A Qualitative Exploration of the Experience of a Single Mindfulness Session with Informal Caregivers

by

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An oral defense of this thesis took place on 22nd October, 2018 in front of the following examining committee:

Examining Committee:

Chair of Examining Committee	Dr. Otto Sanchez
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The above committee determined that the thesis is acceptable in form and content and that a satisfactory knowledge of the field covered by the thesis was demonstrated by the candidate during an oral examination. A signed copy of the Certificate of Approval is available from the School of Graduate and Postdoctoral Studies.

Abstract

Introduction: The purpose of the pilot study was to explore informal caregivers' experience who have completed a short, single mindfulness session. There is evidence to support mindfulness as a non-invasive method for improving psychological and physical well-being.

Methods: The participants (N=6) of the study attended a short, single mindfulness practice session. One-on-one semi-structured interviews were conducted to obtain data and a thematic content analysis method was used for data analysis process.

Results: Six main themes emerged from the obtained data. The identified themes were: 1) comparison of mindfulness to other relaxation methods: 2) initial impression on mindfulness; 3) mindfulness as a relaxation technique; 4) mindfulness as a support for sleep hygiene: 5) mindfulness as an anxiety reduction method and; 6) future integration of mindfulness into daily life.

Discussion: The emerged themes of the study highlighted informal caregivers' perceived effectiveness of mindfulness practice in their daily life, which lays a foundation for future research. Participants perceived a single mindfulness session to be an opportunity to learn a relaxation technique.

Key Words: Mindfulness, Informal Caregivers, Qualitative Exploration

AUTHOR'S DECLARATION

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Farah Tahsin

YOUR NAME

STATEMENT OF CONTRIBUTIONS

I hereby certify that I am the sole author of this thesis and that no part of this thesis has been published or submitted for publication. I have used standard referencing practices to acknowledge ideas, research techniques, or other materials that belong to others. Furthermore, I hereby certify that I am the sole source of the creative works and/or inventive knowledge described in this thesis.

Acknowledgments

Resilience has always been a source of wonder for me. How do we endure the toughest times? I always wanted to explore the strength of human resilience, which inspired me to take on a research journey on the topic of mindfulness. I would like to thank my teachers, and my mentors who always supported my goal.

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Chapter 1: Introduction

Due to the stressful nature of the role of caregiving, formal or informal caregivers often suffer from physical, emotional and psychological exhaustion (Lee et al., 2015). Informal caregivers refer to the unpaid persons who provide care for dependent friends, family members or neighbors (Hurley, Patterson, & Cooley, 2013). As the number of community-dwelling older adults is increasing, the number of informal caregivers of seniors is also growing (Statistics Canada, 2015). In 2015, 27% of the total population of Durham region were 55 and older (Durham Health Stats. 2018). There is a staggering cost of 10.4 billion Canadian dollars per year to provide care for individuals with dementia and the cost is expected to rise over the next decade (Statistics Canada, 2016). Institutionalizing individuals living with dementia causes financial and health system burden. By providing care to individuals with Alzheimer's and dementia, informal caregivers alleviate this ever-increasing burden on health system. According to 2015 Canadian Statistics, one in five Canadians over the age of 45 provides care to a senior with long-term health problems (Statistics Canada, 2015). Therefore, the psycho-social well-being of informal caregivers is an important health issue which can have public health ramifications.

Informal caregivers report high levels of distress and anxiety, which cause financial and health concerns (Hurley, Patterson, & Cooley, 2013). It is important to evaluate evidence-based sources of support to help this population better cope with their caregiving roles and their own daily lives. Recent research suggests that by engaging in a mindfulness-based intervention, caregivers can enhance the self-management of their psychological stress (Hastings & Beck, 2004; Singh, 2014).

Mindfulness-based training is increasingly used as a clinical intervention or therapeutic technique in conjunction with a variety of therapies including stress reduction and cognitive behavioral therapy (Davis & Hayes, 2011; Hastings & Beck, 2004; Singh, 2014; Analayo, 2016). Bishop et al. (2004) have defined mindfulness as a process to: 1) self-regulate attention and bring a non-elaborative awareness to one's experience, and 2) become immersed in one's experience with curiosity, openness, and acceptance. These elements of mindfulness have been investigated from multiple research perspectives (Analayo, 2016, Singh, 2014).

Several mechanisms may come into play when a caregiver regularly practices mindfulness (Singh, 2014). For example, enhanced mindfulness may provide caregivers better emotional self-regulation during periods of acute stress (Analayo, 2016). It may also increase cognitive flexibility when their responses are informed by an awareness of what is unfolding in the present moment, without the distortions of their own emotions and perceptions of the events. If caregivers are aware of their own emotions and are able to regulate their distress, caregiver burnout or fatigue decreases (Singh et al., 2016).

Statement of the Problem

An increasing number of informal caregivers who experience stress, anxiety, are diagnosed with a depressive disorder and are functioning poorly in daily life (Epston-Lubow et al., 2008). Providing care to a loved one is a stressful role; therefore, caregivers in the community need to be well supported. As a result, using various coping strategies might help mitigate the symptoms of a caregiver’s burdens. Mindfulness is considered a relaxation technique, which can increase the subjective well-being of the caregivers. Mindfulness has proven to assist people with emotional distress, anxiety and other negative stressors (Singh et al., 2016). Thus, this generic

qualitative study explored how informal caregivers experienced mindfulness, with a particular emphasis towards the caregivers ' willingness to participate in mindfulness practice sessions in the future.

Purpose of the Study

The aim of this study was two-fold: 1) to explore informal caregivers' perceptions/experiences of participating in a short, single mindfulness practice and 2) to understand the factors that influence their intentions to continue practicing mindfulness in the future. Participants' expectations and experiences during a mindfulness-based session was explored through the in-depth one-on-one, semi-structured interviews. While designing the research proposal, the researcher assumed that the findings of the study would provide an understanding of the perception of single session mindfulness practice among informal caregivers.

The Significance of the Study

According to Baritt (1986), there is a need for research studies that focus on creating a dialogue, which establishes a new line of thinking and assesses a topic with an understudied group. This type of research leads to the improvement in health care practice and heightened awareness on a topic (Creswell, 2000). This qualitative study will shed a light on the efficacy of a brief, single mindfulness session for informal caregivers. Participants' descriptive self-reports and opinions about the session will highlight their perspectives and experiences, which are sparse in current mindfulness literature. This pilot study will also lay the groundwork for future research that may aim to explore perceived appropriateness of mindfulness session among informal caregiver. Moreover, the findings of the study may help inform healthcare providers about the efficacy of providing brief single mindfulness sessions for caregivers to prevent caregiver distress and

burnout. This includes the healthcare providers that may intend to develop mindfulness programs for informal caregivers who provide care and support to persons living with dementia.

Research Questions

The present study aims to explore participants' perspectives of mindfulness. The main research question is, "What is the personal experiences of informal caregivers who have completed a brief, single mindfulness practice session?" The sub-questions are: 1) What are the participants' perspectives on a brief, single mindfulness practice session? (i.e. the length of the session, group vs. individual etc.), and 2) What are the factors that influence the participants' intentions in continuing to practice mindfulness in the future?

Chapter 2: Literature Review

Chapter Overview

In this chapter, a review of existing literature on the topic of mindfulness is presented. This chapter contains sub-sections including the emergence of mindfulness practice in Western psychology, different methods of mindfulness (such as mindfulness-based stress reduction, mindfulness-based cognitive therapy), review of literature on brief mindfulness and single session mindfulness practice. Moreover, this chapter contains a review of literature on the effect of mindfulness on informal caregivers. Even though mindfulness is a novel topic of research in the academia, there are some recurring themes in the current literature such as mindfulness-based stress reduction, and mindfulness-based cognitive therapy (Hastings & Beck, 2004; Singh, 2014; Analayo, 2016). Some research has been conducted on the effects of mindfulness on formal caregivers (physicians, nurses) (Franco et al., 2010; Hoppes et al., 2012), but there has been limited research on the informal caregivers (Hurley, Patterson & Cooley, 2013).

Mindfulness: An Idea Emerged from East and Embraced by West

The concept of mindfulness in Western culture is derived from Buddhist meditation techniques dating back to the sixth century B.C. in India (Bodhi, 2011). Mindfulness training has been found to be useful for reducing physiological and psychological distress (Hou et al., 2013; Ostafin et al., 2006). Western psychologists define mindfulness as an inherent feature of human consciousness that can vary markedly between and within individuals, ranging from a highly mindful state to a highly habitual, automatic or mindless state (Bishop et al., 2004; Kabat-Zinn, 1990).

During the 1970s, mindfulness gained wider attention from psychological researchers and was considered by some to have significant therapeutic potential (Smith, 1975). Perhaps the best-known figure in early mindfulness research in the West is a molecular biologist by the name of Jon Kabat-Zinn, who first introduced a structured mindfulness-based treatment protocol in 1979 at the University of Massachusetts Medical Center. He called the program mindfulness-based stress reduction (MBSR) (Kabat-Zinn, 1990), and offered it to patients experiencing distress related to a range of clinical presentations including chronic pain, anxiety, hypertension, heart disease, cancer, and sexually transmitted diseases. Other mindfulness-based interventions, such as mindfulness-based cognitive therapy (MBCT) target relapse prevention in recurrent depressed individuals (Singh et al., 2016; Teasdale et al., 2000).

Mindfulness has been defined as an elevated level of awareness and enhanced ability to direct one's attention to the present moment without any judgment. Jon Kabat Zinn (1994) has defined mindfulness as “paying attention, on purpose, in a particular way, to the present moment, non-judgmentally.” (p.4). Overall, mindfulness practice is considered a low-risk, self-management tool to alleviate negative physical and psychological well-being (Singh et al., 2016). According to Medvedev, Krägeloh, Narayanan & Siegert (2017), mindfulness has been conceptualized in two different views: state and trait mindfulness. Trait mindfulness refers to a general tendency or characteristic of a person to be mindful. On the other hand, state mindfulness refers to the actual level of mindfulness at a specific moment of time or condition (Park et al., 2013) and therefore, depends on different environmental interactions and conditions. There is a lack of reliable and valid scientific measures to distinguish between state and trait mindfulness. Appropriate measurement tools to examine two different views of mindfulness would contribute in the important clinical and research questions.

Mindfulness-Based Psychotherapies in Western Psychology

Mindfulness-based Stress Reduction (MBSR)

A plethora of empirical research studies has focused on mindfulness-based stress reduction (MBSR) therapy, which as indicated previously was coined by Jon Kabat-Zinn in 1970. MBSR is a concept that is used to guide patients to observe their experience from detached perspectives (Kabat-Zinn, 1984). The eight-week MBSR program consists of a two to three hour meeting each week and daily mindfulness exercises for a period of 45-minutes per day (Kabat-Zinn, 1984).

Nyklicek and Kuijpers (2008) found that MBSR was associated with decreased levels of distress, increased quality of life, and positive affect. Parents of children with developmental delays who completed an MBSR program reported decreased distress and better life satisfaction (Neece, 2013). MBSR has also been shown to be an effective stress management method for informal caregivers. Hou et al. (2013) conducted a randomized trial (N=141), where the group who practiced MBSR showed a greater decrease in depression compared to the control group. In addition, in the three-month follow-up period individuals who participated in the mindfulness-based intervention had a better quality of life, increased self-compassion and decreased perceived stress. Despite these encouraging findings, the literature has also revealed significant methodological shortcomings. In the current MBSR literature, there is a need for more extensive qualitative and better-controlled studies to demonstrate the efficacy of this specific mindfulness program, including the clinical and psychosocial benefits.

Mindfulness-Based Cognitive Therapy (MBCT)

Another mindfulness-based psychotherapy that has received considerable attention from researchers and clinicians is MBCT (Teasdale et al., 2000; William et al., 2000). This treatment protocol, based largely on MBSR, is aimed at reducing the rate of relapse in individuals recovering from major depressive symptoms, by teaching them to recognize early signs of depressive relapse and to respond to them more effectively (Bergomi, Tschacher, & Kupper, 2012).

Teasdale et al. (2003) conducted a randomized controlled trial to evaluate the effectiveness of MBCT among individuals with major depressive disorder who were in the process of recovery. All participants (N=145) continued with their usual treatment whereas the treatment group also received MBCT training. They found that participants who have received MBCT in addition to their usual treatment reported lower number of relapses and recurrences of major depressive disorder. This study suggest that mindfulness-based cognitive therapy can be beneficial for patients with recurring depression as it helps them to dissociate their cycle of ruminative thoughts. Congruent to previous findings, Evans et al. (2008) suggest that MBCT has been proven to be a useful preventative therapy for patients with generalized anxiety disorder. Participants (N=11) enrolled in the MBCT group showed a significant decrease in overall anxiety and depressive symptoms from baseline to the end of the mindfulness program. Overall MBCT has been explored in the current literature from a clinical psychology lens and with an emphasis on measuring the relapse rate/frequency of participants' symptoms.

Brief Mindfulness: A Newly Emerging Area of Mindfulness

Traditionally, mindfulness-based interventions have been designed as several sessions. This design style requires a significant amount of time and resources over the span of several weeks, which can be a barrier for participants. Individuals might be unable to join a mindfulness-based therapy group or continue in a program because of the required time commitment. Caregivers manage multiple roles in their everyday life where investing several weeks in a mindfulness-based program may be difficult. Therefore, a brief, single mindfulness-based practice session was used in the current research project.

Studies looking at the effect of brief mindfulness have shown promising results for participants. A study conducted by Tang et al. (2007) found that five days of a 20-minute meditation training was associated with decreased depression, anxiety, anger and fatigue when compared with a control group exposed to relaxation training only. In addition, they found that there is a decrease in cortisol levels post-intervention, which shows that a brief mindfulness session can have a prolonged impact on psychological well-being.

Lloyd et al. (2016) investigated the impact of a three-minute mindfulness exercise on the recognition memory of participants. Recognition memory refers to the ability to recognize previously encountered events, objects, or people. Participants were exposed to words and non-words as stimuli and later they were tested to see if they could retrieve the previously presented words and non-words. The study found that participants who had completed the three-minute mindfulness practice provided less inaccurate responses during post-intervention information retrieval compared to the control group. Therefore, the study suggests that as little as three minutes of mindfulness practice can have a positive impact on memory. This finding is consistent with previous research findings that mindfulness can improve cognitive performance (Levy et al., 2001).

Fissler et al. (2016) examined if a brief mindfulness can increase the interoceptive awareness among depressed patients. Interoceptive awareness refers to the sensing of the physiological condition of the body and mental representation of the mind. Participants in the mindfulness training group engaged in twenty-five minutes of mindfulness exercise twice a day, seven days a week for three weeks. On the other hand, the control group scheduled regular rest periods to retreat from daily activities. The study found that depressed patients who participated in the mindfulness exercise scored higher on their interoception awareness and decentering ability than their counterparts. Decentering is the ability to view negative events as passing occurrences in the mind, rather than identifying oneself with the events. Therefore, the results of the study showed that the decentering experience has a role in reducing depressive symptoms among participants.

Feldman et al. (2010) conducted research with an undergraduate student population, comparing progressive muscle relaxation training and two different mindfulness techniques (mindful breathing, and loving-kindness meditation). Participants participated in all three interventions (muscle relaxation, mindfulness breathing, and loving-kindness meditation). Each intervention was fifteen minutes long. Participants in the mindfulness breathing group reported greater decentering ability compared to the other groups. This decentering ability of participants made them less emotionally reactive to internal and external experiences (Shapiro et al., 2006). These results suggest that mindfulness of breathing may offer more psychological benefits than other credible stress management approaches. Furthermore, the study provides support for the idea that even a single session mindfulness intervention may result in beneficial, psychological change.

Informal Caregivers and Mindfulness

Previous research has found that informal caregivers experience physical and mental exhaustion due to their caregiving roles (Hurley, Patterson, & Cooley, 2013). The informal caregiver is an individual who aids or takes care of a dependent family member, friend or neighbor without being paid (Hurley, Patterson, & Cooley, 2013). Researchers have found that compared to non-caregiving control participants, caregivers perform significantly worse on cognitive tasks (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Shapiro, Brown, & Biegel, 2007). Research suggests that impaired sleep due to stress was the main mediator of poor cognitive performance. The aforementioned studies emphasize the need for interventions to address the psychological distress of caregivers. Mindfulness has proven to be a useful technique that aids individuals to regulate their emotions (Hurley, Patterson, & Cooley, 2013).

A mixed method pilot study was conducted by Singh et al. (2014) to investigate the effectiveness of mindfulness-based stress reduction treatment for caregivers (N=8) of frail elderly and they found that depressive symptoms, burden, and perceived stress decreased over the eight-week mindfulness program. Qualitatively participants reported that they found mindfulness practice sessions increased their ability to be present with their care recipients and they expressed their intention to continue practicing mindfulness. Furthermore, a series of quantitative exploratory studies reported that mindfulness-based practice benefits caregivers by reducing their stress (Singh, 2016; Duffy et al., 2016) and burnout, (Singh, 2016; Epstein-Lubow et al., 2011), as well as increasing the well-being of the care recipients (Epstein-Lubow et al., 2008; Lavretsky et al., 2008; Innes et al., 2012).

In another mixed methods study conducted by Hoppes et al. (2012), eleven family caregivers participated in an hour of mindfulness session each week for four consecutive weeks. The researchers found that after engaging in four weeks of brief mindfulness sessions, participants showed a statistically significant increase in their level of hope and a decreased level in their sense of burden. In addition, in the qualitative part of the study (semi-structured interviews), participants reported an increased sense of hope, awareness and subjective well-being after the brief mindfulness session. Congruent with the previous findings, the participants expressed their interest in continuing the mindfulness practice in the future. Following a review of the literature, the need to conduct more qualitative research on informal caregivers' perceptions of brief mindfulness sessions is evident, since it is a topic that has not been explored extensively. More in-depth qualitative research can contribute in developing a body of knowledge on participants' understanding of mindfulness.

Single Session Mindfulness Practice

As described above, the effects and benefits of prolonged mindfulness interventions have been explored extensively. Being an informal caregiver is a challenging role (Singh et al., 2016) as caregivers are often occupied with multiple responsibilities and tasks. Therefore, informal caregivers might not find it feasible to commit to a mindfulness intervention that requires multiple days and weeks. Therefore, single session mindfulness is deemed more feasible and applicable for informal caregivers. Currently researchers are focusing now on how brief interventions, as little as a single session mindfulness intervention, may be beneficial for participants. Promising research results inspired the current researcher to explore the topic further.

Mahmood, Hophthrow & Moura (2015) conducted a series of three studies to investigate if a 5-minute, computer-mediated mindfulness practice can increase the level of mindfulness among high school students. Due to various limitations, the first study (N=51) failed to show a statistically significant difference between the mindfulness and control group. However, the later studies showed a statistically significant difference between the two groups; participants in mindfulness group demonstrated increased mindfulness compared to their control counterparts. In the second study (N=90) and third study (N=61), they found that students who participated in a five-minute mindfulness session scored higher on the Toronto Mindfulness Scale (this scale is specifically designed to measure state mindfulness) compared to the control group who were only instructed to take deep breaths during the intervention.

Erisman and Roemer (2010) examined the effects of a 10-minute mindfulness intervention on students. They found that students (n=15) who participated in the brief intervention were less affected (scored higher on a decentering subscale) by watching a distress inducing film clip than participants who were in the control group who only listened to neutral educational information. This demonstrates that a mindfulness intervention as short as ten-minutes can help participants to be less responsive to negative stimuli than their counterparts who have not participated in a mindfulness practice.

Rausch, Gramling and Auerback (2006) also found that undergraduate students (N=387) participating in 20-minutes of either a meditation or progressive muscle relaxation intervention reported lower cognitive, somatic and general state anxiety after exposure to a visual stressor than the control group who were instructed to sit with their eyes closed and relax during the intervention period. Consistent with the anxiety regulatory properties of mindfulness, these results suggest that those participating in the brief group meditation responded more adaptively

to the visual stressor. Watier and Dubois (2016) investigated the effect of a single 10-minute brief mindfulness session on executive attention and recognition memory. They divided the participants into three different groups (brief mindfulness exercise group, attention exercise group, and an arithmetic group). Participants (n=26) who were randomly assigned to the mindfulness group scored higher on a mindfulness scale than the arithmetic control group. However, there was no statistically significant difference among the mindfulness exercise group and attention exercise group.

These studies represent a new line of research that is emerging in the mindfulness field, suggesting that as little as one mindfulness session can be associated with decreased anxiety, stress and negative psychological outcomes for participants.

Summary

The literature review suggests that mindfulness can be considered a non-invasive therapeutic tool for stress reduction and improved psychological outcome. In addition, brief single session mindfulness has proved to be beneficial for psychological well-being of the participants. Informal caregivers have reportedly benefitted from practicing mindfulness exercise. Previous research findings show that practicing mindfulness helps to reduce caregiver distress and burnout; as well, their care recipients' well-being improves. However, there is a paucity of qualitative data on the topic of mindfulness and its perceived effectiveness among participants.

Chapter 3: Methodology

Chapter Overview

This chapter describes the methodology of the current research, including the research design, participant and research site, recruitment process, description of mindfulness session, data collection tools and procedures, and the data analysis process. This chapter also includes a description of the researcher and her relation to the subject, along with information about her role in the study.

Research Design

The generic qualitative research design was chosen as it serves the purpose of this study, which is exploring the phenomenon of mindfulness from the informal caregivers' perspectives. This research approach enabled the researcher to seek the answer to the research question, which was: "What is the experience of the informal caregivers who have completed a brief, single mindfulness session?" The explorative nature of the research question allowed the researcher to guide the interview process, as well as collect the research data in a systematic way. In addition, it provided an opportunity to explore informal caregivers' understanding of the usefulness and application of mindfulness into their daily life.

This explorative qualitative study was conceptually grounded in Braun and Clarke's (2006) thematic analytical model. The researcher used this model to examine the research topic and to create a thematic pattern. The Braun and Clarke's (2006) thematic analytical model follows six steps of analysis: 1) Being familiarized with the collected data; 2) Generating initial codes and

meaning units; 3) Creating themes; 4) Revising generated themes; 5) Defining themes; and 6) Producing the report.

I strictly followed this step-by-step process of thematic analysis during the data analysis process. I read and re-read the collected data to familiarize myself with the concepts, then grouped and organized the data into meaningful units. After finding the codes or meaning units, I clustered similar unit patterns into themes. Those themes guided me to create a meaningful thematic network to present in the research findings. The themes need to be revisited, reorganized and refined several times to make the data analysis more organized and advanced.

The process of step-by-step thematic analysis helped me to systematically unravel the collected data and to obtain insight into the stated research topic. Furthermore, the comprehensive and rigorous process of data analysis helps submerge the researcher in the collected data, which assists in producing a report that represents the findings of the study in a meaningful way.

Research Method

To study the meaning of mindfulness among informal caregivers, I used a generic qualitative approach to address the research question. The primary goal of a qualitative research process is to learn the meaning of a specific phenomenon or topic held by the study participants (Creswell & Poth, 2018). Therefore, the researcher selected this approach to understand the meaning of mindfulness from the perspectives of the study participants. In addition, it provided an opportunity to explore informal caregivers' perspectives about the effectiveness of the mindfulness practice session.

This qualitative research was conceptually grounded in Braun and Clarke's (2006) thematic analytical model. Using this thematic model, the researcher investigated the proposed topic with a qualitative thematic approach. Braun and Clarke's model has been well received because of a strong systematic approach to data analysis.

In the current research study, data was collected using one-on-one interviews with the study participants. This data collection method is in line with the standards of a purposeful sampling, which enhanced the validity of the study. Purposeful sampling aids in collecting rich data with an eye on the research question (Creswell & Poth, 2018). In the present investigation, the purposeful sampling was guided by the research question. Through purposeful variation, maximum variation of sample was ensured. By using a sample of maximum variation, diverge and unique perspectives were captured during data collection process and heterogeneity of sample population was maintained (Creswell & Poth, 2018).

Participant Recruitment

The eligibility criteria for participants included: an informal caregiver who speaks English and is 18 years of age or older. Individuals who already practice mindfulness were excluded as the researcher wanted to explore participants' experience of a brief, single session mindfulness exercise. Participants who have practiced mindfulness before might have a preconceived understanding of mindfulness. Therefore, it would be difficult for the researcher to decipher participants' perceived experience of the current single session mindfulness exercise from participants' overall experience of mindfulness exercise from their previous experiences. The research site for this study was the Alzheimer Society of Durham, which is located at Whitby, Ontario. According to Statistics Canada, 25,000 new dementia cases are being diagnosed every year and an estimated 564,000 Canadians are living with dementia (Statistics Canada, 2016).

Being a caregiver of individuals with Alzheimer's and other forms of dementia is a distressful job (Singh, 2014). Therefore, the Alzheimer Society of Durham was chosen as the research site to understand how mindfulness is perceived by caregivers of individuals with Alzheimer's and other forms of dementia.

Participants were recruited through the organization by circulating emails, word of mouth and snowball sampling. The brochure (Appendix A) asked clients (informal caregivers) of the organization if they were open to participating in a mindfulness session; caregivers who agreed to participate were referred to the researcher for the full informed consent procedure. The study was reviewed by the research ethics committee at the University of Ontario Institute of Technology (REB file #14588) and it was approved by the REB board in November 2017.

Sample Size Determination

The goal of the study was not to create a generalized hypothesis on the topic of mindfulness; rather the goal was to understand informal caregivers' perceptions of a brief, single mindfulness practice session. According to Flick (2007), qualitative research sampling helps construct empirical and purposeful examples to understand the phenomenon of interest in the most scientific way. In addition, Crouch & Mackenzie (2006) suggest that to understand a phenomenon or generic meaning of a topic through a qualitative method, a small sample size is adequate to obtain meaningful empirical data. Hence, given the qualitative design and scope of the current research, it was concluded that a small sample size of five to ten participants with the final sample size to be determined by data saturation, would be an ideal sample size to explore mindfulness practice.

Procedures

Upon receiving permission from the Alzheimer Society of Durham, I screened the respondents (Appendix B: Screening Form), and then contacted and met with prospective participants to discuss the proposed research study.

I read each prospective participant information that explained the purpose of the study, participants' tasks, their rights and terms of confidentiality, the manner in which the research results would be disseminated, as well as the name and contact information of the researcher (APA, 2011; Leedy & Ormrod, 2004). Potential participants' questions related to the study and their rights and confidentiality were answered fully by the researcher. Interested participants signed the consent form (Appendix C), as approved by the University of Ontario Institute of Technology REB.

Description of the Mindfulness Practice Session

After participants signed the consent form, I introduced myself to the participants and reviewed the aim and purpose of the study, answered participants' questions on the length of the mindfulness practice, as well as re-emphasized participants' right to withdraw from the research at any time. Afterwards I introduced the mindfulness instructor to the participants and described the instructor's role in the practice.

The instructor was a certified mindfulness instructor from The Centre for Mindfulness Studies in Toronto. She shared that she had been practicing mindfulness for last ten years and answered participants' questions on her frequency and nature of practicing mindfulness. She explained that participants would take part in a guided mindfulness practice session with her and that she would play some music at the end.

During the 15-minute mindfulness session, participants followed basic meditative techniques as instructed, which included the sitting practice and focusing on breathing. The mindfulness practice included a body scan comprised of observation of the various parts of the body followed by observation of the thoughts in the mind and observation of the breath. The mindfulness practice required a period of silence with an inward focus and an effort to observe the mind. The breath was used as an experiential anchor to the present moment. Participants were also instructed to pay attention to internal and external stimuli, using a breathing technique to guide their attention to their physical and psychological sensations. The final deep breathing exercise incorporated one pointed focus of the mind on the mantra Gauranga, a transcendental sound, to further improve the participants' ability to relax. At the end of the session, she asked participants to open their eyes and she thanked each participant for joining her practice session. The researcher also thanked the participants and then she described the interview procedure. Five out of six participants were interviewed immediately after the session and one participant had to leave due to a prior commitment. The researcher set a later date for that participant to be interviewed.

Researcher Role

As a researcher, I assumed an observer role in this study with an open mind to the responses of each participant. I concentrated on each piece of information conveyed by participants and observed their communicated experiences. I observed participants' body language and took notes. The findings from the notes are reported in a written manner in the data collection section. Focused attention on the participants' experience transcended into the deeper insight of the participants' experiences.

While the participants were engaging in the 15 minutes mindfulness session, I took observation notes (Appendix G: Observation Notes) to collect non-verbal cues and body languages. Participants were instructed to close their eyes while practicing mindfulness; as a result, participants did not notice my observational activities. Moreover, to ensure that my presence in the room was not distracting for the participants, I sat at the corner of the room, away from the instructor. The participants were facing towards the instructor while practicing mindfulness, therefore, I was mostly out of sight of the participants during the session.

The Researcher's Considerations and Interview Approach

One-on-one interviews together with the researcher's field notes provided the data for this research. For a few of the interviews, I had to take a more structured approach such as providing prompts to keep the interview focused on the study topic. This strong involvement of the researcher during the interview process created a more structured interview than I initially assumed would be needed.

Interview Questions

Together with the research question: What is the personal experience of informal caregivers who have completed a brief, single mindfulness practice session?", additional sub-questions were asked of the participants in the study. These questions guided the researcher in obtaining in-depth insight into each participant's personal experiences and descriptions of the mindfulness practice. These questions were as follows:

1) What was your overall experience with this mindfulness session?

You can talk about anything related to this session, for example, whether you liked it or not, whether you found it helpful or not, and how it helped you, or how it didn't help you?

2) Did you feel the instruction during the mindfulness practice was easy to follow? Was it easy for you to bring your attention to breathing? Why or why not?

3) Do you think you will continue to practice mindfulness in the future? Why or why not?

4) Is there anything else about your experience in the session that you would like to share that I did not ask about during this interview?

Additional sub-questions were created to support and guide the researcher to explore the main research question. Therefore, for this study, the main research question guided the development of sub questions and prompts. To obtain information-rich data, the researcher used individual one-on-one interviews (Silverman & Marvasti, 2008). The interviews took place immediately after the mindfulness session ended. In the interviews, participants were invited and encouraged to speak in detail about their experiences of the mindfulness practice. The interview questions were developed with the guidance of the overarching research question. The questions contributed to the interview process; participants shared openly about their personal experiences of the brief mindfulness practice. In sum, the data collection process established thematically substantive data, to the benefit of the qualitative thematic-oriented research (Creswell, 1998).

Interview Procedure

Before the interview process started, I set up the interview space. This room was located on the premises of the Alzheimer Society of Durham, in a quiet area of the building. Upon completion of the mindfulness practice, I began conducting interviews immediately. Due to one participant's prior commitment, she was interviewed two weeks after participating in the mindfulness session. However, a similar methodological procedure was used for each interview. As few of the participants had to sit in the waiting room for a couple of hours to be interviewed; the researcher

arranged a few snacks and beverages for them. Interestingly, the participants did not complain about the waiting time, instead one participant (P5) stated that she was happy to wait and chat with other informal caregivers. Moreover, that participant mentioned that communicating with other participants and sharing their overall experiences felt good. Another participant mentioned that socializing with other participants of the study while they were waiting made her feel like she was "talking to an adult after a long time" (P3).

I met each participant in the hall (in front of the meeting room) at the arranged time, after which they walked to the meeting room. After I placed the "Please Do Not Disturb" sign on the outside of the door, I closed the door and invited the participant to sit on a chair.

To alleviate participants' anxiety, I welcomed the participants to sit. I asked participants how they were and talked about the weather to establish rapport. When I perceived that the participant was comfortable, I began the interview. At this time, I also reviewed the goals of the interview, encouraged the participant to ask questions or express any concerns, and informed the individual that he/she could withdraw from the interview at any time. When I perceived that the participant felt comfortable to speak openly, I informed him/her that I was turning on the audio recorder, and began the interview.

I (re)introduced myself, stated the time, date, location and purpose of the interview, and used a pseudonym for the participant's name. The participant restated that he/she provided consent to participate in the study. It was reiterated that the individual holds the right to withdraw from the study at any time.

After that, I moved forward with the interview. When both parties felt that there was nothing else to be shared in relation to the interview question, the interview was terminated. Then I debriefed

the interviewee about the study and let them know when the summary of the findings would be available.

Additionally, the matters of confidentiality were addressed again and any further participant questions were answered. Finally, I guided the participant to the door of the room, opened the door and said goodbye.

Instruments

As a researcher, I had a dynamic role in this study and am considered an instrument in conducting the research. My tasks included designing and conducting the study, facilitating interviews, analyzing collected data and producing the research report. Therefore, I completed the tasks taking into consideration personal assumptions and biases.

I reflected on my personal bias and assumptions linked to the research question, in an attempt to clarify any personal biases (Fereday & Muir-Cochrane, 2006). Practicing reflexivity enhances a researcher's ability to function as a study instrument (Lincoln & Guba, 2000).

The Researcher’s Background and Training

I have more than five years of research experience in different academic settings. I have been involved in multiple projects that focused on the well-being of informal caregivers and care recipients.

While working on different projects, I noticed that there was a need to explore different wellness techniques that would help informal caregivers to cope with their physical and emotional exhaustion. With an enthusiasm for resilience, I began to explore different evidence-based

strategies to alleviate distressed individuals. My inquisitive interest in mindfulness practice became the topic for my research.

My academic and professional development in the field of behavioral health science motivated me to focus on the topic of mindfulness. With special research training in health science, in addition to the study and practice of different intervention methods, I focused on working with families of children with disabilities and on caregivers of older adults. In addition, I cultivated an appreciation of qualitative research through my graduate program, ongoing coursework and the guidance and support of my thesis committee.

Researcher Bias

I was careful about my dynamic role and kept my assumptions and biases in check; especially during the data collection and data analysis phase, precautions were taken to prevent collecting and analyzing biased data. Thus, I practiced reflexivity, a method used in qualitative research that fosters a way of identifying a researcher's biases, values and attitudes toward the research question, for example, keeping a reflexive journal (Lincoln & Guba, 1985).

Personal Reflexibility

I assumed that the informal caregivers of seniors who participated in the mindfulness practice would share their perceptions and understanding openly with the researcher. In addition, through their descriptions, themes and sub-themes would be identified. Previous research suggests that informal caregivers of seniors experience subjective stress, anxiety, and other negative psychological outcomes. A mindfulness session is perceived as a useful tool to aid their distress

and other negative psychological impacts (Baer, 2003). Therefore, I assumed that participants would perceive a short, single mindfulness practice positively.

Data Analysis

The recorded individual interviews of participants and observational notes of the researcher were the sources of data. The recorded interviews were transcribed. The collected data generated the essential amount of information and were congruent with the chosen descriptive thematic-oriented qualitative inquiry. Additionally, the collected data permitted the researcher to develop knowledge related to the stated research question (Creswell, 1998).

The Initial Steps for Data Preparation

I prepared verbatim transcriptions of each recorded interview. With a focus on details, I reviewed each transcription and compared the transcribed data with recorded interviews. The name of the participants was anonymized and each transcript was numerically identified. The transcripts were archived for future reference. The copies of the transcripts permitted the researcher to organize segments of interview information into different thematic units.

All data were securely stored and the original master (electronic) transcript was saved on a flash drive (password-secured), and one hard copy (master transcript) was handled in the same way. Each interview was prepared and organized in an identical fashion to ensure consistency.

The goal of the data analysis for this particular study was to understand the experience of the participants through their language and descriptions. Braun and Clarke's (2006) thematic analysis model was used for the data analysis step of this study. The following section describes how each data has been analyzed in this research study.

According to Braun and Clarke (2006) model, the first step of the analysis is being familiarized with collected data. In order to immerse myself in the collected data, I read and re-read the transcribed data to ensure that I had an in-depth understanding of the participants' perspective.

The second step is to generate initial codes and meaning units from the collected data. After I read each interview transcript several times to fully familiarize myself with the data, I assigned codes within the interviews (Braun & Clarke, 2013). The codes were written along the margins of transcripts. This particular process served the purpose of collating similar codes into a theme, which led to creating a thematic network. As a single coder, I maintained the rigor of coding by coding each transcript twice. I used a fresh set of transcripts each time of coding, which did not contain highlights or codes written down. This way, I ensured that the codes from each session matched and there were no conflicting codes. Additionally, there was a two-week period between the two rounds of coding, which allowed the researcher to read the transcripts with a refreshed point of view.

The third step of the model is to create themes from the emerged codes and meaning units. To create themes, I investigated the meaning and content of each code. These codes provided guidance in building a thematic network that was defined by the original research question. Following this process of creating overarching themes, six major themes were identified from the data. Each theme shed light on the meaning of practicing mindfulness from the participants' perspective.

The fourth step of the data analysis process is to revise the themes identified during the previous step. There was a spiraling pattern for creating the themes. I reviewed the theme to obtain a

greater understanding of the material and gradually developed an organized structure of basic thematic units.

The fifth step of the analysis is to define themes. I defined six main themes and each of the major themes were described in details.

The sixth and final step is to produce a comprehensive report of the research findings. The study findings are described in detail, and summarized in the next chapter. A coding table helped to organize the direct quotes and generic descriptions of the themes (Appendix F: Coding Table).

Ethical Consideration

The dissertation guidebook of University of Ontario Institute of Technology was used to ensure an appropriate and ethical data collection procedure. The procedure included informed consent from every participant, an appropriate and secure interview setting, password encrypted data storage, confidentiality and minimizing risk for all parties.

Summary

In summary, the descriptive thematic-analytical model was applied in this research study because it aligned with the purpose and goals of this research. This model allowed the researcher to employ the data analysis process necessary to answer the study's research question. Using the analytic-thematic process, I was able to disentangle themes generated by the data, in this case, the experiences of mindfulness among informal caregivers.

Chapter 4: Study Findings

Chapter Overview

Chapter 4 describes the findings of the current study including the descriptive demographic information of each participant and the major qualitative themes that emerged during data analysis. The six major themes were: 1) Comparison of mindfulness to other relaxation methods; 2) Initial impression of mindfulness; 3) Mindfulness as a relaxation technique; 4) Mindfulness as a support for sleep hygiene; 5) Mindfulness as an anxiety reduction method; and 6) Future integration of mindfulness into daily practice

Demographic Information of Participants

A screening form (Appendix B) was used to ensure the sample represented participants from wide demography, which includes: age, sex, care recipient's age, number of years in caregiving role, and educational attainment and employment status. Of the nine participants who signed up for the study, six attended the mindfulness session and participated in the one-on-one interview. All participants were informal caregivers of seniors living with Alzheimer's and other forms of dementia.

Demographic Summary

Table 1 illustrates the demographic information of each of the six participants of the current research study. A summary of descriptive demographic information of the participants is presented in Table 2. The six caregivers who participated in the study were all retired from their jobs, with a mean age of 60-69 years. The average age range was in 70+ years for the care

recipients of the study participants. The study participants were in their caregiving roles for average of 3.375 years. Among six participants, five were female and one was male.

Table 1: Descriptive demographic information of each participant who attended the mindfulness session

Participant (P) number	**Participant's age range**	**Care recipient's age range**	**Number of years in caregiving role (years)**
Participant 1	70+	70+	9
Participant 2	60-69	70+	1
Participant 3	70+	70+	*
Participant 4	70+	70+	0.5
Participant 5	60-69	70+	3
Participant 6	70+	70+	*

1. * Participant did not provide the information

Findings

Six main themes were identified from the obtained data (Table 2).

Table 2: Overview of the six main themes

Themes	Description
Comparison mindfulness to other relaxation methods	Familiarity and awareness of different relaxation techniques
Initial impression of mindfulness	Reactions to different components of mindfulness from a beginner's perspective
Mindfulness as a relaxation technique	Perceived to be aid for relaxation
Mindfulness as a support for sleep hygiene	Perceived to be helpful for improved sleep
Mindfulness as an anxiety reduction method	Perceived to be useful for decreasing anxiety
Future integration of mindfulness into daily life	Feasibility of future application into daily life

Main Theme 1: Comparison of Mindfulness to Other Relaxation Methods

All participants in the study was a beginner of mindfulness practice who was not familiar with this therapeutic tool. Naturally, their initial impression of this introductory brief mindfulness session emerged in their description during the one-on-one interview. From a beginner's perspective, participants described their experience and understanding of the single, short mindfulness practice. Four participants immediately associated their initial impression of the

mindfulness exercise with their previous experience of practicing other relaxation techniques such as a muscle relaxation exercise, yoga, generic deep breathing and stress-reduction therapy.

One participant who has practiced muscle relaxation techniques for a number of years associated her experience in the mindfulness session as similar to a muscle relaxation exercise.

“I used to go to muscle relaxation exercise classes for several years, that's what the instructor has us do at the end of the class, which is very relaxing, we would be deep breathing and we would be feeling our muscle relaxing and we can feel it in our feet and arms and legs, eyes” (P2)

Another participant said that she usually practices deep breathing for relaxation purposes because her family physician recommended the technique to her. She found it helpful to practice deep breathing with a mindfulness instructor.

“I sometimes practice…practice deep breathing on my own but it was interesting to do it with an instructor. Especially the body scanning…following your feet, legs that were interesting” (P1)

Similarly, other participants commented that they use deep breathing technique in their daily lives but did not realize it could be used for mindfulness practice.

“When the lady (the instructor) asked us to you know inhale and exhale, I said to myself wait, I do that every now and then. I do that even without knowing it is mindfulness.” (P3)

“I have recently read…and heard something about deep breathing, it was no different.” (P5)

“I thought it was interesting…practicing (mindfulness) it was nice.” (P4)

One participant reported that as a beginner, he perceived mindfulness as a technique of de-stressing. He described that he had been reading and heard about different relaxation techniques

such as yoga, bracketing worries for a certain time of the week, or channeling stress to different activities such as cycling. However, he associated the aim of mindfulness with those other relaxation techniques.

“I think it is very beneficial to be able to de-stress and this is one of the ways you can de-stress. I have heard different ideas in the past. This is the first time I heard of mindfulness.” (P6)

From a beginner's perspective, someone who is unfamiliar with mindfulness practice, the brief session was perceived as another relaxation method. It was clear from participants' description that they frequently use pharmacological and non-pharmacological relaxation aids in their daily lives. Therefore, they perceived the aim of the brief mindfulness session intuitively due to their prior familiarity with the concepts of other relaxation techniques. Moreover, their previous familiarity with similar relaxation techniques has increased the acceptability of the mindfulness session.

Main Theme 2: Initial Impression of Mindfulness

Participants shared their reactions to different components of mindfulness techniques. Their responses illustrate how an introductory mindfulness practice session may be perceived by beginners. The participants commented on the mechanism of mindfulness (i.e., how mindfulness practice affects mood) and their quasi-religious experience. Participants also reported on the length of the mindfulness session and effect of a group setting for a mindfulness session.

One gentleman reported that he had a difficult time paying attention to his breath as he was concerned about the mechanism of mindfulness. He noted that he was thinking more about the logic behind this therapeutic technique than he was concentrating on the task of breathing.

“It was interesting, I had more difficulty in trying to get into the meditative state than certainly others had... I am a very logical person, and I was sitting and thinking through the logic of it rather than just relaxing...So I don't think I have got as much benefit of it as I could have...I was just thinking about the mechanisms more than anything else.” (P6)

Another participant reported her uncomfortable experience with the mindfulness practice session. As mentioned above, the instructor used a transcendental sound during the deep breathing exercise, which incorporated one pointed focus of the mind on the mantra Gauranga. This exhalation sound made this participant wonder about whether the mantra has any religious connection. She pointed out that in future she would prefer not to say the mantra during exhalation, as she perceived it was moving towards a religious boundary.

“Yeah, I thought it (exhalation sound) was really not in my comfort zone. It was really a little quasi-religious experience, which I was not okay with it.” (P1)

She asked the interviewer the meaning of the sound and asked if the mantra, which sounded like "Gauranga" meant anything in any language. Another participant communicated discomfort with the sound component of the mindfulness practice through her body language (P5). None of the other participants commented on using the rhythmic tone during exhalation.

Participants also commented on the length of the mindfulness session. Five out of six participants reported that a longer mindfulness session would be more effective and would create a better learning experience for them. Participants did not comment on a specific length of time that they would perceive as more beneficial to them.

One participant reported that he would be interested in joining a six to eight-week mindfulness session to learn more about the technique. It is noteworthy that all six participants perceived the single brief mindfulness session to be a learning opportunity rather than a therapeutic technique.

“I was kinda hoping there might be a course of 6 weeks or 8 weeks or 10 weeks or whatever like an evening class so you can go and learn some techniques about mindfulness” (P6)

Four out of six participants reported that a longer mindfulness session would increase the effectiveness of the technique. They also noted the longer session would make their learning experience better.

“I am still a little bit stressed out but if I have been doing an exercise for longer...I probably would be feeling a lot better. I think at home if I can do it even longer it would be good for me.” (P2)

“I really enjoyed her talks, speech. I just thought it was a little short. I could keep listening to her more you know” (P3).

“I didn't think it was too long, you need longer time to learn something. I would have it longer…but when I practice it alone I would practice it for longer may be…” (P1)

“I forget (things) easily, you know. You can’t teach me mind(fulness)…or anything in short time or in fifteen minutes. I think it’s better if I could practice it longer with my wife or in a group…may be here (the research site) then I would remember how to do it (practicing mindfulness) later.” (P4)

The other two participants (P5, P6) commented on their "learning experience" from the single brief mindfulness session.

"You know I love learning every bit of everything. I continuously try to learn on every bit of things. So I think I would keep learning about mindfulness on my own." (P5)

"I would like to learn more about the neurological or psychological aspect of mindfulness on my own." (P6)

Three participants reported that they feel comfortable practicing mindfulness at home in their own comfort zone. One participant explained that due to her caregiving roles, it is hard for her to join a group session. Therefore, it would be more convenient for her to practice mindfulness on her own time.

"I think (it's better to practice mindfulness) alone as it is hard for me to manage time to join...or come to a group session. You know how I am in a rush always" (P1)

"(I would) prefer practicing it at home." (P5)

"(Home)…that would be better for me." (P3)

However, other participants reported that being in a group for a mindfulness session was enjoyable.

"Everyone had a few important things to say, and I am a listener…so I listened to others today and that felt good. We were talking to another lady (while waiting for being interviewed) about taking care of others and it was helpful" (P4)

"I like this (group setting) because then you are out amongst people" (P3)

"(I would like to) learn more about it may be in a group, may be, but then practice it alone." (P6)

Overall participants reported the mindfulness session as a positive experience. Each participant took interest in different components while they described mindfulness. For example, two participants asked a question about the mantra that was used and three participants asked about the psychological and neurological components of mindfulness.

Main Theme 3: Mindfulness as Relaxation Technique

Learning an effective de-stressing and relaxation technique was the most frequently noted experience by the participants. Stress was a theme that consistently emerged from the interviews. Participants identified themselves in a stressful situation and they perceived that practicing mindfulness might help them be more relaxed.

One participant who is adjusting to living alone after her spouse was placed in a long-term care facility due to dementia, portrayed her emotional distress. She explained that being a caregiver for a person with dementia could be lonely and stressful.

"I do know a lot of caregivers do actually get physically sick. With myself, I found I have been very stressed out and one point I was so really sobbing hysterically and one night I was sobbing so dreadfully that I called the distress center, crisis center. After I talked to a couple of people I did feel better but uhh...I think...I don't think anyone can be a caregiver without feeling stressed out." (P2)

Another participant whose husband has early stage dementia explained that household responsibilities and caregiving responsibility are often psychologically and emotionally overwhelming.

“but I say like our house is so big to downsize it, it will be all on my shoulder to get rid of everything and do everything. And I heard it from so many people that it's the caregivers that end up getting sick. Everyone tells me in the hospital, (whispers), "Don't, don't dwell on it." They said if you need to get out and get a cup of coffee call us up. Somebody is available to go out so you could go out.” (P3)

Participants reported that they have believed that during a stressful situation practicing mindfulness can be helpful. They put an emphasis on deep breathing because the breath was used as an external anchor by the instructor.

“It was good to learn how to deep breathe because my doctor keeps telling me to take deep breaths and relax. It's just sometimes...I have so much in my head, I am driving and thinking about something else. Especially stress…I think that's big for caregivers. Nowadays I am too stressed out so I think I can use a few deep breaths every now and then.” (P1)

“Well if you are stressed and if you start doing it (practicing deep breathing), I can see how it would take your mind off you know your worries and so on.” (P5)

Stress was a common theme in the descriptions of the majority of the study participants. They perceived that practicing mindfulness during time of distress might be helpful for their health and well-being.

Main Theme 4: Mindfulness as a Support for Sleep Hygiene

An impaired sleeping pattern was a recurring theme among study participants' interviews. Three participants reported that they perceived mindfulness to be a potential aid for difficulty with

sleeping. Participants felt that the breathing technique could help them to relax before going to bed so they could get a quality sleep.

“So I really think if I work on mindfulness exercises, take time each day and I think probably if I..if I do it may be in the afternoon and then the evening uhh…before I go to bed that would probably be the best time for me...Sometimes I have trouble going to sleep you know, there are things in my mind. So I can really see, I was glad she (instructor) was there to talk to us” (P2)

“(May be) deep breath will help me to sleep.” (P3)

“In the evening…right before I try to fall asleep, I guess. (P6)

Main Theme 5: Mindfulness as an Anxiety Reduction Method

One participant expressed her concern over her mental and psychological well-being. The participant shared that she is taking medications for her anxiety disorders. She thought that practicing mindfulness could be beneficial for her to manage her anxiety. She mentioned that her family physician recommended she practice deep breathing. Similarly, she thought mindfulness could be beneficial to her mental health and well-being.

“I don't want to get depressed because I am already taking a pill for anxiety but what that lady said... (instructor) I will try to practice deep breathing every day, whenever I get a chance. I know my doctor says just take a deep breath and let it out to get...you know..some sanity..., because this way I am going to try that deep breathing because if it (mindfulness) helped her (depression) then it would help my anxiety.” (P3)

Another study participant mentioned that she is always worried and expected mindfulness to be helpful to manage her anxious behavior.

“I am always too worried or anxious about…many things, this or that, here or there. This (mindfulness) thing might help me to slow down a bit.” (P5)

Main Theme 6: Future Integration of Mindfulness into Daily Life

During the interviews, I asked the informal caregivers if they intended to practice mindfulness in the future. All participants replied affirmatively. Participants reported that they would like to join more mindfulness sessions because of its perceived benefit.

“Well, I think I could do it alone at home. Probably the best time it would be before I go to bed and if I can manage to do it in afternoon, I think that would help me” (P2).

Only one participant was interviewed two weeks after the mindfulness session was held, due to scheduling difficulty. She reported that she had been practicing mindfulness regularly before going to sleep.

“I have practiced deep breathing hand on your abdomen and thinking about breathing in and out. and occasionally when I am in bed I do it. It helps before going to sleep” (P5)

Participants' interest in practicing mindfulness before sleeping suggests that they considered the brief mindfulness session to be a relaxing experience, and expressed the desire to integrate mindfulness practices into their daily life.

Summary of the Findings

The research question for this study was: What is the experience of practicing mindfulness among informal caregivers? To explore the research question, six participants who attended the mindfulness program were interviewed about their personal understanding of the experience.

Participants reported on various components of the mindfulness practice session including their overall experience, perceived effectiveness of the session, and the feasibility and acceptability of incorporating mindfulness practice in their daily life.

The systematic data analysis generated six major themes. Each of the participants described their own perception of the brief mindfulness practice session. Moreover, they offered insight into why mindfulness practice can be beneficial to informal caregivers. Additionally, the six themes provided insightful information on how participants have identified a beneficial effect of mindfulness on their psychological well-being and their self-identification of mindfulness as a stress reduction technique.

As the interview progressed, the individual's experiences unfolded. As one participant concluded, "I am on top of the world now" (P3). The findings suggest that participants' initial impression was putting the mindfulness practice session in the context of their previous experience of other relaxation technique. They expressed their understanding of the perceived benefit of mindfulness in their everyday life. Therefore, it can be concluded that the mindfulness practice session was well-accepted by the participants. Participants reported their intention to practice mindfulness and identified its applicability in their daily life. However, participants noted the effectiveness of a mindfulness session could be increased by making the session longer. In addition, a longer introduction to the mindfulness session would facilitate their learning experiences. Two participants also noted their discomfort with the mantra at the end of the practice. They indicated they associated it with religion, which could be a potential barrier to the future integration of mindfulness into their daily lives. During the coding process of the collected data, the words "stress", "relaxation" "learning", and "breathing" came up often.

Participants generously shared their psychosocial challenges as caregivers and identified why mindfulness is relevant and beneficial for caregivers.

Chapter 5. Discussion, Limitations and Recommendations

Chapter Overview

The purpose of this chapter is to present a discussion of the findings of this study. Through creating a roadmap of identified themes, the data reveals how six informal caregivers have described their perception of the brief mindfulness session. The findings revealed the perceived effectiveness, feasibility, and applicability of mindfulness session in their daily life. Additionally, this chapter provides a comparison with previous research findings, the study limitations, and recommendations for further research.

Discussion of the Results

The research question investigated was, "What is the personal experience of informal caregivers who have completed a brief, single mindfulness practice session?" A series of questions and sub-questions were asked in order to thoroughly understand the participants' perspectives. The data obtained through in-depth one-on-one interviews, generated six main themes. The six main themes were: 1) Comparison of mindfulness to other relaxation methods, 2) Initial impression of mindfulness, 3) Mindfulness as a relaxation technique, 4) Mindfulness as a support for sleep hygiene, and 5) Mindfulness as an anxiety reduction method, 6) Future integration of mindfulness into daily life.

The participants of the study shared their perception and expressed their understanding of mindfulness in an insightful way. The data collected shed light on a more extensive topic that was contained by the original research question. For example, the obtained data revealed the breadth of self-management techniques that informal caregivers practice by themselves every

day. Informal caregivers' distress and loneliness in their everyday life were discernable and this reflection emerged through the themes that were generated through the interviews.

This study was an opportunity for participants to share their experience, and additionally, the mindfulness practice session taught them an effective self-management technique in the form of actual support. The findings of the study demonstrated that an exploratory qualitative research design was purposeful, as it provided a broad scope to expand on participants' perspectives that enriched the research question. Moreover, research effort on the effectiveness of single, short mindfulness session among the non-clinical population is sparse. Therefore, the qualitative research design was an effective way to delve into this new area of knowledge and provide the researcher with an increased understanding about the participants' perceived experience of a single, short mindfulness session. In addition, the purposeful sampling approach provided an opportunity to develop an in-depth understanding about the informal caregivers' perspectives of mindfulness as a resource to support their caregiving of seniors with Alzheimer's and other forms of dementia.

The goals of the current research study were 1) to explore informal caregivers' perceptions/experiences participating in a single, short mindfulness practice and 2) to understand the participants' intentions to continue practicing mindfulness in the future.

The first goal of the research study was to understand participants' perceived experience of a single, short mindfulness session.

The overall experience of a single, short mindfulness session (length, duration): Ideal frequency and duration of a mindfulness session are yet to be investigated extensively. Sedlmeier et al. (2012) found that both short-term and long-term mindfulness practice have a positive impact on

the psychological variables of participants. In a quantitative research study, Keune and Fortinos (2010) found that there is not a direct correlation between frequency of practice (one week vs. three weeks) or duration of practice (ten minutes vs thirty minutes) and increased psychological well-being of participants. The current qualitative research study shows that participants perceived the single mindfulness session to be beneficial, as they had learned a new technique. Participants recognized the session as an educational opportunity rather than a therapeutic session. In addition, three out of six participants reported that they would prefer the mindfulness session to be longer than fifteen minutes, in order to provide more benefits for their health and well-being. Even though the literature does not identify an ideal frequency or duration for a mindfulness practice, the current study suggests that individuals can perceive as little as one brief mindfulness session as an educational opportunity.

To the researcher's knowledge, current literature has not explored informal caregivers' perceptions of a single, short mindfulness session. Therefore, the present study is a pilot study to explore this topic among informal caregivers looking after their loved ones with dementia. This pilot study supports the need for exploring the effectiveness of single session mindfulness among informal caregivers with a more robust sample size.

Perceived effect of mindfulness single, short session: There is only a sparse amount of evidence available on the direct effects of the mindfulness-based intervention on the psychological well-being. (Davidson et al., 2003). However, there is abundant data available on the positive effect of the mindfulness-based intervention for stress reduction (Kabat-Zinn, 1981) and the mediating role of mindfulness practice on relaxation (Baer, 2003). Certainly, the current study participants overwhelmingly perceived that practicing mindfulness would be a beneficial aid for stress reduction and relaxation purposes.

The participants perceived relaxation to be an outcome of the mindfulness session. They also perceived mindfulness to have a beneficial effect on promoting sleep. In a mixed-method research study, informal caregivers reported that a brief mindfulness session had a positive effect on their well-being, sleep, depression and caregiving burden (Innes et al., 2012). Congruent with the findings of the Innes et al. study, the participants of the present research reported that they perceived mindfulness to be beneficial for their sleeping problems, depression, and anxiety.

Similarly, by focusing on the relaxation effect of mindfulness, participants reported that they anticipated practicing mindfulness would aid their anxiety symptoms. Keyworth et al. (2014) conducted a mixed method research study with older adults with diabetes and coronary heart disease to understand their perspectives of brief mindfulness program. The participants attended six weeks of a brief mindfulness session (two and a half hours each week). The research explored participants' subjective well-being after participating in the mindfulness program. Participants reported that they had learned to become more mindful, which led them to become less anxious about their physical well-being. Similar to the current study findings, participants shared their anticipation that a brief mindfulness session would be beneficial for their anxiety symptoms. In a recent meta-analysis, researchers reviewed twelve studies (n=578) to examine the effectiveness of mindfulness on individuals with current depressive disorders and anxiety disorders (Strauss, Cavanagh, Oliver, Pettman, 2014). Contrary to our study findings, researchers indicated that the effectiveness of mindfulness was statistically significant for a current depressive disorder but not for current anxiety disorders.

The second goal of the study was to understand how likely participants are to continue practicing mindfulness in the future and their perceived applicability of mindfulness in their daily life. Keyworth et al. (2014) found that older adults with diabetes and coronary heart disease

continued practicing mindfulness as they perceived the technique of mindfulness to be secular and similar to their prior experiences of relaxation (for example: practicing deep breathing). In a pilot study, Olivo et al. (2009) explored whether a brief mindfulness-based stress reduction technique is feasible for patients diagnosed with or at risk of coronary heart disease. After participating in four weeks of Mindfulness-based Stress Reduction (MBSR), 40% of the participants reported that they would be interested in further training as they perceived the training to be beneficial for their health. Similar to the findings of the abovementioned articles, the participants of current study expressed a commitment to continue to practice mindfulness because they accepted mindfulness as a beneficial technique. The participants reported that they frequently use various relaxation techniques such as: muscle relaxation, and deep breathing. Therefore, future practicing of mindfulness exercises is perceived to be appealing and feasible to them. It can be concluded that informal caregivers perceive mindfulness to be feasible and applicable in their daily lives due to their prior experiences with other relaxation techniques and the perceived benefits.

Significance of the Findings

Previous research has shown that informal caregivers experience physical and emotional distress due to their challenging roles of caregiving (Lee et al., 2015). Informal caregivers report a high level of stress and anxiety, which can create financial distress and overall health concerns (Hurley, Patterson, & Cooley, 2013). These findings call for an exploration of aids or techniques that can alleviate caregiver burden and distress.

This current study contributes to the existing mindfulness literature and its perceived effectiveness, feasibility, and applicability among informal caregivers. This pilot study

approached the exploration of mindfulness-based intervention among informal caregivers from a qualitative perspective, which is sparse in current literature. Moreover, the themes and sub-themes of the study provide a body of knowledge about informal caregivers' perceived effectiveness of mindfulness intervention in their daily life, which lays a foundation for future research and program planning. A retrospective or longitudinal research methodology could be used to further explore the long-term effect of mindfulness on caregivers' health and well-being. From the findings of the current study, it is recommended that organizations, which provide support services to caregivers design and facilitate programs that promote different relaxation methods such as mindfulness, and muscle relaxation techniques. From participants' descriptions, it is clear that healthcare providers are encouraging caregivers to be less dependent on psychotropic medications (sleep aid or anxiety aid). Therefore, caregivers are aware that alternative therapeutic tools or non-drug therapy can be beneficial for their health and overall well-being. As a result, they are enthusiastic to join programs such as mindfulness to explore alternatives to pharmaceutical drugs. Moreover, the existence of stress-management programs in community-based organizations will help to educate informal caregivers about alternative strategies and techniques of self-management during emotional distress.

In addition, this study highlights the social isolation caregivers experience in their daily lives. The group effect of the mindfulness session was appreciated by multiple participants, which signifies that there is a need for more engaging program planning to tackle the issue of social isolation among caregivers of individuals with Alzheimer's and other forms of dementia. The issue of social isolation requires strategic priority and policy alignment during program planning and strategy making process for caregivers of seniors.

The findings of the study highlight that the overall well-being of informal caregivers needs to be addressed in the National dementia strategy. From the researcher's experience with the current study population, it can be recommended that a participatory-based research approach is essential to include caregivers' voices in the policy making process. In addition, a participatory-based research design would help to ensure that caregivers' unmet needs are addressed in the dementia strategy.

Limitations

The present study was an exploratory qualitative pilot study, with an aim to explore perspectives/experiences of informal caregivers who participated in a single, short mindfulness session and their perceived feasibility of continuing mindfulness practices in the future. Therefore, the aim of the study was not to prove a hypothesis or to create a theory based on the study findings. The findings of the study were the participants' perceptions and personal opinions and cannot be scientifically attributed to the mindfulness session, given there was not a control group. In addition, due to the nature and design of the study, we could not determine the long-term effect of short, single mindfulness practices.

In addition, inherent in the qualitative research approach, the findings of this study cannot be generalized beyond the research participants. This study recruited its participants from informal caregiver support groups and snowball sampling. The Alzheimer Society of Durham facilitates multiple self-help programs, group activities and events for informal caregivers of seniors with Alzheimer's and other forms of dementia. Participants of this study were active members of different self-help groups and had previously participated in various activities at the research site.

This engaged participant group may have been especially enthusiastic to take part in this mindfulness practice session.

Additionally, the sample might have been prone to social desirability bias. Social desirability in social science research methodology is the tendency of study participants to respond in a manner that is viewed positively by others (Edward, 1957). The participants' regular engagement in self-help interventions as part of the support groups they belong to may have contributed to their positive responses to the mindfulness session.

Recruiting participants from the Alzheimer Society of Durham created a homogenous sample that may not be reflective of the general informal caregiver population. The characteristics of this sample population such as age, gender, sex, caregiving role, relationship with care recipients, and educational and socio-economic status, might be unique and different from other caregivers.

For this qualitative study, the credibility of research was maintained through rich data description, practicing reflexivity, and creating structural coherence (following the interview guide strictly) in each interview, and at the expense of transferability of the research findings. Therefore, the findings of the study might not be transferable to another population such as participants who were not involved in caregiver support groups; however, the rigor of the research was not compromised in terms of credibility. To ensure the credibility of the current research design, following steps were taken: firstly, to reduce the risk of assessment bias, the interviewer (myself) did not facilitate the mindfulness session. The instructor of the mindfulness session left the premises before interviews took place. Secondly, I noted and elaborated my personal reflexivity process that may affect the research design. I practiced personal reflexivity to bracket my own underlying assumptions throughout the course of this research. Thirdly, to

obtain rich description of participants' experience, I asked multiple sub-questions and provided many prompts to ensure that participants' overall experience was captured in detail.

Recommendations for Future Research or Interventions

There is an existing literature gap on the topic of mindfulness among informal caregivers. Therefore, further research on this topic is important in order to understand informal caregivers' perspectives and experiences regarding a mindfulness practice session. To the researcher's knowledge, this exploratory research contributes to the current literature by using a qualitative approach to understand participants' experiences.

The findings of this current study suggested that informal caregivers perceived a brief single mindfulness session to be effective for their well-being, including their psychological well-being (anxiety, stress and sleeping problems). Therefore, it is important for future research studies to explore those variables further by using a mixed methodology research approach. Moreover, multi-pronged research strategies that take into consideration the lifestyle of busy family caregivers and their significant others would contribute to the literature. Multi-pronged research studies can investigate the temporal stability and situational specificity of mindfulness; for example, studies can examine if a single, short mindfulness session can be effective over the long term and if so, then for how many days, years or months. Moreover, future research can examine if the benefits of brief mindfulness practices to the well-being of the care recipients of the practitioners.

The findings of the study do indicate that there is a need and desire among informal caregivers of seniors with Alzheimer's and other forms of dementia for de-stressing techniques such as mindfulness. There is also a need for more research to understand the effectiveness of

mindfulness compared to other relaxation techniques. Since this study focused on informal caregivers' experience of a brief single mindfulness session, future research could apply a similar approach to other sub-groups of informal caregivers. such as: caregivers of children with developmental disabilities, caregivers of individuals with multiple comorbidities, and caregivers of individuals with chronic pain.

Conclusion

The current study's findings suggest that informal caregivers of seniors with Alzheimer's and other forms of dementia perceived a single, short mindfulness session positively. However, there is a need for more research to investigate the effectiveness of mindfulness sessions of different frequencies and durations. Single session mindfulness practice was perceived by the participants to be an opportunity to learn a relaxation technique. Currently, overall health research is interested in alternatives to psychotropic medications and conventional psychological therapies. Teaching mindfulness skills to distressed populations could be an effective alternative aid for stress, sleeping problems, and other negative emotional regulations. However, in the interim, there is a need to conduct additional robust research studies that include randomized control trials to evaluate the effectiveness of mindfulness practice among informal caregivers.

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Appendix A: Participant Recruitment Brochure

Mindfulness Practice Session for Informal Caregivers

Mindfulness Practice Session for Informal Caregivers

You are invited to participate in a research study entitled, "**A qualitative exploration of the experience of a single session mindfulness practice with informal caregivers. "**

This study has been approved by the UOIT Research Ethics Board REB [REB # 14588] on [November 8th 2017].

What do participants need to do?

Mindfulness is a therapeutic technique that has been proven to increase psycho-social well-being of practitioners.

The Goal of the Research:
The aim of this study is two-fold: 1) To explore informal caregivers' perceptions/experiences participating in a single, short mindfulness practice and 2) As a result of this experience, to understand how likely participants are to continue practicing mindfulness in the future.

The Population of interest:

- ✓ a current informal caregiver
- ✓ speaks English and
- ✓ 18 years of age or older.

Research team contact information:
Dr. Wendy Stanyon
(wendy.stanyon@uoit.ca)
Farah Tahsin (farah.tahsin@uoit.ca)
(647-825-4684)

Contact information for the ethics:
The Research Ethics Coordinator – researchethics@uoit.ca
905.721.86683693.
905.721.8669

Funding info: This study is not funded.

Disclaimer:

This information is provided for information purposes only. It is not an endorsement by the Alzheimer Society, and will not affect the support services received by clients from the Society.

The purpose of our proposed research study is **to explore the perspective of informal caregivers on single session mindfulness practice session.** To achieve this goal, we will hold a **mindfulness practice session** to introduce participants to the hands-on mindfulness practice. Then we will

conduct a **one-on-one interview** to assess your understanding and perspective of the practice session. The outcome of the study includes understanding the perception of mindfulness practice among informal caregivers. This project will help lead to the future development of mindfulness practice session for informal caregivers.

Appendix B: Participant Screening Form

Title of Research Study:

A qualitative exploration of the experience of a single mindfulness-based practice session with informal caregivers.

Ethics Approval: This study has been approved by the UOIT Research Ethics Board REB [file # 14588] on [November 8th, 2017].

What is Mindfulness? Mindfulness is a therapeutic technique that has been proven to increase psycho-social well-being of practitioners.

Informed consent: It is important for prospective participants to understand the purpose, procedures, risk and benefits of the study. If you wish to be informed of this study, please contact Farah Tahsin at farah.tahsin@uoit.ca, phone number 647-825-4684.

Screening Questions

- I need to ask the following questions in order to check if you are eligible to participate in our project. **Do I have your consent to proceed? Yes□ No**

If the answer is NO, thank him/her and end the conversation.

- **Are you able to understand and speak English? Yes□ No□**
- **Are you able to provide informed consent? Yes□ No□**
- **Are you a current informal caregiver? Yes□ No□**
- **Have you previously heard about mindfulness? Yes□ No□**
- **Have you previously practiced mindfulness? Yes□ No□**

Appendix C: Letter of Information and Participant Consent Form – Interview Session

Title of Research Study:

A qualitative exploration of the experience of a single session mindfulness-based practice with informal caregivers

You are invited to participate in a research study entitled, "A qualitative exploration of the experience of a single session mindfulness-based practice with informal caregivers".

This study has been reviewed by the University of Ontario Institute of Technology Research Ethics Board [REB # 14588] and originally approved on [November 8th 2017]. Please read this consent form carefully, and feel free to ask the Researcher any questions that you might have about the study. If you have any questions about your rights as a participant in this study, please contact the Research Ethics Coordinator at 905 721 8668 ext. 3693 or researchethics@uoit.ca.

Researcher(s):

Principal Investigator: Principal investigator: Dr. Wendy Stanyon

Graduate student: Farah Tahsin

Co-Investigators: Dr. Brenda Gamble, Dr. Winnie Sun

Departmental and institutional affiliation(s): Faculty of Health Sciences at UOIT

Contact phone number and email of principal investigator:

Phone number: 647-825-4684 E-mail: farah.tahsin@uoit.ca

Purpose:

Mindfulness is a wellness strategy that has been demonstrated to increase psycho-social well-being of practitioners. The purpose of our proposed research study is to explore informal

caregivers' perspectives on a single, brief mindfulness-based practice session and the likelihood that they will practice mindfulness again in the future.

Invitation:

To achieve this goal, we will facilitate a mindfulness-based practice session to introduce participants to mindfulness. Following the session, we will conduct one-on-one interviews with participants to assess your understanding and perspective of the practice session. This project will help lead to the future development of mindfulness-based practice sessions for informal caregivers.

You are invited to participate in the mindfulness practice session because you:

1) Are currently an informal caregiver
2) Are able to provide informed consent
3) Are able to understand and speak English
4) 4) Have not practiced mindfulness previously

Procedure:

In order to achieve a balanced sample of informal caregivers, the researcher will use a screening form to determine eligibility to participate in this study. Once eligibility is confirmed, you will be asked to attend a mindfulness-based practice session that will last approximately 15 minutes. The short mindfulness session will be held at the Alzheimer Society of Durham. Prior to the mindfulness-based practice session, you will be asked to complete of a brief demographic questionnaire. During the practice session, you will be asked to follow the instructions provided

in the mindfulness session. Following the mindfulness-based practice session, you will be asked to participate a one-on-one interview, at a time convenient to you. The interview session will be audio-recorded and you may choose to review the verbatim transcript of the interview.

Potential Benefits:

Mindfulness is a process 1) to regulate attention to initiate a non-elaborative awareness to one's experience, and 2) to immerse into one's experience with curiosity, openness, and acceptance. A plethora of research suggests that by engaging in a mindfulness-based practice, caregivers can enhance the self-management of their psychological stress.

Potential Risk or Discomforts:

There are minimal risks associated with participating in this study. Recognizing that you may experience some physical discomfort during the mindfulness session, due to fatigue, we will limit the mindfulness-based practice to 15-minutes and the interview session to no longer than 20-25 minutes.

Storage of Data:

All data collected will be stored in a personal, password-protected laptop kept in a secure location, accessible only to the researchers named above. You will be assigned a pseudonym that will be used to identify your data. Once a pseudonym has been assigned, any direct identifiers will be destroyed. None of the data you provide will be able to be traced back to you. The data will be archived until December of 2019, after which it will be destroyed. The results of this study may be published in a scientific journal and/or presented as part of a Masters thesis

defense; however, no identifying information will be published. All data will be presented in an aggregated format.

Confidentiality:

Before you participate in the mindfulness-based practice session, you will be asked to complete a demographic questionnaire. Examples of demographic questions include your age, gender, and educational level. This information will be paired with your interview to allow the researcher to better understand the interview data. After a pseudonym has been developed for this data, any direct identifiers will be destroyed. Throughout the study, this information will only be accessed by the researchers named above.

To safeguard your rights to confidentiality and anonymity, both verbal and written information about the objectives of this study will be available to you throughout the study period. You will be asked to provide explicit signed informed consent before participating in this study, and you will be provided with a copy of this consent form. As mentioned above, this study has received ethics approval from UOIT's Research Ethics Board. You will be notified of the use of an audio recorder during the interview session and a verbatim transcript of session can be provided to you for review upon your request. Pseudonyms will be used to preserve your anonymity, and the data will be kept in a secure, password-protected location at all times, accessible only by the researchers named above. All study data will be aggregated and all potential identifiers will be removed to protect your confidentiality.

Your privacy shall be respected. No information about your identity will be shared or published without your permission, unless required by law.

Confidentiality will be provided to the fullest extent possible by law, professional practice, and ethical codes of conduct.

Right to Withdraw:

Your participation is voluntary, and you can choose to withdraw at any point. You can also choose to answer only those questions that you are comfortable with. All information will be held in strict confidence and discussed only with the research team. Withdrawing from the study will not have any negative consequences and will not impact your relationship with Alzheimer's Society of Durham.

If you choose to withdraw from the research study, you do not need to offer any reason for doing so. Please note it will not be possible to withdraw from the study once your data has been anonymized and aggregated and it will be impossible to identify your personal data. You may withdraw from the study before we have anonymized and aggregated your data, which will be January 31st, 2018. Participants can contact the researcher to withdraw via the email address and/or phone number provided on the consent form.

Conflict of Interest: There are no conflicts of interest present in this study.

Debriefing and Dissemination of Results:

Summary of study results will be made available after August 31, 2018. Your involvement in this study will help lead to the future development of mindfulness programs for informal caregivers living in the Durham community. If you wish to be informed of the results of this study, please contact Farah Tahsin at farah.tahsin@uoit.ca.

Participant Concerns and Reporting:

If you have any questions concerning the research study or experience any discomfort related to the study, please contact the graduate student Farah Tahsin at 647-825-4684 or farah.tahsin@uoit.ca

Any questions regarding your rights as a participant, complaints or adverse events may be addressed to Research Ethics Board through the Research Ethics Coordinator – researchethics@uoit.ca or 905.721.8668 x. 3693.

By consenting, you do not waive any rights to legal recourse in the event of research-related harm.

Consent to Participate:

1. I have read the consent form and understand the study being described.
2. I have had an opportunity to ask questions and my questions have been answered. I am free to ask questions about the study in the future.
3. I freely consent to participate in the research study, understanding that I may discontinue participation at any time without any consequences. A copy of this Consent Form has been made available to me.
4. I agree to have to be the one-on-one interview audio recorded.

- I would like to meet a second time to review the transcript of the interview session.

  □ Yes □ No

_____ _____

(Name of Participant) **(Date)**

_____ _____

(Signature of Participant) **(Signature of Researcher)**

Appendix D: Demographic Data Form for Study Participants

This study has been approved by the UOIT Research Ethics Board REB [REB # 14588] on [November 8th, 2017].

Participant Number	**Date**

Please tell us the following information about yourself:

1. Please check one of the following categories that applies to you

   I am a Current Caregiver □ Former caregiver □

2. What is your age range?

   18-29 □ 30-39 □ 40-49 □ 50-59 □ 60-69 □ 70+ □

3. What is your gender: Male □ Female □ Other □

4. What is the highest level of education completed?

   a. No schooling completed □
   b. Some high school, no diploma □

c. High school diploma □

d. College □

e. University (i.e. Bachelor's degree) □

f. Graduate program (ie. Master's; PhD) □

5. What is your employment status?

a. Full-time □

b. Part-time □

c. Casual □

d. Unemployed □

6. Do you currently provide assistance or support to a relative or friend, who is ill, disabled or elderly? □ Yes □No

7. What are the ages of the people you provide care for?

18-29 □ 30-39 □ 40-49 □ 50-59 □ 60-69 □ 70+

8. How many years have you been in your caregiving role? _____

Appendix E: Interview Guide

Topic: A qualitative exploration of the experience of a single session mindfulness-based practice with informal caregivers

Participant number:

Time:

1. **Introduction:** 5-10 min

Review and have participants complete the consent form

Set the stage and purpose for the meeting:

- Study to explore the perspectives of caregivers on a brief mindfulness-based session and the likelihood that they will continue to practice mindfulness

Outline procedures for the interview:

- The session will be audio taped (with participants' permission), the consent signed prior to participating in the study defines the level of anonymity of each participant.
- All comments are important and relevant and we urge you to speak freely and frankly about their experiences

Statement of expectations and outcomes:

- The information gathered from this session will be transcribed and then analyzed by study team investigators.
- We are interested in your opinions to the questions asked and we then summarize them into key ideas and thoughts.
- No individual will be identified and not quote attributed
- A summary of the results of the study will be made available to those interested by either contacting the study office; however, this report will not be available until end of August 2018 (expected and subject to change).

2. Interview Questions:

1. What was your overall experience with this mindfulness-based session? You can talk about anything related to this session, for example, whether you liked it or not; and whether you found it helpful or not. (what you liked, disliked and why; what was helpful or not helpful and why)
2. Were the instructions for the mindfulness-based session easy to follow? Why or why not? (i.e. sequence, wording of the instruction, wording of instructions)
3. What is the likelihood that you will take part in a mindfulness session in future? Is the practice session feasible for you? (i.e. would you rather practice mindfulness alone or in group setting?)
4. Is there anything else about your experience in the session that you would like to share that I did not ask about during this interview?

As we mentioned prior to the session, the interviews will be transcribed and analyzed. All identifiers will be removed; we will use pseudonyms to ensure the confidentiality of data. You can ask to review the verbatim transcript of your interview. Please feel free to contact me in the provided email address or phone number.

Appendix F: Coding Table

Topic	Themes	Description	Quotes
Experience of the brief mindfulness practice session	Comparison of mindfulness to other relaxation techniques	Familiarity and awareness of relaxation techniques	"I used to go to muscle relaxation exercise classes for several years, that's what the instructor has us do at the end of the class, which is very relaxing, we would be deep breathing and we would be feeling our muscle relaxing and we can feel it in our feet and arms and legs, eyes" (P2) I sometimes practice…practice deep breathing on my own but it was interesting to do it with an instructor. Especially the body scanning…following your feet, legs that were interesting (P1) "When the lady (the instructor) asked us to you know inhale and exhale, I said to myself wait, I do that every now and then. I do that even without knowing it is mindfulness." (P3) "I have recently read…and heard something about deep breathing, it was no different." (P5)

			"I thought it was interesting…practicing (mindfulness) it was nice." (P4) "I think it is very beneficial to be able to de-stress and this is one of the ways you can de-stress. I have heard different ideas in the past. This is the first time I heard of mindfulness." (P6)
	Initial impression of mindfulness	Reactions to different components of mindfulness from a beginner's perspective	"It was interesting, I had more difficulty in trying to get into the meditative state than certainly others had... I am a very logical person, and I was sitting and thinking through the logic of it rather than just relaxing...So I don't think I have got as much benefit of it as I could have...I was just thinking about the mechanisms more than anything else." (P6) "Yeah, I thought it (exhalation sound) was really not in my comfort zone. It was really a little quasi-religious experience, which I was not okay with it." (P1)

			"I was kinda hoping there might be a course of 6 weeks or 8 weeks or 10 weeks or whatever like an evening class so you can go and learn some techniques about mindfulness" (P6) "I am still a little bit stressed out but if I have been doing an exercise for longer...I probably would be feeling a lot better. I think at home if I can do it even longer it would be good for me." (P2) "I really enjoyed her talks, speech. I just thought it was a little short. I could keep listening to her more you know" (P3). "I didn't think it was too long, you need longer time to learn something. I would have it longer…but when I practice it alone I would practice it for longer may be…" (P1) "I forget (things) easily, you know. You can't teach me mind(fulness)…or anything in short time or in fifteen minutes. I think it's better if I could practice it longer with my wife or in a group…may be here (the research site) then I

			would remember how to do it (practicing mindfulness) later." (P4) "You know I love learning every bit of everything. I continuously try to learn on every bit of things. So I think I would keep learning about mindfulness on my own." (P5) "I would like to learn more about the neurological or psychological aspect of mindfulness on my own." (P6) "I think (it's better to practice mindfulness) alone as it is hard for me to manage time to join...or come to a group session. You know how I am in a rush always" (P1) "(I would) prefer practicing it at home." (P5) "(Home)…that would be better for me." (P3) "Everyone had a few important things to say, and I am a listener…so I listened to others today and that felt good. We were talking to another lady (while waiting for being

			interviewed) about taking care of others and it was helpful" (P4) "I like this (group setting) because then you are out amongst people" (P3) "(I would like to) learn more about it may be in a group, may be, but then practice it alone." (P6)
Perceived effect of mindfulness	De-stress and relaxation	Perceived to be aid for relaxation	"I do know a lot of caregivers do actually get physically sick. With myself, I found I have been very stressed out and one point I was so really sobbing hysterically and one night I was sobbing so dreadfully that I called the distress center, crisis center. After I talked to a couple of people I did feel better but uhh...I think...I don't think anyone can be a caregiver without feeling stressed out." (P2) "but I say like our house is so big to downsize it, it will be all on my shoulder to get rid of everything and do everything. And I heard it from so many people that it's the caregivers that end up getting sick. Everyone tells me in

			the hospital, (whispers), "Don't, don't dwell on it." They said if you need to get out and get a cup of coffee call us up. Somebody is available to go out so you could go out." (P3) "It was good to learn how to deep breath because my doctor keeps telling me to take deep breaths and relax. It's just sometimes...I have so much in my head, I am driving and thinking about something else. Especially stress…I think that's big for caregivers. Nowadays I am too stressed out so I think I can use a few deep breaths every now and then" (P1) "Well if you are stressed and if you start doing it (practicing deep breathing), I can see how it would take your mind off you know your worries and so on" (P5)
	Improved sleep	Perceived to be helpful for improved sleep	"So I really think if I work on mindfulness exercises, take time each day and I think probably if I..if I do it may be in the afternoon and then the evening uhh…before I go to bed that would probably be the best time for

			me...Sometimes I have trouble going to sleep you know, there are things in my mind. So I can really see, I was glad she (instructor) was there to talk to us" (P2) "(May be) deep breath will help me to sleep." (P3) "In the evening…right before I try to fall asleep, I guess. (P6)
	Anxiety aid	Perceived to be useful for decreasing anxiety	"I don't want to get depressed because I am already taking a pill for anxiety but what that lady said... (instructor) I will try to practice deep breathing every day, whenever I get a chance. I know my doctor says just take a deep breath and let it out to get...you know..some sanity..., because this way I am going to try that deep breathing because if it (mindfulness) helped her (depression) then it would help my anxiety." (P3) "I am always too worried or anxious about…many things, this or that, here or there.

			This (mindfulness) thing might help me to slow down a bit." (P5)
Future Use (applicability)	Thoughts about future use	Feasibility to use in future	"Well, I think I could do it alone at home. Probably the best time it would be before I go to bed and if I can manage to do it in afternoon, I think that would help me" (P2). "I have practiced deep breathing hand on your abdomen and thinking about breathing in and out. and occasionally when I am in bed I do it. It helps before going to sleep" (P5)

Appendix G: Observation Notes

Observation Notes	Subjective reflections
During the mindfulness session, participants were following the instruction without much confusion.	The instructions were easy to follow.
After the mindfulness session was finished, participants 1 and 5 asked the instructor about instructor's own mindfulness practice regime, such as how long she practices mindfulness and frequency of her practice each day.	Participants 1 and 3 both were interested to learn about more about mindfulness practice session and wanted more information about mindfulness.
During the interview Participant 1 were nodding heavily when I asked her if she wants to practice mindfulness in the future. She volunteered to go first in the interview as she had to leave early.	Participant 1 was enthusiastic to practice mindfulness in future. She was in a rush to leave due to her prior commitment.
I had to take a more structured approach for Participant 2. She was only answering in "yes or no" format at the beginning. After ten minutes she seemed more relaxed.	Participant 2 took longer to be comfortable with the interviewer than others.
Participant 3 seemed very enthusiastic about the interview. Before she left the interview room, she mentioned several times that she was so pleased that the interviewer took the time to talk to her. She also mentioned that she does not get the chance to talk to adults often.	Participant 3 had a strong appreciation for the interview process.

Participant 4 interacted with number of staff of the research site and seemed very familiar with the site. She was interviewed two weeks later than the other participants and she was happy that the interviewer came back only for her.	Participant 4 had a close relationship with the staff of the research site.
Participants 5 seemed very happy to be interviewed. When the interviewer asked about her experience about the breathing technique and the exhalation technique, she shrugged and seemed to be more closed off with that topic. However, as the interviewer asked the next questions on the length of the mindfulness session, the participant seemed relaxed again.	Participant 5 did not seem comfortable with the exhalation sound "Gauranga" and did not feel comfortable to continue the topic.
Participant 6 was very social with other participants. He was interacting with other participants and engaging in the conversation with them.	Participant 6 knew a few of the participants from the caregiver support group of Alzheimer's Society of Durham.