Evaluating Visual Art Workshop Participation for the Well-being of Caregivers of Individuals Living with Dementia

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Abstract

Caring for a loved one with dementia stresses caregivers and negatively affects their health due to physical and psychosocial exhaustion. The increasing prevalence of dementia and the absence of effective treatments have underscored the importance of engaging in creative arts to improve caregiver well-being. Capitalizing on creativity through participation in the creative arts as an effective intervention has been shown to reduce the negative impact of caregiving and contribute to better health. This study aimed to evaluate the effects of participating in visual art workshops on the well-being of family caregivers of people with dementia. This convergent mixed methods study interviewed six family caregivers. All engaged in an experiential full-day abstract art workshop called Recharge. Quantitative data were gathered using the Recharge Workshop Impact on Well-being evaluation and analyzed using quantitative statistical analysis. The American Medical Association (AMA) Caregiver Self-Assessment Questionnaire was analyzed using the AMA Caregiver Self-Assessment scoring standard. The qualitative data were collected through informal interviews with the caregivers and analyzed using Interpretative Phenomenological Analysis (IPA). Upon completing the study, the participants reported benefits such as enjoyment, awareness, social connection, creative discovery, and challenges like stress. The study's findings aligned with the well-being theory of positive psychology, validating that the workshop helps promote the well-being of caregivers. The efficacy of the Recharge intervention in reducing stress and improving the well-being of caregivers emphasizes the need for more programs that help family caregivers thrive, contributing valuable insights to the field of arts and health.

Keywords: family caregivers, dementia, well-being, visual arts, mixed method

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Caring for someone with dementia can negatively affect the caregiver's health and overall wellbeing (Cross et al., 2017). In recent decades, the use of the arts has emerged as an effective intervention in helping caregivers thrive (Iron et al., 2020) by decreasing their burden and increasing their social connection (Wharton et al., 2019). Despite evidence of the positive effects of arts participation on the overall well-being of seniors, most programs are designed for dementia patients, and only a few were developed for caregivers (Hutmacher & Schouwink, 2022).

This study implemented the Recharge abstract art workshop and assessed its impact on the well-being of caregivers of people with dementia. This research sought to answer the question of how engagement in abstract arts can help promote the well-being of caregivers of people with dementia. The objectives include evaluating whether a full-day abstract art workshop can help decrease the risk of stress and burnout, assessing whether a full-day abstract art workshop can improve social connection, and evaluating whether a full-day abstract art workshop promotes creative skills or confidence. This research also sheds light on the effectiveness of abstract art programs in lowering stress risks, increasing social connections, regaining creative confidence, and improving the overall well-being of family caregivers of persons with dementia.

Background

Dementia is an umbrella term for a brain disorder that causes symptoms such as a decline in cognitive and thinking skills and a memory impairment; as a result, the individual loses the ability to perform daily tasks necessary for survival (Alzheimer's Association, 2022). The delayed progression of the disease affects not only the individual diagnosed with it but also the community, including the individual's family, and caring for someone with dementia can have a negative effect on the caregiver's health and overall well-being (Cross et al., 2018). The adverse effects of providing care for a person with dementia pose health hazards for caregivers (Hunt et al., 2018).

The quality of life of caregivers is of the utmost importance in dementia care. The arts play a crucial role in helping them flourish due to the promotion of social connection and lingering cathartic effects that contribute to improved mood and enhanced well-being (Hutmacher & Schouwink, 2022; Irons et al., 2020). Brodaty and Donkin (2009) assert that the arts can be a universal intervention to alleviate caregivers' burdens and enhance their quality of life in response to many caregiver challenges. Despite evidence of the positive effects of arts participation on the overall well-being of seniors, including caregivers of persons with dementia (Cohen, 2006), very few arts programs for caregivers of people with dementia are developed. Hutmacher and Schouwink (2022) added that most programs are designed for individuals with dementia or individuals with dementia and their caregivers. The Music and Memory music program provides individualized music to people with dementia. It has been shown that listening to personalized music can improve mood and happiness, decrease anxiety and depression, and improve quality of life-(Buller et al., 2019). The Metropolitan Museum of Modern Art's Meet Me at MoMA program provides people with dementia and their caregivers a guided discussion of the museum's art collection, followed by artmaking reported to have increased engagement and alertness for persons with dementia and a sense of joy to caregivers (Mondro et al., 2020). As the prevalence of dementia continues to rise, alleviating its adverse effects and promoting the well-being of caregivers through the arts is greatly needed.

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Terminology

Family members of persons with dementia are described in several ways, such as a carer or informal caregiver (Irons et al., 2020), care partner or primary care partner (Levenberg et al., 2021), carer or caregiver (Golden et al., 2017), and family caregiver (Kidd et al., 2011; Merrilees et al., 2016). Baker et al. (2018) further described family caregivers of a person with dementia as the spouse and adult child. Various literature also uses different terminology to describe interventions, such as arts-based approaches, arts, and creative arts (Levenberg et al., 2021), creative arts interventions and creative activities (Irons et al., 2020), and participatory arts or participatory arts interventions (Golden et al., 2017). These words encompass but are not limited to singing, songwriting, music, art viewing, dance, pottery, poetry, object handling, and visual arts. Golden et al. (2017) further describe participatory arts as the active participation of the arts rather than passive or observing. This study defined key terms in Table 1.

Definition of Key Terms

Term	Definition
Family caregiver or caregiver	Someone who primarily provides care and makes all the decisions for their loved ones, including those with dementia.
Visual arts	Art processes involving painting and drawing, which can be freestyle or unstructured, using multimedia acrylic, paper, watercolor pastel, and other mediums. The result can be representational or nonrepresentational, including abstract art.
Person with dementia or a loved one	A person diagnosed with dementia.

Dementia caregivers

Caregivers for individuals with dementia have diverse cultural origins. Caregiving is standard and common regardless of race or ethnicity and lasts at least four years, even though two-thirds of caregivers are women aged 65 or older with diverse cultural beliefs and experiences (Alzheimer Association, 2022). Most geriatric patients and people with dementia receive care from their spouses. Even though they are recognized as vital resources for assisting dementia patients, many also struggle with health problems (Pienaar & Reynolds, 2015).

Family caregivers play a crucial role in augmenting the quality of life for dementia patients, often called "invisible second patients" (Brodaty & Donkin, 2009, p1). The impact of assuming the role of a family caregiver, while occasionally beneficial because it can promote caregivers' resiliency and personal growth (Netto et al., 2009), is overwhelmingly negative, characterized by elevated levels of burden and psychological morbidity, as well as instances of social isolation, compromised physical health, and financial hardship (Alzheimer Association, 2022; Brodaty & Donkin, 2009). Caregivers susceptible to adverse outcomes can be identified, as can the factors that alleviate or exacerbate their burden and stress (Etters et al., 2008).

Dementia affects family and friends' overall well-being (Bom et al., 2019; Cross et al., 2018). Depending on their capacity to cope, age, personality, and the availability of social support, caregivers' perceptions of the caregiving burden vary (Cross et al., 2018; Merrilees, 2016). Each caregiver encounters unique challenges, making their struggle individual and distinct. Variables such as culture, socioeconomic status, age, and gender influence the physical and psychological effects of dementia on caregivers (Alzheimer's Association, 2022; Cross et al., 2018; Merrilees, 2016). Merrilees (2016) added the impact of dementia on the lives of caregivers, feelings of guilt, and defeat to the list of caregivers' burdens.

Consequently, caregivers may experience physical symptoms such as high blood pressure, impaired immune function, bodily pain, and sleep disruption resulting in poor sleep quality, and are at risk for developing chronic conditions such as elevated stress hormone levels and coronary disease (Alzheimer Association, 2022; Merrilees, 2016). Beyond relational dynamics, interventions must concentrate on the care partners' health. More than 80% of dementia care partners frequently experience high tension levels, and nearly half report depression (Etters et al., 2008). In addition, dementia caregivers are more likely to be hospitalized and admitted to the emergency room and may die before their loved one (Alzheimer Association, 2022).

Caregivers have expressed experiencing financial difficulties due to their caregiving responsibilities and may not be adequately prepared for the economic challenges that come

with dementia. Individuals may encounter a decrease in earnings because of working fewer hours and facing substantial expenses for the goods and services needed to support their loved ones, such as home updates, assistance with daily tasks, recreational activities, specialized equipment, and medications, as well as other costs like transportation, travel, or accommodation expenses associated with caregiving duties (Bergman, 2019).

Irons et al. (2020) suggested that effective interventions are needed to reduce caregiving's negative impact on caregivers' health and well-being. They indicated that participating in creative activities has been linked to enhanced well-being. Due to its benefits, Fancourt and Finn (2019) encourage people with dementia and their caregivers to engage in the creative arts to nurture social connection, promote creativity, and improve well-being. According to Lokon et al. (2019, we can create and express ourselves in various forms of arts as social beings, and reinforces our creative rights through the United Nations Universal Declaration of Human Rights (1948), stating in Article 27: "Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits."

The caregivers of people with dementia play an essential role in maintaining the quality of life of their loved ones, but it can negatively affect their well-being. Effective intervention is needed through participation in the arts to alleviate the impact of caregiving.

Creativity

Participating in creative activities can positively impact caregivers' well-being (Hutmacher & Schouwink, 2022). A longitudinal study in creativity and aging conducted by Gene Cohen, MD, Ph.D., director of the Center on Aging, Health & Humanities at George Washington University in Washington, DC, showed that the arts have a positive effect on health and illness and foster creativity, communication, collaboration, and self-expression as we age (Cohen, 2006). Creativity is often considered a rare and unique gift, yet there is a belief that creativity is available for everyone. There is no one-size-fits-all definition of creativity; however, when we

examine the qualities and characteristics of creativity, we may find a definition that applies to our creativity. Malchiodi (2007) lists "spontaneity, playfulness, imagination, motivation, originality, self-expression, inventiveness, divergent thinking, and intuition" as some of the key elements. She asserts that people now say that creativity is a human potential, a skill we can improve. Csikszentmihalyi (1997) further defines creativity as "any act, concept, or product that modifies or creates a new domain from an existing one" (p.28). Creativeness is commonly linked to the capacity for emotional expression and the ability to think in an adaptive or divergent manner.

Engaging in artistic endeavors such as dance, music, visual arts, and more have been associated with improved overall well-being. Creativity enables caregivers to acquire alternative viewpoints on the difficulties they encounter, assists them in discovering or creating novel and adaptable approaches to address those difficulties, and facilitates their adaptation and adjustment to caregiving responsibilities (Irons et al., 2020). In addition, caregivers may gain various positive psychosocial benefits from engaging in creative activities. These include fostering social connections, actively participating in the creative process, gaining self-reflection and empathy through creative expression, acquiring new skills through exploration, and experiencing increased self-worth and empathy (Irons et al., 2020).

Benefits of arts to caregivers of dementia

The increasing prevalence of dementia diagnoses and the absence of effective treatments have underscored the importance of non-pharmacological and psychosocial interventions in the arts to mitigate the effects of dementia and improve caregiver well-being (Golden et al., 2017; Irons et al., 2020). As per Brodaty and Donkin (2009), the arts can be used as a universal intervention to address various caregiver challenges, reduce caregiver burden, and improve the caregiver's quality of life. Irons et al. (2020) further suggest that caregivers may benefit from such interventions across multiple domains. Observed through experiential accounts, arts-based interventions are frequently characterized as activities that induce enjoyment and relaxation, and it has been discovered that engaging in creative activities has cathartic effects (Camic et al., 2014; Clark et al., 2018). According to Clark et al. (2018), these effects include improved mood and enhanced well-being beyond the activity. In addition, arts-based interventions can affect the level of behavior, i.e., engaging in creative activities can inspire one to act and conduct differently. It may result in implementing more creative activities in daily life and positively affect relationships and social connections (Camic et al., 2016). In addition, arts-based interventions encourage exchanging information and forming alliances with other caregivers (Clark et al., 2018; Wharton et al., 2019).

The arts provide caregivers with the opportunity to reconcile with their creative selves and creative confidence. Retaining Identity, one of the few caregiver-specific art programs that utilizes visual art (Mondro et al., 2020), has identified creative discovery as one of its central themes. Creative discovery refers to caregivers discovering the advantages of engaging in creative activities for themselves and their loved ones. The development of caregiving skills and a sense of self-affirmation were cited as the most significant outcomes of the experience.

Types of art programs

An emerging field of practice and research is using the arts to promote the well-being of family caregivers of persons with dementia. However, Baker and Yeates (2018) and Wharton et al. (2019) found that most arts-based interventions are designed for the caregiver and the person with dementia to participate together, while far fewer interventions are aimed solely at caregivers. One of the benefits of programs for caregivers and patients together is that the caregivers don't have to find care for their loved ones while they step away from caregiving for their self-care. Letrondo et al. (2023) added that caregivers were often excluded from arts and dementia research, indicating a clear gap in the literature.

Many arts-based interventions offer different creative activities to participants, such as art viewing and art making in a museum or gallery setting, singing and music, dancing, poetry and

songwriting, and music combined with art (Hutmacher & Schouwink, 2022; Irons et al., 2020; Levenberg et al., 2021). The length and duration of the creative interventions varied from 1 to 2-hour sessions and weekly programs between 4 to 20 weeks (Irons et al., 2020). The result of a systematic review of creative arts intervention for caregivers conducted by Irons et al. (2020) showed no art programs, weekly or full-day, were designed specifically for caregivers.

Literature specific to caregivers of people with dementia included modalities such as songwriting (García-Valverde et al., 2022) and photojournalism (Wharton et al., 2019). A webbased participatory arts intervention, including music, visual art, and poetry, was designed for dementia caregivers to receive training and use at home with their loved ones (Golden et al., 2017). Retaining Identity, a study similar to this research, is an eight-week visual art program offered by professional artists who instructed dementia caregivers in four visual art activities (monoprint, Shibori textile (a Japanese tie-dyeing technique), additive/subtractive painting, and contour painting), which they then taught to their loved ones for four weeks (Mondro et al., 2020). The main themes that emerged from the study were caregiver growth, caregiver awareness, and creative discovery. The limitation of this study is that it is not specific to caregivers, and eight weeks is quite long for caregivers.

Using creative art to promote quality of life, this capstone project, designed for family caregivers of people with dementia, aimed to evaluate the effectiveness of a structured full-day abstract art-inspired program on their well-being, contributing to the gap in the literature.

Methods

Study Design

A convergent mixed methods study design was utilized for this study (Creswell & Creswell, 2017) to answer the research question sufficiently. Although mixed methods research can confirm or disconfirm results, it can offer flexibility in data analysis and draw more meaningful

conclusions on the same study. The method also allows a deeper exploration of the study research question, utilizing a blend of qualitative and quantitative data to provide insights into research queries that cannot be solved with either qualitative or quantitative research. The Recharge Workshop Impact on Well-being evaluation (see Appendix A) and American Medical Association (AMA) Caregiver Self-Assessment Questionnaire (Levenberg et al., 2021) (see Appendix B) were used to gather quantitative data analyzed using the American Medical Association's (AMA) scoring standards (Epstein-Lubow et al., 2010). Semi-structured interviews (see Appendix C) were conducted to collect qualitative data and analyzed using the Interpretative Phenomenological Analysis (IPA) (Smith et al., 2022).

Recruitment

Participants were recruited using a poster (see Appendix D) explaining the study. The Alzheimer Society of Calgary was contacted to post flyers on various social media outlets. A follow-up phone call was made to the caregivers interested in participating for any questions, clarification, or conversation regarding the consent form details (see Appendix E). At the start of a discussion, they were informed that they could participate in the workshop without consenting to be part of the study. The participants who met the eligibility criteria were enrolled in the workshop, and a copy of the consent form was emailed to them for review and questions. They could sign and return the consent form electronically or bring the signed copy on the workshop day.

Intervention

The art intervention was a workshop called Recharge, an artmaking program inspired by abstract art designed specifically for family caregivers of people with dementia. The program employed engaging abstract art processes as an expressive modality, enabling transformation through the creative process by emphasizing the process rather than the final products. It was a hands-on experiential workshop developed to provide an opportunity to engage in various abstract art techniques and encourage caregivers to discover the benefits of abstract art through creative play. The workshop was facilitated by adult day program personnel with experience working with people with dementia and caregivers in a long-term care facility setting.

The workshop was a full-day, 6-hour workshop. The workshop comprised a 30-minute check-in and introduction (overview, housekeeping rules, survey, ground rules), a 30-minute presentation and discussion about creativity and burnout, and two 1 hours and fifteen minutes of artmaking and discussion for a total of 3.75 hours that requires sitting, standing, and moving around if desired. Breaks were scheduled as 1-hour lunch, two 15-minute breaks, and a 30minute workshop break, including discussion, surveys, and evaluation.

Study Participants

For this study, a family caregiver is a person who primarily provides care to a dementia patient and makes all the decisions for their loved one. To achieve a homogenous sample per the recommendation of Smith et al. (2009), six qualified participants (aged 47-75) were recruited with various backgrounds, gender, role as caregivers, and employment statuses provided a sample for the study, and all completed the study. To complete the study, the caregivers attended the full-day workshop, completed the surveys, and participated in the interviews. The participants were family caregivers interested in participating in abstract art-inspired programs. The criteria to get enrolled included a signed written consent form, being 45 years of age or older, and being a caregiver of a person with dementia who still lives at home or in a care home, male or female. Participants were able to attend the workshop without agreeing to take part in the study. Furthermore, participants were able to engage in the workshop and other components of the study without agreeing to the follow-up interview or accepting to be audio recorded.

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Sample

The workshop was designed for groups of 6–8 participants, an ideal size per IPA (Smith et al., 2022). This number of participants was manageable to maintain the integrity and quality of the program, and attention was provided to all participants.

Data Collection

The goal was to seek answers to the following questions: Are the program's outcomes, objectives, and goals achieved? Are the abstract art-inspired activities beneficial to the caregivers' overall well-being? Does the Recharge program allow caregivers to engage in creative arts to promote connection with other caregivers and creative discovery?

Caregivers frequently neglect their well-being while tending to the needs of their loved ones. Although providing care is stressful, this study did not assume its participants were under any stress. Before the workshop, participants received the Caregiver Self-Assessment Questionnaires (Levenberg et al., 2021), a previously validated tool developed by the American Medical Association (AMA) (Epstein-Lubow et al., 2010), to get a baseline understanding of the caregivers' stress levels. The participants were asked to rate their physical and mental health on a scale of 1 to 10, as well as to indicate how stressed they felt by answering 16 questions with a "yes" or "no" (Epstein-Lubow et al., 2010).

The Recharge Workshop Impact on Well-being Evaluation survey was provided at the workshop's end. The survey consisted of five questions using a 5 Likert scale ranking by the degree to which they agree with the statement (Strongly Disagree, Disagree, Neither, Agree, Strongly Agree) and a comment section for additional thoughts: (1) Participation in the workshop gave me an increased sense of happiness; (2) Participation in the workshop gave me an increased sense of sense of confidence; (3) Participation in the workshop gave me an increased sense of sense of sense of confidence; (5)

Participation in the workshop gave me an increased sense of creativity; (6) Please provide additional comments.

Two weeks after the creative art intervention ended, semi-structured interviews were conducted using open-ended questions to gain their perspectives (Pienaar & Reynolds, 2015). Participants picked the date and time that worked for them to do an interview using a survey (see Appendix F). Five interviews were conducted over the phone, and one was in person at the participants' preferred location and time. The length of the interviews, on average, was 60 minutes. The interview data were recorded digitally, transcribed into Word format, and transferred to an Excel document for further analysis. Initial themes were created from interview questions and were grouped into various categories. The quantitative and qualitative data analysis outcomes were combined and analyzed in an Excel document using the side-by-side method (Creswell & Creswell, 2017) to identify recurring themes and areas where the data supported one another and produced insightful findings.

Data Analysis

Questionnaire and Survey

The data and responses were interpreted using the (AMA) Caregiver Self-Assessment scoring standard (Epstein-Lubow et al., 2010). A high-stress level is indicated by ten or more "yes" answers, a rating of six or higher for the ranked stress level, or a rating of six or higher for physical health. The completed Recharge Workshop Impact on Well-being evaluation surveys were analyzed and tabulated using quantitative statistical analysis (Creswell & Creswell, 2017; Palys & Atchison, 2021).

Interview

The feedback was transcribed into a table using an Excel document. Each subject's responses were plotted in the corresponding questions for analysis. See Appendix G for the process of generating themes. Following the guidelines of IPA (Smith et al., 2022), the comments were initially analyzed paragraph by paragraph for specific meanings and themes. The comments were further analyzed sentence by sentence to infer broader themes. While taking notes on the initial themes, the interview transcripts were reread and further analyzed to identify and note emerging meanings and themes. The main themes that emerged from comparing the initial comments were plotted in a table with supporting comments from the participants (see Appendix H).

Results

Participants Background

Six participants participated and completed the study. The participants comprised one male and five females; four were spouses, one daughter-in-law, and one son. The average age of the subjects was 62 years. One participant works part-time; one still works full-time; three are retired, and one quits a job to be a full-time caregiver. The participants indicated no previous art background or experience; three female participants mentioned engaging in visual art, such as a Mod Podge glass bottle.

Surveys and Questionnaires

Caregiver Self-Assessment Questionnaire. The participants completed the Caregiver Self-Assessment Questionnaire before the workshop started. Two out of six caregivers who scored high in stress level and health issues experienced a high degree of stress, and four out of six caregivers experienced a mild level of stress.

The caregivers' responses indicated few significant negative and positive themes. Other than stress, the participants have expressed feelings of "upset" due to the changes in their loved ones from their former selves, experiencing health issues, sleep disturbances, and strained to maintain caregiving roles and work. The significant positive theme was the caregivers' satisfaction with the support and respite from an adult day program (ADP) service, family members, and feeling useful and needed. See Table 2 for responses.

Table 2

Caregivers' Feedback

Participant/s	Comments
Caregiver CB, Spouse	"Been upset that my relative has changed so much from his/her former self."
Caregiver BW, Spouse	"Been satisfied with the support my family has been giving me."

Recharge Workshop Evaluation Survey. The survey was administered at the end of the workshop, and all six caregivers participated and completed it. All six participants strongly agreed that participating in the workshop increased their sense of happiness, confidence, joy, and connection. One participant agreed, and five strongly agreed that workshop participation had improved their understanding of creativity.

Key themes from the evaluation comments section were joy, social connection and belonging, a sense of escape, an increased sense of creativity, and admiration for the facilitator.

Joy. All the subjects expressed participating in the workshop increased their caregivers' sense of joy, positive emotions, and time for themselves. They added that artmaking and socialization brought feelings of pleasure and happiness. Two participants expressed feeling special for thinking of the caregivers. See Table 3 for participants' quotes.

Table 3

Caregivers' Feedback

erely enjoyed my day, this was perfect timing. Like this
orkshop is called Recharge, I totally feel recharged and freshed."

Social Connection and Belonging. The participants felt like they were part of a community that understands and supports each other. Caregiving can be isolating. The workshop gave the participants a feeling that they were not alone in their caregiving journey and felt that they had something in common. See Table 4 for comments.

Caregivers' Feedback

Participant/s	Comments
Caregiver KC, Spouse	"Workshop helped develop a sense of commonality and comradery."
Caregiver SB, Spouse	"It was great to talk and laugh with others going through similar issues. It was a great day to talk to all the caregivers.

A Sense of Escape. Participating in the workshop allowed the subjects to disconnect from their caregiving role and experience the day without thinking of anything. According to three participants, planning their day-to-day and social needs, organizing doctor appointments, and finding ways to provide meaningful activities for their loved ones can be overwhelming. A sub-theme that emerged in this theme is respite. The participants were able to experience a respite from caregiving. According to Pienaar & Reynolds (2015), respite "refers to a temporary period of rest or relief from something difficult or distressing." See Table 5 for comments.

Table 5

Caregivers' Feedback

Participant/s	Comments
Caregiver SB, Spouse	"It gave me time to de-stress and not worry about issues at home. I needed this, especially after a few days of water
	disconnection at the house."

Caregiver BW, Spouse "The art was so fun. It was a wonderful day to forget our problems and experience a fun and creative day (BW)."

Increased Sense of Creativity. Participating in the study, the caregivers expressed appreciation for the opportunities for self-expression that lead to the discovery or reconnection of their creative side. Their experience promoted their confidence in trying to discover art again. See Table 6 for comments.

Table 6

Caregivers' Feedback

Participant/s	Comments
Caregiver KC, Spouse	"I totally feel recharged and refreshed. I know I can do a little arts and crafts to get back to happy."

Admiration with the Facilitator. The participants noticed the facilitator's qualifications, skills, and other qualities, such as being personable. They expressed gratitude and appreciation to the facilitator and facilitated participation in the workshop and completion of the study. See Table 7 for participants' comments.

Caregivers' Feedback

Participant/s	Comments
Caregiver SB, Spouse	"He, the facilitator, and the workshop/program have provided very educated, personal, and overall joy to be around."
Caregiver CB, Spouse	"Facilitator is absolutely fantastic at getting so many to feel very comfortable while learning and expressing themselves."

Interview Findings

The qualitative data revealed five main themes: caregiver challenge, caregiver connection, creative discovery, enjoyment, and caregiver awareness.

Caregiver Challenge. Caregiver challenge refers to the feedback in which the subjects describe their experience as the primary caregiver of a person with dementia as stressful due to feeling exhausted, overwhelmed, and unprepared in their role, and increased caregiving role as the disease progresses. Contributing to the stress are the caregivers' increased health issues and the increased need to plan and organize to navigate the day-to-day demands of caregiving—financial problems due to the decision to leave employment to focus on caring for a loved one. See Table 8 for participants' comments.

Caregivers' Feedback

Participant/s	Comments
Caregiver KC, Spouse	"Stressful, I am a "chauffeur."
Caregiver CB, Spouse	"Yes, it has affected my daily life and probably my health somewhat, as I usually feel stressed and find that I don't have much time for myself anymore."

Despite the challenges, two participants also expressed a sense of reward in their journey as caregivers, support from family and friends, and respite from adult day program services.

Caregiver Connection. Participating in the workshop emphasized to caregivers the importance and benefits of being connected to people. Caregiver connection refers to the comment in which the participants expressed a sense of belonging and commonality from the social interaction with other subjects and the facilitator. They expressed positive interaction and gained a deeper understanding that each caregiver has a unique experience in their journey of the disease process. Two caregivers expressed fulfillment in their role despite the hardship; the others found it inspirational. See Table 9 for participants' comments.

Caregivers' Feedback

Participant/s	Comments
Caregiver CB, Spouse	"That dementia is hard work for a caregiver, and everyone is
0 / 1	in a different place on this journey. But many people care
	about me as a caregiver. That I'm not alone in this journey
	with my husband. Also, many people enjoy being
	caregivers and love the person they care for more than
	anything."

Five out of six participants' loved ones attending the same adult day program and their preexisting acquaintances might have contributed to the positive interaction. They may strengthen each other's dynamics and openness to sharing time and experience. One of the participants gained caregiving skills from interacting with other caregivers. See Table 10 for participants' comments.

Table 10

Caregivers' Feedback

Participant/s	Comments
Caregiver BW, Spouse	"I thoroughly enjoyed my time in your workshop, and I learned from other participants of other coping techniques
	and programs that are offered for people living with
	dementia and caregivers' programs."

Creative Discovery. Creative discovery refers to participants' comments on how creativity and creative arts improve their well-being by lowering stress, developing a social connection, and rekindling creativity. Caregivers were proud of their artwork and amazed by its quality and distinctiveness, given the ease of the creative process. Four participants inferred a discovery of their creative side and felt an increased sense of creativity. Two participants have experienced engaging in some form of creative activity and expressed reconnection to their creative side. They want to continue doing it with their loved ones and other family members, such as grandkids. See Table 11 for participants' comments.

Table 11

Caregivers' Feedback

Participant/s	Comments
Caregiver BS, Daughter in law	"I think the significance is showing that I was and am capable of doing something new when I honestly didn't believe that I would have any art ability or creativity."
Caregiver KC, Spouse	Creative side boosted - increased sense of creativity and inspired to do more and explore."

Sub-themes that emerged from creative discovery include engagement, meaning, and accomplishment. The subjects were fully engaged during the full-day workshop by participating in all aspects of the intervention. The participants draw inspiration, connection, and meaning from their artwork from family members, life experiences, travels, memories, and personal preferences. They also felt a sense of accomplishment from completing their artwork and proud of it. Caregiver CS (son) said, "I just picked mine and my loved one's favorite colors and went from there."

Caregiver Enjoyment. Overall, the full-day workshop brought positive feelings and emotions to the participants, leading to other themes such as enjoyment and caregiver awareness. Enjoyment refers to the comment in which the participants experience joy in the creative process, social interaction with other caregivers, decreased levels of stress, and created artwork. A fun and relaxing environment and appreciation for the facilitator also contributed to the feeling of joy. See Table 12 for participants' comments.

Table 12

Caregivers' Feedback

	Participant/s	Comments
the arts you are taken to a place of peace and stres	Caregiver BW, Spouse	"It has shown me that arts and crafts are very relaxing and help me relieve stress. As you are engaging in the arts you are taken to a place of peace and stress- free time, which you seldom have when dealing with this disease."

Caregiver Awareness. The workshop raised caregivers' awareness of caregiving strategies, support and services, knowledge, and skills, such as the importance of self-care in the form of mindfulness and creative arts, to help them become more confident in their role. Participants also learned about the importance of support, the benefits of the arts, and how to identify the signs of burnout/stress, which will help them be more prepared as caregivers and in dealing with challenges. See Table 13 for participants' comments.

Caregivers' Feedback

Participant/s	Comments
Caregiver CB, Spouse	"I learned the word self-compassion rather than self- care. I think that was a really good way of saying to accept what you can and can't do or can or can't be."
Caregiver BW, Spouse	"I thoroughly enjoyed my time in your workshop, and I learned from other participants of other coping techniques and programs that are offered for people living with dementia and caregivers' programs."

Converging Themes

The key overarching findings from the converged results were caregiver challenges, joy, social connection, caregiver awareness, and creative discovery. These themes suggest that the Recharge program can help promote the well-being of people with dementia by helping caregivers develop caregiving skills and encourage self-care.

Another significant finding from the merged data includes the theme of caregiver stress, health issues, and an increased caregiving role challenge that validates the need for more art programs for caregivers of people with dementia. These themes also suggest the need to provide more support to caregivers to help alleviate the burden of caregiving by promoting the well-being of the caregivers through creative interventions such as the Recharge workshop.

Discussion

The results from this study highlighted the devastating effect of caring for a person with dementia. These findings indicated that family caregivers experience stress, exhaustion, an increased caregiving role, health-related issues, and financial difficulties. These results aligned with the data presented by the Alzheimer Association (2022) and the study by Brodaty and Donkin (2009) that caregiving can negatively affect caregivers' physical and psychosocial health and can cause financial strain, validating the need for a program for caregivers of people with dementia.

This convergent mixed methods study found that art-based interventions for family caregivers of people with dementia can facilitate joy, meaning, social connection and engagement, and creativity, undermining the psychosocial effect of caregiving. Mondro et al. (2020) study confirmed that the arts can positively affect the caregiver's well-being.

This study's findings, such as joy, connection, engagement, meaning, and accomplishment, met the criteria of the well-being theory (Seligman, 2011). He discovered that the following components need to be present if an activity is to promote well-being: positive emotion, engagement, relationship, meaning, and accomplishment (PERMA). The participants expressed experiencing positive emotions such as joy, fun, and happiness and were fully engaged during the artmaking process and conversations with other caregivers. The results indicated that the participants developed some form of relationship as they experienced commonality and social connection with other caregivers and the facilitator. Engaging in the art process, the participants integrated personal meaning and connection to their artwork and their role as caregivers. Participants felt proud and accomplished in their beautiful art pieces. Viewed through the lens of well-being theory, it affirms that participation in the Recharge workshop promotes the well-being of the caregivers. Based on the findings of this study, the caregivers experienced reduced stress and found joy, connection, awareness, and creative discovery. These findings were confirmed by the results of the past studies conducted by Camic et al. (14,16), Clark et al. (2018), and Wharton et al. (2019), that engagement in the arts can positively impact caregivers' well-being through social connection enjoyment and decreased stress and caregiving burden. These results make the Recharge workshop a novel social intervention to reduce caregivers' stress, burden, and other physical and psychosocial implications of caregiving.

Strengths and Weaknesses

This study has features that contributed to its strengths. The convergent mixed methods (Creswell & Creswell, 2017) and Interpretative Phenomenological Analysis (Smith et al., 2022) are complementary. Using a consistent process of coding and creating topics using Excel form, the data merging was seamless, resulting in main themes that validated the results from previous studies and answered the study questions. The workshop structure, delivery, and flow were well organized and prepared. A warm and inviting space and atmosphere were established, and the needs and requests of the participants were also met, making the caregivers eager and willing participants.

The study's strengths can be attributed to the facilitator's educational background, work experience, and skills. He manages the adult day program participants' loved ones attend, has worked in dementia care for decades, and is well-experienced in planning and program facilitation.

The art processes were designed to promote engagement, choices, and creative freedom but structured to ensure successful artwork creation regardless of the participants' experience in art and background. Lastly, the mini-education session of the study contributed to positive outcomes. Discussing the topics in self-care, benefits of the art, and signs of stress and burnout helped break the ice, enhancing participants' connection and understanding of the key concepts and allowing them to experience their meaning.

This pilot study also has weaknesses. The workshop did not consider a time for open discussion of caregiving-related topics. At some point during the workshop, participants discussed caregiving issues and challenges related to their role, such as navigating the support and services from the government and home care staff qualification and quality of care provided to their loved ones.

The workshop lacked ground rules for the conversation topic. During the first few hours, there were a couple of moments when one of the caregivers started sharing personal opinions on the current political issues. The other caregivers chimed in, and the conversation felt like a support group session that sidetracked the workshop's primary goal and created awkward moments among the participants. The facilitator did not anticipate that moment and could have moderated the conversation more effectively.

The pilot study's sample size of six caregivers is small, limiting the initial results' generalizability. Due to time constraints, the interview data were not investigated further. In addition, other data collection tools, such as surveys and interview questions, would have been explored to get a more cohesive view of what other researchers are doing, adding to the generalizability of the results.

Recommendations

Future researchers should increase the number of subjects, consider other caregivers for the study to add diversity, and expand the age range of participants to 18 instead of 45. They should also consider an exploratory sequential mixed methods design for more rigorous, detailed, and structured data collection and analysis (Creswell & Creswell, 2017).

The connection between the facilitator and participants benefits the study's success, but the results might not be as genuine or the same without the pre-established connection. For future studies, consider cohorts in which the facilitator doesn't have a pre-existing connection due to potential bias.

The study prepared three abstract art-inspired processes: pouring medium, paper quilling, and mixed media; however, the participants did only two of the art processes due to limited time, lack of interest and confidence in creating the mixed media processes, and caregivers' dwindling energy as the day progressed. Future facilitators should consider using simple art processes such as paper collages and alcohol ink. These techniques are simple, easy, and fast but create beautiful results with abstract features. Sauer et al. (2016) suggested using art processes inspired by abstract art in dementia care using materials such as rice paper, dyes, paints, and inks of all types and techniques such as brush, paint roller, and pipette to stimulate various senses and curiosity.

Future studies should explore other settings that promote creativity, such as community centers or art spaces that are more relaxed and less clinical in appearance and feel. They should also consider implementing the intervention during the spring and fall and structuring the program into a six- to eight-week program with one to two hours and one art process per session.

Practice Considerations for Future Facilitators

The time required to plan, organize, and implement the workshop is considerable and can be overwhelming for one person. A diverse implementation team educated in dementia care, with art process design experience and facilitation, is valuable in delivering the program to the community and various settings.

The costs associated with the study, such as supplies, food, beverages, and other related expenses, can add up and contribute to the program's discontinuation or failure to expand.

Building partnerships with local organizations such as Alberta Caregivers is recommended. Another consideration is applying for grants to ensure the program's sustainability and potentially reach a more diverse and broader audience.

While the workshop is believed to have promoted caregivers' well-being, the pilot study cannot account for other factors influencing caregivers' well-being. Further research is recommended into the benefits of abstract art-inspired interventions for family caregivers of people with dementia.

Conclusion

Dementia can negatively impact family caregivers' physical and mental health. The rising number of dementia diagnoses and lack of treatment highlight the importance of visual arts to alleviate its effects and improve caregivers' lives. The need for art programs designed especially for family caregivers of people with dementia is often overlooked despite the evidence that caregivers benefit from it.

This convergent mixed method study provides evidence that family caregivers of people with dementia experience stress and other caregiver-related issues, such as an increased caregiving role, financial strain, and health issues. It offers evidence that caregivers can find fulfillment, joy, and meaning in caring for their loved ones, and while caregiving can be exhausting, it can also be rewarding. This study also presents evidence that participating in the arts can be an effective tool for family caregivers of persons with dementia who are trying to fulfill their roles while coping with day-to-day caregiving challenges.

Adapting caregiver-specific programs, such as the Recharge workshop, to support caregivers may lead to more innovative programs that promote the quality of life of family caregivers and people with dementia. Moreover, adopting the workshop would be a step toward creating dementia-friendly communities.

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Appendix A

The Recharge Workshop Impact on Well-being Evaluation

Initials	5:		Da	ate:	
1.	Participation in the w	orkshop gave me	an increased	sense of hap	piness.
	Strongly disagree	Disagree	Neither	Agree	Strongly Agree.
2.	Participation in the w	orkshop gave me	an increased	sense of con	fidence.
	Strongly disagree	Disagree	Neither	Agree	Strongly Agree.
3.	Participation in the w	vorkshop gave me	an increased	sense of joy.	
	Strongly disagree	Disagree	Neither	Agree	Strongly Agree.
4.	Participation in the w	orkshop gave me	an increased	sense of con	nection.
	Strongly disagree	Disagree	Neither	Agree	Strongly Agree.
5.	Participation in the w	orkshop gave me	an increased	sense of crea	ativity.
	Strongly disagree	Disagree	Neither	Agree	Strongly Agree.
6.	Please provide additi	onal comments:			

Appendix B

Caregiver Self-Assessment Questionnaire

https://www.healthinaging.org/sites/default/files/media/pdf/Caregiver-Self-Assessment-

Questionnaire.pdf

Appendix C

Recharge Post Workshop Interview Questions

- 1. How would you describe your experience of being a primary caregiver?
 - How has it affected your day-to-day life and health?
- 2. Was there anything you learned as part of the workshop that can help you in the future as you care for your loved one with dementia?
 - During your participation in the program, did you pick up any information that would be useful to you in the future when dealing with dementia?
 - Did you learn anything in the workshop that will help you go forward as you deal with dementia as a caregiver?
- Over the course of the workshops, was there anything you learned about yourself? How about your loved one?
- 4. Was there anything you gained from interacting with other participants?
- 5. From your perspective, how might engaging in the arts help you manage being a caregiver?
- 6. What got you interested in the workshop?
 - Did you engage in artmaking before becoming a family caregiver or is this a more recent interest?
- 7. Can you tell me about the pieces you have created during the workshop?
 - What significance are they to you?
 - Where did you draw your inspiration from?
 - What do you think these art pieces might say about you as a person?
- 8. Do you have anything else you would like to tell me about the workshop?

Appendix D

Recruitment Poster

ARE YOU A FAMILY CAREGIVER OF A PERSON WITH DEMENTIA AND HAVE AN INTEREST IN THE ARTS?

YOU ARE INVITED TO PARTICIPATE IN CREATING ABSTRACT ART AND SHARE YOUR EXPERIENCE.



Who do I need?

• Family caregivers of people with dementia, 45 years and older.



What is involved?

• 7-hour workshop with 5 hours of abstract art making.

For more information, contact Ali Cada: (403) 797-0695 Email: <u>acada@ufl.edu</u> Ali Cada, a master's student in the University of Florida's Arts in Medicine program, is evaluating how engaging in abstract art activities can help promote caregivers' well-being. If you are interested, please get in touch with him using the information below to learn more about the study and find out whether you are eligible to participate. Your participation is voluntary and will not be compensated, and your information will be kept confidential.



This study is approved by the University of Florida Institutional Review Board #202302022.

Appendix E

Consent Form

UF Institutional Review Board UNIVERSITY of FLORIDA

RESEARCH PARTICIPANT INFORMED CONSENT FORM

Please read this document carefully before you decide to participate in this research study. Your participation is voluntary, and you can decline to participate, or withdraw consent at any time, with no consequences.

Study Title:

Study on the Impact of the Abstract Art Program on Caregivers of Dementia Patients

Person(s) conducting the research:

Alison Cada, Arts in Medicine graduate student Email: <u>acada@ufl.edu</u> Phone #: +1403-797-0695

Jennifer Lee, Faculty Mentor Email: jlee@arts.ufl.edu Phone#:352-733-0880

Purpose of the research study:

The purpose of this study is to see if abstract art process intervention can improve wellbeing, promote social connection, and reconnect with the creative side.

What you will be asked to do in the study:

You will be asked to answer assessment, evaluation, and survey forms to participate in the study- You will also be asked to engage in a full-day workshop to create art using abstract art-inspired processes requiring mild physical activity similar to household chores. In addition, you will participate in a 30-minute education session about creativity and burnout. The workshop will include three 75-minute artmaking sessions and discussions that require sitting with some standing and moving around. You will have one scheduled 15-minute break between sessions and a 1-hour lunch break, but you can take a break anytime. Lastly, you will be asked to participate in an informal conversational interview, which will be scheduled later.

Participants may attend the workshop without agreeing to take part in the study. Furthermore, participants may engage in the workshop and other components of the study without agreeing to the follow-up interview or accepting to be audio recorded.

Time required:

The total time required for your participation is no longer than 9 hours. It includes 30 minutes of reading and signing the consent form, participating in a full-day workshop that involves three artmaking and discussion periods of 75 minutes each, with 15-minute breaks in between, 30 minutes of education about creativity and burnout, and 30 minutes for answering a post-workshop survey. The individual interview you will be asked to participate in a week after the workshop will last one hour.

Risks and benefits:

There are no direct benefits for you from participating in the study.

Confidentiality:

You will be assigned with a code number to which only the PI will have access. Any information-you will provide will be kept confidential to the extent provided by law, and no information that would identify you will be used in reports about the study.

Compensation:

You will not receive compensation for participating in the workshop or study. However, there is no cost for your participation, and I will provide food such as snacks, a catered lunch, beverages, and art supplies free of charge.

May the researcher(s) benefit from the research?

I may benefit professionally if the study results are presented at meetings, conferences, or scientific journals.

Withdrawal from the study:

You are free to withdraw your consent and to stop participating in this study at any time without consequence. You can decline to answer any questions from surveys, questionnaires, and interviews you don't wish to answer. With your permission, information collected before withdrawn consent will be used.

Audio recording and Photography

As part of your participation in the research, you will be audio recorded during the interview, and the art pieces you create will be photographed. The audio recordings will be transcribed for reporting purposes.

Neither your name nor personal information will be identified on this picture or recording. If recordings are done via Zoom or other similar virtual software, please shut off your camera if you do not want your image to be recorded. Confidentiality will be

strictly maintained. However, when the above is shown or heard, others may be able to identify you.

The above picture or recording will be destroyed once this research study has been completed.

I agree to the option of being audio recorded and art pieces to be photographed.I DO NOT agree to the option of being audio recorded or art pieces being photographed.

If you wish to discuss the information above or any discomforts you may experience, please ask questions now or contact one of the research team members listed at the top of this form. If you have any questions regarding your rights as a research subject, please contact the Institutional Review Board (IRB02) office (University of Florida; PO Box 100173; Gainesville, FL 32610; (352) 392-0433 or irb2@ufl.edu.)

Agreement:

I have read the procedure described above. I voluntarily agree to participate in the procedure and have received a copy of this description.

Participant Name		
Participant Signature	Date	
Name of Person obtaining informed consent		

Signature of Person obtaining informed consent

Date

Appendix F

Interview Date Survey

Initials:		Date:	
Gender: Age	e:		
Working: Yes: Full	-time, Part-time	No	
Engaging in creati	ve arts/craft" No	Yes:	list:
Role: Spouse	Sibling	Children	Others:
Interview date qu	estions:		
I wish to participa	te in the interview	w:	
Yes			
No			
My preferred date	e/s:		
Day/Montl	h		
Day/Montl	h		
Any date			
My preferred form	n of interview:		
Phone			
Zoom			
In-person i	nterview @ home	2	
Other loca	tion:		
My preferred time	2:		
Between 9	am to 12noon		
Between 1	pm to 5 pm		
Other:			
Special request:			
Please indi	cate any request 1	to ensure a cor	nfortable interview exper

Appendix G

Interview Analysis Table

	Interview Analysis Table														
			Initial		Initial		Initial		Initial		Initial		Initial	Merged	Other
	POST WORKSHOP INTERVIEW QUESTIONS	BW	Theme	BS	Themes	CLB	Themes	кс	Themes	cs	Themes	SB	Themes	Themes	Themes
1	How would you describe your experience of being a primary caregiver?														
	How has it affected your day-to-day life and health														
2	Was there anything you learned as part of the workshop that can help you in the future as you care for your loved one with dementia?														
	During your participation in the program, did you pick up any information that would be useful to you in the future when dealing with dementia?														
	Did you learn anything in the workshop that will help you go forward as you deal with dementia as a caregiver?														
3	Over the course of the workshops, was there anything you learned about yourself?														
	How about your loved one?														
4	Was there anything you gained from interacting with other participants?														
5	From your perspective, how might engaging in the arts help you manage being a caregiver?														
6	What got you interested in the workshop?														
	Did you engage in artmaking before becoming a family caregiver or is this a more recent interest?														
7	Can you tell me about the pieces you have created during the workshop?														
	What significance are they to you?														
	Where did you draw your inspiration from?														
	What do you think these art pieces might say about you as a person														<u> </u>
															<u> </u>
8	Do you have anything else you would like to tell me about the workshop?														

Appendix G

Key Themes Analysis Table

Theme						
Main Participants' comments	Supporting Participants'	Other Participants'				
	comments	comments				
Discussion and Analysis:						