

What are the Experiences of Family Caregivers Participating in an Arts-based (Collage)
Intervention?

A Secondary Analysis

by

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Abstract

Current social and demographic trends include a shift toward an elderly population, an increase in life expectancy and an increase in chronic disease, all of which contribute to increased care needs. Family members are depended upon to take on the caregiving role for those with physical or functional limitations. As a result of the stressors associated with the caregiving role, many caregivers experience caregiver burden, which is the negative impact upon caregivers' physical, emotional, financial, and social lives. Arts-based interventions demonstrate potential as an innovative method to alleviate stress and contribute to improved quality of life and well-being for family caregivers. The purpose of this paper-based thesis was to first investigate what is presently known in the literature about arts-based interventions, commonly used arts-based interventions, and the benefit of arts-based interventions for family caregivers and for older persons. This was accomplished through a literature review. Second, I completed a secondary analysis to explore if family caregivers experienced therapeutic benefit from participating in an arts-based intervention, collage-making. Using Interpretive Description, I analyzed seventeen workshop evaluation surveys that elicited family caregivers' experiences from a collage-making workshop. Findings from this research study revealed that family caregivers valued the socialization benefit of the workshop, they indicated the need for respite care to support them in their role, and they increased their awareness of available resources in the community. These findings provide valuable insight for clinicians, researchers, policy-makers, and family caregivers. The knowledge can help health professionals be more mindful to family caregivers' needs for support and the importance of socializing with other caregivers, and provides indication for future research to explore other types of arts-based activities that are flexible to caregivers' busy schedules.

Preface

This thesis is an original work by Janelle Ostby. No part of this thesis was previously published. The research project, contained within this thesis, received research ethics approval from the University of Alberta Research Ethics Board. The project name is “What are the Experiences of Family Caregivers participating in an Arts-based (collage) Intervention? A Secondary Analysis”, No. Pro00071223, March 8, 2017.

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CHAPTER ONE

Introduction

Canada's population is aging with approximately 5 million Canadians aged 65 years and older (Bremault-Phillips et al., 2016; Employment and Social Development Canada, 2015). Currently, there are more individuals in the 65 years+ age demographic compared to those aged 15 years and younger (Statistics Canada, 2015). Furthermore, the oldest-old, or those over 85 years of age are among the fastest growing segments of the aging population (Eifert, Adams, Morrison, & Strack, 2016). Demographic trends include an increase in life expectancy and an increase in chronic disease, coupled with a health care system challenged to meet the demands for care with limited resources and rising costs (Canadian Caregiver Coalition, 2013). This raises significant concern because frailty and chronic diseases are more prevalent in an aging population, which is often accompanied by substantial interventions to meet personal and health care needs. The increased demands for care means that family caregivers are relied on to meet many of these needs (Bastawrous, 2013; Eifert et al., 2016; Faucher & Garner, 2015; Pruchno & Gitlin, 2012; Williams, Wang & Kitchen, 2014).

The increased demands placed upon caregivers can cause caregiver burden, which can progress to burnout if caregiver needs and self-care are not addressed. Caregiver burden involves the demands and responsibilities of caregiving that can affect caregivers' physically, mentally, financially, and socially (World Health Organization, 2004). There is a substantial body of literature addressing caregiver burden. This burden results from caregivers trying to balance personal, social, family and professional responsibilities with caregiving duties (Duxbury, Higgins & Schroeder, 2009; Faucher & Garner, 2015; Quinlan & Duggleby, 2009).

Due to the stressors caregivers are exposed to while in a caregiving role, interventions that have the capability to alleviate stress, can assist in building coping and resiliency skills, and are flexible to caregivers' schedules, are relevant to explore. A review of the literature shows that creative activities demonstrate potential in reducing caregiver stress (Chancellor, Duncan & Chatterjee, 2014; Faucher & Garner, 2015; Losada et al., 2010; Pienaar & Reynolds, 2015; Walsh, Martin & Schmidt, 2004; Walsh, Radcliffe, Castillo, Kumar, & Broschard, 2007; Walsh & Weiss, 2003;). For example, art-making has been gaining attention with practitioners and researchers alike because of the therapeutic benefits that creative pursuits can provide to caregivers. Some of the benefits that have been reported in the literature include reducing stress and anxiety, enhancing positive emotions, improving mood, increasing self-worth, and promoting feelings of social connectedness that contributes to a sense of purpose and belonging (Malchiodi, 2005; Perruzza & Kinsella, 2010; Pienaar & Reynolds, 2015; Stuckey & Nobel, 2010).

Overview of the Problem

There are currently just over eight million Canadians, or 28% of the population, who are providing caregiving support to a family, friend, or neighbor (Statistics Canada, 2015). Caregivers assist the care recipient with both activities of daily living (ADL) and Instrumental Activities of Daily Living (IADL). ADLs include: personal hygiene, toileting, and eating (Alberta Health Services, 2010; Canadian Institute for Health Information, 2011). IADLs include: meal preparation, housework, medication management, shopping, and transportation (Alberta Health Services, 2010; Canadian Institute for Health Information, 2011). Care recipients typically receive help with at least one ADL and 4.4 IADLs (Pruchno & Gitlin, 2012).

Role strain from caregiving affects caregivers' physical and mental health. Chronic stress from caregiving affects self-reported health, health symptoms, and illness (Duxbury et al., 2009; Wan, 2011). Caregivers, who indicate increased levels of stress, have poorer self-rated health, decreased physical function, and higher levels of depression (Pruchno & Gitlin, 2012; Wan, 2011; Williams et al., 2014). Other physical and emotional impacts include feeling tired, anxious, overwhelmed, alone and isolated, angry, loss of appetite, and sleep deprivation (Williams et al., 2014). Without strategies to mitigate these adverse effects on caregiver health and well-being there will be a significant further impact on their ability to continue in the caregiving role.

Purpose and Significance of Study

The purpose of my thesis is to explore family caregivers' experience in participating in an arts-based intervention. The results will help inform further arts-based interventions with caregivers including how they might support caregivers in their role. The information obtained from this study could help to inform health care policy, clinical practices, education, and research.

Thesis Structure

This is a paper-based thesis and I have organized it into four chapters. Chapter 1 is an introduction and includes the background, problem statement and purpose for my thesis research. Chapter 2 is a targeted literature review on the current state of knowledge regarding the use and benefits of arts-based interventions. Chapter 3 is the research paper of secondary analysis I carried out. I describe the study design, methods, findings, and a discussion. Chapter 4 is the summary and concluding chapter of this work. I discuss implications and recommendations

based on the findings from both my learning from the literature review and my research study. I added appendices following Chapter Four.

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CHAPTER TWO

Literature Review

I conducted a literature review to provide an overview on how arts-based activities are used for therapeutic benefits within healthcare. I reviewed four overarching and relevant areas: (1) The history of the use of arts-based activities, (2) Commonly used arts-based activities, (3) Therapeutic benefits of arts-based activities for caregivers, (4) The benefits of older persons engaging in arts-based activities. I will discuss each of these areas in this chapter.

Arts-based Activities

The use of arts-based activities such as drawing, drumming, creative movement and play as part of a creative therapeutic process, individuals of all ages are able to express thoughts and feelings in a way other than verbal means that would otherwise be difficult to articulate (Archibald, Scott, & Hartling, 2013; Fraser & al Sayah, 2011; Malchiodi, 2005). The Ontario Art Therapy Association (2014) subscribes to the idea that the process of making art is inherently therapeutic as it takes into consideration thoughts, feelings, behaviors and spirituality within the process. Arts-based activities do not rely on language or verbal skills. They offer opportunities to access experiences in a controlled manner; focus concentration on a single activity, shutting out intrusive thoughts, and encourages creative thinking. Furthermore, arts-based activities can be used to explore issues of relationships, family loss, life transitions, abuse and development. Arts-based activities may be aimed at resolving emotional conflict, increasing self-awareness and self-esteem, building social skills, changing behavior, increasing coping skills, and developing strategies for problem solving (Ontario Art Therapy Association, 2014).

History of the use of arts-based activities

Creative arts-based activities were gaining recognition back in the 1930s and 1940s when psychotherapists and artists became aware that self-expression through nonverbal modalities such as painting, music making or movement showed promising results for individuals with mental illness (Malchiodi, 2005). It was used as a creative process for individuals to explore their feelings, work through emotional struggles, facilitate self-awareness, manage behavioral issues and addictions, develop social skills, and to reduce anxiety and increase self-esteem (The National Coalition of Creative Arts Therapies Associations, n.d.). Following World War II, poster art was the modality predominantly used to communicate health messages to the public (Fraser & al Sayah, 2011). Using art-making for the purpose of self-expression has contributed to benefiting health in powerful ways and thus has been embraced by many different cultures (Stuckey & Nobel, 2010). Throughout recorded history, the use of the arts such as pictures, stories, dances and chants have all been used as part of healing rituals (Stuckey & Nobel, 2010).

In recent years, arts-based activities have been used for their therapeutic benefits in various patient populations (Walsh & Weiss, 2003; Stuckey & Nobel, 2010; Walsh, Martin & Schmidt, 2004; Camic, 2008). For example, engaging in art-making has been shown to make a difference for people with mental health needs, Alzheimer's Disease, chronic illness, head injuries, substance abuse problems, physical disabilities, and developmental disabilities (National Coalition of Creative Arts Therapies Associations, n.d.). This is due to increasing recognition that participation in arts-based activities provides health and subjective well-being benefits. Research studies have shown promising results that engaging in arts-based activities, either as an observer or through applying one's creative efforts, reduces stress and anxiety, enhances positive emotions, improves mood, increases self-worth and other psychological states, and promotes

feelings of social connectedness and a sense of purpose and belonging (Malchiodi, 2005; Perruzza & Kinsella, 2010; Pienaar & Reynolds, 2015; Stuckey & Nobel, 2010).

Commonly used arts-based activities

Within the literature, common arts-based activities that have been utilized as interventions for therapeutic benefits include: music engagement, visual arts, movement-based creative expression or performance arts, and literary arts or expressive writing (Fraser & al Sayah, 2011; Stuckey & Nobel, 2010). Art- and music-making, dance and drama, creative writing and all forms of play are participatory and require individuals to invest energy in them (Malchiodi, 2005). For example, art-making involves individuals as active participants in the therapeutic process which can involve arranging, touching, gluing, stapling, painting, forming and many other tangible experiences (Malchiodi, 2005). The experience of doing, making and creating can energize individuals, redirect attention and focus, and alleviate emotional stress, allowing clients to concentrate in a more fulsome manner on issues, goals and behaviors (Malchiodi, 2005).

Music. Music is one of the most widely used modalities of art and healing due to its soothing effect and the fact that it does not require complex technological approaches (Stuckey & Nobel, 2010). The use of music as a form of therapy has shown positive results in restoring emotional balance and decreasing anxiety. Research has shown that music can calm neural activity in the brain and may assist in restoring effective functioning in the immune system via the actions of the amygdala and hypothalamus (Malchiodi, 2005).

Visual arts. Visual arts-based activities include photographs and drawings. Photovoice and photo elicitation, for example, have been gaining more popularity in health research. Photo elicitation is used as a means of eliciting thoughts and feelings regarding certain phenomenon

captured in selected photographs. Photovoice involves participants taking photographs themselves as a modality to share their ideas, thoughts or worldview (Faucher & Garner, 2015; Fraser & al Sayah, 2011). Participants using these methods have reported feelings of empowerment and liberation with their ability in making their experiences visible (Fraser & al Sayah, 2011). In their literature review, which included the years 1995 thru 2007, Stuckey and Nobel (2010) discussed a qualitative study that involved women with diagnoses of cancer and were experiencing cancer-related difficulties such as fear for the future, pain, sleeplessness, role loss, activity restriction, reduced self-confidence, and altered social relationships. Engaging in different types of art-making activities such as textiles, card making, collage, pottery, watercolor, and acrylics, helped these women in four major ways. First, it helped them focus on positive life experiences, relieving their ongoing preoccupation with cancer. Second, it enhanced their self-worth and identity by providing them with opportunities to demonstrate continuity, challenge and achievement. Third, it enabled them to maintain a social identity that resisted being defined by cancer; and fourth, it allowed them to express their feelings in a symbolic manner.

Movement-based creative expression. There has been increasing interest in dance and movement in recognizing the benefits of motor activity between the mind and body. This is based on the assumption that body and mind are interrelated given the psychotherapeutic use of movement as a process that furthers the emotional, cognitive, and physical integration of the individual (Stuckey & Nobel, 2010; Malchiodi, 2005). Movement based creative expression focuses on nonverbal, primarily physical forms of expression as healing tools. The movement of the mind and body in a creative way leads to a reduction in stress and anxiety as it effects changes in feelings, cognition, physical functioning and/or behavior (Malchiodi, 2005; Stuckey & Nobel, 2010).

Literary arts. Poetry is the most popular form of expressive writing (Fraser & al Sayah, 2011). Research in this area has shown that poetry has helped people find their voice and tap into wisdom they already have but do not experience because of difficulty with finding words in ordinary language (Stuckey & Nobel, 2010). Journaling is another method of expressive writing where individuals access the “unconscious self” (Stuckey & Nobel, 2010). Journaling has been associated with creativity, spiritual awareness and expansion of the self.

Therapeutic benefits of arts-based activities for caregivers

The healthcare system focus today includes a shift from inpatient care to increased care in the community setting and technological advancements that permit individuals to receive various treatments in the home setting. Furthermore, an aging population, which is associated with increased care needs and assistance, sees informal caregivers being depended upon more than ever to provide care to those who need it. Because of the demands of caregiving, there are many negative effects on caregivers including physical, mental, social, and economic. In recent years, researchers have given attention to studying the use of art-making to understand the therapeutic benefits that this type of creative activity can provide to caregivers; for example, in reducing anxiety and stress.

Walsh, Radcliffe, Castillo, Kumar, and Broschard (2007) carried out a pilot study on family caregivers of patients with cancer to test the effects of art-making classes on reducing anxiety and stress, as creative activities are thought to promote amusement, pleasure, and distraction from worry. The researchers in this study highlighted that psychological symptoms, rather than physical symptoms, are overwhelming to family caregivers. Furthermore, they state that art-making as an activity to provide help for family caregivers is based on the philosophical assumption that making art is an innate characteristic and that creative activities will strengthen

psychological health. The art-making activities used in this study included decorating jewelry boxes, monoprints, watercolor paintings, silk scarves or wall hangings, mandela creations, mosaic tile trays, and ribbon gems. Following the 2-hour art-making class, post-test results indicated a significant reduction ($p < 0.01$) in anxiety and stress among the 69 family caregivers.

In another research study, Walsh and Weiss (2003) offered creative arts activities (poster making, monoprint art, mandela creation, silk wall hanging, and greeting card to keep or send to others) to family caregivers and patients at inpatient and outpatient cancer center settings. The purpose was to evaluate the infusion of art into nursing care of family caregivers and patients. Quotes from participants in this study included “I almost forgot how stressed I was”; “This is fun and helps me to relax”; “I immediately felt better when I started choosing the colors for the poster image”. Results from this study were reported as highly significant ($p < 0.01$) on three self-report measures that showed lowered stress, reduced anxiety, and increased positive emotion after participation in the arts activities. Furthermore, involvement in the activities appeared to augment positive communication between family caregivers and care recipients, between care recipients and nurses, and between family caregivers and nurses.

The benefits of older persons participating in arts-based activities

Cohen (2006) draws attention to the benefit of older persons participating in the arts as a means of health promotion to improve wellness. He points out that endeavors to promote health and prevent disease among the aging population are limited when the focus is on targeting problems. He indicates that health promotion in the aging population is successful when one realizes the potential of those who are aging. He specifically highlights the importance of focusing on creativity with aging to recognize the positive impact of the arts on health and

illness. The use of the arts demonstrates promise for promoting individual and community health with potential to alleviate demands on future health care systems (Cooley, 2003).

In their scoping review, Fraser et al. (2015) examined a body of work that explores the linkage of arts, aging, and quality of life and/or health. Their review included research spanning a 40-year period, with the majority of the research published after the year 2000. Arts-based activities from the studies they reviewed included music, painting, drawing, dance, theater or drama, writing and photography. Aging persons were older adults aged 65 years of age or older. Results from their review revealed evidence of growing interest in the contribution of the arts to health and quality of life for older persons. Participation in arts-based activities was mainly active (e.g. painting or drawing) vs. passive (e.g. viewing artwork). Several positive effects were reported by engaging in arts-based activities and these have a link to quality of life and/or health. The effects that were reported included improved mental, emotional, physical, and psycho-social health; more social connection, new learning; enhanced cognitive functioning; increased creativity; promotion of a sense of purpose; a source of recreation and leisure; increased appreciation for aesthetics; the opportunity to leave a legacy; and therapeutic/healing benefits.

The body of knowledge regarding art-making and its benefits with family caregivers is limited, but slowly growing. A review of the literature regarding the history of arts-based activities indicates potential for provision of therapeutic benefits by way of improving well-being and quality of life. Research studies using arts-based activities with older persons and family caregivers have shown the health benefits that art-making can produce. As family caregivers can be inundated with caregiving responsibilities, art-making activities need to be further explored as an innovative and creative option to alleviate some of the stressors and burden that many caregivers experience.

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CHAPTER THREE

What are the Experiences of Family Caregivers Participating in an Arts-based (Collage) Intervention?

A Secondary Analysis

Background

Arts based interventions involve using arts as part of a creative process. Examples include the use of music, dance or expressive movement, literary arts such as poetry, or visual arts such as drawings and collage-making. Arts based activities have been shown to assist in the exploration of one's emotions and thoughts, to resolve emotional turmoil, cultivate self-awareness, manage behavioral issues, improve social skills, reduce anxiety and bolster self-esteem (Ontario Art Therapy Association, 2014; Wang & Li, 2016). The use of arts in health care has been seen in a variety of patient populations such as people with cancer, persons with dementia, and in older persons, which are those in the 65 years+ demographic (Camic, 2008; Chancellor, Duncan, & Chatterjee, 2014; Cheung, Saini, & Smith, 2016; Pienaar & Reynolds, 2015; Wang & Li, 2016). For example, the benefits of older persons engaging in arts-based activities have included improvements in physical and mental health, cognitive functioning, learning, well-being, and a greater social connection and sense of purpose (Fraser et al., 2015). Other areas where arts-based activities demonstrate value are in health promotion, disease prevention, and policy development (Camic, 2008).

The use of arts-based interventions is based on the philosophical assumption that art-making is an innate characteristic (Perruzza & Kinsella, 2010; Walsh, Radcliffe, Castillo, Kumar, & Broschard, 2007). This is because the requirements for participation in arts-based activities include a variety of tangible experiences learned in childhood, such as cutting,

arranging, gluing, and verbal and physical expression (Malchiodi, 2005; Walsh & Weiss, 2003). Engaging in arts-based activities does not require language or verbal skills. In fact, arts-based activities have assisted in the expression of thoughts and emotions that can be difficult to put into words (Archibald, Scott, & Hartling, 2013; Eggenberger et al., 2004; Fraser & al Sayah, 2011; Malchiodi, 2005). Feelings and experiences are not strictly limited to verbal language, which is what makes expressive modalities, such as arts-based interventions, useful in helping with communication of thoughts and stories not easily articulated in verbal communication (Malchiodi, 2005; Stuckey & Nobel, 2010; Walsh, Martin, & Schmidt, 2004; Walsh et al., 2007; Walsh & Weiss, 2003). As a result, the use of arts-based activities opens up a new world for exploring lived experiences (Eggenberger et al., 2004).

Some of the different arts-based interventions used with family caregivers include drawing, painting, coloring, and collage-making. Pienaar and Reynolds (2015) explored the benefits of family caregivers of persons with dementia participating in a 5-week creative arts program. Five over-arching themes resulted from their study. These included positive emotions while doing art work; social interaction with other caregivers, and the camaraderie and the encouragement received; the art program was a source of respite; relaxation after making art that enabled them to return to their caregiving role in a better emotional state; and expressing a desire to continue on with their newfound creative art-making activity. Similar benefits from participating in arts-based activities are reflected in the literature such as restoring emotional balance, decreasing anxiety, and producing feelings of empowerment and liberation (Fraser & al Sayah, 2011; Malchiodi, 2005; Stuckey & Nobel, 2010; Wang & Li, 2016). Additionally, family caregivers have reported decreased depression, enhanced social and psychological well-being, and an increase in enthusiasm, confidence and social support (Camic, Baker, & Tischler, 2016).

Research has shown that when family caregivers engage in arts-based activities their concentration is focused on a single activity, shutting out intrusive thoughts, and inspires creative thinking (Lang & Lim, 2014; Ontario Art Therapy Association, 2014). When thoughts are focused and redirected, stress is then alleviated (Lang & Lim, 2014; Malchiodi, 2005; Walsh et al., 2007; Walsh & Weiss, 2003).

Participating in creative arts-based activities is an innovative method of involving oneself in something that has meaning and benefit, especially during a difficult or challenging life situation (Perruzza & Kinsella, 2010). Many caregivers experience caregiving as a challenging life situation, given the emotional, psychological, physical, financial, and social impact that caregiving has on caregivers' lives (Bastawrous, 2013; Losada et al., 2010). Caregivers' responsibilities can limit their ability to engage in beneficial activities (Bastawrous, 2013; Losada et al., 2010; Walsh et al., 2004). As a result, collage-making, as one example, is readily accessible with no difficulty to complete in most settings or environments. Therefore, family caregivers are able to participate in arts-based activities, such as collage-making, independently in their own home or if desired, in a community setting. Increasing evidence from research on the benefits of arts-based interventions continues to demonstrate improvements in well-being and quality of life and in self-reported health (Camic & Chatterjee, 2013).

While the literature on the use of arts-based interventions with family caregivers is limited, what is known thus far regarding the benefits of arts-based interventions reveals promising results. With the demographic shift toward an elderly population, an increase in chronic disease and other physical ailments that require care needs, the demand for family caregivers will continue to be an essential resource (Bastawrous, 2013; Faucher & Garner, 2015). Given what is known about caregivers' stressors and demands within the caregiving role, it is

vital to explore what therapeutic benefits arts-based interventions can provide to caregivers. Advancing the body of knowledge regarding caregivers' experiences, challenges, and support needs, can assist in sustaining caregivers in their role by informing policy development and clinical practice.

Research Design and Methodology

I completed a qualitative research study using a secondary analysis approach. I used Interpretive Description with a single data set. The data set was the Workshop Evaluation Survey responses (see Appendix) completed by 17 caregivers from the primary study.

Source of Data in Primary and Secondary Analysis*

Research Component	Purpose	Primary or Secondary
Collage making workshop	Make collage to express experience with caregiving and with home care	Primary
Interview	Further explore experience with caregiving and with home care	Primary
Follow-up Telephone Survey	Workshop evaluation feedback	Secondary*

*The findings reported in this thesis are the result of the secondary analysis.

Method

In my secondary analysis I used data from a primary research study that was a mixed method design using qualitative and arts-based methods. The primary research study was comprised of 23 caregivers who were providing care and support to a family member with chronic health conditions and who were receiving home care. The focus of the primary research study was to elicit the experience of caregiving by family caregivers. It explored both the experience of family caregivers and what their experience with home care was like. The use of collage was used with the caregivers as a means to tell their story and express their feelings. The use of art as a form of therapy was not the intention in the primary research study.

In my secondary analysis I used Interpretive Description to guide me as I sought to uncover whether or not family caregivers reported any therapeutic benefit from participating in an arts-based intervention, which in this case was the collage-making workshop. The basis and purpose of Interpretive Description is to provide a qualitative approach to understanding a clinical phenomenon of interest to nursing. Its intent is to capture and describe themes and patterns within the subjective experience of the participant and to generate an interpretive description that can inform clinical knowledge of relevance to nursing (Thorne, Kirkham, & O'Flynn-Magee, 2004). Unlike traditional qualitative approaches, Interpretive Description assumes that investigators continue to explore meanings and explanations that will lead to findings suitable for practical clinical application (Thorne et al., 2004).

Aim

As a result of the potential that arts-based interventions have demonstrated with family caregivers, the purpose of my secondary analysis was to explore whether or not family caregivers, caring for persons at least 65 years of age or older, report therapeutic benefits from participating in a collage-making workshop. Gaining insight into therapeutic benefits from arts-based interventions may help to advance knowledge about caregivers' experiences and challenges within the caregiving role. The goal of gaining insight is to improve health and social policy development and inform clinical practice in order to help sustain caregivers in their role.

Ethics

I received ethical approval through the Health Research Ethics Review Board at the University of Alberta, Edmonton, Alberta, Canada. I did not require additional informed consent as this study was a secondary analysis. The Primary Investigator for the original study received

informed consent for any future data analysis from the original participants, provided any future research on their data went through the required ethics approval process at the time.

Setting

The participants in the original research study attended one of three 4-hour collage-making workshops held at a venue in Edmonton, Alberta. Following the workshop, the caregivers took part in one-hour interview about their experience of a) caregiving for a family member who was also receiving home care, and b) on the experience and meaning of their collage. They also took part in a telephone workshop evaluation survey to provide feedback specific to attending a collage-making workshop. The follow up telephone survey was the data set for my secondary analysis.

Sample

The PI recruited participants for the primary study using her contacts from the Alberta Caregivers Association, the public home care program, caregiver support groups, the media, and her home care network. Of the 23 caregivers from the primary study, 19 were female, 4 were male. Ages range between 45 to 86 years of age. Nine females were care providers for their husband; 2 for their mother; 1 for their father; 2 for both their mother and father; 2 for their daughter; 1 for their son; 1 for a friend; and 1 for an aunt whom she said was like her mother. Of the male care providers, all 4 were caregivers for their wife. The care recipients in the primary study range in age from 32 to 97 years of age. The sample for this research study included 17 family caregivers. Out of the total of 23 caregivers, 20 completed the telephone follow up survey. However, in keeping with my focus of caregivers providing care to persons from the aging population, 3 surveys were excluded, as the care recipients from the excluded surveys were

less than 65 years of age. As a result, there were a total of 17 participants included in this study, all of whom assigned their own alias to be used throughout the study.

Data

The research team collected the original data between March 2015 – March 2016 using a telephone workshop evaluation survey that was conducted over the telephone after the workshop had taken place. They specifically asked caregivers if they found the collage-making activity therapeutic and to specify why or why not. The participants were all family caregivers and ranged in age from 45-86 years of age. The research team used the telephone survey to obtain feedback about the workshop, the techniques used, and the experience attending the workshop. They recorded all responses completed by hand during the call using the survey tool.

Data Analysis

I analyzed all data collected from the 17 included Workshop Evaluation Surveys (see Appendix). I followed the process of Interpretive Description to analyze the data. I used constant comparison and thematic analysis of the Workshop Evaluation Survey data. I coded data line-by-line and then I was able to see recurring themes and patterns in the data. Throughout the analytic process, I identified categories and used language that reflected the participants' language as much as possible. Thorne et al. (2004) indicates that interpretation of data is more than coding and organizing data, it is an intellectual process of inquiry that requires the researcher to move back and forth in the data, in an iterative manner, constantly questioning what the data means and interpreting what is happening. By following this process, I was able to maintain the original intended meaning of the data and this allowed me to engage in the creative processes foundational to qualitative data analysis.

Results

All the participants responded positively regarding the format of the workshop, with a majority of participants stating an appreciation for the social atmosphere of the workshops. Many stated that this was conducive to them sharing their experiences with one another and helped them to not feel so alone in their caregiving journey. Regarding the collage-making exercise, participants found it to be an activity that helped them have insight into their situation as it allowed them to think about their caregiving experience; for many they had never been in a space or environment that enabled them to have time to think and reflect.

I identified six predominant themes in the data based on the participants' feedback and comments. The themes were that the collage-making workshop: (i) Promoted Socialization, (ii) Provided Therapeutic Benefit, (iii) Increased their Awareness, (iv) Inspired Them to Make a Difference, and (v) Facilitated Self-Expression. Some of the themes had sub-themes and I illustrated them below in Table 1.

Table 1: Themes and sub-themes

Theme 1	Promoted Socialization Sharing Stories Not Alone
Theme 2	Provided Therapeutic Benefit Insightful Respite Care
Theme 3	Increased their Awareness Self-Care Need for Help Resources
Theme 4	Inspired Them to Make a Difference
Theme 5	Facilitated Self-Expression

Theme 1: Promoted Socialization

Participants spoke about the format of the workshop and answered questions specific to the collage-making exercise, revealing a pattern related to socialization. When asked what they

liked best about the workshop, participants commented on the interaction and sharing of stories with others, which led many participants to further state that it helped them to not feel alone.

Sharing stories.

Most participants spoke about how the interaction and discussions that took place during the workshop were an excellent opportunity to share stories with one another. This involved participants engaging in verbal discussions, sharing their personal caregiving journeys and their experiences with each other. They openly discussed that the collage-making exercise enabled them to share their caregiving story. Many said that hearing what other caregivers went through and how they managed challenges were helpful. The following quotes reflect this:

“Opportunity to sit down with other caregivers, connect, listen to other people’s stories.”
(*Rocky*)

“I liked hearing people’s stories best. We all have our story to tell. Sometimes good to hear if other people’s stories are better or worse.” (*Joly*)

“Good to learn about other people’s problems, then my own problems seem small in comparison.” (*Mr. X*)

Not Alone.

Participants spoke to the benefit of the discussions that took place during the workshop and the collage exercise as it reinforced that they are not alone in the caregiving journey. Participants appreciated hearing what other caregivers were going through, comparing their own story to that of others. Participants said that doing so helped them feel that others had it worse off than they did. For others, it seemed to be a sense of relief that other caregivers were going through similar situations or challenges as them. Hearing other caregivers’ share their story appeared to provide encouragement that they were not alone. This theme is captured in the following quotes from different participants:

“It brings back to me how much harder other people have it, my story is not as difficult.”
(*Blue*)

“I learned some people were worse off, which gives me courage to keep going.”
(*Lavonne*)

Theme 2: Provided Therapeutic Benefit

Participants said that engaging in the collage-making exercise was helpful in gaining insight into their feelings and in seeing how other caregivers manage their situations and process their thoughts. They felt this helped their stress level, made them feel better about their situation, and was a source of respite. Many indicated receiving restorative and beneficial results, described as therapeutic benefits, in their affirmative response to the question: “Did you find making a collage exercise a therapeutic activity?” This is reflected in the following participants’ quotes:

“Yes, I found the collage part therapeutic and liked to write and express my feelings and share with others; I also made a friend there.” (*Pawny*)

“Yes, I actually entered into the activity. I was actually in the activity, I was very focused, so therapeutic; clarified where I have been and where I am now.” (*Judith*)

Two participants stated that they did not find the collage exercise therapeutic. However, when prompted only one of the two provided rationale and it was that they felt that even though there were many resources or pictures they couldn’t find any to use that they liked or that they felt reflected what they were feeling. One participant indicated that they found the collage exercise “a little bit” therapeutic but did not expand further. For the participants that provided comments on the therapeutic benefit of the collage exercise, two sub-themes were that it provided insight and attending the workshop was a source of respite.

Insightful.

Many participants spoke about their own collage and the collages of the other participants as an exercise that provided insight into themselves as caregivers and insight into the caregiving journey they all shared. Several participants spoke about how the collage exercise helped them get in touch with their feelings and emotions about being a caregiver. This was reflected in the following participants' quotes:

“I liked the exercise of collage as it made me think of myself and where I was in my journey with my dad.” (*Jane*)

“Seeing other people's collages, it gave a lot of insight into them and caregiving. It was a very appropriate venue to open discussion about caregiving.” (*Amin*)

“Gave people a chance to see how they were feeling, gave insight into how they felt.” (*Tinker*)

Other participants spoke about gaining insight regarding the complexity of the caregiving role and insight into their own caregiving situation. Caregivers commented that they had an appreciation for hearing about other caregivers' experiences and the different ways caregivers thought about their caregiving role. This is reflected in the following participants' quotes:

“Knowledge around how others think so differently, what they were cutting out, I saw how people process differently.” (*Sparky*)

“Doing the collage I learned how I feel about the experience, how it evolved over time, what is important to me.” (*Bella*)

“Yes, I actually entered into the activity, I was actually in the activity. I was very focused, so therapeutic, clarified where I have been and where I am now.” (*Judith*)

Respite Care.

Participants spoke about the collage exercise as a form of respite by saying it allowed them to get their mind focused on something other than their caregiving responsibilities. It allowed them some time for a mental escape. In addition to the workshop and collage exercise being a source of respite, several participants also spoke to the need for respite care in the home to allow caregivers to attend workshops, such as the one attended for this study. One participant commented that she was almost not able to attend the collage workshop due to difficulty finding someone to remain with the care recipient. The following quotes reflect the sub-theme of the collage activity being a form of respite and reflect participants' need for respite:

“Yes, I got to tune out what was going on in my head, it was a respite.” (*Sparky*)

“It was healing because it was a moment I took time for myself.” (*Bella*)

“It was hard to get respite care to attend the program, we need volunteers to give respite care.” (*Tinker*)

Other participants spoke about how their caregiving role impacted their time and how it could affect participation in the collage workshop or the possibility of completing a similar activity again on their own. This was reflected in the following participants' quotes:

“No, was feeling overwhelmed with caregiving and did not want to take the time.” (*Toothpick*)

“No, do not have time with caregiving.” (*Shilo*)

“No, I do not have time and I would need encouragement.” (*Granny*)

Theme 3: Increased their Awareness

The collage exercise increased participants' awareness in several areas. The need to look after themselves (self-care) was a common pattern. They said that the collage-making workshops and related conversation and socialization that occurred also increased their awareness of the need for caregivers to receive much more support from both government, by way of supports such as tax breaks and as well, from the healthcare system. They gained an awareness of available community resources that they could use, such as Alberta Caregivers Association. The awareness that they gained also made it evident to them that the lack of information shared with caregivers about caregiving, home care, and related supports was lacking. Some were a little shocked at what they did not know.

Self-care.

Many participants spoke of becoming aware of the importance of taking care of themselves. Some did not realize that they were in fact neglecting their own needs and caregiving often superseded their own self-care. This was reflected in the following participants' comments:

“The collage brought to my attention that I’ve been neglectful in terms of taking care of me.” (*Jane*)

“I learned that I needed to be of value myself before I could care for my husband.” (*Pawny*)

The collage exercise helped participants realize that they needed to take the time to care for themselves and that self-care was important. Awareness of this was identified in participants' comments that they were taking better care of themselves and focusing on diet and exercise. As one participant stated:

“I am taking better care of myself, focusing on what I eat and exercise.” (*Amin*)

Need for Help.

Participants spoke about how the workshop discussions and collage exercise highlighted their need for help; either through reaching out to other family members and friends or through the government and formal healthcare system. Recognizing their need for help or support and talking with other caregivers gave them some tools they could use to seek that help and support following the workshops. Two participants referred to themselves as being “*in a dark place*” but they had not recognized that until they started working on their collage. They then said that it suddenly struck them that perhaps they needed to get some help such as counseling or therapy for themselves. The following participants’ quotes reflect this theme of realizing the need for help:

“Yes, I wanted to give the message to government about the story, that we need help as caregivers.” (*Toothpick*)

“I saw others, what they were encountering and what they saw as vehicles to help them out. We came to the conclusion that we need more help from government, AHS, Capital Health.” (*Tinker*)

Another participant spoke about the difficulty she felt when coming to the realization that she needed more help. This same participant said the following:

“I learned that I need help, not to strive for perfection anymore, prioritize things you can do, what’s important, let the rest go like lawn maintenance.” (*Shilo*)

After the workshop, one participant shared her collage with family, friends, her support group and her healthcare providers. As a result, she was referred to a counselor for support. In addition, the support group she shared her collage with was planning to build on what she shared

and complete a collage about hope. Another participant provided feedback that as a result of realizing the need for help; she was attending a program twice per week, specifically a support program for burdened, overwhelmed caregivers.

Resources.

Several participants talked about gaining knowledge about available resources that they could use right away. They spoke of the acquired knowledge as something that could directly affect their lives for the better. Several participants commented that it was the discussions with the other workshop participants that increased their knowledge about available services. This was reflected in one of the participant's quotes:

“I gained the most knowledge from the other participants in the group, through the camaraderie.” (*Pawny*)

Participants spoke about gaining awareness of organizations such as Alberta Caregivers Association, the government home care program, and other home care companies that they could get assistance from. Further, others spoke of awareness about available resources that could connect them with other services or just get information about services they might need in the future, for example, they mentioned being connected to Pilgrims Hospice and attending a government session about home care and long term care. This provided the opportunity through which to receive additional contacts for resources.

Theme 4: Inspired them to Make a Difference

Some participants commented about feeling inspired to contribute further to helping caregivers based on the knowledge acquired at the workshop. Although not everyone was in a position to help anyone other than themselves, the notion about the importance of reaching out and helping the plight of caregivers in general was discussed as important. Some specific

comments on this were that what took place at the workshop could make a difference in practice and policy; they felt workshops such as the one they attended had helped them feel that their voice was heard and that it was important. Having the opportunity to talk, make their collage, reflect on their own caregiving journey as well as the caregiving journey of others helped them see the need for compassion for all caregivers. One participant felt inspired to advocate for caregivers and acted on this inspiration by writing a letter to the Ministry of Health and then contacted their MLA at the Provincial and Federal levels. This participant also voiced her concerns to Home Care, which resulted in receiving improvements to their care. A second participant went on to facilitate a support group program for caregivers and feels inspired to also do something for caregivers through her church. A third participant stated that, as a result of the knowledge gained at the collage-making workshop, she became a member of a provincial board for young life through their church. The following participants' quotes reflect how the workshop created inspiration:

“I am now on a provincial board for young life through my church.” (*Pawny*)

“I was spurred on to do some advocacy work, wrote letter to the Ministry of Health.”
(*Joly*)

Theme 5: Facilitated Self-Expression

A few participants commented that the collage-making exercise was beneficial as a way to express their feelings. It allowed them to express things that are difficult to verbalize. When asked if the collage was a good way to share experiences on caregiving, one participant stated that the collage exercise was an opportunity to express herself more than she would normally be able to do. A second participant spoke about liking to express her feelings and share them with others through the collage. A third participant commented that the collage exercise helped her to

capture her feelings and express what is important to her. The following quote captures this theme:

“Yes, it was a good way to share cause it brought feelings into the open, defined feelings, helped me focus in or articulate the feelings, cause feelings inside are like a lake of moving water, solidified on paper is good.” (*Bella*)

Discussion

The participants’ feedback from participating in a collage-making workshop adds valuable information to a limited, yet growing body of knowledge regarding the benefits of arts-based interventions. I identified that a few key areas require further exploration. These areas emerged through exploring the themes that were identified and in understanding and interpreting what the participants said. First, the participants’ feedback provided affirmation that socialization, and not being isolated, is an important influencing factor affecting the caregivers’ quality of life. Second, participants indicated the benefit of respite, the continuing lack of respite, and the absolute need for governments and home care programs to provide respite to support caregivers in their role. Third, exploring a variety of arts-based media and activities is important, as there are likely other arts-based interventions that will allow caregivers the opportunity to a) reflect on how they feel about caregiving and what their own needs are, and b) enable them to share their caregiving journey. The ability for caregivers to tell their story and feel that their voice is important was in itself therapeutic.

Benefit of Socialization

An important over-arching theme to emerge was the socialization that being with a group of caregivers enabled. These results demonstrate the benefit to caregivers of having a forum to get together and share their story with others who understand what they are going through. The

collage-making exercise gave them something to focus on as they talked about their own journeys. Participants in a group setting experience the opportunity for personal exchange with others, who are in a comparably stressful situation, as emotionally relieving and supportive (Berwig, et al., 2017). Participants highlighted the value of comparing their journey to other caregivers. When caregivers see others coping well it provides a sense of reassurance, as well as when others are worse off, it makes caregivers feel better about their own situation (Melunsky et al., 2015). Caregivers benefit from getting together with other caregivers, not only to share their own stories but also to be understood by others who can identify with the role and challenges of being a caregiver. Support groups are well documented as an intervention that helps to normalize experiences and improve social connections, as well as to provide support (Wennberg, Dye, Streetman-Loy, & Pham, 2015).

This highlights the importance of caregivers having appropriate settings to get together, with consideration of location, travel, venue, and the time and help from others to allow attendance at these types of interventions. However, caregivers can be so involved in providing for the needs of the care recipient that isolation ensues and socialization becomes rare or nonexistent (Otis-Green & Juarez, 2012). For those caregivers who are socially isolated and lack socialization, their personal health and wellbeing are negatively impacted (Otis-Green & Juarez, 2012).

As a result, thinking about creative ways to connect caregivers to one another requires further exploration. For example, technology and social media are readily available and are viable options that could be used by caregivers who are not easily able to leave their home. Remote interventions could provide social support through online networks and chat forums, thus overcoming the dependency on location (Berwig et al., 2017). For example, peer-led online

support groups are reported as easy to set up and inexpensive to run, with enrollment being immediate, and no limits being placed on the number of participants allowed in the group or the length of time participants remain members of the group (Klemm, Hayes, Diefenbeck, & Milcarek, 2014).

There are online support groups that are facilitated by healthcare professionals; however, these may be restricted in size, offered for a limited time period, or may place potential participants on a waiting list. Either way, participants find these effective if each participant contributes to the supportive exchanges within the group (Klemm et al., 2014). Other examples of options that promote socialization between caregivers include videoconferencing and telephone-based group interventions. These methods have been shown to improve self-efficacy, reduce feelings of burden, distress, and depression and improve quality of life (Berwig et al., 2017). Ultimately, when caregivers are supportive with one another, and have opportunities to share experiences and knowledge, it helps relieve the pressures and burdens of caregiving, mitigate depressive symptoms, reduce angry feelings, and increase quality of life and social support (Chien et al., 2011).

Caregivers Need Respite

The participants in this study clearly indicated that participation in the collage-making exercise provided therapeutic benefit as they saw it as a form of respite. Engaging in the collage-making was an opportunity for them to focus their thoughts on something other than their caregiving responsibilities. Research has shown that when caregivers engage in creative activities, they feel a sense of relief from worries, and results in a reduction in stress and anxiety, with an increase in positive emotions (Stuckey & Nobel, 2010; Walsh et al., 2004).

Even though the literature supports the benefits of caregivers participating in arts-based interventions and caregivers indicate an interest to engage in such activities, many caregivers are not able to participate due to not having someone to remain with the care recipient. The lack of respite is a barrier that affects many aspects of the caregiver's life. For caregivers to take time away for themselves requires access to alternative care arrangements (Pienaar & Reynolds, 2015). The lack of support for caregivers is a barrier preventing not only in engaging in arts-based activities, such as collage-making, that demonstrate therapeutic benefits but is a barrier to instrumental activities of daily living such as getting their hair done, their own dental appointments, banking, shopping to name a few.

The need for better respite was clear and was reflected in the participants' feedback. The findings in this study and the literature indicate that caregivers are voicing the need to receive respite care (Bremault-Phillips et al., 2016; Lilly, Robinson, Holtzman, & Bottorff, 2012; Walsh et al., 2007) but it is still not clear that they are heard or that respite care is improving. The provision of respite would allow caregivers the opportunity to engage in not only leisure, but would also allow them to maintain their own activities required to live a quality life.

Opportunities for Arts-based Interventions

Caregivers' feedback on the creation of a collage was profound for many by realizing the need to take better care of themselves and that it helped them have insight into their own emotions and caregiving journey. Since many caregivers in this study gained insight through the collage exercise, this could imply that health care professionals were not paying close enough attention to caregivers by either not asking enough questions or not asking the right questions. Questioning and assessing how caregivers were feeling and managing within their caregiving role is vital given the significant role they play in their loved one or a care recipient's life whom

they support. In fact, it has been noted in the literature that family caregiver assessment was very weak and caregivers were not being asked how they were doing or even if caregivers had what they need to continue providing care (Feinberg & Levine, 2015). Furthermore, some participants indicated through their feedback that they had a preference to engage in an activity different from collage-making. A few participants mentioned journaling as their preferred method of an arts-based activity. Therefore, it is worth exploring a variety of arts-based activities for caregivers to engage in and important to find out what works for caregivers to suit their preferences and situation.

It is also important to consider that the workshop in this study was a one-time, 4-hour workshop. Therefore, it is worthwhile to explore caregivers' experiences based on workshops that vary in duration, for example, one-day workshops or a series of workshops. The fact that caregivers attended the workshop in this study indicates that caregivers were willing to engage and explore activities that were of benefit to them.

Rigor

The four criteria for establishing rigor in qualitative research include: credibility, dependability, confirmability, and transferability (Guba, 1981; Krefting, 1991; Morse, 2015). Credibility refers to the degree to which the findings are accurately reflected and dependability refers to the ability to obtain similar results if the study were to be repeated. I attended to credibility and dependability by maintaining an audit trail using hand-written notes and through the use of a reflective journal. This helped to capture the thought process and decision-making process throughout the analysis and interpretation of findings. In addition, I consulted with the primary researcher, who is also my thesis supervisor, as a resource to confirm validation of findings. Confirmability refers to the extent of the findings being supported by the research

participants and not researcher bias. I attended to confirmability by linking caregivers' quotes with my findings in order to substantiate and clarify the analytic logic. Finally, transferability refers to the ability of the findings to be applied in other contexts. I attended to transferability through the provision of a rich background description of the research participants, including the research context and setting.

Study Limitations and Strengths

Although the data analyzed represents family caregivers, it has been collected solely from the Edmonton, Alberta region. As well, the data analyzed consisted of participants caring for individuals 65 years of age and older; therefore, results may not be representative of caregivers in other age groups. Research studies using secondary analysis have limitations given that the researcher was not involved in the primary collection of data. One strength of this study is that it adds valuable information to a limited, yet growing body of knowledge regarding the beneficial use of arts-based interventions with family caregivers. The knowledge gained from this study has potential to inform policy makers, health care professionals, and future research.

Summary

Given the demographic shift toward an elderly population, an increase in life expectancy and an increase in chronic disease, family caregivers will continue to be an essential commodity. In order to ensure that family caregivers are able to continue to meet the demands for care, it is vital that innovative options are available and accessible to family caregivers to sustain them in their role. Exploring creative options will help to support caregivers and contribute to their overall health and well-being.

These findings shed more light on the effectiveness and usefulness of arts-based interventions for family caregivers. It opens a new world that uncovers the caregiving journey

for family caregivers. Not only does it allow caregivers to gain insight into their journey, emotions, and needs; but it also provides an innovative method for health care professionals to assess caregivers, allowing caregivers to share aspects of their caregiving journey.

Further research is needed to build on the use of arts-based interventions with family caregivers. It is important to explore other types of arts-based activities, in different settings and for various durations. Given the complexity and demands of the caregiving role, finding creative arts-based activities that assist in supporting caregivers is imperative.

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CHAPTER FOUR

Summary

My work presented in this thesis demonstrates that arts-based activities have beneficial effects for family caregivers. Outcomes include feeling less stressed and anxious after participating in arts-based activities. The activity creates a new focus for caregivers, allowing them to tap into their creativity and provides a source of respite. Caregivers also indicate the value in how the arts-based activity provides an awareness and insight into their own caregiving situation and emotions; many caregivers did not realize that they were not coping well and needed help. The demand on family caregivers to provide care will continue given the demographic shift toward an ageing population, an increase in life expectancy and in chronic disease. It is essential that innovative methods such as arts-based interventions continue to be explored, as advancing knowledge in this area will assist in supporting caregivers and sustaining them in their role.

This paper-based thesis was designed to explore if family caregivers experienced therapeutic benefit from participating in an arts-based intervention, collage-making. I accomplished this by first completing a literature review regarding the use of arts-based interventions. My literature review provided a current state of knowledge pertaining to the types of arts-based activities that are used with caregivers, and the benefits achieved from participating in arts-based interventions, for caregivers and older persons. Second, I completed a secondary analysis using Interpretive Description to examine if family caregivers who participated in a collage-making workshop experienced therapeutic benefit. My data set included workshop evaluation surveys (n=17). This study revealed five over-arching themes that capture how family caregivers benefited from participating in a collage-making workshop. The findings from this

study help in understanding the experiences and challenges caregivers encounter, as well as what caregivers indicate they need to support them in their role. Based on this thesis I am able to offer implications and recommendations for research, nursing practice, policy, and education.

Implications and Recommendations

Research

This study was based on one workshop that was held over a 4-hour period. Further research would be beneficial to explore benefits of other types of arts-based interventions. For example, would caregivers report similar results if they engaged in music therapy or some type of creative dance class? Follow up is required with caregivers after participating in arts-based activities, especially to find out if any caregivers have the interest to pursue participation in arts-based activities on their own. This is based on the indication from the literature that some caregivers do in fact desire to continue with their newfound creative activity (Pienaar & Reynolds, 2015). It would be beneficial to elicit the thoughts and feelings of caregivers at various intervals of time after partaking in an arts-based intervention to find out how long the achieved benefits lasted, or if the benefits lasted for only the short-term. Also, it might be worthwhile to explore whether or not benefits were longer lasting if the workshop was held as a series of workshops over a longer duration of time. In addition, regarding caregivers who cannot get out of their home to attend workshops, either by choice or circumstance, it would be valuable knowledge to explore the opportunity for remote interventions compared to in-person workshops. For example, social media could be one means to explore, as this might increase access to social support for some regardless of time, distance or mobility (Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016).

Nursing Practice

Nurses are a constant presence in the lives of clients and their families, being placed in situations where they have intimate knowledge of both clients and families' needs (Walsh, Martin, & Schmidt, 2004). Therefore, nurses need to ensure that they are assessing caregivers' situations, finding out how caregivers are coping, ensuring that caregivers have what they require to continue functioning in their role, and that caregivers feel supported in their role. The findings in this study support the benefit of caregivers having the opportunity to socialize with other caregivers for its supportive benefit. The importance of support for caregivers was clear when they discussed the value in sharing stories and in not feeling alone. This should serve as a reminder to nurses that assessing the sources of support for caregivers and providing timely and accurate information on resources is not only important but also necessary.

Caregivers could also be encouraged to participate in arts-based interventions; nurses are in a prime role to determine caregivers who are willing and able to participate in arts-based activities (Walsh, Radcliffe, Castillo, Kumar, & Broschard, 2007; Walsh & Weiss, 2003). It requires very little time to initiate a referral, participate in, or encourage caregivers to partake in arts-based activities (Walsh & Weiss, 2003). The Canadian Home Care Association (2015) recommends the vital need to support family caregivers through programs that safeguard their health and to provide information and resources essential to the caregiving role. Nurses are being encouraged to help in establishing creative programs where caregivers can participate in arts-based interventions (Walsh et al., 2007). Another important aspect for nurses to be aware is that some caregivers desire to continue with their creative and other leisure activities. However, this study's findings and the literature continue to reveal that family caregivers experience barriers in doing so unless adequate respite is provided (Pienaar & Reynolds, 2015). It is "unethical" to

offer caregivers a meaningful, stress-relieving experience without the opportunity to take it further (Pienaar & Reynolds, 2015).

Education

Based on the participants' feedback and what is known in the literature, it is important to educate family caregivers on the benefits of engaging in arts-based interventions. Based on findings from participants' feedback, caregivers do not always recognize they are in need of help and may not be coping as well as they might think. Many caregivers in this study increased their awareness into the need for self-care and realized they had to look after their own wellbeing in order to take care of someone else. Therefore, it is important to educate caregivers on arts-based activities as being a method of gaining insight into one's emotions and caregiving situation that can help identify how one is feeling and what resources or lack thereof exist.

It is equally important that healthcare professionals are also educated about the benefits of arts-based interventions and to be aware of available resources for caregivers (Eggenberger et al., 2004; Walsh et al., 2004; Walsh et al., 2007; Walsh & Weiss, 2003). Healthcare professionals need to be aware of the importance of assessing caregivers, ensuring to ask questions related to caregiver coping and supports. In addition, health care professionals need to identify any barriers preventing caregivers from taking time for themselves, whether it is a self-care break or to attend a workshop or program, such as an arts-based workshop or support group.

Policy

Policy implications include the need for funding and development of programs for caregivers that provide the opportunity to engage in arts-based interventions for the purpose of achieving benefits similar to the findings in this study. Furthermore, programs for caregivers need to be designed for flexibility around caregivers' needs and goals; and that programs are

accessible and provide sustainability for the caregiver (Canadian Home Care Association, n.d.; Pienaar & Reynolds, 2015). Additionally, caregivers need to be included in policy-making discussions and decisions so that policy initiatives suit the needs of the caregivers. It is important that policies and programs equip caregivers with the knowledge, skills, and respite in order to continue in their role (Canadian Home Care Association, n.d.).

Conclusion

This research study examined experiences of family caregivers in participating in an arts-based activity (collage). The findings of this study provide valuable knowledge for clinicians, researchers, policy-makers, and family caregivers. For example, increasing our knowledge regarding the benefits caregivers receive from the use of arts-based interventions will help health professionals pay closer attention to family caregivers' needs for support. It will also increase awareness in the value caregivers place on social interaction with other caregivers, and provide indication for further research using various arts-based interventions with family caregivers. These findings are significant because the understanding gained from exploring the benefits of arts-based activities for caregivers adds to the growing, yet limited body of knowledge in this area (Castora-Binkley, Noelker, Prohaska, & Satariano, 2010; Chancellor, Duncan, & Chatterjee, 2014; Fraser & al Sayah, 2011; Perruzza & Kinsella, 2010; Pienaar & Reynolds, 2015; Stuckey & Nobel, 2010; Walsh et al., 2004).

Furthermore, the research findings are timely given the current demographic trends that include a population that is aging and an increased life expectancy with an increase in chronic disease, all of which contribute to care needs. Furthermore, with a formal health care system placing expectations on family to provide essential services, family caregivers are being impacted today and in the future more than ever before. The negative impacts that family

caregivers can experience places their own health and wellbeing in jeopardy. If the overall health and wellbeing of the caregiver is jeopardized, then the health and wellbeing of the care recipient is also jeopardized. Research has stressed the need for realistic methods and innovative approaches to access caregivers and provide solutions to improve caregivers' wellbeing (Castora-Binkley et al., 2010; Chancellor et al., 2014; Perruzza & Kinsella, 2010; Pienaar & Reynolds, 2015; Stuckey & Nobel, 2010; Walsh et al., 2004; Walsh et al., 2007; Walsh & Weiss, 2003).

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Appendix

The Use of Collage Techniques as a Means of Eliciting Story About Home Care and Caregiving: The Family Caregiver's Perspective.

You recently participated in a workshop that was part of a research study where you created a collage to represent what it means to you to receive home care and be a caregiver for a family member. We would like to obtain your feedback about the workshop. The information that you provide will be linked to your pseudo name or alias. It will be used to inform the development of future workshops for family caregivers and it may also be used to supplement the data that were gathered for the research project.

Would you like for me to proceed with the survey questions?

1. Did you like the format of the workshop?
2. What did you like best about the workshop?
3. What did you like least about the workshop?
4. Was the time (please circle): Just right too long too short
5. Did you find making a collage exercise (check all that apply)
 - Useful to you in thinking about your caregiving role
 - A fun leisure activity
 - A therapeutic activity
 - Something you would do again on your own
 - A good way to share your experience on caregiving
 - Other _____
6. Why or why not?
7. Did you gain knowledge or understanding at the workshop? What kind of knowledge did you gain?
8. How did the knowledge that you gain impact your life?
9. Do you have suggestions for how to improve the next workshop for family caregivers?

Thank you for taking the time to complete this evaluation survey!

If you have any questions, please contact Kelly Shaw (Research Assistant) at: 780-492-5914 or ktshaw@ualberta.ca.