Development of The Caregiver’s Guide to Self-Care

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Dedication

To all family caregivers taking care of their loved ones.

“Caregiving often calls us to lean into love we didn’t know possible.”

- Tia Walker
Abstract

Family caregivers of individuals with dementia are experiencing a high rate of stress and burnout. Practicing stress management techniques have been shown to reduce stress among this population. The present thesis outlines the evolution of a self-care manual developed to respond to the gap in literature for family caregiver resources. The Caregiver’s Guide to Self-Care aims to reduce stress levels by providing them with information regarding dementia, how to access funding and community resources, stress identification, and stress management techniques. The stress management techniques in the manual were chosen based on empirical literature. The intended participants, setting, and design are described in the thesis. The results section includes the final version of The Caregiver’s Guide to Self-Care. Future recommendations include evaluating the manuals effectiveness in reducing stress by collecting data.
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Chapter I: Introduction

Description of Agency

The agency where The Caregivers Guide to Self-Care manual was developed is a non-profit organization offering adult day programs, education, training and counselling for individuals with dementia and their loved ones who reside in the Champlain region.

When an individual is diagnosed with any type of life altering disorder or disease, much attention is given to this individual. Once diagnosed, the individual receives considerable sympathy and support from family members and friends. They also often receive professional help in the form of medical and psychological supports, dealing with the emotions that follow their diagnoses. For example, cancer patients, who have been recently diagnosed, visit psychologists to help them cope with their new-found struggles (Fitzpatrick, 2016). Although it is important for these individuals to receive this attention, what the family members and caregivers simultaneously struggle with may be overlooked. A diagnosis can create an immense amount of stress for the family, specifically for those suffering from dementia. Dementia causes an individual to experience confusion, disorientation, severe memory loss, extreme mood swings, and unfounded suspicions about family (Alzheimer’s Association). In addition to cognitive symptoms, dementia can also diminish a person’s physical functions such as, swallowing, walking, and speaking (Alzheimer’s Association). As the person with Alzheimer’s ability to function independently weakens spouses, children, and other family members of the person with dementia have limited options and are often placed in a position to become the primary caregiver.

Discovering a loved one has been diagnosed with dementia can be very difficult. As dementia results in the loss of memory, family members often feel that they are about to lose their loved one (Drossel, Fisher & Mercer, 2011). Feelings of grief are common with the loss of their companion (Mace & Rabins, 2007). Family members often feel helpless and uncertain when dealing with their loved one being diagnosed with Alzheimer’s (Tsai, Tsai, & Li, 2016). Furthermore, a study conducted in 2016 by Tsai, Tsai and Li found that family members identified that they felt isolated throughout the process of becoming a caregiver while casting self-blame on themselves for not being able to fulfill the needs of those who have been diagnosed with dementia. Adding to that, families also felt strain and distress by the one-sided affection from their loved one (Tsai et al., 2016). When a spouse becomes a caregiver, the dynamic of the relationship shifts dramatically from equal partners to caregiver and dependent. Often the patient’s main caregiver is their partner. This means that the patient develops a dependency on their partner that was not there prior to the diagnosis. It is also difficult for children of the individual with dementia as they begin to care for the person who previously provided for them. Similar to the relationship between both partners, the dynamic between the parent with dementia and the child also changes and both are required to navigate this new territory.

In the more advanced stages of dementia, the individual will lose mobility skills. The caregiver may have to take on responsibilities of maintaining another person’s hygiene. Some tasks may include assisting the individual with dementia with toileting, bathing, mobility, diet, and administering medical treatments. This can be especially difficult when the person with dementia is a spouse or parent, due to the shift in the relationship dynamic. Some of these emotional struggles may stem from feelings of anger or resentment linked to a sense of uncertainty of the situation, lack of help from others, frustrating behaviour from the person with dementia and embarrassment due to the new behaviour exhibited by the person with dementia (Mace & Rabins, 2007). There is also a stigma associated with dementia, which can lead to
further emotional strain (Mace & Rabins, 2007). Mace and Rabins (2007) stated that family caregivers can feel guilty as a result of spending time away from the person with dementia. They will often lose their temper with the person with dementia, and limit their independence such as, not allowing the person with dementia to drive or enrolling the person with dementia in a day program without seeking their input (Mace and Rabins, 2007). As the disease progresses, individuals with dementia are unable to stay at home alone, often obligating caregivers to attend to their needs on a continued basis (Drossel et al., 2011). Having to constantly care for another individual and rarely finding a moment to be by themselves, family caregivers experience added stress and fatigue as a result (Takai, Takahashi, Iwamitsu, Oishi, & Miyaoka, 2011). A dementia diagnosis can also cause a variety of financial issues. The individual may have to stop working due to their symptoms of dementia or the caregiver may have to stop working to care for the individual, which can result in a loss of income (Mace & Rabins, 2007). Medical costs, costs for in-home care, legal fees, and housing costs can contribute to financial problems (Mace & Rabins, 2007).

Professional caregivers, such as respite workers, nursing home workers, and in-home personal support workers, who care for patients with dementia are found to experience a high level of stress and emotional burnout (Mackenzie & Paragine, 2003). MacKenzie and Paragine (2003) found that professional caregivers often reported being overwhelmed with their duties and emotional exhaustion after spending eight hours a day attending to the patients. If a professional caregiver struggles with emotional exhaustion over a series of work shifts yet can seek relief at the end of the day, the implications are concerning for a non-professional caregiver, providing 24-hour care, without a break. Additionally, most professional caregivers have completed ample amounts of training and education programs in order to manage the emotional side effects effectively, whereas family members of individuals with dementia are thrown into the situation with no real training on how to handle the disorder or manage their own self-care.

According to Brodaty (2003), those caring for people with dementia are the highest population needing support for psychological distress. Caregivers for individuals with dementia are often pre-occupied worrying about the person with dementia so much that they are unable to recognize that they may be experiencing burnout caused by stress. This stress can be a result of a multitude of factors, including having to constantly orient the person with dementia on topics such as; where they are, what time it is, what they are doing, and even who they are. The caregiver may also have to begin to cue the individual with dementia regarding toileting, getting dressed, eating, and many other daily activities. As individuals with dementia are at a high risk of wandering and getting lost, caregivers may also become fatigued, and emotionally strained as they have to be vigilant regarding the individual’s whereabouts. While there is an abundance of research and literature on the topic of dementia, the majority of the information focuses on how to care for the person with dementia and there is limited material on self-care for the caregiver. Of the literature available on self-care, many of the publications can be costly and timely to read. Although numerous agencies do offer brochures on how to deal with the stressors that accompany being a caregiver of someone with dementia, they are brief and do not provide concrete examples on how to do so. Therefore, more resources are needed to help the caregiver deal with the changes they are experiencing. Caregiver stress may come in the form of anger, denial, exhaustion, depression, and social withdrawal (Alzheimer’s Association). Identifying this stress may be difficult for a caregiver who is left feeling overwhelmed with the current situation. This research paper will aim to identify the gap in resources while developing a self-care manual for family caregivers of individuals with dementia.

This thesis includes four succeeding chapters. First, is the literature review of the impact on caregivers for individuals with dementia will be discussed, including consideration of prior
research, while evaluating the differences within the research. Relaxation techniques and caregiver training will also be discussed in relation to managing caregiver burnout. Presented next, will be an overview of the methods involved in creating a caregiver self-care manual. This methodology will address inclusion criteria (caregivers for individuals with dementia), setting for delivery of manual information, materials, measures, and the assessments included in the manual. Additionally, this thesis will summarize the components resulting in the manual. The final chapter will include a review of the thesis. Strengths, limitations, and multilevel challenges that were present throughout the development of this proposed thesis manual will be discussed. The overall implications and summary of the thesis and how it can benefit the Behavioural Psychology field will also be deliberated in this section.
Chapter II: Literature Review

Dementia

Dementia is an umbrella term used to describe symptoms in which people experience memory loss and difficulty with daily functioning (Alzheimer’s Society, 2018). According to the Alzheimer’s Society (2018), the most common types of dementia are: Alzheimer’s disease, vascular dementia, frontotemporal dementia, and Lewy body dementia. The Alzheimer’s Society (2018) found that approximately 564,000 Canadians are currently living with dementia. It is anticipated that the number of diagnoses will increase to 937,000 people within the next 15 years (Alzheimer’s Society, 2018). It was stated that Canadians spend 10.4 billion dollars per year caring for individuals diagnosed with dementia (Alzheimer’s Society, 2018). It is not only those who are diagnosed with dementia that are affected by the disease. The Alzheimer’s Society (2018) notes that 1.1 million people (individuals diagnosed, friends, and family members) in Canada are affected by dementia.

The common type of dementia, Alzheimer’s disease (AD), was first discovered and diagnosed by Dr. Alois Alzheimer (as cited in Karran, 2016). Dr. Alzheimer (as referenced in Karran, 2016) stated that AD consists of two factors; something he called “plaques” and “tangles”. Marr (2016) explains that plaques are the clumping of a protein referred to as beta amyloidal whereas tangles refers to a tau protein that twists and ‘tangles’, preventing nutrients from reaching their target. Specifically, when an individual has AD these plaques and tangles clump together and prevent signal and nutrients transfers between nerve cells resulting in the death of brain cells (Marr, 2016). The death of these brain cells affects the individual with AD in every way; how they feel, how they think, and how they act (Marr, 2016). Marr (2016) stated that the individual’s ability to communicate, make decisions, and remember facts diminishes. Additionally, individuals diagnosed with AD have tendencies to act out of character, have physical outbursts, be apathetic, be withdrawn and lose much of their physical mobility (Mace & Rabins 2001). Mace and Rabins (2001) emphasized that AD is an irreversible progressive degeneration of brain cells, which ultimately results in death. Although medications are available to manage the side effects of AD, there is currently no known cure (Alzheimer’s Society, 2018).

Vascular dementia occurs when brain cells are deprived of oxygen due to the blood supply in the brain being blocked or damaged (Alzheimer’s Society, 2018). Chiu, Chen, Keung, Hua, and Tang (2006) suggest that the symptoms of vascular dementia are similar to those of AD as the individual’s ability to make decisions, plan, and organize is affected. Furthermore, vascular dementia may cause delusions and depression (Chiu, Chen, Keung, Hua, & Tang, 2006).

Frontotemporal dementia differs from AD as it affects only one section of the brain (Alzheimer’s Society, 2018). They suggest that frontotemporal dementia is most often the cause of cells shrinking or enlarging resulting in cell death. According to Mace and Rabins (2001), the main symptoms of frontotemporal dementia include: distractibility, inhibition, withdrawn behaviour, behaviour repetition, incontinence, loss of insight, and speech problems. Individuals with this type of dementia often experience a change in personality; for example, a person who was previously outgoing with high energy becomes quiet and withdrawn (Mace & Rabins, 2001).

Lewy body dementia is a blend of AD and Parkinson’s disease (Mace & Rabins, 2001). The Alzheimer’s Society (2018) reported that individuals with Lewy body dementia progressively lose their memory, language, and reasoning skills. Additionally, depression and anxiety often accompany a diagnosis of Lewy body dementia (Alzheimer’s Society, 2018). Like
Parkinson’s, Lewy body dementia causes stiffness of muscles, stooped posture, and body tremors (Mace & Rabins, 2001). Chiu et al. (2006) found that visual hallucinations such as, seeing people, and children, often occur.

All of these types of dementia impedes on the individual’s ability to complete daily tasks independently. As a result, loved ones may often become primary caregivers to help the person with dementia complete daily functions.

**Family Caregiver Experience**

Many experiments have been conducted to study the effect a diagnosis of dementia can have on family members. Tsai, Tsai and Li (2016) conducted a study to determine the experiences of family caregivers for individuals with dementia. The aim of the study was to identify the ways in which family caregivers are suffering and their coping methods (Tsai et al., 2016). Tsai et al. (2016) found that family caregivers experienced feelings of helplessness and lack of control in regard to the progression of the dementia. The study (2016) also discovered that family caregivers cope with these experiences by relying on help from community resources and self-empowerment. They (2016) completed semi-structured in-depth interviews with four volunteer family caregivers. The interview was created to help determine themes that the family caregiver may feel throughout the process of caring for their loved one with dementia (Tsai et al., 2016). The themes were determined through qualitative research of dementia studies (Tsai et al., 2016). In addition to feelings of helplessness, the participants stated that they felt constantly challenged by the demands of being a caregiver for someone with dementia coupled with guilt due to their inability to care for the individual with dementia (Tsai et al., 2016). The study (2016) identified that stress was commonly experienced by the participants as a result of the diminishing and one-sided relationship, strain from taking on multiple roles, and feelings of being socially isolated. Additionally, family caregivers increasing self-awareness and knowledge of health helped them cope with the stress of the dementia diagnosis (Tsai et al., 2016). Family caregivers for individuals with dementia experience stress at a high rate while they try to manage the many difficult behaviours associated with dementia (Tsai et al., 2016). Despite being able to identify positive and negative experiences among family caregivers, the study failed to measure the reliability and validity of the themes. Additionally, the study only included four family caregivers, such a small sample size may not accurately represent the overall population of family caregivers for individuals living with dementia. Although treatment to decrease stress levels were not implemented, the researchers were able to identify methods that family members were using to cope with the stress associated with dementia (Tsai et al., 2016).

Using a variety of self-report questions, Takai, Takahashi, Iwamitsu, Oishi, and Miyaoka (2011) conducted a study to determine the predictive factors of quality of life (QOL) in family caregivers for individuals with dementia. They found that caregivers who experienced burnout and depression have difficulty managing the difficult behaviours and psychological needs of the individual they are caring for (Takai et al., 2011). Their study included 48 males and 70 females, all of whom were family caregivers for people with dementia. The participants were instructed to complete three assessments including the World Health Organization Quality of Life 26 Questionnaire (WHO-QOL-26), the Pines Burnout Measure and the Beck Depression (BDI-11) Inventory (Takai et al., 2011). The WHO-QOL-26, developed by the World Health Organization in 1998 (as cited in Takai et al., 2011) is a 26-item self-report assessment intended to measure an individual’s QOL focusing on the physical, psychological, social, and environmental aspects. The second assessment, the Pines Burnout Measure created by Pines, Aronson, and Kafry in 1981 (as cited in Takai et al., 2011), is also a self-report comprised of 21 questions regarding
physical, emotional, and mental exhaustion. The questionnaire used a 7-point scale from 1 (never) to 7 (always) and classifies results into four groups: no burnout, risk of burnout, burnout present, and clinically depressed. The final assessment, the BDI-11, is a 21 self-report questionnaire that measures severity of depressive symptoms (Beck, Steer, & Brown, 1996). Each question can be answered by choosing one of the four statements, which have a number value (Beck, Steer, & Brown, 1996). In addition to having the caregiver complete the assessments, Takai et al. (2011) used the participants’ medical records to determine the severity of the cognitive impairment and neuropsychiatric symptoms for the individuals with dementia. Neuropsychiatric symptoms included some of the following delusions, hallucinations, agitation, aggression, depression, anxiety, and irritability (Takai et al., 2011). Takai et al. (2011) found that the severity of neuropsychiatric symptoms and scores of the assessment were negatively correlated. This meant that the higher frequency of neuropsychiatric symptoms resulted in a lower score of burnout/depression across all three assessments (Takai et al., 2011). Using a stepwise multiple regression analysis, the researchers found depressive symptoms to be the highest predictor for a low QOL (Takai et al., 2011). The assessment additionally revealed that family caregivers experience negative psychological effects due to the long-lasting interpersonal relationship with the individual with dementia (Takai et al., 2011). It is clear from the study that levels of depression and anxiety in caregivers directly affect their ability to manage the physical and emotional needs of the dependant (Takai et al., 2011). The fact that the individuals diagnosed with dementia were in the early stages at the time of the study while caregivers who care for individuals in the later stages of dementia are not represented is seen as a limitation (Takai et al., 2011).

**Stress Assessments**

Self-report assessments have been widely used among researchers to identify stress within the caregiver population. Valente et al. (2011) conducted a study assessing how family caregivers perceive their own health. Through self-report questionnaires (Valente et al., 2011) found that individuals with a poor perception of health were at a greater risk of suicide. Additionally, they discovered that caregiver anxiety was a significant predictor of poor health. Valente et al. (2011) stated that subjective health evaluation such as the Beck Depression Inventory is equivalently reliable and valid as compared to more complex health measures. They suggest that self-report evaluation for family caregivers can be useful for designing treatments to decrease anxiety and depressive moods while increasing physical and emotional health (Valente et al., 2011).

In 2016, Sarabia-Cobo designed a treatment for family caregivers of individuals with dementia with the goal of increasing stress management and heart coherence with caregivers. Sarabia-Cobo (2016) described heart coherence as a physiological state when the heart is at an optimal health. To obtain baseline scores for burden, the researcher had the participants complete the Zarit Burden Interview (ZBI) (Sarabia-Cobo, 2016). Similar to burnout, burden is defined as a high level of responsibility that causes emotional stress (Saraia-Cobo, 2016). Using results from the ZBI, it was found that 69.8% of family caregivers within the study experienced severe levels of burden. Baseline results of the study (2016) revealed that 69.8% of family caregivers experienced severe burden; however, in post-treatment the levels of severe burden decreased to 58.7%.

The ZBI, created by Zarit, Orr, and Zarit in 1985, is a 22-item self report questionnaire typically used to assess levels of burden within family caregivers. To calculate scores, the ZBI uses a 5-point scale with 0 meaning “never” and 4 meaning “nearly almost always”. The interview consisted of statements of feelings such as “Do you feel angry when you are around
your relative?” and “Do you feel embarrassed over your relative’s behaviour?” (Zarit et al., 1985). The answers are calculated to provide a single score ranging from 0 to 88 (Seng et al., 2010). According to Seng et al. (2010) the higher the score the higher rate of burden being experienced. The items in the interview target the caregiver’s health and well-being in the area of: psychological health, social life, finances, and the caregiver-patient relationship. Seng et al. (2010) compared the ZBI to a variety of other stress assessments to measure its reliability and validity. Seng et al. (2010) determined Cronbach’s alpha was adequate with value of less than 0.7. The researchers concluded that the ZBI established good reliability and validity in assessing the burden of caregivers of individuals with dementia. Seng et al. (2010) explain that the ZBI is effective and useful in identifying stress among caregivers. The simply worded questions combined with the easy scoring method gives can give caregivers the opportunity to complete questionnaires independently.

Studies of this kind demonstrate the effectiveness of using self-report assessments to measure a variety of symptoms experienced by family caregivers. These assessments can help family caregivers identify their stress. Completing the self-report assessment that is easy to use can be the first step to identifying and managing caregiver stress.

**Caregiver Skills Training**

Workshops and manuals implementing caregiver skills training have also been used as a means to decrease caregiver fatigue. In 2011, Drossel, Fisher, and Mercer created a manual for Dialectic Behavioural Training (DBT) to teach family caregivers how to manage certain behaviours associated with dementia. The implementation of the DBT manual was found to increase caregiver coping strategies and enhance emotional well-being while decreasing fatigue and depressive moods (Drossel et al., 2011). Prior to implementation of the manual, participants completed a variety of assessments to determine their current state of coping skills acquisition and stress level including the *Caregiver Burden Inventory* created by Novak in 1989 (as cited by Drossel et al., 2011) and the *Way of Coping Checklist Revised* created by Vitalano, Russo, Carr, Maiuro, and Beckey in 1985 (as cited by Drossel et al., 2011). Drossel et al. (2011) developed two goals while creating the manual; decreasing harmful behaviour and increasing quality of life. To reach these goals the authors (2011) taught DBT throughout eight sessions. Family caregivers were provided with step by step procedures on how to practice mindfulness techniques, interpersonal effectiveness, emotional regulation, and distress tolerance (2011). Mindfulness was used to engage clients to observe their own behaviour and cognitive state while describing experiences over the course of giving care to a family member with dementia (Drossel et al., 2011). Drossel et al. (2011) taught social problem-solving strategies as a means to promote interpersonal effectiveness. To teach distress tolerance the researchers (2011) had the participants focus on skills of acceptance and pain management. Finally, emotional regulation emphasized feelings and self-care with the goal to increase participation in pleasurable events (Drossel et al., 2011). Participants completed the assessments a second time, post-treatment (Drossel et al., 2011). The results showed that family caregivers experienced an increase in social functioning, problem solving skills, and emotional well-being (Drossel et al., 2011). Furthermore, the study (2011) concluded that implementing the DBT manual decreased family caregivers’ level of fatigue and frequency of depressive moods. Limitations of this study include a small sample and a high drop-out rate (Drossel et al., 2011). Although teaching the entire DBT manual to family caregivers is unrealistic, certain step by step procedures from the manual, such as mindfulness, can be more easily provided to family caregivers to practice independently. More specifically, mindfulness can be used to help caregivers become aware of their emotional states and urges (Linehan, 2017).
Professional Caregiver Interventions

There is a wide variety of research that looks at the effects of caring for an individual with dementia among professional caregivers. In 2016, Clauss, Hoppe, O’Shea, Morales and Steidle reduced caregiver fatigue by implementing an intervention program encouraging daily reflection of work events among professional caregivers for individuals with dementia. The participants in the study (2016) included nurses who work in the home of patients. Some of the professional caregivers’ regular duties consisted of caring for the patients’ hygiene, mobility, diet, and medical treatments (Clauss, Hoppe, O’Shea, Morales, & Steidle, 2016). The criteria required the nurses to work at least 35 hours per week with individuals with dementia (Clauss et al., 2016). The researchers (2016) hypothesized that by having professional caregivers reflect on certain moments during their shift would decrease levels of emotional exhaustion. Prior to the intervention the participants had to complete two assessments pertaining to their current state of emotional exhaustion and fatigue (Clauss et al., 2016). The assessments include the Maslach Burnout Inventory, to measure emotional exhaustion, and the Fatigue Exhaustion Recovery Scale, which measured fatigue (Clauss et al., 2016). The study (2016) had a treatment group and a control group to compare scores. The control group did not receive any type of intervention (Clauss et al., 2016). In the treatment group, the nurses were instructed to think of a positive moment they had experienced on that day (Clauss et al., 2016). After they were given time to identify and think about the moment, the nurses participated in a mindfulness exercise of deep breathing (Clauss et al., 2016). Upon finishing the mindfulness exercise the researchers (2016) asked the participants the following questions about the positive moment they previously identified: What happened exactly? Where did it happen? What did you see/hear? What did you say or do? The nurses were instructed to repeat the exercise they had just completed at least once a day during their work breaks (Clauss et al., 2016). Once the nurses participated in the intervention for ten days the Maslach Burnout Inventory and the Fatigue Exhaustion Recovery Scale was administered again (Clauss et al., 2016). Through the second set of test results, the researchers (2016) found that the work reflection significantly reduced the nurses’ level of emotional exhaustion and fatigue compared to the control group. This study (2016) demonstrates that a short intervention repeated daily can greatly improve a caregiver’s well-being. Deep breathing and work reflection can be an effective method to reducing caregiver stress and fatigue (Clauss et al., 2016). One limitation identified by the researchers, was the participants’ willingness to partake in the intervention as the treatment may not generalize to non-willing caregivers; in other words, it was suggested that only willing volunteers be chosen for future intervention (Clauss et al., 2016). Additionally, the nurses in the study were able to complete the exercise during their work breaks; (Clauss et al., 2016) whereas family caregivers may not have to opportunity to find time to complete this method.

This study was able to reduce emotional exhaustion and fatigue within professional caregivers. As family caregivers and professional caregivers with dementia experience similar situations, equivalent benefits may be accomplished if implemented with family caregivers. Research and results of this experiment will assist in the development of fatigue management techniques such as using work reflection.

Stress Management Techniques

In a 2016 study, by Sarabia-Cobo, treatment aimed at increasing stress management and heart coherence was implemented among family caregivers. The intervention was successful in improving emotional and physical welfare of the caregiver through teaching emotional self-control techniques (Sarabia-Cobo, 2016). The study (2016) used the Zarit Burden Interview (ZBI) to identify stress levels among caregivers and the Personal Stress Reliever (PSR) to
measure heart health. The PSR is a PC software that coaches individual through preventing and controlling stress via deep breathing techniques (Sarabia-Cobo, 2016). Sarabia-Cobo (2016) defined burden as a high level of responsibility causing stress. The study (2016) was implemented over the course of three months with one-hour weekly sessions. The first two sessions included a discussion of stress and how it affects individuals while the remaining sessions consisted of learning how to monitor heart rate (Sarabia-Cobo, 2016). Throughout the sessions the participants continuously used the PSR (Sarabia-Cobo, 2016). The PSR instructed the family caregivers to practice deep breathing by describing how to breathe within the centre of their chest (Sarabia-Cobo, 2016). At post-treatment the number of caregivers experiencing severe levels of burden decreased by 11.1% (Sarabia-Cobo, 2016). This study demonstrated that having family caregivers participate in deep breathing exercises can decrease the level of stress they experienced (Sarabia-Cobo, 2016) However, this experiment involved the use of costly machines to measure heart rate and to guide participants through relaxation techniques which makes replication difficult.

O’Donnell (2018) conducted a study to test the effectiveness of using Mindfulness-Based Stress Reduction (MBSR) and Progressive Muscle Relaxation (PMR) to decrease feelings of depression, burnout, and loneliness among family caregivers of individuals with dementia. Using self-report assessments prior to the intervention and one-year post-treatment, the researcher (2018) discovered that MBSR and PMR techniques were successful in decreasing caregiver stress. After one year of practicing MBSR and PMR activities, participants reported reduced feelings of isolation and depression while feelings of self-compassion and sleep quality increased. (O’Donnel, 2018). The study above demonstrates that combining the use of MBSR and PMR techniques can be an effective practice to increasing overall health among family caregivers for individuals with dementia. Step by step procedures for PSR and MSBR can be easily administered to family caregivers. Providing these resources to family caregivers can allow them to engage in the activity independently.

**Manual Effectiveness**

Training manuals to teach skills to a specific population have been widely used within the field of psychology. More specifically, training manuals to teach Dialectical Behaviour Therapy (DBT) have been distributed since 1993 (Linehan, 2017). The current version of the DBT training skills manual is the favoured method of treatment for individuals with borderline personality disorder (BPD) (Linehan, 2017). The manual, created by Linehan (2017), includes modules to teach individuals with BPD mindfulness, emotional regulation, interpersonal effectiveness, and distress tolerance. Linehan (2017) describes the skills to be learned (checking the facts, deep breathing and managing emotions) and suggests methods in how individuals can practice these skills. For example, Linehan (2017) defines mindfulness as being present in the moment and acting without judgment. She elaborates on the subject of mindfulness, then offers clients the opportunity to practice the skill by providing handouts for journaling and self-reflection within the manual.

In 1988, Halpert created a program to provide elderly family caregivers with community resources such as, respite services, personal support workers and support networks. The Volunteer Information Provide Program (VIPP) (Halpert, 1988), was a resource manual that senior caregivers could use independently. The VIPP was given to caregivers to take home and to access community resources at their discretion (Halpert, 1988). Halpert (1988) found that providing caregivers with this information improved how they managed stress, administered medicine, and approached personal care. Furthermore, Halpert (1988) concluded that the VIPP met the informational needs of family caregivers by equipping them with existing community
organizations. Halpert’s study (1988) demonstrates the effectiveness of providing caregivers with helpful community resources in addressing caregiver stress management.

Summary

A dementia diagnosis can alter a person behaviourally, cognitively, and physically. This review revealed the issues that family caregivers can potentially experience when caring for an individual with dementia. Primarily, it was found that family caregivers experience high rates of stress and burnout (Takai et al., 2011). Previous studies were reviewed to determine interventions and assessments that developed effective treatment in managing and identifying caregiver burnout. Some of these treatments included work reflection and breathing techniques to increase family caregivers’ overall health.

In conclusion, the research demonstrates the effectiveness of using stress management techniques to decrease stress levels among family caregivers. It is difficult transitioning to a caregiver role for another individual who previously did not need to be cared for. Daily, family caregivers experience a wide variety of stressful situations arising from their duties as a caregiver. It is hypothesized that the development of a manual that provides strategies to navigate resources and identify and manage stress could facilitate caregiver’s ability to decrease their feelings of burnout and increase a sense of well-being.
Chapter III: Methods

Participants

Although Human participants where not used during the development of the manual, it was developed for non-professional caregivers caring for individuals with dementia. It was intended for spouses, children, parents, extended family, friends or any individual caring for someone with dementia, specifically those living independently in-home with family and not currently residing in a retirement/nursing home. The target participant was the spouse of the person living with dementia; however, any caregiver can benefit from the manual. The manual was provided to participants at the beginning of a 2-hour information session. Participants may have been referred to the session by community agencies or other support workers.

Design

The Caregivers Guide to Self-Care was constructed as an applied thesis for the Honours Bachelor of Behavioural Psychology program. This thesis is a non-experimental design since there are no independent or dependent variables. The purpose of the manual was to provide family caregivers of individuals with dementia with an easy-to-use, empirically proven, method of identifying, and decreasing stress. In addition to stress management, the manual included information regarding the process of accessing funding and community agency navigation. The material within the manual was produced through research of empirical studies and community resources.

The manual was comprised of six sections including, an introduction to dementia, agency navigation, how to access funding, stress identification, stress management, and a section of techniques for interacting with the individual with dementia. The manual was designed so that it could be delivered in a one-time 2-hour information session. During the 2-hour session, a PowerPoint presentation was presented along with modelling of some techniques recommended in the manual and a practice session of the ZBI assessment (Appendix A). Sessions occurred monthly. Each information session targeted new participants; however past participants with additional questions were welcomed as well. During these sessions, the caregivers were instructed on how to navigate and effectively use the manual (i.e how to interpret the result of the stress assessments, how to engage in mindfulness or seek community resources offering mindfulness practices, accessing community funding and programs, etc.). During sessions, caregivers were allotted time to ask questions.

Setting and Apparatus

It was recommended that the manual implementation session occur in a conference type room in the community agency building. This room possessed chairs for each participant and facilitator. As participants were encouraged to practice progressive muscle relaxation techniques, it was recommended that the chairs should be cushioned and have built in arm- rests to optimize comfort. A PowerPoint presentation was delivered during the information session outlining each section of the manual. The room included a computer and projector device for the PowerPoint. The chairs were placed in four rows of five while facing the projector screen. Sessions were not delivered to more than twenty people at one time to ensure personal attention to questions and assistance can be delivered. During the information session, the doors were closed to minimize distracting loud noises and to retain privacy of the participants. Most of the participants were over the age of 60; therefore, accessibility options were considered. The room was on the lower level of the building to reduce any difficulty in gaining access to the room.
table with refreshments including, water, coffee, tea, cookies, and muffins were placed at the back of the room.

**Measures**

Due to time constraints, the efficacy of the manual was not tested. However, a social validity measure in the form of a satisfaction survey (Appendix B) will be administered via mail to each participant three months following the information session. This is to allow time for the participants to navigate the manual and seek out recommended resources. In addition to the satisfaction survey, participants will also receive a phone call at the 3-month follow-up to further discuss recommendations to improve the manual. The satisfaction survey and phone call will allow staff from the community agency to make future changes to enhance manual satisfaction.
Chapter IV: Results

Product

The Caregiver’s Guide to Self-Care is included in Appendix C. The manual was created for family caregivers to use independently at home. The practices incorporated in the manual are supported by empirical evidence. Information on how to access community agencies and step-by-step instruction for completing the stress management techniques are also outlined in the manual.

The following is a breakdown of each section presented during the information session.

Section 1-Introduction to dementia: The introduction section informed the caregivers of the different types of dementia and their symptoms. A brief description on the different types of dementia including: frontotemporal, Lewy body, vascular, and Alzheimer’s Disease was presented on PowerPoint and verbal explanation was provided for each. A more thorough description of the types and symptoms was included in the caregiver self-care manual provided to the participant.

Section 2-Agency Navigation: The agency navigation section was an assortment of agencies and community resources for the local area that support families with dementia. A breakdown of how these agencies interact with each other and requirements for programs were explained. This section also included a variety of services provided by these agencies that could benefit the caregiver and the individual living with dementia including, day program services, supportive counselling, and education programs. Job descriptions of potential professionals a caregiver might encounter was also included in this section to assist them with understanding the role that each professional may play (i.e. social worker, doctor, pharmacist etc.)

Section 3– How to access funding: In this section, a guide on how to access funds for employment insurance was presented to participants.

Section 4- Stress Identification: This section included the ZBI assessment (Appendix A) to assist the caregivers in identifying stress. The facilitators demonstrated how to use the assessment to identify stress and to interpret the results. Participants were given the opportunity to complete the assessments during the session, once it was modelled by the facilitators or to take it home and complete it on their own time. Instructions on how to complete the questionnaire were included in the manual.

Section 5- Stress Management: Ways and methods to reduce stress, such as progressive muscle relaxation (PMR), mindful breathing, and positive reflection techniques was presented in the fifth section. During this section, facilitators modelled PMR and mindful breathing techniques. After the PMR and breathing techniques were demonstrated, the participants were given the opportunity to practice and ask questions of the facilitator’s strategies. The participants were also provided with step by step instructions on each technique within the manual in order to practice them independently. In addition to the step by step procedure, the manual also provided caregivers with a list of resources and community services such as in-person and online support groups.

Section 6- Helpful Tips: The final section provided additional resources to help the caregiver care for their family member such as: a list of long-term care facilities, personal support worker agencies, and ways to comfort the person living with dementia.
Chapter V: Discussion

Summary

A gap in the availability of user-friendly resources was found for caregiver stress management and dementia information, which prompted the creation of a The Caregiver’s Guide to Self-Care. The purpose of this thesis was to construct a manual that would provide family caregivers of individuals with dementia with methods and information to facilitate stress management and navigate community resources.

Empirical based evidence for stress management techniques were researched for the population of caregivers for individuals with dementia. Some of the techniques were originally used with professional caregivers, nurses, and personal support workers, and modified to be applicable to with family caregivers. A variety of stress identification methods were analysed in relation to effective within the specific population. The Zarit Burnout Interview (Zarit, Orr, and Zarit, 1985) was selected due to it being widely used within the family caregiver population and user friendly. Community resources were also gathered to enhance family caregiver time management and assist navigation of the unfamiliar health care system for individuals with dementia.

Strengths

A prime benefit of this manual was the inclusion of both stress management techniques and helpful community resources. These stress management techniques were included in the manual due to the empirical evidence that supports their success in reducing stress levels among caregivers for individuals with dementia. More specifically, authors found that work reflection (Drossel, Fisher & Mercer, 2011), deep breathing exercises (Sarabia-Cobo, 2016), MSBR and PMR (O’Donnell, 2018) were effective methods in increasing stress management skills; thereby decreasing the effects of stress overall. The manual also included up to date information regarding local support groups, day programs, personal support worker agencies, and how to access funding. A supplementary strength is the monthly information sessions where users of the manual are taught how to navigate the manual and are given the opportunity to ask questions. Consequently, the manual was written in lay terms to ensure that it was easy-to-use and user-friendly. Pages within the manual were also provided to give users and opportunity to create personal resources and record their thoughts. Most importantly, the manual is cost-effective as it does not require additional materials to participate in the stress management techniques.

Limitations

A significant limitation of this manual is the potential lack of family caregiver involvement. Due to the placement being at a day program where transportation is provided, there was limited interaction between the creator/administrator of the manual and the family caregivers. The lack of interaction means that the information provided in the manual is based solely on review of empirical research and not on primary interactions with family caregivers. Another limitation includes the upkeep of current information regarding community resources such as location, pricing, and times. The results of the stress identification method may not be fully accurate as it is a self-report questionnaire open to interpretation.

Although users of the manual will receive a phone call at the 3-month follow-up for feedback regarding the manual, no client data is recorded. For this thesis, due to time constraints, the caregiver self-care manual was not empirically evaluated to determine effectiveness.
Multilevel Challenges to Service Implementation

At the Client Level

A client-level challenge for the self-care manual is the caregiver’s motivation to use the manual. Family caregivers are provided with a variety of documents and brochures from health care professionals; this might overwhelm the caregiver leading them to avoid reviewing any of the information given. Additionally, the caregivers time availability to thoroughly review the manual may be limited as they are busy caring for their loved one with dementia and other daily responsibilities. An additional challenge is the lack of evaluation to measure if the manual is being used as it was intended, since the manual is brought home by the caregiver.

At the Program Level

A significant program level challenge is the lack of data collection to ensure the effectiveness of the manual. Since the manual will not be empirically tested, the effectiveness of the approach cannot be verified. Secondly, delivery method of the self-care manual could be a challenge. Although the users of the manual can attend a monthly information session regarding the manual, one-on-one review of the manual would optimize its benefits.

At the Organization Level

As the manual contains location specific services, the location of the manual user can be a great challenge. The manual was created for caregivers in the Prescott-Russell Area. Although the stress management techniques do not depend on geographical circumstance, the agencies, and resources provided in the manual can only be accessed by individuals in the Prescott-Russell area.

At the Societal Level

Stigma and lack of understanding is a significant issue within the societal level. When individuals are diagnosed with dementia their brains are physically changing, causing them to engage in irregular and sometimes harmful behaviours. This can be embarrassing for the caregiver. This social stigma may cause family caregivers to be reluctant to seek out community resources or social supports.

Recommendations for Future Research

As stated in the limitations section, recommendations for future research would include examining the effectiveness of the manual using human participants. Ideally, data regarding the participants stress levels before and after receiving the self-care manual would be collected. In addition to data collection for the effectiveness in the manual, it is suggested that data for enrolment in services that are provided in the manual could also be acquired. Moreover, individuals who have cared for a loved one with dementia could be encouraged to contribute to the content of the manual. In the future, recommendations and testimonies from caregivers, who have had a difficult time managing stress in the past, should be taken into consideration. Upon receiving feedback from users at the three-month follow up, it is recommended that alterations be made according to suggestions from users.
Contribution to the Field of Behavioural Psychology

Any new material founded on empirical evidence presents a contribution into the field of behavioural psychology. This thesis contributes to the field of behavioural psychology in a variety of ways. Mainly, this thesis responds to the identified gap in the literature that self-care of caregivers is often overlooked and an area of need. The population of caregivers for people with dementia experience a high level of stress (Tsai, Tsai & Li, 2016). Using empirically supported methods, this thesis was designed to reduce this stress among that specific population.
References


Appendix A

The Zarit Burden Interview

Created by: Zarit, Reever, and Back-Peterson (1980)

Please circle below the response that best describes how you feel

0: Never
1: Rarely
2: Sometime
3. Quite Frequently
4. Nearly Always

1. Do you feel that your relative asks for more help than he/she needs?

0 1 2 3 4

2. Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?

0 1 2 3 4

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

0 1 2 3 4

4. Do you feel embarrassed over your relative’s behaviour?

0 1 2 3 4

5. Do you feel angry when you are around your relative?

0 1 2 3 4

6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?

0 1 2 3 4

7. Are you afraid what the future holds for your relative?

0 1 2 3 4
8. Do you feel your relative is dependent on you?
   0 1 2 3 4

9. Do you feel strained when you are around your relative?
   0 1 2 3 4

10. Do you feel your health has suffered because of your involvement with your relative?
    0 1 2 3 4

11. Do you feel that you don’t have as much privacy as you would like because of your relative?
    0 1 2 3 4

12. Do you feel that your social life has suffered because you are caring for your relative?
    0 1 2 3 4

13. Do you feel uncomfortable about having friends over because of your relative?
    0 1 2 3 4

14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one, he/she could depend on?
    0 1 2 3 4

15. Do you feel that you don’t have enough money to take care of your relative in addition to the rest of your expenses?
    0 1 2 3 4

16. Do you feel that you will be unable to take care of your relative much longer?
    0 1 2 3 4

17. Do you feel you have lost control of your life since your relative’s illness?
    0 1 2 3 4

18. Do you wish you could leave the care of your relative to someone else?
    0 1 2 3 4

19. Do you feel uncertain about what to do about your relative?
    0 1 2 3 4
20. Do you feel you should be doing more for your relative?

0 1 2 3 4

21. Do you feel you could do a better job in caring for your relative?

0 1 2 3 4

22. Overall, how burdened do you feel in caring for your relative?

0 1 2 3 4

Now that you have answered all the questions above, you must add up all your scores. Add up each number you have selected from questions 1-22. The number you have just calculated represents your level of burden. Scores are categorized in 4 sections.

0-21: Little to no burden

21-40: Mild to moderate burden

41-60: Moderate to severe burden

61-88: Sever burden
Appendix B

Satisfaction Survey

The purpose of this survey is to get you, the user’s opinion, on the effectiveness of The Caregivers Guide to Self-Care. Your answers from this survey will help improve its success in helping the caregiver population. Thank you for taking the time to complete this survey.

Place an “X” under the categories that is most applicable.

<table>
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<tbody>
<tr>
<td>The manual included a helpful description of dementia symptoms</td>
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<tr>
<td>The manual was easy to use</td>
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<tr>
<td>Information regarding community resources (support groups, counselling programs) were up to date</td>
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<tr>
<td>The stress identification (ZBI) was easy to use</td>
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<tr>
<td>The stress management techniques in the manual were easy to practice</td>
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<tr>
<td>The Caregivers Guide to Self-Care helped reduce my stress levels</td>
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<tr>
<td>I would recommend the Caregivers Guide to Self-Care to other family caregivers.</td>
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