting, free of charge. Each virtual session was 60-min-long led by a licensed art therapist over the course of six weeks. In this six-week class, time was spent on knitting (or crocheting) a scarf using colors that reflect the participants mood. Participants learned a new stitch in each session. Participants obtained their own supplies/materials for the course, which include knitting needles (size 8) and worsted weight yarn in any or all of the colors.

In the first session, the art therapist provided a brief introduction about the knitting and crocheting course, and what will be taught at each session. The researcher introduced self and discussed research project topic. Participants were made aware of the opportunity to participate in the research study on caregiver burden and how the knitting and crocheting course effects burden levels. The first session included a discussion on the difference between knitting (using two knitting needles) and crocheting (uses one crochet hook). The art therapist demonstrated the process for knitting cast and crochet chain Participants learned how to cast on or chain the number of stitches for the width of the scarf project. For example, an 18 stitch yarn will give 4 inches, which equals 4.5 stitches for each inch.

The second session focused on the knit (gives a smooth V) and the Purl stitch (gives a horizontal raised bar). Participants also learned the single crochet stitch and the half double stitch. The art therapist demonstrated the various stitch techniques. She showed how to add one chain for the turning stitch at the end of the row for the single crochet, and two chain stitches for the half double crochet stitches.

The third session included a review of the knit and purl stitch. A new stitch was taught called the Seed Stitch, which consists of alternating knit and purl stitch throughout the row. Then, alternating the pattern on the next row so that all knit stitches from the previous row will be purled and all the purled stitches from previous will now be knit.

In the fourth session, new stitches were discussed and demonstrated. The new stitches included the Knitting Seed Stitch and Knitting Rib Stitch. Rib stitch creates a stretchy fabric that can be used for the cuff of a sweater sleeve, or winter hat. Crochet Treble stitch (also called Triple stitch was also demonstrated. The art therapist showed some crochet work done by her son where he crocheted smiley face images within a square.

In the fifth session, stitches from the previous session were reviewed. Participants learned a simple open lace stitch for knitting. The art therapist also demonstrated different methods for creating a Crochet Granny Square.

Session six was the final day in the knitting and crocheting class, Participants were taught how to bind off on both knitting and crochet projects. Time was taken to give participants to share their work they have done so far.

**Participants/setting/sample**

Participants in the study were informal caregivers of individuals with chronic and disabling disease. Participants were recruited through advertisements in newsletters, social media, and emails. Information about registering for the Knitting and crocheting course, the study, and informed consent were available on the Henry Ford Caregiver website. The sample size target was five to ten, because that is an acceptable size for a virtual art therapy session to be conducted comfortably, allowing some time to assist individuals who may be having technical difficulties during sessions.

Seven adults volunteered to participate in the study. The inclusion criteria specified that participants must: be 18 years of age or older, a relative/friend/significant other to a person with at least one chronic and disabling disease, have access to a computer and internet, and understand English. No prior artistic experience was required. Exclusion criteria were younger than 18 years old, no access to computer/internet, and having difficulty communicating.  Additional Art therapy participants (but not research subjects) included interested hospital staff members and or their family and friends, who had seen the advertisements were also encouraged to attend. The sessions maximum number of participants allowed up to 28 individuals.

**Ethics**

The study protocol was reviewed and approved by the appropriate review boards. Informed consent was obtained by the researcher from interested caregivers prior to data collection and the knitting and crocheting art course. Information about the study was discussed via telephone prior to participation. No remuneration was offered for participants. All data retrieved for analysis was de-identified. The rights of privacy for all participants was observed at all times.

**Evaluation Methods**

**Demographics**

A questionnaire was used to collect the care recipients’ demographic details such as age, gender, medical diagnosis, and whether they received medical care by a Henry Ford Health provider. The questionnaire was also used to collect demographic information about the caregivers that included employment status, educational level, marital status, having a chronic illness, receiving medical care from a Henry Ford Health provider, other responsibilities besides caregiving, knitting and crocheting experience, relationship between them and their care recipient, duration of caregiving, and whether they lived with the care recipient/ loved one.

A survey (Appendix C) was sent via survey monkey to caregivers at the end of the art therapy course. This survey focused on the overall satisfaction of the art therapy course. It consisted of 8 items. Two questions, using a Likert scale, ranging from strongly disagree to strongly agree were about the art therapy course and the art therapist. The remaining questions were regarding age, gender, ethnicity, comments about course, how they felt about the course, and how they heard about it.

**Modified Caregiver Strain Index**

Caregiver burden was measured using the Modified Caregiver Strain Index (MCSI) tool (Appendix B). It Includes 13 items can be used to help determine caregivers’ level of strain, which has consequences on caregivers’ overall health. Questions cover four major categories or domains, which include physical health, emotional health, social interactions, time demands, and finances. Scoring for each question is 2 points for each ‘yes’, 1 point for each ‘sometimes’ response, and 0 for each “no” response. The higher the score, the higher level of caregiver strain. The maximum score is 26. The caregivers were further categorized as having low (≤9), moderate (10-18), and high strain (19-26) as per their MCSI scores.

**Data Analysis**

Descriptive analysis including numbers, percentages, SD, and mean were used to detail the demographic variables of the participants and care recipients. Non-parametric Wilcoxon Signed Ranks test was used to examine the overall MCSI mean difference at baseline (T0) and after art therapy course ended (T1). The data was evaluated using SPSS statistics version 25. Statistical significance was set at the conventional p<0.05.

**Results**

**Demographical description of participants/care recipients**

Sixteen individuals registered for the art therapy course. A total of seven participants met the eligibility criteria and consented to participate in the study. The demographic data of the seven participants are described in Table 1**.** More than half of the caregivers were in the age range between 50 and 59 years old (57%). All participants were female. About half of the participants were Caucasian/white ethnic background (42%), and the remaining participants were African American/Black (57%). Most were married, educated with a college degree, and working.

More than half (57%) of caregivers had a chronic illness, and 85% received medical care form a Henry Ford health provider. %). Besides the caregiving role, 57% of caregivers reported they had other responsibilities such as work commitments or caring for their own family (children/grandchildren). Majority of caregivers (72%) had prior experience with knitting and crocheting, and most did not miss any sessions (72%). Most caregivers cared for their mother or father (72%). Most caregivers (71%) lived with the care recipient (patient) and had cared for their loved one for >3 years (85%).

 Table 2 depicts the demographic details of the care recipients**.**  The care recipients were mostly male gender, aged 75 years and above (57%). Most of the care recipients had a medical diagnosis of Dementia (72%).

**Modified Caregiver Strain Index**

**Pre-intervention/ Baseline (T0) MCSI**

As per the MCSI score, the subjects were categorized as having mild, moderate and severe level of strain with the score as < 9, 10-18, and 19-26 respectively (Table 3)**.** Most of the caregivers (42.8%) had moderate and severe (42.8%) level of strain. The remaining caregiver participants were in the mild category of strain level (14.2%).

Table 4 illustrates that most of the caregivers (71.4%) always had disturbed sleep. 57.1% and 42.8% said they always felt inconvenience and physical strain respectively. 42.8% always had to do family adjustment. 71.4% of caregivers verbalized that they always had to make changes in their personal plans in order to provide care for their patients. About half (57.1%) always had upsetting behavior. 57.1% always felt upset because the person they cared for changed so much from his/her former self. 71.4% of the caregivers were always burdened due to work adjustment.

The highest areas of burden identified by most caregivers were: disturbed sleep (71.4%) (Question #1- Physical Domain); having to make changes in personal plans to provide care for their loved one (71.4%) (Question #6- Social Domain) and always feeling burdened due to work adjustment (71.4%) (Question #11- Financial Domain).

**Postintervention (T1) MSCI**

After art sessions ended, most of the caregivers had mild (42.8%) and Moderate (42.8%) level of strain. Only 14.2% of participants were in the Severe category of strain level (Table 5). Table 6 illustrates that the majority of the caregivers (71.4%) always had disturbed sleep. 57.1% and 42.8% said they always felt inconvenience and physical strain respectively. 42.8% always had to do family adjustment. 71.4% of caregivers verbalized that they always had to make changes in their personal plans in order to provide care for their patients. About half (57.1%) always had upsetting behavior. 57.1% always felt upset because the person they cared for changed so much from his/her former self. 71.4% of the caregivers were always burdened due to work adjustment.

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| **Statistical Analysis** Using a pretest strain score and a posttest strain score variable, the Wilcoxon signed rank test was used to test the Null hypothesis that the median of the differences between the posttest and the pretest equal zero. In other words, the null hypothesis (H0) is that there is no difference between burden scores before and after the art course intervention.Below are three tables (table a., table b., table c.)**Descriptive Statistics** |
|   | N | Mean | Std. Deviation | Minimum | Maximum |
| Pretest Strain Score | 7 | 15.71 | 6.800 | 5 | 23 |
| Posttest Strain Score | 7 | 11.43 | 6.051 | 4 | 20 |

**Table a Interpretation:** There are 7 pretest scores and 7 posttest scores.The standard deviations are provided. The mean for the pretest (15.71) is HIGHER than the mean for the post test (11.43). With a higher mean, one can infer that post test results will be lower. In order to know whether there is a statistical difference, a Wilcoxon Signed Rank test was completed- see Table b.

**Wilcoxon Signed Ranks Test**

|  |
| --- |
| **Ranks** |
|  | N | Mean Rank | Sum of Ranks |
| Posttest Strain Score - Pretest Strain Score | Negative Ranks | 7a | 4.00 | 28.00 |
| Positive Ranks | 0b | .00 | .00 |
| Ties | 0c |  |  |
| Total | 7 |  |  |
| a. Posttest Strain Score < Pretest Strain Score |
| b. Posttest Strain Score > Pretest Strain Score |
| c. Posttest Strain Score = Pretest Strain Score |

**Table b interpretation:** The Wilcoxon Signed Ranks Table provides the number of participants that have negative ranks, positive ranks, and ties.

* **Negative ranks:** There were 7 cases where there were a post test strain score lower than a pretest strain score. Which is of course what we are hoping for.
* **Positive ranks:** There were 0 cases where the post test strain scores were higher than the pretest strain score. So in this case the participants has a lower severity of strain as measured on the post test.
* **Ties:** There were 0 cases where there was a tie. This means that the post test and pretest

strain scores were equal.

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| --- |
| **Test Statisticsa** |
|  | Posttest Strain Score - Pretest Strain Score |
| Z | -2.375b |
| Asymp. Sig. (2-tailed) | .018 |
| a. Wilcoxon Signed Ranks Test |
| b. Based on positive ranks. |

**Table c interpretation:** The Z value is -2.375, and the significance is .018. Since significant value is less than 0.05, one can conclude there was a statistically significant difference between pretest and post test strain scores. We would reject the null hypothesis and accept the alternative hypothesis. Therefore, in analyzing this data, it is safe to presume that the intervention of the art intervention of knitting and crocheting was a success in improving caregiver burden.

**Survey Results**

After sessions ended, a survey was sent via survey monkey to caregiver participants to be completed. Results of survey were reviewed and analyzed. Most of the caregivers were made aware of the knitting and crocheting course from Facebook/social media (42.85%), followed by newsletter (28.5%), email (14.2%), and employer (14.2%). No caregiver heard about the course from doctor’s office. Most of the caregiver participants (85%) strongly agreed about recommending the course. 100% of the participants had positive comments about how they felt about the course (Question #3).

**Table 1:** Demographical description of caregivers (n-7)

|  |  |  |
| --- | --- | --- |
| **Caregiver demographics (n=7)**  | **Responses**  | **N (%)** |
| **Age** | 60-69**50-59**40-49 | (1) 14%**(4) 57%**(2) 28% |
| **Gender** | **Female** Male  | **(7) 100%**(0) 0% |
| **Ethnicity** | AA/BlackCaucasian/White  | (4) 57%(3) 43% |
| **Employment** | **Yes**No  | (**6) 85%**(1) 15% |
| **Education level** | High school/GEDSome college**College graduate**  | (0)0%(2)28%**(5) 72%** |
| **Marital Status** | **Married**Single Separated/Divorced/widowed  | **(4) 57%**(1) 14%(2) 28% |
| Have a chronic illness | **Yes**No | **(4) 57%**(3) 43% |
| Receive medical care from a HF health provider | **Yes**No | **(6) 85%**(1) 14% |
| Other responsibilities besides caregiving | **Work commitments** **Taking care of own family** | **(4) 57%****(4) 57%** |
| Knitting/crocheting experience | **Yes**No | **(5) 72%**(2) 28% |
| # of missed Knitting/ crocheting sessions |  **0**1-2>3 |  **(5) 72%**(1) 14%(1) 14% |
| Relationship between caregiver and recipient |  SpouseMother/fatherClose Friend/relative | (1)14%**(5) 72%**(1)14% |
| Duration of caregiving |  1-2 years>3 years | (1)14%**(6) 85%** |
| Living with care recipient/patient | YesNo | **(5) 71%**(2) 28% |

**Table 2: Care recipient demographics (n=7)**

|  |  |  |
| --- | --- | --- |
| **Care recipient demographics (n=7)** | **Responses**  | **N (%)**  |
| Age | 60-69**70-79**>80 | 1(14%)**5(71%)**1 (14%)  |
| Gender  | **Male** Female  | **4 (57%)**3( 42%)  |
| Medical Diagnosis  | **Dementia** Cancer Epilepsy  | **(5) 71%**(1) 14%(1) 14% |
| Receive medical care from a HF provider  | **Yes**No  | **(5) 71%**(2) 29% |

**Table 3: Level of Strain among caregivers (N=7), pre-intervention**

|  |  |
| --- | --- |
| **Strain Level (pre-intervention)**  | N (%) |
| Mild  | 1 (14.2) |
| Moderate | 3 (42.8) |
| Severe | 3 (42.8) |

|  |  |  |  |
| --- | --- | --- | --- |
| **Items** | **Always (2)**  | **Sometimes (1)** | **Never (0)** |
| ***My sleep is disturbed*** | **5 (71.4)** | 2 (28.5) | - |
| ***Caregiving is inconvenient***  | **4(57.1)** | 2(28.5) | 1 (24.2) |
| ***Caregiving is a physical strain*** | **3 (42.8)** | 3 (42.8) | 1 (14.2) |
| *Caregiving is confining*  | 2 (28.5) | 5 (71.4) | - |
| ***There have been family adjustments*** | **3 (42.8)** | 1 (24.2) | 3 (42.8) |
| ***There have been changes in personal plan*** | **5 (71.4)** | 1 (14.2)  | 1 (14.2) |
| There have been other demands on my time | 1 (14.2) | 5 (71.4) | 1 (14.2) |
| *There have been emotional adjustments*  | 4 (54.1) | 2 (28.5) | 1 (14.2) |
| *Some behavior is upsetting* | 4 (57.1) | 2 (28.5) | 1 (14.2) |
| *It is upsetting to find the person I care has been change so much from his/her former self* | 4 (57.1) | 3 (42.8) | - |
| ***There have been work adjustment*** | **5 (71.4)** | 1 (14.2) | 1 (14.2) |
| *Care giving is financial strain.* | 1 (14.2) | 1 (14.2) | 5 (71.4) |
| *I feel complpletely overwhelmed* | 1 (14.2) | 1 (14.2) | 5 (71.4) |

**Table 4: Strain amongst the caregivers as per Modified Caregiver Strain Index (N=7) pre-intervention.**

**Table 5: Level of strain among caregivers (N=7), Post-intervention**

|  |  |
| --- | --- |
| **Burden/Strain (pre-intervention)**  | f % |
| Mild  | 3 (42.8) |
| Moderate | 3 (42.8) |
| Severe | 1 (14.2) |

**Table 6: Strain amongst the caregivers as per Modified Caregiver Strain Index (N=7) Post-intervention**

|  |  |  |  |
| --- | --- | --- | --- |
| **Items** | **Always (2)**  | **Sometimes (1)** | **Never (0)** |
| My sleep is disturbed | 3 (42.8) | 1 (14.2) | 3 (42.8) |
| Caregiving is inconvenient  | 2 (28.5) | 1 (14.2) | 4 (54.1) |
| Caregiving is a physical strain | 2 (28.5) | 3 (42.8) | 2 (28.5) |
| Caregiving is confining  | 2 (28.5) | 4 (54.1) | 1 (14.2) |
| There have been family adjustments | 2 (28.5) | 3 (42.8) | 2 (28.5) |
| There have been changes in personal plan | 2 (28.5) | 4 (54.1) | 1 (14.2) |
| There have been other demands on my time | 2 (28.5) | 5 (71.4) | - |
| There have been emotional adjustments  | - | 6 (85.7) | 1 (14.2) |
| Some behavior is upsetting | - | 5 (71.4) | 2 (28.5) |
| It is upsetting to find the person I care has been change so much from his/her former self | 1 (14.2) | 5 (71.4) | 1 (14.2) |
| There have been work adjustment | 1 (14.2) | 3 (42.8) | 3 (42.8) |
| Care giving is financial strain. | - | 1 (14.2) | 6 (85.7) |
| I feel completely overwhelmed | - | 5 (71.4) | 2 (28.5) |

**Discussion**

In the present study, burden levels were assessed amongst caregiver’s, of individuals with chronic or disabling disease. Post test resultsshowed significant improvement in burden levels among all caregiver participants, which suggests that the virtual knitting and crocheting course was a success. However, there are a few things to consider that may have impacted results, which include the following:

* **Small sample size-** therefore findings cannot be generalized to the general caregiver population.Although the art course was advertised through social media/Facebook, email, newsletter, recruiting caregivers continues to be a challenge, due to caregivers begin unavailable due to caregiving duties/ having other responsibilities/commitments.
* **Lack of control group-** challenge to know whether the actual knitting and crocheting art OR the support guidance by the art therapist impacted burden scores
* **Attendance-** was tracked and several of the caregivers missed 2-3 sessions, and some more than 3 sessions the course. I questioned whether to use data from a participant who only attended twice.
* **Sample bias-** Knitting and crocheting experience was not part of inclusion criteria, perhaps caregivers with more experience felt more comfortable and relaxed with the course

The MCSI tool was very useful at identifying caregiver burden prior to the start of knitting and crocheting sessions. It covered four major domains of strain, which included physical, social, emotional, and financial. Caregiver burden was presented in several different domains in this study; physical, social, and financial. As per findings, high level of strain was reported in terms of sleep disturbance, changes in personal plans, and work adjustments. All such factors are the major contributors of stress. Previous studies indicate informal caregivers with a chronic illness is associated with sleep disturbance. For example, a study completed by Chang (2013) revealed that as many as 50-70% of caregivers for a family member with dementia experience sleep disturbance.

Many studies recognized that caregiving although has positive aspects for the caregiver, it is often a highly stressful task. Caregivers often face problems including physical, emotional, social, and financial. In this study most of the caregivers had severe levels of strain (42.8%) and moderate levels of strain (42.8%). Only 14.2% of caregivers were in the mild category of strain level. Such findings are partially supported by one study completed by Kumar et al. (2015) that indicated mild to moderate burden (63%) among caregivers of stroke survivors.

The caregiver participants in the study all had positive response to the knitting and crocheting course. Caregivers indicated they felt relaxed, peaceful, and empowered, which may have helped alleviate some of their burden experienced with caregiving. The majority strongly agreed on recommending the course. The participants remained engaged during the sessions. The majority attended every session. There was minimal data missing from the survey sent via SurveyMonkey, which indicates that survey items were easy to understand, and appropriate.

Future studies should consider the following:

1. A larger sample size. A larger research sample size can be more effective in determining the statistical significance of caregiver burden improvement,
2. Focus on a specific care recipient population (ex. Dementia, MS, cancer, stroke) Include other variables such as coping strategies, co-morbidities of caregivers, quality of life for the caregiver
3. Include care recipient variables such as hospital readmissions, cognitive function of recipients, and functional status before and after art course.
4. Fewer art therapy sessions. There were a few caregiver participants that missed 2-3 sessions, and some more than 3. It was questionable if the data from the participant who only attended two sessions should have been included. Therefore, it may be beneficial to decrease the number of art therapy sessions, or even offer more sessions on other days to help improve attendance/participation.
5. Measure caregiver burden scores, possibly after six months to see the longer-term effects of the intervention.

Recommendations for CARE program stakeholders:

1. Continue virtual option with knitting-crocheting course. Majority attended
2. Incorporate MSCI tool for caregivers who enroll/register for their course. Tool can be completed prior to course, reviewed by CARE staff. Upon review, staff can recognize different aspects of caregiver burden early, and assist the caregiver by referring them to other appropriate services that may be offered by the CARE program. For example, in areas of high social strain (ex. Juggling between caregiving and time for personal plans), CARE staff can assist with the application of respite care to provide some relief for the caregiver. In the area of emotional strain, such as worrying about the person they are caring for, and/or having concerns about how they will manage, providing patient/family education on the recipient’s chronic disease and medication may also provide some relief.

**Sustainability measures**

As the population ages living longer with chronic and disabling diseases, there will be an increase in reliance on informal caregivers to help keep loved ones stable and outside of the emergency rooms. Caregivers and their burden should be recognized and acknowledged across health care organizations. Caregiver support programs should incorporate various forms of interventions that will help reduce caregiver burden, such as Art therapy. Art therapy can be used for many things such as help people recover from trauma, encourage interaction, stimulate positive visuals, and provide comfort. The Henry Ford CARE program had sufficient funds, and adequate staff to continue with the virtual art-based knitting and crocheting course.

**Implications for nursing, organization, healthcare, policy, patients**

It is important to identify the factors of the burden on the caregivers of people with dementia living in the community to prevent early nursing home placement, deterioration of caregiver's health and reduce the adverse health outcomes for care recipients. A health-related policy should be formulated to help informal caregivers receive more professional assistance. This can be done by including a section in the paperwork adding a check off box when the individual is at a dr. office “are you a caregiver.” If a patient identifies themselves as a caregiver, further caregiver assessment and Modified Caregiver Strain Index should be completed. Once an individual has identified they are a caregiver and completed forms and index, nurses can review and determine if caregivers and their family members could benefit from art therapy courses and refer them.

**Dissemination**

Plans to present and discuss research findings and recommendations with the CARE coordinators are in place. Also, a project poster board will be created to be presented to the American Academy of Nurse Practitioners.

**Conclusion**

This study found that a six-week course of art therapy course of knitting and crocheting significantly reduced caregiver burden in caregivers of patients with chronic and disabling conditions. It is highly recommended that a virtual knitting and crocheting course continue to be offered to caregivers to help reduce burden levels.

**Appendix A**



**Appendix B**

**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. Your situation may be slightly different, but the item could still apply.

**Yes, On a Regular Basis=2 Yes, Sometimes =1 No=0**

|  |  |  |  |
| --- | --- | --- | --- |
| **Modified Caregiver Strain Index**  | **Yes= on a regular basis** | **Yes= sometimes**  | **No** |
| My sleep is disturbed  |  |  |  |
| Caregiving is inconvenient  |  |  |  |
| Caregiving is a physical strain  |  |  |  |
| Caregiving is confining |  |  |  |
| There have been family adjustments  |  |  |  |
| There have been changes in personal plans  |  |  |  |
| There have been other demands on my time  |  |  |  |
| There have been emotional adjustments  |  |  |  |
| Caregiving is a financial strain  |  |  |  |
| Some behavior is upsetting  |  |  |  |
| It is upsetting to find the person I care for has changed so much from his/her former self |  |  |  |
|  There have been work adjustments  |  |  |  |
| I feel completely overwhelmed  |  |  |  |

**Total Score = -----------**

**Appendix C**

**Survey**

**Please complete the survey below. This survey has 8 questions and should take less than two minutes to complete.**

1. **I would recommend this program**

Strongly Agree Neutral Strongly Disagree

1. **The Art Therapist, Kelly Darke, was effective**

Strongly Agree Neutral Strongly Disagree

1. **I feel \_\_\_\_\_\_ after the sessions ( add your own feeling in the text box).**
2. **Do you have any comments or suggestions for the knitting and crocheting course?**
3. **How did you hear about the knitting and crocheting art sessions?**
	1. Employer
	2. Facebook/social media
	3. iCARE4U e-newsletter
	4. Morning post newsletter
	5. Doctor’s office
	6. Website
	7. Other- please specify
4. **How old are you?**
	1. Under 18
	2. 18-39
	3. 40-49
	4. 50-59
	5. 60-69
	6. 70+
5. **What is your gender?**
	1. Female
	2. Male
	3. Other
6. **What is your racial or ethnic identity? Please select all that apply**
	1. African-American/ black
	2. East Asian
	3. Middle- Eastern
	4. American Indian/ Alaskan Native
	5. Pacific Islander
	6. South Asian
	7. Southeast Asian
	8. Caucasian/ white

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