Providing Care to a Loved One Diagnosed with Dementia:

The Biopsychosocial Impact on Caregivers

by

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Abstract

For the person living with a dementia, there becomes a dependency on others that is typically taken on by a close female relation within the family. These informal carers provide invaluable service to the person living with dementia and a more in-depth understanding of the experiences of informal carers is required to ensure that their needs are identified, and we better understand how best to support them.

My study examined the experiences of informal caregivers providing care to a family member diagnosed with a dementia. I investigated their experiences using a narrative approach that allowed for the voices of the carers to be heard, and I identified key issues that the 10 female participants reported in relation to their caregiving roles. The study was designed to answer the research question:

1) What is the biopsychosocial impact on an informal caregiver providing care to a loved one diagnosed with a dementia?

Previous research was mostly quantitative in nature and focused primarily on the experiences of the person living with dementia. My study utilized a qualitative research process and thematic analysis through one-to-one in-depth interviews based on open-ended questions. This method enabled caregivers to give voice to their experiences. Three main themes were developed from the data (1) biological impact (2) sociological impact and (3) psychological-emotional challenges. The findings help us better understand the informal caregiver experience of providing care to a person living with a dementia and offer insight into the value of engaging informal caregivers of persons living with dementia in service development, implementation, and also with respect to technological research in the use of devices in support of the carer journey. The study provides a vision for the equal integration of social work services into healthcare teams as well as identifying the need for specific skills and training in social work related to the field of dementia and service provision.

Keywords

Caregiver, Dementia, Dementia Caregiver, Informal Carer, Informal Caregiver, Informal Dementia Carer, Carer, Dementia Support, Psychosocial, Carer Support, Informal Carer Support, Caregiver Support, Caregiver Burden, Caregiver Experience

Abstrait

Pour la personne atteinte de démence, une dépendance se forme généralement avec la personne féminine qui a un lien étroit avec elle. Ces gens qui acceptent d'être un aidant naturel fournissent un service inestimable à la personne atteinte de démence et nécessitent une compréhension plus approfondie de ce rôle pour assurer que leurs besoins soient identifiés de manière à mieux les soutenir. Mon étude a examiné les expériences des aidants qui fournissent des soins à un membre de la famille atteint de démence. J'ai étudié leurs expériences en utilisant une approche narrative qui a donné une voix aux aidants et qui a permis que celle-ci soit entendue. J'ai identifié les problèmes clés que les 10 participantes ont signalés en relation avec leur rôle d'aidant. L'étude a été conçue pour répondre à la question de recherche :

1) Quelle est l'approche biopsychosociale d'un soignant naturel qui offre des soins à un proche diagnostiqué avec une démence?

Les recherches antérieures étaient principalement de nature quantitative et se concentraient principalement sur les expériences de la personne atteinte de la démence. Mon étude a utilisé un processus de recherche qualitative et une analyse thématique par le biais d'entretiens individuels approfondis basés sur des questions ouvertes. Cette méthode a permis aux aidants de faire connaître leurs expériences. Trois thèmes principaux ont été développés à partir de données: (1) l'impact biologique, (2) l'impact sociologique, et (3) les défis psycho émotionnels. Les résultats nous aident à mieux comprendre l'expérience des aidants à fournir des soins à une personne atteinte de démence et offrent un aperçu sur la valeur de leur engagement. De plus, ces mêmes résultats appuient l’importance de la formation des aidants et à la mise en œuvre des services disponibles, sans oublier la composante technologique du parcours de ces personnes indispensables. L'étude fournit une vision pour intégrer des services de travail social au sein des équipes des soins de la santé en identifiant les besoins de compétence et de formation spécifiques liées au domaine de la démence.

Mots clés

Soignant, Démence, Soignant de la démence, Soignant informel, Soignant informel, Soignant informel de la démence, Soignant, Soutien de la démence, Psychosocial, Soutien des soignants, Soutien des soignants informels, Soutien des soignants, Fardeau des soignants, Expérience des soignants

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My brother, David, has always been the example of accomplishment and success in our family. Since the start of my new lifepath in 2004, he has been my background booster squad. Don’t worry, your comment of my being the smartest person you know (but would deny ever saying) will never be shared with anyone; your secret is safe with me.

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Introduction

During the fall of 2004, I was the victim of a workplace violence incident which resulted in my exploring new career options. This event led me to the field of social work. It was through my process of healing that I reflected on the ‘why’ of the incident and began to wonder about what would cause someone to want to suddenly engage in a violent episode against another human. Social work seemed the best place to begin informing myself of the potential for earlier intervention to negate the possibility of a reoccurrence of a similar incident that had many personal ramifications.

Through the four years of my undergraduate degree, I had the opportunity to complete a placement at the Alzheimer’s Society of Sudbury-Manitoulin North Bay and Districts. The experience of working with persons living with dementia was informative and I was fortunate to participate in the carer group support program which was extremely impactful. At around the time of this placement, I became aware of a close family member being diagnosed with frontotemporal dementia. The impact on the spouse of this family member was insidious in all aspects of their day-to-day life. The carer was aware of services in the community but opted to provide care on their own and soon isolated themselves from others in the family without explanation. These experiences increased my interest in dementia and the working of the human mind; it also created a passion towards helping those providing care to their loved ones that had been diagnosed with a dementia. This culminated in my desire to undertake my own research in this area as the final requirement for the Master of Social Work program at Laurentian University.

I felt it important that the impactful nature of providing care to a person living with dementia be made as visible as possible. This would assist with informing other potential carers, community leaders, and service providers regarding the impact and needs of these carers. Previous research related to this phenomenon of caring for a person living with dementia was primarily quantitative in nature and did not allow for the voice of the caregiver to be heard. I conducted one-on-one interviews using open-ended questions designed to encourage the research participants to share their experiences. My qualitative study has advanced the understanding of the informal carer experience in a northeastern Ontario setting by highlighting the challenges of the caregiver experience.

The findings offer insights to the potential of engaging informal carers in the creation of policy related to provision of services and the concept of sameness. I further identify the need for trauma-informed service provision and discuss the role of social work in the care of the caregiver.

Chapter 1 - Literature Review

A review of the literature was conducted using three multidisciplinary research databases, (1) EBSCO host utilizing the following databases: Academic Search Premier, General Science Abstracts, Humanities Abstracts, PsychINFO, Social Sciences Abstracts, Social Work and Social Service Work Abstracts, SocINDEX with full text and (2) ProQuest, and (3) Google Scholar. The search used the following keywords: psychosocial impact on caregivers and dementia, caregiver stress and dementia, dementia, Alzheimer’s disease and care needs, dementia and treatment approaches, caregiver fatigue and dementia, dementia treatment interventions, dementia caregivers and depression, carers of persons with dementia, grief and the carer experience of grief, supports for carers of persons living with dementia, and what is needed to support the informal caregivers of persons living with dementia. The search resulted in both quantitative research articles and qualitative research articles. There was no date limit used to define this search and I did not search using any language other than English. This literature review will begin with a definition of dementia followed by a discussion of the more prevalent forms of dementia. I will then discuss the experience of caregivers: the challenges of caring for a person with dementia, the psychosocial effects, and the possibility of financial strain. The approaches in support of the carer of a person living with dementia will also be explored as a review of type, modality, and effectiveness. I will end with a critique of the literature reviewed.

Definition and Prevalence of Dementia

Dementia is not a disease; dementia is a term used to describe a series of symptoms that may be caused by a variety of disorders that affects the brain (Argonin et al. 2004; Burton, 2011; Veterans Affairs Canada, 2010). The Alzheimer's Society of Toronto (2021, p1) defined dementia as "a set of symptoms that may include memory loss, changes in mood, and difficulties with thinking, problem solving and language. While they may seem small at the start, they can affect the day-to-day lives of people with dementia." A more formal definition of dementia is contained within the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) which states that dementia is a major neurocognitive disorder with evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains of (1) learning and memory (2) language, (3) executive function, (4) complex attention, (5) perceptual-motor, and (6) social cognition (APA, 2023). Unlike many other diseases or disorders there is no known cure or vaccine for any type of dementia.

Researchers from around the world have identified the increasing prevalence of dementia in communities (Chene, 2006; Shaji, et al., 2000; Zwaanswijk et al., 2013). Further, the World Health Organization (2017) estimated that there are 47 million people currently living with a dementia around the world and that this number is expected to increase three-fold by the year 2050. It is reported that each year, there is an increase of nearly 10 million cases of persons living with dementia (Wang et al., 2021). Whitehouse (2012) states the incidence of persons living with dementia in northern Ontario is expected to increase by 30% in the next 20 years. There are more than 130 types of dementia that may afflict an individual during the course of their lifespan; a few of these dementia types are diagnosed more often than others. Alzheimer’s disease and vascular dementia account for approximately 88% of all diagnosed dementias (Alzheimer Canada, 2023).

According to the US National Institute of Neurological Disorders and Stroke, the most commonly diagnosed types of dementia are Alzheimer’s disease, Vascular dementia, Lewy-Body dementia, and frontotemporal dementia (National Institute of Neurological Disorders and Stroke, 2010). Alzheimer’s disease is the most common form of dementia being diagnosed today; Alzheimer’s Disease accounts for approximately 68% of all diagnosed dementia cases. Most people will exhibit symptoms of Alzheimer’s disease at approximately 60 years of age but there are some instances where an early-onset form of Alzheimer’s disease can afflict an individual at approximately 30 years of age (Alzheimer’s Ontario, 2023). The disease will cause a gradual decline in an individual’s cognitive abilities over a span of approximately seven to 10 years (National Institute of Neurological Disorders and Stroke, 2010). There are several types of dementias, which are similar to Alzheimer’s disease in several ways.

Vascular dementia is caused by damage to the brain related to cerebrovascular or cardiovascular events. The most common cause for vascular dementia would be a stroke and this type of dementia accounts for approximately 20% of all diagnosed dementias (National Institute of Neurological Disorders and Stroke, 2010). It is not uncommon for a person with Alzheimer’s disease to be diagnosed with vascular dementia or vice-versa; both of these dementia types have similar symptoms and side effects. Vascular dementia affects both genders and the incidence of this type of dementia is known to increase with advanced age (Alzheimer’s Ontario, 2023). In most instances the onset of Alzheimer’s disease is a slow progression which is opposite to that of vascular dementia as symptoms of vascular dementia are sudden onset and coincide with a cerebrovascular or cardiovascular event. If an individual continues to experience having strokes, then the severity of effect of the vascular dementia type can increase; some individuals have even been known to show improvement in their symptoms when no further strokes are experienced (Alzheimer’s Canada, 2023; Gross & Shua-Haim, 1997). The third-most diagnosed type of dementia is Lewy-Body dementia (National Institute of Neurological Disorders and Stroke, 2010).

Lewy-Body dementia was discovered in the early 1900s by Dr. Freiderich Lewy who discovered that abnormal structures in the brain, referred to as Lewy-Bodies, were the cause of a variety of cognitive and physical changes in a person (Lewy-Body Dementia Association, 2023). Lewy-Body dementia is a type of dementia that is referred to as a progressive dementia due to the fact that it affects all of an individual’s abilities, both cognitive and physical, over a relatively short period of time, and is similar to Alzheimer’s disease in the effect it has on an individual. The last form of dementia being presented in this chapter is frontotemporal dementia.

Frontotemporal dementia is an umbrella term used to describe a number of disorders that can affect the frontal and temporal lobes of the brain (Alzheimer Canada, 2023; National Institute of Neurological Disorders and Stroke 2010). It is believed that Frontotemporal dementia accounts for up to 10% of all dementias currently being diagnosed (National Institute of Neurological Disorders and Stroke, 2010). The areas of the brain affected by Frontotemporal dementia are associated with personality, behaviour and language which can lead to Frontotemporal dementia often being misdiagnosed as Alzheimer’s Disease (Mayo Clinic, 2010; National Institute of Neurological Disorders and Stroke, 2010). The cognitive declines associated with dementias have caused individuals to be reliant on their families in many aspects.

The Experience of Caregivers

Due to the ever-increasing numbers of persons afflicted with a dementia there is a need for an increase in available caregiver supports. This need for increased supports for informal caregivers has continuously been identified through the completion of qualitative research, quantitative research, and mixed methods research. With the Canadian government’s move to home-based care, the majority of care being provided to persons afflicted with a form of dementia is now occurring in the home of a family member or in the home of the care-recipient. In fact, informal caregivers provide approximately 80% of the care for persons with dementia still living at home (Alzheimer’s Association, 2023). In 2015, Alzheimer’s Disease International estimated that the annual global number of informal care numbers was approximately 82 billion hours (Alzheimer’s Disease International, 2023). The Organization for Economic Cooperation and Development (OECD, 2004) defined informal care as being provided by a caregiver that can be the spouse/partner, other members of the household, relatives, friends, neighbours, or others, that usually have a pre-existing social relationship to the person they are providing care for; this work is typically unpaid (pg.18).

Persons with dementia often have a heavy reliance on their families being the cornerstone for provision of their care and support (Chene, 2006; Farina, 2017; Shaji et al., 2009; Zwaanswijk, et al., 2013). It has been reported that up to 75% of persons with dementia are being cared for in the homes of the family members providing this care (Chene, 2006; Glueckauf et al. 2005; Shaji et al. 2009). Older spouses, daughters and daughters-in-law have been identified as the key persons within family units providing this required care to the person with dementia (Glueckauf et al. 2005; Shaji et al. 2009; Truzzi et al. 2012; Weitzman et al. 2000). The diagnosis of dementia can prove to be devastating to individuals and will lead to future challenges in areas such as activities of daily living and socialization. Additionally, caregiving challenges can be faced by the person providing the daily care required. Varik et al. (2020) stated that informal caregivers to persons living with dementia are exposed to family conflicts, financial burdens, emotional strain, and relationship deprivation (pg.557).

Challenges for Caregivers

The majority of challenges that caregivers will have to contend with are behavioral in nature. These may include all or some of the following behaviors: changes in personality, sexual aggression, wandering, exit-seeking, lack of motivation, diet, depression, and sleeplessness, resistance to care, agitation, aggression, and violence. Additionally, the level of carer burden is also increased with activities of daily living such as meal preparation, housework, and shopping (Reed et al. 2020). To better support caregivers in home settings, it is important to know what is seen as their highest priorities or their biggest challenges. In 2009, a quantitative research study was conducted, led by Nichols, which explored just what topics were of the greater import to informal caregivers.

In a quantitative study of 165 caregivers, Nichols and his colleagues (2009) ascertained the topics that were the most important to caregivers. Those caregivers identified behavioral problems, and challenges to healthy lifestyle and activities. The results suggested that there was a significant importance placed on activities by caregivers of those with mild, moderate, or severe cognitive impairment; these findings were also identified in previous research by Glueckauf et al. (2005).

Glueckauf et al. (2005) identified other behavioral concerns: changes in behavior, personality, wandering, exit-seeking, lack of motivation, diet, depression, sleeplessness, resistance to care, agitation, aggression, violence and maintaining cognitive ability without further deficit. Dementia progresses in stages, and it is the associated congruence of behavioral problems with these declines that has been identified as the principal source of strain on caregivers as suggested by Shaji et al. (2009). The strain of having to provide care to loved ones, while handling increasing behavioral episodes, is also seen as the top contributor to caregiver depression (Alfakhri, et al., 2018; Adams & Sanders, 2004; Chene, 2006; Levkoff, 2000; Srivastava, et al. 2016; Truzzi, et al., 2012; Weitzman & Zwaanswijk, et al. 2013). Similar findings were also identified by Roger et al. (2015), in which a qualitative study was conducted in Ireland — using a phenomenological approach — that explored the experience of informal carers with the aim of identifying the supports required for the care of older adults in their homes. The burden of caring — the effect the role of caring had their health and wellbeing — was identified as a common theme in the study as well as the lack of formal supports that met the needs of the informal carers. Findings of caregiver burden were further substantiated by Badawoud et al. (2023) when they conducted a qualitative study — in

Saudi Arabia — that focused on caregiver burden, coping techniques, and medication knowledge. The study identified that carers experienced a moderate to high level of burden and that there was a need for services that would work to improve the quality of life of the informal caregivers. In other studies that focused on the burden of providing informal care to a person living with dementia, one domain that presented as being a negative aspect was disturbed sleep or lack of sleep (Liang et al 2020). Further, the negative impact on the carer's health was reported to be a significant health problem that affected both the physical health and mental health of the informal caregiver (Liang, et al 2020). Still other researchers identified some of the health concerns related to reduced sleep, interrupted sleep or lack of sleep overall as cardiovascular disease, depression, stroke, and anxiety (Liang et al. 2020; Smyth et al. 2020; Leggett et al. 2018; Wolff et al. 2016). Low quality and quantity of sleep was also identified by Smyth et al (2020) in their study on disrupted sleep and other associated factors in carers of persons living with dementia while Peng et al (2019) suggests that more than 90% of informal caregivers of persons living with dementia experience disrupted sleep.

Psychosocial Effects of Caregiving

The reviewed literature demonstrated that the lack of social and familial supports was also contributive to the impaired psychosocial functioning of caregivers. When faced with a lack of social supports it became clear to Chene (2006) that caregiver depression, stress and anxiety was evident when providing care to loved ones; this was further supported by Posner (2015) and later by Hwang et al., (2021) stating that up to 76.5% of all dementia caregivers have experienced anxiety. Researchers further identified lack of supports in the area of local health services, along with the substantial gap in caregiver need, when compared to available services; this is compounded by the caregivers' families lack of support, both financial and assistive, coupled with ongoing criticisms related to the type of care being provided (Glueckauf, et al. 2005; Shaji, et al. 2009; Weitzman et al. 2000). The majority of caregivers were prone to experience, or had experienced, deteriorations or reductions in their mental health status; all informal caregivers were identified as being at substantial risk for emotional disorders, in particular, depression and anxiety (Alfakhri, et al. 2018; Adams, et al. 2004; Chene, 2006; Glueckauf et al. 2005; Shaji, et al. 2009; Truzzi, et al. 2012; Weitzman et al. 2000; Zwaanswijk, et al. 2013).

Financial Strain of Caregiving

The financial strain and stress of caring for seniors, who may be experiencing the onset of disabilities associated with advanced age, may be a difficult part of providing care to persons living with dementia than any other medical condition associated with aging (Barnett, 2013; Brodaty & Donkin, 2009). The financial strain may be attributed to a number of factors such as low-income single-parent families, dual-parent single income earner families or lack of financial resources being contributed by the senior needing care. Hurtig (1999) reported that the National Council of Welfare indicated the number of poor families in Canada increased by an incredible 42% between 1980 and 1997; two out of every three women are considered to be impoverished. It was further reported that the instance of single mothers living in poverty was 43% and those under the age of 25, living in poverty, was 91.3% (Hurtig, 1999, p.127).

Since the 1980s there have been observable improvements in the economic situation for seniors. Although there has been success with the combined public/private retirement income system there is still frequent occurrences of poverty amongst seniors. The more vulnerable members are seniors who live alone, women over the age of 80 years, visible minorities, and immigrants (NACA, 2005); it is reported that approximately seven percent of seniors live under the Low-Income Cut-Off. This figure would be considerably higher when accounting for unattached seniors and women in particular (NACA, 2005). It is estimated that 258 000 seniors were living under the after-tax Low-Income Cut-Off in 2003 and that approximately 154 000 (or approximately 60%) of that number were unattached women (NACA, 2005). There are several factors to be considered for these figures: 1) older women tend to have lower incomes because their wages were inferior while employed; 2) women live longer, which means that they are at greater risk of using up their savings as time goes by; 3) women who are divorced or separated have much lower retirement incomes than do single women and widows; and 4) most divorced women do not claim a portion of their former spouse's pension despite being entitled to it (NACA, 2005). A report completed by the Canadian Association of Social Workers (CASW) in 2004 also listed several factors that contributed to women in poverty.

The Canadian Association of Social Workers (CASW) reported that two of the primary reasons for poverty amongst women were the low wages for women's work and no wages for women's work. In 2001 women accounted for approximately 70% of the part-time labour force (CASW, 2004). There is also the expectation that women will quit paid work or work part-time to provide care for children or others in the family and this also has a direct impact on life-long earnings. This impact on earnings will also impact a women's eligibility for pensions and employment insurance (CASW, 2004). The financial position of persons participating in the literature I have reviewed is of interest as low-income and middle-income families were most represented within the bodies of research (Glueckauf et al., 2005; Shaji et al., 2009; Weitzman & Levkoff, 2000). The importance of this would be the implication that low-income and middle-income families would be less able to provide third-party care for their loved one with dementia than would high-income families; not being able to provide additional care may lead to higher instances of caregiver stress, depression, or anxiety. The suggestion that caregivers of persons diagnosed with a dementia present with higher instances of self-reported depression and anxiety was further supported in research completed by Cooper et al. (2007) and Posner et al. (2015) respectively.

Although I view the inclusion of low-income and middle-income families as a strength in the studies that I have reviewed, it must be mentioned that the exclusion of higher income families may be seen as a deficiency (Glueckauf et al. 2005; Shaji et al. 2009; Weitzman & Levkoff, 2000). The fact that high-income families were excluded from the studies leaves a gap in our understanding regarding these families' experiences. Further, it may have been assumed that high-income families are better able to hire private help to assist with the provision of care and thereby are not exposed to the stress that this provision of care entails for less financially able caregivers. Another reason for this assumption may be that, due to the higher level of income, these families do not experience an associated financial hardship that lower income families may experience.

Supportive Interventions for Caregivers

Identifying the impacts and challenges for informal carers of persons living with dementia is needed in developing programs and services that support the care of these persons in their homes. Queluz et al. (2020) conducted research related to the understanding the needs of caregivers of persons with dementia and identified that needs were related to emotional health, physical health, and receiving help from others. Further, it was noted that there were needs related to addressing information gaps and addressing the education/learning needs of the carers. These findings were further supported in a study conducted by Bressan et al. (2020) that indicated current treatments for a person living with dementia are focused on preserving the autonomy and functional independence of the individual. The study also found that caregiver needs were related to receiving and accepting support for the myriad of tasks requiring completion, the receipt of information to assist in expanding their knowledge and skillset in providing care, and information to assist in developing their ability to cope (Bressan et al. 2020). Bressan et al (2020) further identified that there needs to be access to flexible and timely formal care that is tailored to the needs of the caregiver rather than the focus being on the needs of the person living with dementia. Technology has also been studied and utilized in the support of the person providing care to a person living with dementia in an attempt to lessen the burden of providing care and with the intent of facilitating a more restful sleep than currently experienced. For instance, the use of smart home technology was studied by Ault et al (2020) through the installation of a series of smart devices such as sensors, smart bulbs, pressure mats, and speakers the homes of the participants. Ault et al (2020) indicated that the system — known as the

Night-time Wandering Detection and Diversion system — demonstrated a marked decrease in carer depression and anxiety, improved the quality of their sleep with longer periods of sleep being reported by the participants, and was successful in enhancing the safety of the person living with dementia and their respective caregiver.

There appears to be a variety of approaches to supporting the carer of persons living with dementia through education, respite, support groups, and counseling. Support groups were identified to be helpful in reducing isolation and increasing social support for carers and families of the person living with dementia (Bressan et al. 2020; Chien et al., 2011). The support groups are reported to encourage carers to share personal experiences while learning from others while facilitating social engagement. Several modalities were utilized with the group therapy sessions such as online, phone groups, in-person, and web-based options. As identified by several researchers, there is no strong evidence to suggest that there are gains in any aspect by participants and that there is a need for more effective outcome measuring tools (Pinquart & Sorenson, 2006; Queluz et al., 2020). The effectiveness of individual counseling conducted by a counselor, social worker, or other clinician that provide family counseling or psychotherapy is reported to be a positive experience for the carer of the person living with dementia (Whitlatch & Orsulic-Jeras, 2017). Queluz (2020) identified the use of Cognitive Behavioural Therapy and the use of Acceptance and Commitment Therapy – coupled with mindfulness – as having a positive outcome for carers. The Centre for Addiction and Mental Health (CAMH, 2010) states that Cognitive Behavioural Therapy – commonly referred to as ‘CBT’ - is “an intensive, short-term (six to 20 sessions), problem-oriented approach” (p.2) and that it allows the individual to learn how to experience a reduction in emotional problems by (1) identifying distortions in thinking, (2) seeing thoughts as ideas about what is occurring rather than accepting them as fact, and (3) ‘standing back’ from ones thinking to consider the situation from different perspectives (p.3). Harris (2006) states that the goal of Acceptance and Commitment Therapy — commonly referred to as ACT — “is to create a rich and meaningful life, while accepting the pain that inevitably goes with it” (p.3). Further, Acceptance and Commitment Therapy can be both a short-term or long-term behavioural therapy that can be successfully used with individuals, couples, or groups (Harris, 2006). These results echoed a 2019 meta-analysis, conducted by Collins and Kishita (2019), of the effectiveness of mindfulness and acceptance-based interventions that identified mindfulness-based stress reduction, mindfulness-based cognitive therapy, acceptance and commitment therapy, and dialectical behaviour therapy as all being effective in the reduction of carer burden. Respite hours are often allotted to the carers of persons living with dementia.

The primary purpose of respite is to allow time away from the role of providing care that would facilitate the carer’s ability to have time outside of the home to pursue their own interests or needs ((Whitlatch & Orsulic-Jeras, 2017). Adult day programs are also considered a type of respite service in that it may allow the carer to continue working, run errands, maintain relationships within the family or social network, and/or participate in other activities that focus on the self-care of the person providing care to the person living with dementia (Queluz, 2020; Whitlatch & Orsulic-Jeras, 2017). In a study conducted by Neville et al (2015) the lack of reliable and convenient respite was identified as a frequent concern that added to the caregiver’s level of burden. There were many factors brought forth by participants that indicated having a formal caregiver not arriving on time or not arriving at all, the completion of too many forms, long wait lists, and not being able to schedule respite at a time convenient for the carer which were all complicit to the increasing levels of caregiver burden (Neville et al., 2015).

Informal Caregiving During the COVID-19 Pandemic

Humans have experienced pandemics — such as the Spanish Flu, severe acute respiratory syndrome coronavirus (SARS-CoV), H5N1 bird flu, Middle East respiratory syndrome (MERS) coronavirus — throughout history (Ryoo et al., 2020) and in the year 2020, humankind again witnessed the spread of SARS-CoV-2 virus which is more commonly referred to as the COVID-19 pandemic (World Health Organization, 2020). This virus spread globally and lead to a worldwide pandemic that saw nations introduce comprehensive public health measures and restrictions in an attempt to slow the spread of the virus (World Health Organization, 2020). Nations around the world responded with lockdown restrictions of varied intensities that encompassed economic and social activities (Aledeh & Adam, 2020; Liu et al., 2020; Ryoo et al., 2020). Prior to the pandemic and associated lockdown measures it was stated that engagement in social activities, a productive daily routine, physical activity, avoiding isolation, sharing the burden of providing care, and regularly attending support group meetings were all useful strategies for the reduction of anxiety and stress both for the person living with dementia and the informal caregiver (Austrom, et al., 2018; Cohen et al., 2020; Hughes, et al., 2014). This was not supported during the pandemic as some of the reduction in social activities included the closure of day programs which afforded the opportunity for socialization for the person living with dementia as well offering a respite opportunity for the informal caregiver (Queluz, 2020; Liu et al., 2020; Ryoo et al., 2020; Whitlatch & Orsulic-Jeras, 2017). These measures have had a variety of impacts on the person living with dementia, the informal caregiver, and on the systems that support these persons.

Liu et al. (2021) reported that there was a measured decline of 2.5% in the rate of diagnosis for dementia that has since declined steadily. This decline was attributed to the lack of access to services amidst the COVID-19 pandemic. Further, there was an identified increase in responsive behaviours such as agitation, psychosis, and anxiety (Liu et al., 2021). Other institutional impacts included a rise in emergency admissions related to increased responsive behaviours (Gomez-Ramiro et al., 2021). The impact on the informal caregiver was reported to be a worsening quality of life and increased anxiety (Baumbusch, et al., 2022). The impact of these measures on the person living with dementia were reported to be increased anxiety, concerns about social isolation, and loss of confidence in being able to participate in society (Giebel et al., 2021; Talbot & Briggs, 2021; Zwiers et al., 2021). Additionally, the ongoing measures led to increased carer tasks and responsibilities and many informal carers reported they felt unable to adequately fulfil their caregiving roles and that there were increased carer fatigue, burnout, and stress (Daley et al., 2022; Harris & Titier, 2022). With the reduction in respite opportunities — related to restrictions and fear of spreading or contracting the virus — many informal carers began to experience burnout and an inability to meet their own needs which led to carers expressing feelings of anger, frustration, and resentment (Daley, et al. 2022; Harris & Titier, 2022). Further, due to the imposed restrictions many carers reported reduced face to face social interactions which led to feelings of loneliness and isolation being frequently reported (Daley et al., 2022). Roach et al. (2021) reported that there was an increased reliance on technology for social interactions, but these modalities were considered to be problematic for a number of reasons such as the person living with dementia being present, less available time for the carer due to increased caring requirements, and a lack of familiarity with the technology by the carer. Further, carers reported the use of video calls was often confusing, of limited value, and they could not fully express their challenges related to caring for a person living with dementia due to the lack of depth in their connection to the agency worker providing virtual supports as well as not feeling able to be fully open due to the person living with dementia being present (Daley, et al., 2022; Roach et al., 2021). However, not all impacts on carers were negative as indicated in research by Tulloch et al. (2022) wherein caregivers reported being more connected to their personal values and what was important to them in life. It was further identified that informal carers found strengths in their ability to provide care during challenging times; in their ability to be kind, through generosity, courage to advocate for the person living with dementia, and their ability to adjust how care was delivered (Tulloch et al., 2022). Positive psychology was identified of being particularly useful in researching the positive nature of caregiving during the COVID-19 pandemic as it has a focus on personhood with a strengths-based approach (Tulloch et al., 2022).

Conclusion

This chapter was a review of the available literature as it pertains to the ever-growing prevalence of dementia in communities. The increasing volume of cases was highlighted along with the growing concern as it relates to a northern Ontario context; I was able to determine the types of dementia that are more commonly diagnosed — including rare dementias — worldwide and provided the definition, identified the area of the brain impacted, and the potential behaviours that may be exhibited by the person living with dementia. The impact of caring for a person living with dementia by an informal caregiver was also reviewed. Further, the impact of providing this care during the COVID-19 pandemic to a person diagnosed with a dementia was explored. As suggested in the literature, this impact is seen throughout many aspects of the informal carer's life including financial, familial, social, psychological, physical, and emotional.

The literature clearly identified that the majority of carers will be impacted by mostly behavioural changes — and their ability to respond to the changes — in personality, sexual aggression, wandering, exit-seeking, lack of motivation, diet, depression, sleeplessness, resistance to care, agitation, aggression, and potential violence exhibited by the person living with dementia. There was a vast amount of literature that focused on the person living with dementia and were quantitative in their approach to the topic. There was a limited amount of qualitative research articles at the outset of my project in 2013 but this perceived gap in qualitative research has been greatly reduced. When reviewing the literature related to informal carers of persons living with dementia, the same was evidenced when I attempted to locate qualitative research articles specific to the informal carers of persons living with dementia. The literature did identify that there are supports for informal carers of persons living with dementia. However, it was noted throughout the literature that there was a need for outcome measurement tools with improved specificity as the current opinion expressed in the research is that there is little to determine the efficacy of approaches; the exception recognized in the reviewed literature would be the use of Cognitive Behavioural Therapy and Acceptance Commitment Therapy which produced positive results for the carers. The following chapter will review the methodology, the rationale for the study and will define the qualitative approach to research.

Chapter 2 – Methodology

This chapter is on the design and methods of my study. I will begin with the rationale for the use of a qualitative approach and will define what is a qualitative approach to research. My study used a purposive sample to examine the experiences of 10 northeastern Ontario female caregivers using semi-structured individual interviews. The interviews were analyzed using a thematic analysis. Further, the recruitment strategy, procedures for conducting the research, the research questions, data collection, and the process for data analysis will be explained. This chapter will also review my responsibilities and role as the researcher, the process utilised for the validation of findings within the research and will conclude with the ethics of the research.

Rationale for the Study

When I started my research in 2012[1], there was a lack of qualitative studies of Canadian origin that delved into the biopsychosocial impact on the caregiver when providing care to a loved one with dementia. To the best of my knowledge, at that time, I could find no qualitative articles of Canadian origin available and certainly no qualitative articles from a northeastern Ontario perspective. Of the five qualitative studies available on the biopsychosocial impact on the caregiver of people living with dementia, one was conducted in Britain (Fontaine et al., 2007), one was conducted in Australia (Shanley et al., 2012), and three were conducted in the United States of America (Chaston, 2010; Ho et al., 2008; Mackenzie et al., 2009). Due to the lack of qualitative research into the

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[1] I had to leave my studies from 2015 to 2022.

biopsychosocial impact on the caregiver providing care to a loved one diagnosed with a dementia, and the overabundance of research into the needs of the person with dementia, my study may contribute to the literature as it explored the lived experience of the caregiver, in particular, the biopsychosocial impact on the caregiver. There are varied rationales for conducting qualitative research into the psychosocial impact on caregivers providing care to a loved one with a dementia.

For instance, one reason for conducting this research was to provide a better understanding of the care-giver experience when providing care to a loved one with a dementia, which may assist in addressing the decided lack of both Canadian and northern Ontario content in this area and the lack of qualitative content in general. With the projected increase of community-based dementia in northeastern Ontario (Whitehouse, 2012), coupled with the anticipated need for appropriate services and supports, there needs to be more qualitative research focused on challenges unique to this geographical setting, which is an underserviced area, so that effective services can be developed and offered.

Northeastern Ontario is comprised of rural communities, isolated rural communities, and urban settings. This unique composition of communities requires approaches that can address their diverse needs, which can be found through conducting qualitative studies as this form of inquiry allows for the unique needs of each community to be seen through the voice of the caregivers in those communities. Secondly, this research may serve to assist agencies when planning for programs in their communities and highlight the need for some of these programs to be directed towards caregivers in general but more specifically caregivers of loved ones with dementia. This research will hopefully be useful to social workers advocating for clients, in this care-giving role, for improved and much needed respite or counseling services. Thirdly, the research focused on the experiences of the caregiver providing care to a loved one with dementia; the majority of literature focuses primarily on the experience of the person with dementia and not the caregiver. In order to provide appropriate support and services to the caregiver of a person with dementia it is vitally important to understand the needs of the person utilizing the services; this can be realized by conducting qualitative studies that focus primarily on the caregiver experience. Finally, it is the hope that this study may assist local agencies, such as the Alzheimer's Society and the Victorian Order of Nurses, in their planning efforts for the provision of services and programming. Thus, my research question was: "What is the biopsychosocial impact on the caregiver providing care to a loved one with dementia within a northeastern Ontario context?"

Qualitative Research

As described above, I used a qualitative approach to this study. Hays and Singh (2011) defined qualitative research as the study of phenomena or topic in context; qualitative research is exploratory in nature. The exploratory nature of qualitative design also tends to ask the "how" and "what" of a topic rather than focusing on the "why" of the topic being studied (Hays & Singh, 2011). When considering the use of a qualitative approach it is necessary to consider that "the word qualitative implies an emphasis on the qualities of entities, on processes and meaning that are not experimentally examined or measured (if measured at all) in terms of quantity, amount, intensity, or frequency" (Lincoln & Guba, 1985, p. 8). Therefore, qualitative researchers are “interested in the who, what, when, where, why, and how of a phenomenon” (Hays & Singh, 2011, p. 8). Further, Hays and Singh (2011) stated that the “report often describes and tells a story, and typically includes participant quotes” (p. 8). I interpreted this to mean that the qualitative approach to research allows researchers to bring forth the voice and image of participants found in the data. The Social Work Code of Ethics and Standards of Practice resonate with the principles of qualitative research.

For instance, McCoyd and Shdaimah (2007) supported this relationship stating that “qualitative social work research connects with social work values” (p.340). Further, McCoyd and Shdaimah (2007) stated that these values are international in scope and “include commitments to the dignity and worth of all human beings, the alleviation of human suffering, the delivering of quality and competent service, the production of a professional body of knowledge, and to social justice itself” (p.341). Social work has changed dramatically in such a way that social workers now provide services rooted in the concept of justice and recognizing the intrinsic worth of each individual person (McCoyd & Shdaimah, 2007). Historically, recipients of a religious organization’s material relief received instruction in proper behaviour and moral living. The approaches of the persons providing this instruction would develop the skills that later became the foundation of social casework (Durst, 2007).

When comparing the Ontario College of Social Work and Social Services Workers Code of Ethics and Standards of Practice for Social Workers (2008) to the approach utilized during qualitative research one can recognize that the respective concepts resonate one with the other. The Standards of Practice for social workers state that a social worker, or social service worker, will advocate for change for the overall benefit of society, the global community, the environment and in the best interest of the client (OCSWSSW, 2008). Further, the intrinsic worth of a person shall be respected by the social worker and social service worker in their professional relationship with them (OCSWSSW, 2008). All of these factors were instrumental in the selection of qualitative research as the approach for my study.

The use of a qualitative approach to my study allowed for the caregivers to be seen as individuals. The participants were provided the opportunity to share their experiences with others using their own words. This study allowed them to state who they are and share their experiences in caregiving. Further, they were able to state how this experience had affected them, be it positive or negative, and what this experience had come to mean to them. The use of a qualitative approach to this study was the most appropriate method as it humanized the caregiver experience in a way that may allow others, such as counselors and researchers, to see and feel the caregiver journey as simply more than a numerical representation.

Recruitment Strategy

This study utilized several strategies to recruit participants from within the Greater Sudbury community. I approached the Director of the Alzheimer’s Society Sudbury-Manitoulin district with a recruitment request (See Appendix 1, Letter of Introduction for Directors/Directors of Care). I requested that a Recruitment Poster (See Appendix 2, Recruitment Poster) be posted on the Society’s bulletin board and that the Recruitment Poster be handed out by counselors during support group meetings. In addition, I approached the various long-term care homes Directors of Care with a recruitment request (See Appendix 1, Letter of Introduction for Directors/Directors of Care); I requested that a Recruitment Poster (See Appendix 2, Recruitment Poster) be posted on both the Resident Council and Family Council bulletin boards. There was a need for an inclusion criterion to assist in identifying appropriate participants for this study. The following inclusion criterion was utilized in the selection of participants:

1) they must have been identified in the caregiving role providing direct care to a loved one with dementia; and
2) participants must have been 18 years of age or older.

A snowball effect was realized during the recruitment process as applicants identified other potential participants. This led to an expanded approach to participant recruitment wherein the Registered Nurse of the Killarney Health Centre — after hearing of this study and subsequently reviewing its purpose — recommended this research study to clients of the health centre. There was active participation from members of the Club Age D'Or, located in Hanmer, Ontario, after some participants reported positive feedback to their membership. A purposive sampling strategy is an approach to selecting participants that meet the needs of the research in order to satisfy the research inquiry through the perspective of the participants (Esterberg, 2002). A purposive sampling strategy was utilized to obtain a total of 10 participants from within the Greater Sudbury area and outlying rural areas. The Greater Sudbury area, which is located in northeastern Ontario, and is considered to be a mid-sized urban community. Boydell et al. (2006) stated that Greater Sudbury has a "total population of slightly more than 150, 000 over 5,398km [3,354 square miles]" (p.183). Participants in this study were from both an urban and rural settings from the Greater Sudbury area. Statistics

Canada (2006) provides that rural areas are defined as “outside the commuting zone of larger urban centres, outside census metropolitan areas and outside other urban areas with a core population of 10, 000 or more.” Urban areas are defined by Statistics Canada (2011) as “having a population of at least 1,000 and a density of 400 or more people per square kilometre.” It was hoped that the research participants for this study would be of both genders but that did not come to fruition.

Procedures

There were several forms utilized during the course of this study that included:

1) Letter of Introduction to Directors/Directors of Care;
2) Research Recruitment Poster;
3) Letter of Information for Participants;
4) Informed Consent;
5) Demographic Questionnaire;
6) Semi-Structured Interview Guide; and
7) Community Resource List.

The Letter of Introduction to Directors/Directors of Care (see Appendix 1) was utilized to introduce me as the researcher and to provide an introduction into the type of research being conducted, the purpose of the research being conducted and the research question itself. Once the introduction had been successful, a Research Recruitment Poster (see Appendix 2), which introduced the researcher and provided the details of the proposed study to potential participants, was posted in a highly visible location. A Letter of Introduction for Participants (see Appendix 3) introduced me as the researcher, stated the type of research being conducted, the purpose of the research and the research question itself. The Letter of Informed Consent (see Appendix 4) included full disclosure of the purpose of the study, the anticipated benefits of the study, a confidentiality clause as well as ensuring that participants were aware of their rights associated with participating in this study. The Demographic Questionnaire (see Appendix 5) was the first data collection instrument utilized in the study.

The purpose of the Demographic Questionnaire (see Appendix 5) was to collect data that assisted in identifying the diversity of study participants such as gender, age, and financial status. The use of the Semi-Structured Interview Guide (see Appendix 6) ensured consistency of the questions asked of the study participants while ensuring to provide an open forum for the study participants to bring forth topics of their own for discussion. The final instrument utilized during the course of this study was the Community Resources List (see Appendix 7). This list was provided to study participants at the conclusion of each one-to-one interview sessions. The Community Resource List provided the study participants with a quick reference guide, in the event that there was an emotional need that arose during the one-to-one interview portion of the study, with counseling services in the Greater Sudbury Area. Ethics Approval from Laurentian University Research Ethics Board was granted in 2012.

Data Collection

Data was collected using a Demographic Questionnaire (See Appendix 5) and a one-to-one semi-structured interview utilizing a Semi-Structured Interview Guide (see Appendix 6) with each of the 10 caregivers providing care to a loved one diagnosed with dementia. The interviews were conducted in a place of each participant’s choosing (their home or a secondary location such as the Alzheimer’s Society Community Room, Laurentian University Library, or the Sudbury Central Library Community Room). At the time of each one-to-one interview, participants were asked to read and sign a Letter of Informed Consent (see Appendix 4); this document was explained by me to study participants to ensure a complete and thorough understanding. At the beginning of the interview, participants were asked to complete a Demographics Questionnaire (see Appendix 5). Once the participants had signed the Letter of Informed Consent (see Appendix 4) and completed the Demographic Questionnaire (see Appendix 5) a Semi-Structured Interview Guide (see Appendix 6), comprised of open-ended questions, was utilized; this had been developed in order to allow the caregivers to express their opinions in their own words. This approach allowed for a much freer exchange between the interviewer and participant. The use of a one-to-one interview strategy further allowed participants to share in the direction of the study through the self-direction of the information they wished to share during the study. The semi-structured interviews were recorded digitally on a voice-recorder and then transcribed verbatim for the purpose of thematic analysis. Upon completion, I reviewed the transcripts with each participant for reflection, clarification, or expansion on the recorded responses. Ethics Approval from the Laurentian University Research Ethics Board was granted in October 2014.

Further, the participants were able benefit in the creation of a safe environment, through the use of the one-to-one interview process, in which they shared their thoughts, experiences and feelings (idiosyncratic information). As suggested by McQuarrie and McIntyre (1990), the use of individual interviews promotes a deeper sharing of one's experiences (idiosyncratic information) more so than what may have occurred in a group meeting. Hesse-Biber (2006) postulates that the use of an in-depth interview allows for participants to provide richness and depth to their responses. Hence, the individual interview appeared to have been better suited for the aims of this project especially since the participants did not know each other and the topic for discussion was potentially emotionally challenging. As anticipated, each one-to-one interview took approximately one to one-and-a-half hours to complete.

Interview Questions

The interviews began by personalizing the caregiver and their relationship to the person receiving care as well as the length of this relationship. For the purposes of this research study there were four open-ended questions that were asked of each participant (see Appendix 6):

1) What has this caregiver journey been like for you as the caregiver of a person with dementia?
2) Since diagnosis, what has been the response from family and friends?
3) Has there been an impact in your personal health related to the role as a caregiver?

4) If you work outside the home, has there been an impact to your work related to the role as a caregiver?

Other questions pertaining to the impact on quality of life were included: (1) has your caregiving experience prevented your participation in activities such as dining out or attending movies, and (2) how has your caregiving experience influenced your current living arrangements?

It was anticipated that there may be an emotional response evoked during the interview process. In order to address this possibility, I provided a list of community resources (see Appendix 7). In addition, I have a B.S.W. degree and have worked in a long-term care facility with caregivers of people with dementia for three years; although as a researcher, I did not provide any counseling. As a practising clinician with a B.S.W. degree, I was able to provide immediate assessment, intervention, and referral. Importantly, I also arranged for the research participants to be able to speak with Janet Bradley, a Registered Social Worker experienced in working with caregivers providing care to persons with dementia. To my knowledge, none of the participants needed to meet with a social worker but all expressed their gratitude of having this resource readily available to them.

Approach to the Analysis of Data

I transcribed each audio-recorded interview verbatim and manually coded. As part of the process of coding and analysis, once the research participants had been identified they were provided with a pseudonym in order to protect and respect their confidentiality and anonymity. Thematic analysis, a qualitative data analysis method, was used for identifying, analysing, and reporting patterns (themes) within the text data. Braun and Clarke (2006) state that thematic analysis does not derive from, nor is it tied to, a particular epistemological or theoretical position. Themes were identified — through the participants shared experience of the same phenomena — after I read and reread the printed text data multiple times. The data was analyzed utilizing the methodology described by Creswell (2009).

For the purposes of this research, the eight steps that qualitative researchers should follow, as outlined by Creswell (2009), when conducting, coding, and analyzing their qualitative research data, and the resultant data text sets, were followed. These steps are detailed as follows:

Step 1: This step organized all the research material. This was realized through the creation of document files and a digital archival record of the 10 original research interviews, transcripts, and field-notes. Pseudonyms and identification numbers were created and stored in an identity file as well as a process file that has a copy of each step taken in the research process.

Step 2: This step was a review of my research questions in order to ensure their relevancy to the study; the questions were revised as required. This review was conducted at the conclusion of each of the one-to-one interviews with the purpose of ensuring that the questions were relevant to the information being shared by the study participants.

Step 3: In order to develop a sense of the data collected, I read each file at least twice in order to assist my awareness of all of the pieces of data (including convergences and differences) that may be placed into the larger context of the study.

Step 4: This step involved de-contextualizing the data. De-contextualizing the data is a process that divides the data into individual units or segments. Each unit or segment had only one concept contained within them and were divided based on the meaning of the units. I recorded codes in the margins of the printed data units or segments and, as anticipated, some segments or units had more than one code (they were placed into more than one category).

Step 5: This step is a continuation of the de-contextualization process mentioned in step four. I looked closely for indications that the concepts were relevant to the research questions; they were highlighted, and notes were written down when key utterances or repetitive aspects were discovered.

Step 6: Once steps four and five had been completed I then re-contextualized the data; I developed an organizing system based on the identified concepts and sorted the text units into these categories. This assisted with identifying the underlying concepts and relationships contained in the data.

Step 7: This step required further sorting of the text and further coding of the sorted text; axial coding was used for this stage as it allowed for the making of connections between the identified categories.

Step 8: The final step involved the refining and elaboration of the core concepts or categories. It is at this step that I identified examples of text (participant quotes) that provided for the participants own voice to be heard through their use of rich thick descriptions they expressed in the interview. The use of rich thick descriptions was utilized in this study. Creswell (2007) justified the use of this strategy by stating that “rich, thick description allows the reader to make decisions regarding transferability because the writer describes in detail the participants or setting under study” (p. 209). Lincoln and Guba (1985) state that transferability identifies the extent that results can be transferred to other settings and context with different participants. A concept map was created to visually demonstrate the core concepts and sub-themes of the study; this allowed for a visual representation of the relationships between the themes. Concept maps are a general method utilized to describe an idea about a topic in a visual/pictorial form (Pokharel, 2009).

Strategies for Validating Findings and Researcher Reflexivity

Merriam (1998) has stated that “clarifying the researcher’s assumptions, worldview, and theoretical orientation at the outset of the study” would be one way to help ensure validity in qualitative research (p. 205). Merriam (1998) is further supported by Creswell (2007) through his statement that “the researcher comments on past experiences, biases, prejudices, and orientations that have likely shaped the interpretation and approach to the study” (p. 208). I kept a journal during the entire research study in which I recorded my thoughts, dilemmas, realignment of themes, and numerous attempts to reframe the research question, constantly reflecting and rethinking the study process. Barry and O’Callaghan (2008) illustrated that reflexive journal writing can be useful in generating and demonstrating new understandings vital to extend practice. Additionally, I employed critical reflection, a process that conjures the identification of deep-seated assumptions with the key purpose being to identify and implement changes to practice (Fook & Askeland, 2007). My supervisors assisted with reviewing the themes and subsequent sub-themes I had identified, which in turn allowed me to identify areas that required further reflections and study. Once the potential themes were identified, an in-person meeting was held with both thesis supervisors — Dr. Diana Coholic and Dr. Leigh MacEwan — with the purpose of ensuring that a thorough understanding, and review of the potential themes was evident. This provided the opportunity to ensure that I had interpreted the data correctly and that the research processes had been adhered too. The interviews were semi-structured which allowed the participant to explore and provide information which they felt was important for readers of this research to know; this approach provided richness to the data that could not have been realized through the use of a more rigidly structured interview.

Furthering the brief description above regarding research reflexivity, I will note that there are no financial disclosures associated with this area of inquiry however, there are personal disclosures that require mentioning. I have long wondered as to why I am most interested in the caregiver’s perspective when providing care to a person with dementia. My interest in dementia became academically entrenched during my participation in a third-year student placement at the Alzheimer’s Society of Sudbury-Manitoulin where I witnessed many instances of caregiver stress through participation in the Alzheimer’s Society Support Group Program and found that something within me really resonated with the stories that were being related to me during these group meetings. Further, upon graduation from the Laurentian University School of Social Work Honours of Bachelor Social Work program I became employed in a long-term care setting.

Having been employed in this setting for three years I had borne witness to several instances of caregiver stress and despondency. It had been related through several informal discussions that caregivers have a story to be told that would prove relevant to other caregivers, agencies and other professionals providing services to families that have a loved one diagnosed with dementia. My role as the researcher in this research study was to ensure an accurate telling of the participant's stories and to ensure that these stories are brought to the appropriate organizations; the idea being to provide the perspective of the participant in identifying the need for services and supports.

Research and Professional Social Work Ethics

When conducting research with human participants one of the questions that researchers must answer is whether or not their research is ethical. Ethics is a term used to distinguish between acceptable and unacceptable behaviour; this behaviour is shaped and defined by sets of morals, principles, and guidelines (Ray, 2011). Furthering this definition towards qualitative inquiry, researchers Hays and Singh (2012) stated that "ethics is a set of guidelines established within a professional discipline to guide thinking and behaviour" (p.68). It is the application of these moral rules and professional codes of conduct that guide the collection, analysis, reporting and the publication of research that determine if research has been, or is being, conducted with the highest ethical standards possible. As such, through the application of the standards set forth by both the Laurentian University Research Ethics Board and the Ontario College of Social Workers and Social Service Workers Code of Ethics I was able to provide the highest standard of ethical research possible. Approval for this research study was granted by the Laurentian University Research Ethics Review Board in 2012.

Conclusion

In this chapter, I demonstrated the steps required to conduct this research study, the rationale for the study, the methods used, the analysis of the data, the setting for the research study as well as the sample size. The use of the qualitative approach to this research study was aptly suitable as it allowed for the depth of the caregiver experience to be shared. The next chapter will explore the results of this research study, what findings were developed in relation to the caregiving experience when providing care to a loved with a dementia and how these caregiving experiences can assist in shaping program design that supports and enhances the caregiver experience in northeastern Ontario regardless of rural or urban setting.

The research study participants, all informal caregivers, that were interviewed provided their caregiving experiences — unique unto themselves — complete with self-reflection, observations of the current system and suggested recommendations for both service provision and future caregivers. It is hoped that thru disseminating the research study findings there will be an increased awareness of the caregiver experience and the resources, supports, and programs that are required to ensure a positive outcome for the one receiving the care and — just as importantly — the person(s) providing the care.

Chapter 3 – Research Findings

In this chapter, I will present the results of my research from the data gathered in 2012-14 from semi-structured interviews with 10 female participants; they ranged in age from 38 to 73 years old and all were actively providing care to a loved one diagnosed with a dementia or had been prior to the death of the person living with dementia. The participants were provided with a transcript of the interview for their review; this allowed them to verify the accuracy of the transcript and to add any additional information they felt would be pertinent to share. This study was designed to address the following question:

1) Is there a biopsychosocial impact on the caregiver providing care to a loved one diagnosed with a dementia.

The resulting data gathered from these semi-structured interviews was analyzed and organized into three main themes: biological, psychological, and sociological issues related to the caregiver experience. This chapter will explore each of the three key themes and their respective subthemes: sleep, signs and symptoms of depression, signs and symptoms of anxiety, grief, anger, frustration, fear, isolation, and changes in activity (see Table 2).

The objective of this research was to explore the first-hand experiences of people providing care to a loved one diagnosed with a dementia; to explore if there was a biopsychosocial impact experienced during this caregiving and to share the respective experiences of the participants. There were personal thoughts, feeling and experiences shared by the 10 research participants which were consistent with the data found within the available qualitative studies of the caregiver experience that I reviewed, and with the experiences shared by family members in my own daily practice. There were many personal thoughts, feelings, and experiences that the research participants shared during the one-to-one interviews. There were instances of fear, anger, frustration, despair, fatigue, helplessness, and depression revealed during the interview process; there were also positive experiences shared during the one-to-one interviews such as stronger familial bonds and moments of joy and happiness.

All research participants for this study were females ranging in age from 38 to 73 years of age (see Table 1). The research participants were identified as daughters, sisters and spouses of loved ones diagnosed with a dementia. There were four participants that were no longer providing care to a loved one as their family member had died and six participants were currently providing care to their family member; the spouses of two of the remaining six research participants had been placed into long-term care homes. Income levels were self-identified through the use of a Demographic Questionnaire (See Appendix 5); income levels ranged from less than $20 000 annually to more than $50 000 annually. Some of the research participants were retired, employed full-time or employed part-time.

Table 1
Profile of Participants

Participant*	Age	Relationship to PLWD	Living with PLWD	Urban or Rural Location	Income Level (self-identified) Canadian $
1	53	Daughter	yes	Urban	50 000+
2	73	Spouse	yes	Urban	20 001 – 35 000
3	38	Daughter	no	Rural	20 001 – 35 000
4	68	Sister	yes	Rural	35 000 – 50 000
5	55	Daughter	no	Urban	50 000+
6	52	Spouse	yes	Rural	50 000+
7	65	Daughter	no	Urban	20 001 – 35 000
8	72	Spouse	yes	Urban	35 001 – 50 000
9	70	Spouse	yes	Urban	< 20 000
10	64	Sister	yes	Rural	< 20 000

*All participants are female

Upon review of the three themes and subsequent subthemes, there were clear indications of change in the lives of the participants. The biological theme was used to identify possible areas of change in participants' patterns of sleep, eating patterns and weight gain or loss. The psychological theme was used to identify any changes in participants' mental health status while the third theme — sociological — explored and identified possible areas of change in family relationships, employment status, regular daily activities, or recreational activities and in respective friendship networks.

Table 2

Table of Themes

Main Themes	Sub-Themes	Sub-Sub-Themes
Biological	Sleep	1) Hyper Vigilance
		2) Exhaustion
Psychological/Emotional Challenges	S&S* that could be related to Depression	1) Low Mood
		2) Social Withdrawal
		3) Loss of Interest in regular activities
		4) Self-Disclosure
	S&S* that could be related to Anxiety	1) Related to Care Duties
		2) Related to Decision Making
		3) Related to Safety Concerns
		4) Related to What Will Happen Next
	Grief	1) Anticipatory Grief
		2) Related to Death
		3) Loss of Role/Identity
		4) Change in Relationship with Care Recipient
	Anger	1) At the Diagnosis/Illness
		2) At the Care Recipient
		3) At the ‘System’
		4) At Members of The Family
		5) With Themselves
	Frustration	1) With The ‘System’
		2) With Members of the Family
	Fear	1) Making the Wrong Decision
		2) Elopement of Care Recipient
		3) Family Judgement for Decisions
		4) Lack of knowledge
Sociological	Isolation	1) disconnected from Friendship Network
		2) Disconnected from Family Network
	Changes in Activity	1) Social Supports
		2) Home Routine(s)
		3) Work Routine(s)
		4) Change in Employment Status
		5) Change in Family Dynamic
		6) Change in Role Identity

*Signs and Symptoms

I will now discuss the findings using verbatim quotes that will serve to illustrate each theme and subtheme. For the purposes of de-identifying the participants and their respective family members, all names have been changed to a pseudonym.

Biological

The first main theme identified during this study was related to biological factors. In this research, I was able to identify the impact or changes in the overall quality of sleep being experienced by the participants. I was able to identify changes in quality of sleep, the amount of sleep being realized by participants, changes in routine to accommodate sleep, and other strategies employed to ensure they had a modicum of rest. The main biological theme identified during this research, sleeping patterns and the lack of sleep, was identified by nine of the ten research participants. Kelly shared that she and her husband experienced a lack of sleep stating,

> *"We put alarms on our doors because she – I found her outside at four o'clock in the morning – tried to get into my car…in the pouring rain…she had her arms full of her purse, my shoes and a bunch of other things that she gathered on the way...other nights she'd be awake at one o'clock in the morning and I could hear her rummaging…nobody was allowed to sleep."* Further, *"I mean my husband didn't sleep all that well either and there were lots of times he would sleep downstairs just so he could get some sleep."* Prior to her mother moving in with them, Kelly shared that she would average approximately 6 hours per night *"and from my mom*

> *coming in, probably about 4 hours per night; she's been her [long term care home] since February [approximately 8 months] and I'm still only getting 4 hours of sleep."*

Lori is providing care to her mother and father (deceased) and was able to share that,

> *"I don't have time to sleep; it was worse when she lived with me, now she is in [the retirement home] and I still have to help with everything; I would prefer having her with me than put her in a place that she wouldn't like or that we wouldn't we like…but that is not realistic, I wouldn't be able to* [provide around the clock care]*."*

Kathy indicated that sleeping at night had become difficult stating,

> *"I sleep sometimes…like this week I slept all night but I take sleeping pills…sometimes, a whole week, I won't sleep and when I can't sleep I get up around one o'clock and I take one [a sleeping pill]."*

Tammy identified that sleep was also difficult in achieving stating,

> *"Sometimes I sleep…sometimes I'm awake at three and stay awake til five…I was awake at four today."* Further, Tammy explained *that "oh my God, I'm usually crawling into bed by 9:30 and try to read…it's one of my things…if I read for half an hour I'm lucky and then I'm out."* When asked to clarify why she is waking up at three or four in the morning Tammy shared,

> *“my head…what’s going on in my head I guess…sometimes I’m just awake..in my mind…whatever, I have no idea why.”*

Sherry and Kim provided care to their sister and identified that although their sister did not require much care during the night, they found that their sleep was interrupted stating,

> *“I don’t get it…a lot of sleep…I didn’t sleep…like sometimes I’d sit out here a lot with her. Like we had a baby monitor and we put one out here [in the living room where her sister slept on a hospital bed] and I slept in the bedroom. You know, I’d listen to that but every night I wasn’t out here but I’d hear her and come out or sometimes I’d just sit here. I wouldn’t go to bed; I’d just sit here for a while or lay on the couch.”*

Tina was providing care to her mother and shared that,

> *“the sleeping part I felt like I had a young baby in a way because I was like, even though I was sleeping, I was like hyper-alert so that I could, if she woke up, I would hear her. By the last couple of years it was easier in a way because I just slept in the same room because she was weak and – I was just afraid I guess – that she would try to get out of bed.”*

Tonya provides care to her husband and identified that sleep was a concern and approached her doctor stating,

> *"I need sleep so I went to my doctor and told him that I needed something cuz I was ruminating all night. I have to do security checks, dog is in, woodstove doors closed, lights are all out…I need something because I sleep but wake up at twelve and then I'm awake until 1:30 and then I'd sleep until 3:30 and then I'm up at 5 and then I'm like I gotta still work 8 hours."*

Jodi was providing care to her husband and shared that, although she was able to sleep, she also.

> *"only slept with one ear open; one night he did get up while [daughter] was here…by that time we had a system…we learned one of us would be ready and we'd carry a cell phone and if we got into trouble then the other would come with the car."*

Cindy was providing care to her husband and shared that sleep was difficult to obtain stating,

> *"I'd sort of lie across the chesterfield with my legs over his legs so he couldn't get out and I'd have three really good hours of sleep."*
>
> Cindy further shared that her sleep at night was,

> *"not well; I just worried about him, you know you read that they are going to be up at night…that they're going to be doing things…he never did that but there was still that worry."*

Psychological – Emotional Challenges

Many of the participants in this study noted experiencing emotional challenges, self-disclosed diagnoses of mood disorders such as depression and/or anxiety, and also shared moments of somatic experiences that included loss of appetite, feelings of guilt, moments of anxiousness, and exhaustion. According to the US National Institute of Mental Health (NIMH, 2016) some of the signs and symptoms of depression are: persistent sad, anxious, or "empty" mood; feelings of hopelessness, or pessimism; Irritability, frustration, or restlessness; feelings of guilt, worthlessness, or helplessness. Further, other signs and symptoms can be a loss of interest or pleasure in hobbies and activities; decreased energy or fatigue; moving or talking more slowly; feeling restless or having trouble sitting still; difficulty concentrating, remembering, or making decisions; difficulty sleeping, early-morning awakening, or oversleeping; appetite and/or weight changes; thoughts of death or suicide, or suicide attempts; aches or pains, headaches, cramps, or digestive problems without a clear physical cause and/or that do not ease even with treatment.

Cindy was providing care to her spouse and shared that,

> *"I had a really lost feeling and of being depressed and trying to work through that* [placing her spouse into a long term care home]*…I would have been dead by Christmas; I was really that far gone. I was really hanging on by a very thin thread and I was on anti-depressants – it wasn't good…my world was becoming smaller and smaller."*

Lori is providing care to her mother and father (deceased) and shared that,

> *"I am the oldest so like need to be strong for everyone else; as you can see, I'm not that strong because I cry a lot…I have no energy lately; the last week, it's been very very bad…I feel like sleeping all the time but I just don't have time to sleep.."*

Tonya is providing care to her husband and stated,

> *"I'm tired. I'm tired. I'm just tired you know and he'll say 'oh, just lay down' but it's not that type of tired that you can lay on the couch and sleep for two hours; I'm mentally exhausted…take my happy pill kind of thing; I am not saying I am depressed, I am on something, I went to my doctor. I stopped taking it during the summer for 3 months – I was off – but then right off the bat the sleeping was staggered, the moods were up and down, up and down, never level and I caught myself a few times. Like, I'd be driving and I'd be mad at him and I'd be going into [name of town] and I caught myself not even knowing how I got there…next thing I know I'm pulling into [name of a store] and I never heard a song on the radio and I caught myself bitching to myself going fuck fuck fuck fuck and I went, okay, back on. I went back to [the doctor] and said I know when I need something; I'm not afraid to say I need something. Help me through this."*

Tammy is providing care to her mother and shared that,

> *"I think I was losing it; He [the doctor] asked me last time I talked with him if I was depressed and I said no, which I'm pretty sure he knows I am. I said I was just exhausted; he said 'yeah Tammy, it's written all over your face'."*

The participants of this study openly shared how their journey of providing care to a person living with a dementia had impacted aspects of their daily life as well as how their mood seemed to also be impacted. The purpose of the definitions being provided was not to diagnose but to give a frame of reference as what potentially may be being experienced by the participants. In order to discern precisely what the participants were sharing within the context of their caregiver journeys, I reviewed the American Psychological Association (2023) definition of anxiety and fear as,

> *n. an emotion characterized by apprehension and somatic symptoms of tension in which an individual anticipates impending danger, catastrophe, or misfortune. The body often mobilizes itself to meet the perceived threat: Muscles become tense, breathing is faster, and the heart beats more rapidly. Anxiety may be distinguished from fear both conceptually and physiologically, although the two terms are often used interchangeably. Anxiety is considered a future-oriented, long-acting response broadly focused on a diffuse threat, whereas fear is an appropriate, present-oriented, and short-lived response to a clearly identifiable and specific threat. —anxious adj*

The need for Canadian context in this study was identified in the literature review chapter which led me to review the definition and causal factors with the Centre for Addiction and Mental Health (CAMH, 2023) which states that the causal factors for anxiety disorders are: stressful or traumatic life event(s), family history of anxiety disorders, childhood development issues, alcohol, medications, or illegal substances, and other medical or psychiatric problems. Further, the Centre for Addiction and Mental Health (CAMH, 2023) identified some of the signs and symptoms of anxiety as being anxious thoughts (e.g., "I'm losing control"), anxious predictions (e.g., "I'm going to fumble my words and humiliate myself"), anxious beliefs (e.g., "Only weak people get anxious"), and the avoidance of feared situations (e.g., driving). Further, the avoidance of activities that elicit sensations similar to those experienced when anxious (e.g., exercise), subtle avoidances (behaviours that aim to distract the person, e.g., talking more during periods of anxiety), safety behaviours (habits to minimize anxiety and feel "safer," e.g., always having a cell phone on hand to call for help), and excessive physical reactions relative to the context (e.g., heart racing and feeling short of breath in response to being at the mall) were also provided as signs and symptoms of anxiety (CAMH, 2023).

Kathy is providing care to her husband who was diagnosed with dementia eight years ago. Kathy shared that her anxiousness — or fear — is related to what the future may hold for her and her spouse — as he begins to show declines in his cognitive ability — and her ability to manage his care and behaviours at that time by stating,

> *"he will come to be worse than he is now"* and, when asked if she is ready for these anticipated changes, Kathy further shared that *"I*

> *don't think so but I'll have to get ready; it's hard – yes, he will change but what do I do? I don't know what to do."*

Kelly's mother moved into her home for approximately four years pre-placement and there were several moments identified that led to much anxious moments for Kelly and her spouse. When sharing her experience of having to place alarms on the exits to her home, the anxiety — or fear — she experienced was evident in the following statements,

> *"Am I going to get to the door? Is she already out the door? I hope she doesn't fall down the stairs because it's not the best landing, she's wandering around in the dark; I'm still only getting about four hours of sleep just because of, I guess, for the longest time I still heard the alarm on the door and things like that."*

Anger and frustration were present with several of the research participants. Their anger was evidenced towards a variety of reasons and at times was directed at their loved one diagnosed with dementia. Further, frustration was evident towards services, family members and their situation.

Kathy shared that due to her husband's behaviours towards social outings that she would be "mad" and that she leaves him in the matrimonial home on his own for brief periods of time; time that she used to help calm herself through varied activities of either visiting a friend or going to the local [store name] store. Kathy shared,

> *"He is more aggressive and stubborn…..he will come out of the room with his hat on and that's when we're going to the mall. I say*

> *we can't go right now – that I have something to do."* Further, since her husband is not easily directed,
>
> *"He is just like a kid – sometimes I get mad – I give him shit a little bit – that doesn't work so I realize that he's sick but sometimes I leave him here and I go. He is able to stay alone for an hour or so; I hate to go to the mall but I go somewhere else – [name of store] or I visit a friend – I have to go because I get so mad. Frustrating."*

Kelly had become frustrated with the varied services being provided to her mother as they would change the principal care provider which led to a lack of understanding — and her observation — that important communication related to safety was not being accomplished successfully. Further, frustration was evident as the time of care was inconsistent. Kelly shared,

> *"CCAC helped out a fair amount but they did not understand that timelines were very important. So, when I had somebody coming in at eight in the morning, if they didn't show up until nine – because they had another client – they didn't understand that my mom could be down the street."* Kelly was at work prior to the timed arrival of the caregiver and shared,
>
> *"I mean, I can't call my mom. She can't pick up the phone — she doesn't know how to work it anymore — she can't call out 911 or anything like that; I'd call and there'd be no answer, no answer, no answer. So, I would wait another 15 minutes and call again with no*

> *answer, no answer and then I would go home and nobody's there yet. They'd show up 15 minutes later, you know, so I called CCAC and the company they were dealing with and say listen, like you don't understand, my mom will go for a walk and not come back."*
> Kelly did share that service improved after several telephone calls in reference to this situation and stated,

> *"They actually finally understood — I had everything set up — they would send somebody from eight to nine and I would pay a private caregiver from nine to one. CCAC would then send back someone to work from one to three; they ended up at one point just sending someone from eight to three3 in the afternoon because I think I was going to have a nervous breakdown."*

Sherry and Kim were frustrated at the lack of respite hours they were being offered. They live in a rural area and the nearest city or town of any consequence is a fair distance away in good weather driving conditions. Sherry and Kim both shared that,

> *"The government tells you to take them home and they will help; I could only get six or eight weeks of unemployment when I took my leave of absence to help [Kim] and when they sent someone to the house it was only going to be for four hours."* The rural location of Kim and Sherry's home seemed to not have any bearing on the amount of respite hours being offered. Both Kim and Sherry provided that

> *"What's one hour a day — or two — somebody just coming in to look at her or maybe to wash her up and clean her up? We were lucky with her; she wasn't cranky or anything; she was always so pleasant."* When asked what would have been more beneficial to them in a rural setting both sisters responded,

> *"They could have sent someone to come in for even a day and say 'well you go out and enjoy yourself'; they would do this [respite hours] for maybe four hours; I said four hours is no good to us because if we want to go to [name of town] then you have to have a whole day. It's an hour and a half there and back."* Kim further shared that,

> *"They didn't give us anything other than four hours – if someone didn't have family or friends to come in and help do stuff like that then I don't know what they'd do. There's cooking, there's laundry — all this stuff you have to do — you have to do that yourself. Everything."*

Tina also shared her frustration related to services that were being provided to help in caring for her mother stating,

> *"I've been dealing with more people lately. At CCAC, the Victorian Order of Nurses and um, it's, I find a slow process and you have to deal with so many people before you get an answer. Sometimes I wish they were able to provide a little bit more care, but I shouldn't*

> *be complaining."* Further, *"you see, the service they provide, it is minimum. Like in my mother's instance, she refuses to shower so we have to push her to shower all the time. CCAC, they go in, well it's strictly for showering. If there's a mess in the room, they don't do any of that so I'm having to go a lot more often. Like they've made changes; they don't have homecare anymore."*

Tina was providing care to her mother and experiences moments of frustration and anger when in conflict with her siblings; this conflict was related to the level of care and support that Tina had been providing and the difference of opinion in that care on the part of her siblings. Tina shared that,

> *"The first two years I was hurt and upset and I couldn't figure out why my family was acting like this; I was very angry at times. Somewhere — after about two years — I had a talk with myself and said I'm going to have a nervous breakdown trying to juggle all these balls like a juggler so I have to let go of something because I will probably have a nervous breakdown. I realized there were some things I couldn't change and one of them was my so-called family's attitudes and beliefs; I had to — in my mind — pretend that they weren't really my family."* This also led to frustration with the numerous different caregivers that were becoming involved with the care of her mother. Tina shared,

“Like it doesn’t seem to me to make sense to have a different person every time with her memory issues. The catch with CCAC was that like my sister wanted less of mom’s money to be used for private caregivers so CCAC could send somebody in the morning and at night to get her dressed and undressed every day of the week but it would be a different person so that was the next battle as well” Further, *“some of the caregivers were less invested than others shall we say; the last year or so it got a little more challenging. Note that my mother was always safe but I’d come home and I’ll never forget some of the things; some were just like my mom would be in front of the TV and just made me angry because, just because she had dementia, does not mean she’d lost her mind; it would be like a little kid, just put in front of the TV so that was a little upsetting.”*

Tammy shared that her relationship with her family had caused her moments of anger and frustration. I noted that during the interview, Tammy’s non-verbal language and paraverbal were indicative of someone being frustrated and angry. Tammy states that her father: *“Is 77, extremely stubborn; pretty controlling. His word has pretty much been gospel in the house. Especially with my mom and of course with the Alzheimer’s definitely what he says goes. He put his foot down and said no [*to following up with a geriatric specialist] *it would just upset her, leave it alone*. *He’s her husband right? So*

> *what do you do? It makes me angry – I think he could have benefited from it, the Alzheimer's Society is right there….he just won't go in [in denial?] oh total denial; I want to kick his ass…little bit of anger there…..it's upsetting."* Further, there seems to be anger present in her relationship with her siblings. This is evidenced in Tammy's own words stating, *"Anger. Very angry and angry with them. Yeah, I was getting very angry with them, snapping. Snapping a lot. Not wanting, when I did have time to go out, not wanting to go out. Not wanted to be around people. I think I was getting a little depressed. Yeah, they were becoming very aware of that. I didn't want to go to their house."*

Tammy provided that the burden of continual care to her mother rested mostly with her and on the rare occasion one of her siblings did provide some assistance,

> *"My brother, my other brother, was in last month for one full day. Came in early in the morning; came to my place for coffee. Said don't worry about mom, I've got her for the day which was fantastic, and he did. Then he called me about 5 o'clock and said sorry I have to head out early, but she's got dinner, she's fine. Which means she is sitting there alone in the living room in her chair eating by herself, so I went to my mom's; I was laying on my couch reading – a little bit angry."*

Grief and guilt were also present in the lived experiences of the research participants. The concept of grief and guilt is multi-dimensioned for those in the role of the caregiver; anticipatory grief, grief related to loss of role-identity, loss of relationship and loss associated with lifegoals such as retirement plans. Guilt is also evidenced wherein participants questioned placing their loved one in long-term care too soon and for not being able to provide the required care in their home. There was also guilt evident for their thoughts, feelings and emotions towards their loved ones related to the change in their relationship dynamic. Tina was providing care to her mother and shared that,

> *"I think in the grieving process* [referencing moving back to a normalized routine] *it's been the loss, but also the loss of how busy I was because I never stopped. Like I was at work or I was at home and I did all the cooking and certain things had to be done* [speaking to the loss of role identity]. *I think all of that combined plus the grieving over the last three weeks of her life — which was pretty bad in my opinion — I haven't really socialized yet."*

Tonya is providing care to her husband and shared her feelings of guilt when discussing their retirement plans and the changes that she is anticipating having to make to them stating,

> *"Our plan is to live on [name of town] for the rest of the summer and live in [name of state] or somewhere hot for the winter. That's our life; la te da da. Put the brakes on. That stopped so that's why I sort*

> *of have indifferent feelings about what I want to do when I retire. Do I want to? I'm 54 at that time; that's young to be sitting around looking after somebody. Am I going to get old and crotchety and not care what you look like?* [In reference to the care and appearance of her husband]. *Ah who gives a shit if your hair's washed today, you're just sitting at home…….do I stay here if he continues being this sick? Do I place him where I'm going to be sitting every day at home? No, that's not to be, but then he is my husband and the father of the kids. Then I'm going to get family saying 'well Tonya, you put him in a home; well, I'm just saying in five years you put him in a home and you're out doing things.' Well am I supposed to sit there all day and hold his hand?*

The contemplation of placing her husband into a care facility had caused Tonya to feel guilty at being able to continue on with her day-to-day life post-placement, and having to explain to the extended family why she would not be daily by his side. Tonya shared that she was not wanting to have the conversation with her husband's family related to not ending her plans for continuing to work or to continue following through on their retirement plans. Tonya stated,

> *So, I've got that guilt feeling like what happens if….so, I'm just playing my cards every day. Some days are good – some days are bad."*

Jodi provides care to her husband and shared her thoughts post-placement in a long-term care home stating,

> *"I'd come* [to the home] *but what good was I to him because I wouldn't take him out you know….on the same hand, I'm not going to abandon him. I couldn't live with that either myself. My own standard I guess let alone, I guess, the love I have for the man."*

Cindy provided care to her husband and shared this thought on her feelings post-placement into a long-term care home for her husband,

> *"He couldn't articulate anything anymore; he just didn't speak. So, and then, sort of losing him as far as not thinking that he knew who I was. They are always sort of happy to see you. No, I think it was just company and if I missed a few days then I'd feel terrible. Once he was in the home and a lot of guilt over that too, a lot of guilt over the home thing."*

Sociological Factors

The third main theme identified during this study was related to sociological factors. This research was able to identify the impact or changes in family dynamics, friendship networks, and recreational activity. Further, it sought and was able to identify change in role identity and employment status. Individual families have their own level of function or dysfunction which in turn makes each caregiver experience unique in their own way. Some families were reported as being resistant, disbelieving in the diagnosis (and what that would mean moving forward), supportive and in some instances combative; this last point was related to mistrust/distrust.

Kathy is 73 years of age and providing care to her husband; she has adult daughters. Kathy shared that at times her daughters' lack of involvement,

> *"Makes me mad. I called my daughter last night and talked to her – the one in [name of town] – I called and I said can you come and get your dad for the weekend? No. It didn't work. They are so busy. I said 'hey, one of these days you're going to get old.' You can come and get him and bring him to camp for a day or two. No, don't have time."*

One of Kathy's daughters lives closer and has come to her parent's home more regularly. Kathy shared that,

> *"She comes and it's 'mom I got this'; she's here about an hour but she comes."*

Kelly is 53 years of age and was providing care to her mother — who had moved in with her and her husband — and shared that she felt supported by her two brothers and sister. Kelly explained that her siblings lived in rural areas that would not be appropriate for their mother if she had left their homes to explore her surroundings; there were safety concerns in Kelly's own home so she felt that rural farm settings would only increase the risk of their mother becoming lost. Kelly shared that they communicate regularly stating,

> *"I sat down at my computer and sent them all an email explaining everything that's been happening. We talk regularly and we see and visit; we're actually a pretty close family. I sent them all an*

> *email, this is what's happening, this is what I've done. I hope you're okay with it – send me back and the one brother I thought I might have difficulties with sent me back 'A-OK, do what you need to do'; I was prepared to send them back an email to anybody who said anything that I've got her bags packed, come and get her because I can't do it anymore."*

Lori is a widowed 65-year-old mother of adult children and she had been providing care to both her father and her mother; her father has since died due to complications related to his dementia so is currently only providing care to her mother. Lori shared that her family and friendship network are supportive in her efforts to provide care to her mother stating,

> *"My friends are always supportive; I participate in some groups too — woman's groups — they are very supportive. My family is very supportive, especially my daughter, she does things when I can't do it; she's constantly supporting me."*

Lori further shared that her family also lived in close proximity to each other stating,

> *"She moved in with me about a year after my husband died; everything was okay. Like my son lived [in close proximity] so we were always, well, like there was always family. My daughter lived [in close proximity] to us; that's why I say the family is close."*

Tina is a 55-year-old single parent of an adult child and described her family support network as a negative experience. Tina shared that,

> *"Well, I was my mother's Power of Attorney for everything in her will and then, that going back to [year] after I had my mother deemed financially incapable, my sister kind of pulled a fast one on me and took my mother to a lawyer and had herself and my brother-in-law – and myself – made Powers of Attorney. All equal but any 2 out of the 3 could make decisions so I knew that my life was going to be very challenging to say the least."* Further, Tina shared that she *"knew it would be a fight. I had no idea at the time how bad it would get at times but I was the one like on the ground, arranging care. I have 2 sisters and 1 brother. My brother and the sister that was Power of Attorney were always telling me what to do — calling me — not happy with anything I did. My other sister just stayed out of it; so it was not very much fun that part of it."*

Tina described her experience as difficult and that she and her sibling attended court numerous times in an attempt to resolve their issues related to the care of their mother. Tina states,

> *"Back then it was very, it was probably the worst of it because not only was I adjusting to a new job, and not you know living at my cute little house in the south-end with my son, but it was also trying to figure out what was the best way to keep mom safe when I was at work and fighting with my family; who, if I said black, they said white. If there was anything they could, it felt like if there was anything that they could do to make my life more difficult they were*

doing it." Further, *"then when they'd come to visit it was even worse because they just, it was like are these really my family members or maybe I just never noticed these kinds of things; it was like I wasn't there, I was invisible and they asked mom what she would like – they'd ask one question and off they would go. It went to court. We had all together three court dates, three Consent Capacity Board hearings and I had numerous visits with my lawyer, signed all kinds of affidavits. I was accused of all kinds of things by my siblings. So no, it never did get resolved except that somewhere in the next 6 months the last part of the legal dilemma – or fight – should be completed because now that my mom passed on this last legal document that the judge has to sign off on and so then it's done after all those years."* Tina describes her feelings during this process stating that "*the first two years I was hurt and upset, and I couldn't figure out why my family was acting like this and I was very angry at times. So yeah, there was a lot of anger and a lot of times I guess that I felt I hated them but when it came right down to it I hated what they did and then especially the last part — like when she was dying in those three weeks — it didn't make sense what they did and it just felt very hurtful. To her. I could handle what they did to me and all the names they called me but that seemed a total lack of respect for their mother who was dying. That was horrible, I hated what they did then and I lost all my respect for them then."*

Tammy is a 38-year-old single woman providing care to her mother on a 24-hour basis; her father and siblings are not as actively involved with the care being provided. Tammy shared that her relationship with her father is,

> *"Pretty stressed; his word has pretty much always been gospel in the house – especially with mom. I think that we should be doing, she should be doing, more and going to the Alzheimer's Society and doing day things. Like, they have all kinds of things going on there all the time; I think she'd benefit greatly from it but yeah, that just didn't pan out. She [referring to her mother] doesn't want to take her pills so whether she remembers or not she doesn't care; if my father is there, he doesn't make her take them – I have to make sure I'm there in the morning, or someone is up there by at least noon to get her morning pills in and then again at supper."*

Tammy also shared that her relationship with her siblings and her one sister-in-law was not supportive at first, but she has experienced a recent positive change in that regard stating,

> *"I remember doing her hair once and my sister-in-law is a very chatty lady and she popped in after having a run and came in. I was curling my mom's hair and of course my mom turned her head; the curling iron didn't leave a mark or anything but enough to scare her completely and didn't want the curling iron back at her head. Yeah and then my sister-in-law was leaving and she said 'oh do be careful there's no burning again'. Yeah, I bit my tongue very hard*

> *but she got it, I think my look was enough, you know, you're not helping. If you're not going to help, get out."* Further, *"definitely, definitely with my one sister-in-law it got a little rough for a while. Yeah, basically if I didn't specifically ask for whatever it was, if I needed something there was nothing. No support. She would run in briefly on her runs when she has time in the mornings, pop in, have a drink of Gatorade, say hello and she's gone. The odd time, she would bring some muffins or cookies to the house. She might have a tea and then she'd leave."*

Tammy further shared that she has seen a recent change in the support from her siblings and their respective spouses stating,

> *"I find, especially over the summer, my one brother who lives in [name of town], him and his wife – the same one – I find they are making more of an effort. I think, I think they are starting to see how much of an impact that it's having on me and not in a good way. Yeah, so there's definitely support there. That brother actually took, wow, we were well over a year after the diagnosis before he even accepted it that that's what it was. He was still fighting me on it. There was a lot of denial; it's just depression, I don't know why she's on those damn pills, she just needs to get outside and it's like oh my God, really?"*

Sherry, 68 years of age, and Kim, 70 years of age, are sisters that had been providing care to their sister — diagnosed with Alzheimer's disease — in the privacy of their own home. Both sisters shared that they provided support to each other, but they also felt supported by extended family and from within their own community,

> *"Our sister-in-law came down there that first while all the time; came down and helped every night. Now, it's such a bad winter and every night she'd come down and help with her, you know, put her to bed or to help her just before she went to sleep because we'd have her in bed already but she'd help with everything. Yeah, the whole family was really good and I mean even people around town offered to help. I mean they were really good; the people around here are usually like that. They're really good, really helpful."*

Jodi is a widowed 72-year-old that had been providing care to her husband; he had been diagnosed with Alzheimer's disease and she provided care in their family home. Jodi shared that her experience with her husband — although challenging due to his behaviour of leaving the home on numerous occasions without much-needed supervision — was positive in that she felt supported by her neighbours, her family, past work-knowledge, and her faith,

> *"One night he's running, going off to the police station and why are you going to the police station?* [her husband's response] *I'm the police chief and he did leave here. Off he went and I was trying to stop him so I call one of the neighbours to get up, get Fred*[2]*, he's going. They didn't get him fast enough and then the next neighbour*

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[2] Pseudonyms are used to ensure that there are no potential identifiers.

> *was there — he's chasing Fred now — he can't catch him but then the younger fellow* [the neighbour' s son] *got in his father's truck and I got in the truck with him and the fathers chasing him down; we realize that we're not going to catch them so then I come back home here and the police called, 'Jodi, we have somebody named Fred here'; yes, I'll be right there so he knew me, he knew our phone number – he did that about three times."* Further, *"I don't know what it was, I guess because I was a nurse because I had all these things in our lives and I had the assistance and my sister was good. I have a strong faith; I'm in church often and I have been through lots of life events, it's really held me up and I know to find joy, I know to give thanks and I should."*

Cindy is 70 years of age — a mother of adult children and a grandmother — who had been providing care to her husband. Cindy shared that there are challenges with her adult children stating,

> *"Mary[3] was always, my daughter was always, she was always accepting. She didn't like it and for a while there we didn't, well we don't see very much of the kids anyways but for a while she was bit nervous, and I would go down and I'd take three days and go somewhere, and she'd look after Larry[4] and she was okay."*

Cindy's experience with her daughter was much different than the one she had with her son stating,

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[3] Pseudonym

[4] Pseudonym

> *"My son, no. I don't think so* [when referring to her son's acceptance of his father's diagnosis] *We don't talk very much. The summer that Larry had to go into care he did phone and say that he was sorry for behaving the way that he was, but he was going to come out and try to help me out. But he came twice and that was it but he never went to see Larry in the nursing home. No, and I still don't* [referring once again to her son's acceptance]*, it's a shame because Mary always said that I like Frank*[5] *better than her. I always felt bad about that. He won't accept emails, so I usually have to phone him and leave a message for whatever I want but he doesn't phone back."*

It was evident that there were changes occurring in every aspect of the research participants lives; none more so than in the changes related to activity and social participation.

Jodi is a widowed woman of 72 years of age — a mother of adult children and is a grandmother — she was providing care to her husband. Jodi shared that they had an active social life but experienced many changes post-diagnosis stating,

> *"We travelled with friends and we did, we had a camp but we sold it. He would go golfing about four times a week and I'd be like are we going to camp? We going to camp? It wasn't fun and then he wasn't handy, nor I and getting the water in was the stone that broke the camel's back so I said lets sell it. We liked to walk, we used to dance, we would golf but I*

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[5] Pseudonym

> *wasn't very good. We'd go out a few times late on a Sunday afternoon or something like that; then I had a group that I'd golf once a week that I would do and nine holes was plenty for me. We liked to travel, we'd go to movies on Friday night; we went to church together, I go to church more than he did but still he, going to church was important and we did that as a family."*

Tammy is a single 38-year-old daughter that is providing care to her mother on a 24-hours basis; the amount of time required for this commitment has also impacted her personal life as witnessed in her statement,

> *"I'm a 38-year-old woman – single now. I was seeing someone last year for a while; didn't work out, I think a little bit because of my mom. Not specifically her but just because I was there so much – a lot of responsibility. It was a little too much for him to take, I think."* Further, *"before my mom I think it was, I guess I was a bit selfish maybe. At least I feel like I was like that now; maybe not really selfish just you know especially when you're young and single and doing whatever. Everything is about you and your own things and your parents are supposed to be, parents are supposed to be the ones that look after you, right?"*

This self-assessment of her personality led to further discussion related to the activities that Tammy enjoyed doing prior to becoming the care-provider for her mother. Tammy provided that she was very active and there were many activities that she enjoyed stating,

> *"Oh God, anything outdoors; kayaking, running, boating; just getting out with friends. I like my time alone; reading, big reader, so I don't really get that anymore. It's been a huge change. I don't know – life was life. Not so many worries, not so much pressure. I had free time, time with friends, work was easier, you know, everything, because we're self-employed; we have our own business. I've taken over all the books which she used to do; that's added on as well as the shifts and looking after her."* Tammy also shared that, *"all my free time was gone. Oh my God, can I just have dinner in my own home? You know what I mean? I just want to sit and do my own things for just one day. I have no free time."* Further, *"that's why I actually agreed to come here today; just taking off for the day, this is my time, I got excited when I hit the highway. This is a day out, this is exciting."* When asked where her thoughts were on this day out, Tammy responded, "*Well right now it's with my mom. I mean otherwise, I will think about it all day off and on but at least it's in the distance because I know my brothers there, my dad will go in and out. You can still, we can leave her alone for a couple of hours."*

Tina is a single 55-year-old mother of one adult child; she had been providing care to her mother in her mother's home. Tina shared that prior to becoming the care-provider to her mother that she was socially active stating,

> *"I had my own little house in the [area of city] with my child — who was then about 16 or 17 — and I would visit my mother and I worked full-time, and I had friends and I would do things with my friends on my days off or*

> *putter around my house; we would talk about old times and we would go shopping - window shopping or otherwise. Just get together at each other's homes because we all had kids of different ages; relaxing on our days off. My mom was on her own in her house then and that changed. I started to keep a closer eye on her and visited her more. I left my son at the house in the [area of city] and he was 18 by then I guess; so I kind of checked on him but I lived at my mothers with her. At first it was, there was probably like very little socializing because I wasn't quite sure what was going on with her; so, let's say the first six months at least weren't that great but from what I can remember I didn't do any socializing."*

Lori is a widowed 65-year-old mother with adult children and was providing care to her mother in the privacy of her own home. Lori shared that there were changes in her social life once she moved her mother into her own home stating,

> *"Well, I don't go out as often, I'm tied to having to organize things for her. Well, I think I'm busier now than when I was working. As I say, it takes a lot – it's daily. I would say every hour or so I think about her. I would go to the theater at least twice a month; just the movie theaters at least once a week. But no, I don't even go to the theaters maybe once a year now.*

Kelly was providing care to her mother; her mother eventually moved into Kelly's home when it became unsafe for her to continue living in her own residence. Kelly shared that there were significant changes in her private and social life during the four years that her mother had been living in their matrimonial home. Kelly stated,

> *"I've been married for 30 years; we have no children, so my time and my husband's time was our time. We got to do what pretty much everything we wanted. Ummm, sorry. We camped a lot, fished, four-wheeling; a lot of outdoors, boating. That definitely stopped — my husband pretty much lived downstairs because, sorry, because my mom didn't like him after she started with the dementia. He was her favourite son-in-law until this started. So ummm my mom and I pretty much lived upstairs and he lived downstairs. She* [referring to her mother] *liked to camp a lot too so in the beginning she came with us but it was again difficult because of my husband. Then it got to the point where we couldn't do much of anything."*

Kathy is a 73-year-old mother of adult-aged children, and she provides care to her husband; he has a diagnosis of Alzheimer's disease. Kathy also has physical impairments of her own, yet this hasn't interfered with her ability to provide care to her family. Kathy shared that she also experienced changes in her social life stating,

> *"We used to go everywhere; now we can't go because he doesn't feel like going and sometimes, he's moody and sometimes grouchy — I don't like this, I don't like that and people don't like me — he doesn't like people to talk to him and he will answer them and answer very roughly. We used to go to the rodeo or country jamboree — anything like that — we used to go out to dinner and movies. Once and a while we will go to '[a local restaurant] or whatever but he doesn't like that, he gets tired fast."* Further, *"a lot of change like we stay home a lot and if we go to a party or something 10 o'clock he's ready to come home so it's very different. I can't*

> *go shopping, he hates to go shopping; I would go every day. He is in the [name of a social club] —– it's a good thing because he goes two or three times a month — I go too but, I mean, I have to drive him. I don't go to the meeting, but we go to the breakfast and supper and all that; 8 o'clock he's tired, let's go home."* Kathy's husband used to attend the day program at the local Alzheimer's Society location but ended up not continuing. She shared her thoughts on this stating, *"Yeah, I wish he would still go; well sometimes I went shopping, grocery shopping or get back into my work, vacuum and clean the house* [when her husband was attending the day program]. *He follows me everywhere — he's like a kid."*

Tonya is a 52-year-old mother of adult children who is providing care to her husband in their matrimonial home. Tonya shared some of the activities she enjoys engaging in by stating,

> *"I like being around a lot of people all the time; I like people at my house. I like lots of company; I like cooking for people and having people over. Laughing and talking and sharing a bottle of wine and just that type of stuff. I'm not a game player so people say come and play cards – God forbid no – talk, laugh and listen to music. I like girly things; I'm not a diva. I like going to the spa; getting my nails done. Massages, I've always done that. Jim*[6] *has 54 first cousins — I have five — so I had a hard time getting used to that; there's always parties in [name of a town] so we always*

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[6] Pseudonym

> *went; all his family seemed to be in [place of origin] so we go to [place of origin].”*

With the decline in her husband’s cognition there have been changes that have occurred in her relationship with her husband; relational expectations have been compromised and Tonya stated,

> *“I love him dearly….dearly. He’s been a very good provider, good to my kids; we’ve always had lovely homes, beautiful cars. He drives, he has a big [name] truck; don’t ask me about trucks and he has a [name of truck] and I drive a [name of car]. We have nice cars; we live in nice houses. I’ve been provided for. Anything I ever wanted; I can get to reason. I love him for that, we’ve been good. The kids have had everything, but we went from that to I’m not in love with him and I feel bad saying it but I just, it’s a different world I’ve got now. He’s more my, I’m having to look after him rather than him looking after me. Like as a partner, you want the man to look after you. I want to be able to drive to Toronto and I can sit back in either vehicle, put the seat back and just listen to some tunes. Now, I gotta drive. Like I want to be looked after; I want to be taken care of. I want to be able to go out for dinner or actually come home and have supper ready.”*

Cindy is a 70-year-old mother of adult children and had been providing care to her husband for 10 years in their matrimonial home. Cindy described how her social activities changed stating,

> *"We used to do [sport], we were [name of club] members, we were well-travelled; but yeah, we had a lot of fun camping. There was social isolation and I'm a social butterfly; I just love being around people — finding out what's going on, who's doing what to whom. But I'm not really very good, I've never been really good about doing it on my own. It's always sort of Fred that starts it and he could talk to absolutely anybody and then I could talk to absolutely anything once he got started you know and he'd go off somewhere else and then I'd be having a great time on my own; so I'm finding it quite the challenge now to try and get back into doing different things. My world was becoming smaller and smaller, you know. Like never did anything on the weekends and evenings."*

The participants shared their thoughts, feelings, emotions, and experiences of providing informal care to a loved one diagnosed with a dementia. Using rich and thick quotations demonstrates the key themes of the biopsychosocial impact on the informal caregivers of loved ones diagnosed with a dementia. In the next chapter, I will discuss the findings and their importance for service providers, policy makers and other informal caregivers of loved ones diagnosed with a dementia.

Chapter 4 – Discussion of Findings

In this chapter I will discuss the findings of this qualitative research project as they relate to the research question. Further, the meaning and importance of these findings will be presented. The findings of the research will also be examined in relation to previous studies and literature on caregiving for persons diagnosed with a dementia. The purpose of the qualitative research was to address the main question:

> What is the biopsychosocial impact on informal caregivers providing care to a loved one diagnosed with a dementia?

With the steadily increasing prevalence of dementia in communities (Chene, 2006; Shaji, et al., 2000; Wang et al., 2020; Zwaanswijk, et al., 2013) the role of the informal caregiver in the context of providing care to a person living with dementia will continue to increase in importance in relation to research, policy creation, and service creation in support of the informal caregiver. This qualitative study explored the experiences of the informal caregivers of persons living with a dementia. The major findings from this research encompassed the biological, psychological/emotional, and sociological aspects of being an informal carer to a person living with dementia. It also provided for the identification of subthemes related to sleep, signs and symptoms of depression, signs and symptoms of anxiety, grief, anger, frustration, fear, isolation, and changes in activity. This chapter will discuss the findings in light of the literature through the caregiver experience, the psychological/emotional challenges, the biological impact, financial impact, and the sociological impact on the carer's journey.

Caregiver Experiences

The move to home-based care in Ontario saw the provincial government initially invest $1.1 billion over a four-year period (Ontario, 2010). The funds were expected to provide a continuum of service that would allow for seniors to maintain their health, independence, and dignity of staying in their homes (Ontario, 2010). This ongoing funding was a key investment when considering that up to 75% of persons living with dementia are being cared for in the home of the family members providing this informal care (Chene, 2006; Forina, 2017; Glueckaug et al., 2005; Shaji et al., 2009). This was reflected in this study where eight of the 10 care recipients lived with the person providing the care. In my study, the caregivers of persons living with dementia were all female and comprised of four spouses, four daughters, and two sisters (see Table 1). This mirrored the results in studies completed by Glueckauf et al., 2005, Shaji et al., 2009, and Weitzman et al., 2000 wherein they identified that older spouses, daughters, and daughters-in-law were identified as the key person within the family providing this care. Truzzi et al (2012) noted that the burden of care for familial informal caregivers of persons living with dementia led to chronic stress and that more than 50% of familial caregivers report suffering from some form of burden which is frequently associated with depression and anxiety.

Psychological - Emotional Challenges

The experience of emotional burden and consequences was reflected in my study where eight out of the 10 informal carers either self-identified a diagnosis of depression or presented with the signs and symptoms of what could be depression; signs and symptoms of what could be anxiety were also evidenced in several of the participants and appeared to be situational rather than a chronic presentation. Many of the participants shared that their experiences of anxiety were related to the conflict between family members in relation to the level of care that the person living with dementia was receiving, financial decisions being made by the carer, minimising the effort required to care for the person living with dementia, and the denial of the diagnosis by family members. These factors contributed to the levels of perceived burden in providing care that was consistent with previous research conducted by Varik et al., (2020) that found that conflict existed between family members as it relates to denial of diagnosis, role responsibility, decision-making, and the effort required to provide care to a person living with dementia. There were six participants that presented with signs and symptoms that could potentially be indicative of depression. This finding was similar to research previously conducted by Badawoud et al. (2023) in which the level of caregiver burden was found to be moderate to high.

Two of the 10 participants self-disclosed that they had been diagnosed with depression related to the burden of providing care to their family member living with dementia. There were four participants that indicated their need to connect with their family physician as they came to the realization that they would require assistance in their carer journeys. These findings were consistent with previous research conducted by Alfakhri, et al., (2018), Srivastava, et al. (2016), and Zwaanswijk, et al. (2013) whom all identify the confirmed diagnoses of depression — or the signs and symptoms of potential depression — impacting the informal family carers of persons living with dementia. There were also participants in this study that presented with signs and symptoms similar to that of anxiety.

The participants shared their self-perceived anxiety was related to anticipatory grief which found them wondering about what comes next and whether or not they were prepared for what comes next. Further, some participants shared that they did not know what to do when reflecting on the next steps of their journey. Other participants shared their self-identified anxiety and fear was related to the safety of the person living with dementia such as falling down the stairs in the dark or leaving the home unattended. There was one participant that shared their family member living with dementia had attempted to drive the carer's car away during a rainy night while another participant stated their spouse had been found to be at a local high school on the several occasions that he had eloped from their matrimonial home.

Another participant also shared their loved one had been discovered on foot travelling southbound on a local highway in an attempt to reach southern Ontario for the purpose of reporting to his [name of a sports team]. Some shared their concerns related to others not providing the same level of care or familiarity with the person living with dementia which led to concerns about responsive behaviours towards post-placement staff, with respite workers or towards the carer themselves. The previous research conducted by Chene (2006) — and later by Hwang et al. (2021) — also was consistent with the findings of my study in that more than 76.5% of the participants had presented either with diagnoses of anxiety and depression or with the signs and symptoms that could potentially be anxiety or depression. Alfakhri, et al., (2018) stated that the majority of caregivers were prone to experience, or had experienced, deteriorations or reductions in their mental health status which mirrored previous research that stated all informal caregivers were identified as being at substantial risk for emotional disorders, in particular, depression and anxiety (Adams, et al. 2004; Chene, 2006; Glueckauf et al. 2005; Shaji, et al. 2009; Truzzi, et al. 2012; Weitzman et al. 2000; Zwaanswijk, et al. 2013). Several participants in this study also shared multiple reasons they had been experiencing moments of anger and frustration with their caring experience.

Participants of this study shared their feelings of anger and frustration towards their family members due to their perceived lack of familial support. Still others shared their family were in denial of the diagnosis of dementia, its current level of severity, and related level of difficulty of providing care on a daily continuous basis. The participants shared there was little insight as to the care needs of the person living with dementia and the related demands it had on the carer’s daily life. Still others shared they were involved in conflicts within their family that related to decisions being made, financial expenditures, and expectations that the carer would provide the necessary and required care outside of what may have been provided through publicly funded agencies. The findings were similar to the findings in a study by Varik et al. (2020) that stated informal carers are exposed to family conflicts which led to emotional strain. The diagnosis of a dementia, responsive behaviour and needs of the person living with dementia also led to some participants feeling anger.

Four of the 10 participants in this study shared their anger at the diagnosis and the impact it had on their life, the life of the person living with dementia, and their life plans. All of the participants expressed moments of anger and frustration as it related to various limiting aspects of providing care such as the limiting social aspects of providing care to the person living with dementia. For instance, there were identified reductions in friendship networks where previous activity such as camping, quadding, organized sporting activities, shopping, outings, personal time, dining, pursuit of other forms of recreational activity were all significantly reduced or discontinued altogether. This was similar to findings by Reed et al., (2020) and Varik et al., (2020) who found there to be relationship deprivation amongst carers of persons living with dementia and increased carer burden as it related to the care demands and needs of the person living with dementia. All 10 of the participants were females, where four were the eldest daughters, two were sisters and the remaining four were the spouses of the person living with dementia. This was consistent with the previous studies that found the burden of providing care became the responsibility of older spouses, daughters, and daughters-in-law (Glueckauf et al. 2005; Truzzi et al. 2012; Shaji et al. 2009; Weitzman et al. 2000). Four of the 10 participants of this study stated some of their frustration and anger was related to their experiences with homecare services and respite services.

Queluz et al., (2020) stated there was a need for consistency in the services that supported the care of the person living with dementia and that this was also instrumental in helping the informal carers to experience less burden in their caregiving experience. Some of the participants frustration and anger was directed at agencies that had become involved in the care of the person living with dementia due to inconsistencies related to frequently changing contracted agency staffs such as the personal support workers, the lack of understanding for the carers need for punctuality, as well as the need for consistent and predictable time of service provision by contracted agencies. This was consistent in studies conducted by Roger et al., (2015) and later by Badawoud et al., (2023) that found the need for formal supports as a requirement to reduce the burden of providing informal care to a person living with dementia. Four of the 10 participants in this study took umbrage with the lack of respite hours — the lack of sameness — when considering urban versus rural locations of the person living with dementia and the needs of the informal carer. The participants located in rural areas shared that they received 4-hours per week in the form of respite hours which was the amount of time allocated to the other 6 participants that lived in urban areas. The purpose of respite — and its importance in supporting the wellbeing of the carer — was stated in studies completed by Whitlatch and Orsulic-Jeras (2017) and again by Queluz (2020). For the four rural area recipients of respite hours, for them to complete their own medical appointments, run errands such as groceries or banking, or to engage in social activities in support of their wellbeing the majority of the 4-hours was spent driving to the nearest urban centre which typically left them with 15-30 minutes of activity time. When compared to the participants in this study that were located in an urban area, the majority of their respite hours were spent engaged in actual activity that supported their wellbeing rather than using the majority of their hours for transportation. In discussing the services provided in the home, participants of this study shared they felt there was a lack of practical in-home services to assist with light housework — such as laundry — as a need that was lacking. Still others discussed their observation regarding the rigidity of service-providers. Participants shared that if service providers were scheduled to attend the home and the visit or task did not occur — such as bathing — then the allotted time was not able to be utilised for any other task. Participants shared they felt this could be an effective support in completing other daily tasks such as light housekeeping. The participants in this study all had moments they shared that clearly added to their level of burden with some expressing resigned acceptance of their situation. Other factors that may have led to the perceived level of burden, perceived anxiety, and either perceived depressive symptomology or self-identified diagnosis of depression and anxiety could be related to a lack of restful sleep.

Biological Impact

The importance of sleep for informal carers has been discussed in many studies with the averaged recommendation for sleep to be seven to eight hours (McKibbin et al. 2005). As stated by Liang et al., (2020), evidence of disturbed sleep being a significant health problem affecting both physical and mental health has been widely reported since the early 1980s. These previous findings were also evidenced in this study that found seven of the participants identified their inability to either maintain a regular sleep pattern, experience uninterrupted sleep, and regularly experienced a lack of restful sleep. Participants suggested that their sleep issues were related to their fears that the person living with dementia would exit the home, be exploring the home at night and potentially fall, and/or being disruptive while gathering up items in the home at night that were of interest to them. Some of their fears related to nighttime elopement proved true when three of the 10 participants reported their loved one had exited the home without accompaniment or supervision; this resulted in heightened awareness at night and the implementation of strategies to ensure the safety of the person living with dementia should elopement reoccur. Although elopement from the home did not occur for four of the 10 participants, they had concerns about this occurring which contributed to their sleep issues. Some of the problem-solving to address the need for quality sleep found participants altering their sleeping arrangements with their spouses so that they could be well-rested. Still other participants were not able to clearly identify why they couldn't attain periods of restful sleep but would sit up nights in the room with the person living with dementia should they awaken and require care, attempt to leave their bed or their home environment. Some participants described their sense of exhaustion which found them unable to sleep that added to their burden of providing care. Some participants informed their family physician of their sleep deprivation and obtained a sleep-aid to assist on nights that restful sleep eluded them.

Financial

Previous studies by Brodaty and Donkin (2009) reported the financial strain of providing informal care to a person living with dementia was a greater burden that any other medical condition associated with aging. The financial strain of providing care to a person living with dementia was also reported in a subsequent study completed by Barnett (2013). These studies were reflective of the National Council of Welfare report that two out of three women are considered to be impoverished (Hurtig, 1999). This was not found to be a factor in my study with the exception of one of the 10 participants. This participant reported that they felt there was insufficient paid time-off allowed under their employment insurance benefits; they were only permitted a total of 8-weeks paid time off work to support their loved one with around-the-clock care. In consideration of the financial ability of some participants, it could be a case of lower income families were unable to be connected to this study due to not having access to the services that would have been able to refer them. It may also be a result of not having the ability to take time from work to participate and/or potentially not wanting to make use of their allotted respite hours. Although there appears to have been little financial consequence related to providing care to a person living with dementia, there were both negative and positive sociological findings in this study.

Sociological

Several earlier studies reported the higher incidents of caregiver burden (Chene, 2006) when providing care to a person living with dementia and how this can be compounded by a lack of social and familial supports, and ongoing criticisms of the type of care being provided (Glueckauf, et al. 2005; Posner, 2015; Shaji, et al. 2009; Weitzman, et al. 2000). This was also evidenced in my study through four of the 10 participants sharing their negative experiences they had with either their siblings or progeny. It was reported by one of the four participants that there were several court appearances related to the ongoing conflict pertaining to cost expenditures for care. This participant also worked full time hours, was a single parent, and provided care to their parent when they were not scheduled for work. There were also negative experiences with three of the participants in that there was little to no support provided by their families in the caring role regardless of the need.

Of the four participants reporting negative experiences, one of the four participants reporting a negative experience of providing care, was able to identify a shift towards more acceptance of the diagnosis and an increase in the involvement of their siblings and respective spouses. There was a noticeable increase in the number of visits to the family home to offer assistance such as hair washing, staying at home in a sentinel capacity to allow the carer some respite time, and coffee-chats that allowed for adult conversation with the visiting sibling. This was found to be the one element that validated the carer in their role that allowed them to continue with their caregiving journey with less burden than what they previously had experienced. One of the more severe impacts, as shared by the participant, was the end of their relationship when their fiancée ended the engagement. The participant shared that their former fiancée indicated that there was a lack of time being spent together for their own needs to be met and that they felt there was little point in continuing the relationship. There was one participant that reported a 50/50 split in the support received by their progeny; one adult child supported the participant while the other adult child would not accept the diagnosis and did not engage in the discussions related to care needs of the person living with dementia. Not all the experiences were negative as five of the 10 participants shared they had positive support from their siblings from the outset. These participants shared that their family was supportive, involved and — if not able to be immediately involved — then they provided positive feedback and support of the decisions that had been made. While some of the five participants reporting a positive experience, two of the five shared that they found support from withing their rural community by other residents and one of the five participants stated they found strength in their faith.

Conclusion

In this study, I explored the caregiver experience of providing informal care to a person living with dementia and the findings of this study consistently reflect the literature. Further, the findings of this study enhance and add to the body of literature on the informal carers of persons living with dementia. The participants of this study expressed their thoughts and feelings on their role as a caregiver to a person living with dementia. They shared their concerns, fears, negative experiences, criticisms they received from family, as well as the observations they had in relation to services they had received in the course of their carer journeys. There were also positive aspects identified in the story-sharing of several participants. Several participants shared they had positive communication with their respective siblings, while others shared the strength they found through the support of their communities or from their employer. It was also noted that several participants were surprised at their own sense of calm, acceptance, and resilience in light of all that they had shared of their carers journey.

The aforementioned themes demonstrate the comprehensive aspect of the caregiver experience, the challenges, the demands, the successes, and the growth of either the participants or their respective family members. In the next chapter, the importance and meaning of the findings will be explained as they pertain to policy makers, service providers, social workers, and other family caregivers either just starting their carers journey or in the midst of it.

Chapter 5 - Conclusion

In this chapter, I will discuss the importance of the findings in this study in the context of dementia-care service delivery in Ontario, potential approaches to improve care in support of the caregiver based on these findings, the limitations of the study, and lastly the implications for social work practice.

Overall, the findings of this study were consistent with the studies conducted previously over the past 40 years. In that time, there have been several enhancements to the healthcare system in Ontario as well as Canada-wide. However, these enhancements such as the move to homecare-based services, the implementation of Ontario's 'Aging At Home' strategy - and its subsequent financial investments – have all been in the interest of aligning services, expenditures and supports with the patient needs at the forefront. To date, there has been little investment in the needs of the carer in Ontario.

The needs of the caregiver are clearly not recognized as the priority in the provision of services especially when viewing the practices currently in place with Home and Community Care Support Services (HCCSS); formerly known as the Community Care Access Centre (CCAC). Respite hours are allocated on a needs-based scale that looks at the person receiving the care and not at the specific needs of the person providing the care. There is also little in the way of standardized outcome assessment tools. Knowing if the services provided are of any assistance is essential in the planning of future offerings and can also help to guide adjustments to current services so that they can be more effective and be of more support to the informal carer of a person living with dementia. As mentioned in the literature review chapter, the COVID-19 pandemic greatly impacted the services available to carers of persons living with dementia as there were reductions in services provided in the home, a noticeable reduction in the number of workers being able to go into the care-recipients home, and less access to services that would provide a diagnosis which would in turn allow access to support services. However, in hearing the comments of the research participants in my study, some of the system issues existed prior to the pandemic so I recently conducted an environmental scan during the final writing of this thesis to help inform myself of the process to access service and what services are available.

The homecare system in Ontario has undergone several changes in the past 20 years and is more recently undergoing further change in a move away from the Local Health Integration Network (LHIN) system of care access and provision to a system of Ontario Health Teams (OHTs). This new system is reportedly designed to encompass the entirety of a person’s journey through the health system such as in-hospital care, post-hospital care, primary care, mental health, addictions, and the Home and Community Care Support Services programs (HCCSS).

Home and Community Care Support Services is the standalone agency that was formerly under the direction of the Northeastern Ontario Local Health Integrated Network (NELHIN) and is the Ontario Health agency responsible for coordinating in-home and community-based care in Ontario. This also includes the awarding of contracts to third-party providers who then will have care staff provide the identified care-needs in the home. For instance, in Sudbury there are only a limited number of contracts awarded to prequalified for-profit companies which receive volume-provider contracts and there are only a couple of companies that are awarded overflow contracts. To explain, volume-provider contractors are guaranteed a set percentage of all the care in a particular area while the over-flow providers do not have volume guarantees and can accept or select clients off a waiting list. Most providers in the north are not time-specific providers and will only commit to a window of time based on the specific needs of the person receiving the care. This system of care in northern Ontario was hit especially hard during the pandemic as many homecare staffs are employed by multiple agencies simultaneously or they were also employed in a long-term care home setting. With the restrictions issued by the province of Ontario during the pandemic, healthcare staff were forbidden to work in multiple care settings which also had an impact on homecare recipients. The Home Community Care Support Services (HCCSS) also provide respite hours to carers of persons living with dementia.

The participants in my study shared they were provided with four hours of respite each week, which they were able to use for their own personal needs while a contracted care provider stayed with the person living with dementia. This did not account for the difference between urban care recipients versus rural care recipients which can have a profound impact when the time required to drive anywhere is taken into consideration. For urban care recipients, they can potentially divide the four hours of respite into one-hour segments allowing them to leave the home four times per week. The rural recipients of respite hours in my study could not benefit from this as they all lived a significant driving distance from the nearest urban center and the four hours they received would only allow for a once per week drive to their nearest urban center to quickly run an errand to a hardware store, bookstore, department store or to have a brief moment in a café; this could not occur during the winter months due to the unpredictability of the weather and road conditions. There did not appear to be equity in the assigning of respite hours.

Additionally, there are programs and services in support of the person living with dementia from the Alzheimer Society of Ontario, and more specifically the Alzheimer Society of Sudbury-Manitoulin North Bay and Districts. The Alzheimer Society of Sudbury-Manitoulin North Bay and Districts offers multiple support groups for the person living with dementia as well as the person providing care. The support is much needed but for those with limited respite supports, these too may not be of benefit due to lacking resources to access them. There is also a day program for persons living with dementia that can be accessed as a form of respite to the care provider.

This program is designed to assist in maintaining the strengths of the person living with dementia while also respecting their culture and spiritual beliefs (Alzheimer Society, 2023). This program allows the carer to have time to attend to their own healthcare needs, social needs, or even to continue their employment. The number of daily spaces in this program are limited and they only operate on a Monday to Friday schedule. This program is not offered in any rural area outside of the main centers of Sudbury, Espanola, North Bay, and Sturgeon Falls which highlights the lack of equity in the support of caregivers of persons living with dementia outside of an urban setting. Even those living within the geographical boundaries of an urban setting may not have access due to the limited capacity of these programs. The limited capacity of these day programs is impacted by several factors such as funding, location, and the ability to have proper staffing levels to support a larger number of persons accessing the day programs. There is also private pay for services offered by many for-profit organizations.

In northern Ontario, there are many companies to choose from ranging from small-in-size to large national-level companies. They all provide a range of services that cost from $19.00 per hour to $50.00 per hour that could help some carers in receiving services that are more suitable to their needs. These fees are also charged for drivetime and in a northern Ontario context this could equate to several hours of extra billing per visit and may be financially unfeasible for some carers that are on fixed incomes. The needs of a person living with dementia are an ongoing 24-hour per day, 7-day per week requirement which led to the majority of the participants in this study exhibiting signs of exhaustion.

Their own words lent credence to this observation as many stated they did not sleep, had little time for personal care or interests, constant conflict with siblings, and self-disclosed diagnoses of depression or anxiety. Many still exhibited what appeared to be hypervigilance related to founded and unfounded fears of elopement, negative thoughts, self-doubt, low mood, anxiousness, mental and emotional fatigue, sadness, sorrow, and exhaustion. Many have shared their experiences of caring for a person living with dementia that included their attempts to navigate a convoluted system of services that would aid in the care of the person living with dementia while also supporting their own need for care. While terms such as caregiver burnout have been researched in the past, and these participants all exhibited symptomology consistent with caregiver burnout, they also appear to show indications of experiencing a traumatic event in their life.

A traumatic event is an event or series of events that has caused a lot of stress in a person’s life and are typically viewed with a sense of helplessness, horror, threat of serious injury or death, or serious injury (Centers for Disease Control and Prevention, 2023). How people respond to trauma varies but some may present with feelings of fear, grief, and depression. Physical and behavioral responses include nausea, dizziness, and changes in appetite and sleep pattern as well as withdrawal from daily activities (Centers for Disease Control and Prevention, 2023). Currently, services are provided to the person living with dementia with the opportunity to supplement the services through private contract providers at the carers own expense. However, it would be beneficial that services being provided directly to the carer include a trauma-informed approach.

The Trauma-Informed Care Implementation Resource Centre (2023) provides the six tenets of trauma-informed care as being: safety, trustworthiness and transparency, peer support, collaboration, empowerment, humility, and responsiveness. There is a lack of cohesiveness in the services being provided to informal carers of persons living with dementia, as stated in previous research they are the most vulnerable cohort of carers yet there is little in the way of investment to support their needs in a more collaborative cohesive equitable approach. With a trauma-informed care approach coupled with approaches rooted in positive psychology, mindfulness, Cognitive Behavioural Therapy (CBT), and Acceptance and Commitment Therapy (ACT) there may be a more positive experience possible for informal carers of persons living with dementia.

In the past 40 years, the impact of providing informal care to a person living with dementia has not abated. The phenomena of providing care to a person living with dementia has grown exponentially with the identified growth in cases; this too will only grow with the anticipated three-fold growth in diagnoses of persons living with dementia worldwide (World Health Organization, 2017) and the 30% growth in northern Ontario (Whitehouse, 2012). However, more research needs to be conducted in this area as society moves steadily into a post-pandemic reality where services were reduced for carers of persons living with dementia. There was a direct correlation between the reduction in access to services and a decrease in the number of diagnoses of dementia (Liu et al. 2021). There should also be more research into the use of technology, similar in scope of a study conducted by Ault et al., (2020), where they tested the effectiveness of the Night-time Wandering Detection and Diversion system, which could potentially support informal carers in their role. There would also be the need for education to be provided to the carer as technology itself can lead to some added stress despite the overall identified benefit.

Limitations of the Study

My research study sought to explore the experiences of providing informal care to a loved one diagnosed with a dementia and as with any research study, there are limitations. The research focused on the caregiver — and not the person living with dementia — that included 10 female participants. There were no male participants included in the study and this was not by design but could be due to several factors such as generational, indicative of women in society providing the majority of care, the lack of comfort in sharing their experiences, and could also be related to the time constraints of the study itself. The study was limited in representing a diverse sample of participants, with the sample comprised of two Indigenous women and the remaining sample identifying as white. All participants identified as being in heterosexual dyads.

The setting for this research study was exclusive to northern Ontario by design which may have limited the diversity of the participants when considering gender, ethnicity, and socioeconomic status. For the qualitative approach of the study, the sample size was adequate, but a larger scale study could be realized. There was no focus on spirituality, religion, or belief systems as a means of support for the carer during their caregiving experience, and perhaps if I had asked questions about this, discussion would have occurred in this area.

Implications for Social Work Practice

The population in Canada is aging, and there is a need for social workers that are well-trained in the needs of carers. It will be important that social workers to be professionally trained in positive psychology, trauma-informed care, and in solution-focused brief therapy approaches and also in mobilizing for broad systemic change. Not only is Canada aging, but there are also areas of the country whose population centers are not as heavily concentrated as others which can lead to a lack of equity in the application of service provision. Advocacy is a core tenet of social work practice and social workers should engage in efforts to address system change as it relates to the role of a caregiver.

Social workers have a long history of advocacy for change both for the profession of social work and social service work which in turn is of benefit for the communities serve. Examples of this can be found in the establishment of the Social Work and Social

Service Work Act and most recently, the successful advocacy campaign that allows for Registered Social Workers to have access to the title, ‘psychotherapist’ (OASW, 2023). Through similar efforts, social workers will not only bring forth necessary change but will also assist with establishing the role of social workers with the public, health agencies, and with federal, provincial, and community governments. Social workers bring a diverse set of skills to their work and their efforts can create positive change.

Social workers need also to participate in the development of programs and services that can deliver quality, timely, and appropriate services to an already burdened system of care; that social workers can also assist in the development of specific tools needed to measure the unique needs of each informal caregiver. There is a place for social work in the care continuum of both private and public services and social workers can be instrumental in facilitating collaboration which can then lead to targeted, comprehensive, and effective service offerings and delivery. This would require an investment by health authorities to embed the practice of social work on equal terms of value and quality within multidisciplinary teams.

Conclusion

There was a profound effect on me that occurred when sitting with the women that participated in this study; listening to their stories and bearing witness to the all-encompassing and pervasive biopsychosocial toll on each of them moved me greatly. Having listened to their words and seeing the sorrow, fatigue, exhaustion in their eyes and their voice, witnessing how some wore it like a cloak of sorrow, I have grown greatly in my empathy, dedication, and desire to support the informal carer of a person living with dementia; to advocate and be the instrument for their voice where needed and necessary. Conducting this study also affirmed my belief in my choice of profession and subsequent field of work; it affirmed that my area of study was valid, is needed, has importance, and is of value.

This study should serve to awaken society to the complexities of providing care to a person living with dementia and its overall impact on the person living with dementia, their informal carer, their broader family, and the community they live within.

In conclusion, the findings of this study have highlighted the importance of hearing the voice behind the care. It challenges us to be mindful of the services created to support carers in their role so that they are scoped according to the needs of these caregivers. With the increasing prevalence of dementia within our communities (Zwaanswijk et al., 2013) and the anticipated 30% growth in northern Ontario over the next 20 years (Whitehouse, 2012) it becomes more imperative for federal, provincial, and municipal government to cohesively collaborate with the public sector, the for-profit sector, the not-for-profit sector as well as the individuals providing the care. It has to become a shared responsibility of our society to support the informal caregivers of persons living with dementia as it leads to a healthier community in many respects including financially, ethically, and morally. With the move to home-based care by governments, and with more than 80% of care for persons living with dementia provided by an informal carer (Alzheimer’s Association, 2023), the current healthcare system is not positioned to meet the growing needs of over-burdened — and underserved — caregivers. This is a situation that is becoming more apparent in a post-pandemic society where all levels of the healthcare system are overburdened and chronically understaffed. An unknown author wrote, “Everyone has a story to tell… if only someone would listen… if only someone would ask.”

References

Adams, K.B. and Sanders, S., (2004). Alzheimer’s caregiver differences in experience of loss, grief reactions and depressive symptoms across stage of disease. *Dementia,* 3(2), 195-210. doi: 10.1177/1471301204042337

Alfakhri, A.S., Alshudukhi, A.W., Alqahtani, A.A., Alhumaid, A.M., Alhathlol, O.A., Almojali, A.I., Alotaibi, M.A., Alaqeel, M.K., (2018). Depression among caregivers of patients with dementia. The Journal of Health Care Organization, Provision, and Financing, 55, 1-6. doi: 10.1177/0046958017750432

Alzheimer’s Association (2010). Alzheimer’s disease facts and figures. *Alzheimer’s & Dementia: The Journal of the Alzheimer’s Association,* 6, 159-194. Retrieved from http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf

Alzheimer Canada (2021). *Defining Dementia by type.* Retrieved from https://alzheimer.ca/sites/default/files/documents/ASC_What-is-dementia-info-sheet_en.pdf

Alzheimer Canada (2010). Defining dementia by type. Retrieved from http://www.alzheimercanada.com/ad_definingdementiabytype.htm.

Alzheimer’s Disease International (2023). World Alzheimer Report 2015: The global impact of dementia: An analysis of prevalence, incidence, costs, and trends. Retrieved from https://www.alzint.org/resource/world-alzheimer-report-2015/

Alzheimer Society (2023). The Health Bistro Day Program. Retrieved from https://alzheimer.ca/sudburymanitoulin/help-support/programs-services/health-bistro-day-program

American Psychiatric Association (2023). The Diagnostic and Statistical Manual of Mental Disorders, fifth edition. Retrieved from https://www.psychiatry.org/psychiatrists/practice/dsm/updates-to-dsm

American Psychological Association (2023). *Anxiety. Retrieved from https://www.apa.org/topics/anxiety*

Argonin, M.E. (2004). Dementia Defined. In D. Carlat, (Ed.)., *Practical guides in psychiatry-Dementia* (pp. 2-14). Philadelphia: Lippincott Williams & Wilkins.

Aronson, J., Neysmith, S.M. (1999). The retreat of the state and long-term care provision: implications for frail elderly people, unpaid family carers and paid home-care workers. In P. Armstrong (Ed.)., *Feminism, political economy, and the state*: *Contested terrain* (pp. 91-123). Toronto,ON: Canadian Scholars' Press. doi: 10.1080/19187033.1997.11675315

Ault, L., Goubran, R., Wallace, B., Lowden, H. and Knoefel, F. (2020). Smart home technology solution for night-time wandering in persons with dementia. *Journal of Rehabilitation and Assistive Technologies Engineering,* 7, 1-8. doi: 10.1177/2055668320938591

Austrom, M. G., Boustani, M., and LaMantia, M. A., (2018). Ongoing medical management to maximize health and well-being for persons living with dementia. *Gerontologist*, 58 (2014), S48-S57. doi: 10.1093/geront/gnx147

Babbie, E. (2007). *The Practice of Social Research*, 11th edition. Belmont, CA: Thomson Higher Education.

Badawoud, A.M., AlQaheeb, Y.K., AlZahrani, S.S., AlGhamdi, R.A., Alanazi, E.A., AlFozan, S.M., AlJafer, N.S., Asiri, I.M., and Alotaibi, F.M. (2023). The Level of Burden among Caregivers of Patients with Alzheimer's Disease in Saudi Arabia. *International Journal of Environment Research and Public Health, 20, 2864-2876.* doi: 10.3390/ijerph20042864

Barnett, A. (2013). Pathways of adult children providing care to older parents. *Journal of Marriage and Family,* 75, 178-190. doi: 10.1111/j.1741-3737.2012.01022.x

Barry, P. and O'Callaghan, C. (2008). Reflexive journal writing. *Nording Journal of Music Therapy*, 17(1), 55-66. doi: 10.1080/08098130809478196

Baumbusch, J., Cooke, H.A., Seetharaman, K., Khan, A., Khan, K.B. (2022) Exploring the Impacts of COVID-19 Public Health Measures on Community-Dwelling People Living With Dementia and Their Family Caregivers: A Longitudinal, Qualitative Study. *Journal of Family Nursing*, 28(3), 183-194. doi: 10.1177/10748407221100284

Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3(2), 77-87. doi: 10.1191/1478088706qp063oa

Bressan, V., Visintini, C. and Palese, A. (2020). What do family caregivers of people with dementia need? A mixed-method systematic review. *Health and Social Care in the Community,* 28, 1942-1960. doi: 10.1111/hsc.13048

Brodaty, H., and Donkin, M. (2009). Family caregivers of people with Dementia. *Dialogues Clinical Neuroscience,* 11, 217-228. doi: 10.31887/DCNS.2009.11.2/hbrodaty

Burton, J. (2011). John Hopkins Medicine: Geriatric Education Centre Consortium – Dementia and Delirium. Retrieved from http://www.hopkinsmedicine.org/gec/series/dementia.html.

Canadian Association of Social Workers (2004). Women’s Income and Poverty in Canada. Retrieved March 10, 2009 from Laurentian University Library Databases.

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada (2010). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.* Retrieved from www.pre.ethics.gc.ca

Centre for Addiction and Mental Health (2010). Cognitive Behavioural Therapy: An information guide. Retrieved from https://www.camh.ca/-/media/files/guides-and-publications/cbt-guide-en.pdf

Centre for Addiction and Mental Health (2023). Cognitive Behavioural Therapy: An information guide. Retrieved from https://www.camh.ca/en/health-info/mental-illness-and-addiction-index/anxiety-disorders

Centers for Disease Control and Prevention (2023). Coping with a Traumatic Event. Retrieved from https://www.cdc.gov/masstrauma/factsheets/public/coping.pdf

Chaston, D., (2010). Younger adults with dementia: A strategy to promote awareness and transform perceptions. *Contemporary Nurse,* 34(2), 221-229. doi: 10.5172/conu.2010.34.2.221

Chene, B. (2006). Dementia and residential placement: A view from the carer’s perspective. *Qualitative Social Work*, 5(2), 187-215. doi: 10.1177/1473325006064257

Chien, L. Y., Chu, H., Guo, J. L., Liao, Y. M., Chang, L. I., Chen, C. H., & Chou, K. R. (2011). Caregiver support groups in patients with dementia: A meta-analysis. *International Journal of Geriatric Psychiatry*, 26, 1089–1098. doi:10.1002/gps.2660

Cohen, G., Russo, M. J., Campos, J. A., and Allegri R. F. (2020). Living with dementia: increased level of caregiver stress in times of COVID-19. *International Psychogeriatrics*, 32(11), 1377-1381. doi: 10.1017/S1041610220001593

Collins, R.N., and Kishita, N. (2019). The Effectiveness of Mindfulness-and Acceptance-Based Interventions for Informal Caregivers of People With Dementia: A Meta-Analysis. *The Gerontologist,* 59(4), e363-e379. doi: 10.1093/geront/gny024

Creswell, J.W. (2009). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*, Third edition, California, USA: SAGE Publications.

Creswell, J.W. (2007). *Qualitative Inquiry & Research Design – Choosing Among Five Approaches,* Second Edition, California, USA: SAGE Publications.

Creswell, J. W. and Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39(3), 124-131. doi: 10.1207/s15430421tip3903_2

Durst, D., (2007). Social Welfare and Social Work Education In Canada: Slipping to the Right. *Journal of Comparative Social Work,* 2, 1-14. doi: 10.31265/jcsw.v2i1.28

Esterberg, K.G., (2002). *Qualitative Methods in Social Research*. Boston, USA: McGraw-Hill.

Farina, N., (2017). Factors associated with the quality of life of family carers of people with Dementia: a systemic review. *Alzheimer's & Dementia,* 13, 572-581. doi: 10.1016/j.jalz.2016.12.010

Fook, J., and Askeland, G.A. (2007). Challenges of Critical Reflection: ‘Nothing Ventured, Nothing Gained.’ *Social Work Education: The International Journal*, 26(5), 520-533. doi: 10.1080/02615470601118662

Giebel, C., Cannon, J., Hanna, K., Butchard, S., Eley, R., Gaughan, A., Komutavelli, A., Shenton, J., Callaghan, S., Tetlow, H., Limbert, S., Whittington, R., Rogers, C., Rajagopal, M., Ward, K., Shaw, L., Corcoran, R., Bennett, K., and Gabbay, M. (2021). Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: a qualitative study. *Aging & Mental Health*, 25(7), 1281-1288. doi: 10.1080/13607863.2020.1822292

Glueckauf, R.L., Stine, C., Bourgeois, M., Pomidor, A., Rom, P., Young, M.E., Massey, A., and Ashley, P. (2005). Alzheimer’s rural care health line: linking rural caregivers to cognitive-behavioral intervention for Depression. *Rehabilitation Psychology*, 50 (4), 346-354. doi: 10.1037/0090-5550.50.4.346

Gomez-Ramiro, M., Fico, G., Anmella, G., Vazquez, Mireia., Sague-Vilavella, M., Hidalgo-Mazzei, D., Pacchiarotti, I., Garriga, M., Murru, A., Parellada, E., Vieta, E., (2021). Changing trends in psychiatric emergency service admissions during the COVID-19 outbreak: Report from a worldwide epicentre. *Journal of Affective Disorders,* 282, 26-32. doi: 10.1016/j.jad.2020.12.057

Government of Canada (2005). National Advisory Council on Aging: Seniors on the margins. Retrieved from Laurentian University Library Databases.

Gross, J. S., Shua-Haim, J. R. (1997). Multi-infarct Dementia: a common form of Dementia associated with cerebrovascular disease. *Geriatrics,* 52, 95-112.

Harris, R. (2006). Embracing Your Demons: An overview of acceptance and commitment therapy. *Psychotherapy in Australia,* 12(4), 70-76. doi: 10.3316/informit.545561433272993

Hays, D.G. and Singh, A.A. (2011). *Qualitative Inquiry in Clinical and Educational Settings.* New York, NY: Guilford Press.

Hesse-Biber, S. (2006). The practice of feminist in-depth interviewing in S. Hesse-Biber and P. Leavy (Eds), The Practice of Qualitative Interviewing (pp. 111-148). Thousand Oaks, CA: Sage

Hughes, T. B., Black, B. S., Albert, M. and Glitin, L., (2014). Correlates of objective and subjective measures of caregiver burden among dementia caregivers: influence of unmet patient and caregiver dementia-related care needs. *International Psychogeriatrics,* 26(11), 1875-1883. doi: 10.1017/S104161021400240

Harris, M.L. and Titler, M.G. (2022) Experiences of Family Caregivers of People with Dementia during the COVID-19 Pandemic. *Western Journal of Nursing Research*, 44(3), 269-278. doi:10.1177/01939459211055773

Ho, C.J., Weitzman, P.L., Xingjia, C. and Levkoff, S. E., (2000). Stress and Service use Among Minority Caregivers to Elders with Dementia. *Journal of Gerontological Social Work.* 33(1), 67-88. doi: 10.1300/J083v33n01_06

Hurtig, M. (1999). *Pay the Rent Or Feed The Kids – The Tragedy And Disgrace of Poverty In Canada.* Toronto, Canada: Thompson Publishing.

Hwang, Y., Connell, L. M., Rajpara, A. R., and Hodgson, N. A., (2021). Impact of COVID-19 on Dementia Caregivers and Factors Associated With their Anxiety Symptoms. *American Journal of Alzheimer's Disease & Other Dementias,* 36, 1-8. doi: 10.1177/15333175211008768

Joppe, M. (2000). *The Research Process*. Retrieved from http://www.ryerson.ca/~mjoppe/rp.htm.

La Fontaine, J., Ahuja, J., Bradbury, N. M., Phillips, S., & Oyebode, J. R. (2007). Understanding dementia amongst people in minority ethnic and cultural groups. Journal of advanced nursing, 60(6), 605-614. doi: 10.1111/j.1365-2648.2007.04444.x

Lester, S. (1999) '*An introduction to phenomenological research*,' Taunton UK, Stan Lester Developments. Retrieved from www.sld.demon.co.uk/resmethy.pdf.

Lewy-Body Dementia Association (2010*). Is it Lewy-Body?* Retrieved from http://www.lbda.org/category/3437&cfid=10457087&cftoken=64968861/what-is-lbd.htm.

Leggett, A., Polenick, C. A., Maust, D. T., & Kales, H. C. (2018). "What hath night to do with sleep?": The caregiving context and dementia caregivers' nighttime awakenings. *Clinical Gerontologist,*41(2), 158-166. doi: 10.1080/07317115.2017.1352057

Liang, J., Aranda, M. and Lloyd, D. A. (2020). Association between Role Overload and Sleep Disturbance among Dementia Caregivers: The Impact of Social Support and Social Engagement. *Journal of Aging and Health,* 0(0), 1-10. doi: 10.1177/0898264320926062

Lincoln, Y.S. & Guba, E.G. (1985). Naturalistic Inquiry. Retrieved from http://www.qualres.org/HomePeer-3693.html.

Mackenzie, C.S., Wiprzycka, U.J., Hasher, L., and Goldstein, D. (2009). Associations Between Psychological Distress, Learning, and Memory in Spouse Caregivers of Older Adults. *Journal of Gerontology: Psychological Sciences,* 64B(6), 742-746. doi: 10.1093/geronb/gbp076

Mayo Health Clinic Staff (2012). *Lewy-Body Dementia*. Retrieved from http://www.mayoclinic.com/health/lewy-body-dementia/DS00795 mayo clinic staff.

McCoyd, J.L.M. and Shdaimah, C.S. (2007). Does Qualitative Social Work Research Produce Salubrious Effects? *Social Work*, 52(4), 340-349. doi: 10.1093/sw/52.4.340

McQuarrie, E.F., and McIntyre, S.H. (1990). "What the group interview can contribute to research on consumer phenomenology." In E.C. Hirshman (Ed.), Research in consumer behavior. Vol. 4, 165194. Greenwich, Conn.: JAI Press.

Merriam, Sharon (1998). *Qualitative research and case study applications in education*. San Francisco: Jossey-Bass.

National Institute of Neurological Disorders and Stroke (2010). *Disorders and Dementias.* Retrieved from http://www.ninds.nih.gov/disorders/Dementias/detail_Dementia.htm.

National Institute of Mental Health (2016). *Depression.* Retrieved from https://www.nimh.nih.gov/health/topics/depression/index.shtml

Neville, C., Beattie, E., Fielding, E. and MacAndrew, M. (2015). Literature review: use of respite by carers of people with dementia. *Health and Social Care in the Community,* 23(1), 51-63. doi: 10.1111/hsc.12095

Nichols, L. O. Martindale-Adams, J., Greene, W.A., Burns, R., Graney, M.J., & Lummus, A. (2009). Dementia caregivers' most pressing concerns. *Clinical Gerontologist*, 32, 1-14. doi: 10.1080/07317110802468546

Ontario Association of Social Workers (2023). Advocacy and Government Relations. Retrieved from https://www.oasw.org/Public/Public/Advocacy_and_Research/Advocacy Government_Relations.aspx?hkey=dd590195-67b2-4d07-a61d-36db698363a8

OECD: The Organization for Economic Cooperation and Development (2005). The OECD Health Project. *Long-term care for older people in Paris.* Retrieved from https://read.oecd-ilibrary.org/social-issues-migration-health/long-term-care-for-older-people_9789264015852-en#page117

Ontario (2010). Aging At Home Strategy, The Kings Printer for Ontario, 2012-2023. Retrieved from https://news.ontario.ca/en/backgrounder/14133/aging-at-home-strategy

Ontario College of Social Workers and Social Service Workers (2008). *Code of Ethics and Standards of Practice handbook.* Ontario College of Social Workers and Social Service Workers. Retrieved from http://www.ocswssw.org/en/code_of_ethics.htm

Peng, H.L., Lorenz, R.A. and Chang, Y.P. (2019). Factors associated with sleep in family caregivers of individuals with dementia. Perspectives in Psychiatric Care, 55(1):95–102. doi: 10.1111/ppc.12307

Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: Which interventions work and how large are their effects? International Psychogeriatrics, 18, 577–595. doi:10.1017/S1041610206003462

Pokharel, B. (2009). Concept Mapping in Social Research. *Tribhuvan University Journal*, 26 (1), 1-6. doi: 10.3126/tuj.v26i1.2609

Posner, B., Sutter, M., Perrin, P.B., Ramirez Hoyos, G., Arabia Buraye, J. and Arango-Lasprilla, J.C. (2015). Comparing Dementia caregivers and healthy controls in mental health and health related quality of life in Cali, Colombia. *Psicologia desde el Caribe,* 32, 1-26. doi: 10.14482/psdc.32.1.6273.

Ray, S. (2012). *Ethics Defined*. Retrieved from http://bowvalleycollege.ca/about-bvc/applied-research-and-evaluation/research-ethics-board-(reb).html

Reed, C., Belger, M., Andrews, S.J., Tockhorn-Heidenreich, A., Jones, R.W., Wimo, A., Dodel, R. and Haro, J.M. (2020). Factors associated with long-term impact on informal caregivers during Alzheimer’s disease dementia progression: 36-month results from GERAS. *International Psychogeriatrics,* 32(2), 267-277. doi: 10.1017/S1041610219000425

Roach, P., Zwiers, A., Cox, E., Fischer, K., Charlton, A., Josephson, C. B., Patten, S.B., Seitz, D., Ismail, Z. and Smith E. E. (2021). Understanding the impact of the VOCID-19 pandemic on well-being and virtual care for people living with dementia and care partners living in the community. Dementia, 20(6), 2007-2023. doi: 10.1177/147130122097639

Roger, D., Neill, M.O., and Nugent, L., (2015). Informal carers' experiences of caring for older adults at home: a phenomenological study. *British Journal of Community Nursing.* 20(6). 280-285. doi: 10.12968/bjcn.2015.20.6.280

Ryoo, N., Pyun, J-M., Baek, M. J., Suh, J., Kang, M. J., Youn, Y. C., Yang, D. W., Kim, S. Y., Park, Y. H. and Kim, S. (2020). Coping with Dementia in the Middle of the COVID-19 Pandemic. *Journal of Korean Medical Science,* 35(42), 1-21. doi: 10.3346/jkms.2020.35.e383

Schwandt, T. (2007). *The Sage dictionary of qualitative inquiry*. Third edition. Thousand Oaks, CA: SAGE Publications.

Shaji, K.S., George, R.K., Prince, M., and Jacob, K.S. (2009). Behavioral symptoms and caregiver burden in Dementia. *Indian Journal of Psychiatry*. 51, 45-49. doi: 10.4103/0019-5545.44905

Shanley, C., Boughtwood, D., Adams, J., Santalucia, Y., Kyriazopoulos, H., Pond, D., and Rowland, J., (2012). A qualitative study into the use of formal services for dementia by carers from culturally and linguistically diverse (CALD) communities. *BMC Health Services Research,* 12, 354-365. doi: 10.1186/1472-6963-12-354

Smyth, A., Whitehead, L., Quigley, E., Vafeas, C. and Emery, L. (2020). Disrupted sleep and associated factors in Australian dementia caregivers: a cross-sectional study. *BMC Geriatrics,* 312, 1-7. doi: 10.1186/s12877-020-01726-1

Srivastava, G., Tripathi, R.K., Tiwari, S.C., Singh, B., Tripathi, S.M. (2016). Caregiver burden and quality of life of key caregivers of patients with Dementia. *Indian Journal of Psychological Medicine.* 38(2). 133-136. doi: 10.4103/0253-7176.178779

Statistics Canada (2000). Crime Statistics. *The Daily.* Retrieved from http://www.statcan.ca/Daily/English/050721/d050721a.htm

Statistics Canada (2005). *Family Violence in Canada: A Statistical Profile 2005. Canadian Centre for Justice Statistics.* Catalogue No. 85-224-XIE. Retrieved from http://www.statcan.ca/cgi-bin/downpub/listpub.cgi?catno=85-224-XIE2005000.

Statistics Canada (2006).What's urban? What's rural? Retrieved on August 21, 2015. http://www41.statcan.ca/2006/3119/ceb3119_002-eng.htm

Statistics Canada (2011). From urban areas to population centers. Retrieved on August 21, 20015. http://www.statcan.gc.ca/subjects-sujets/standard-norme/sgc-cgt/notice-avis/sgc-cgt-06-eng.htm

Truzzi, A., Valente, L., Ulstein, I., Engelhardt, E., Laks, J., and Engedal, K. (2012). Burnout in familial caregivers of patients with Dementia. *Official Journal of the Brazilian Psychiatric Association.* 34(4), 405-412. doi: 10.1016/j.rbp.2012.02.006

Tulloch, K., McCaul, T. and Scott, T.L. (2022). Positive Aspects of Dementia Caregiving During the COVID-19 Pandemic. *Clinical Gerontologist,* 45(1), 86-96. doi: 10.1080/07317115.2021.1929630

Varik M, Medar M, Saks K. (2020). Informal caregivers' experiences of caring for persons with dementia in Estonia: a narrative study. *Health & Social Care in the Community*. 28(2), 448–455. doi: 10.1111/hsc.12877

Veterans Affairs Canada (2010). *Definition of Dementia.* Retrieved from http://www.vac-acc.gc.ca/clients/sub.cfm?source=health/Dementia.

Wang, S., de Almeida Mello, J., Declercq, A. (2021) Assessing psychosocial interventions for informal caregivers of older people with early dementia: a systematic review of randomized controlled evidence. *Frontiers in Bioscience-Landmark,* 26(9), 556-571. doi: 10.52586/4967

Weitzman, P.F., and Levkoff, S.E. (2000). Combining qualitative and quantitative methods in health research with minority elders: lessons from a study of dementia caregiving. *Field Methods*, 12(3), 195-208. doi: 10.1177/1525822X000120030

Whitehouse, M. (2012, March 26). dementia to Rise Dramatically in Sudbury: Report. The Sudbury Star. Retrieved from http://www.thesudburystar.com/ArticleDisplay.aspx?e=3514911.

Whitlatch, C. J., Judge, K., Zarit, S. H., & Femia, E. (2006). Dyadic intervention for family caregivers and care receivers in early stage dementia. The Gerontologist, 46, 688–694. doi:10.1093/geront/46.5.688

Wolff, J. L., Spillman, B. C., Freedman, V. A., & Kasper, J. D. (2016). A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Internal Medicine*, 176(3), 372. doi: 10.1001/jamainternmed.2015.7664

World Health Organization. (2020, March 11). WHO Director-General’s opening remarks at the media briefing on COVID-19–11 March 2020. Retrieved from https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-atthe-media-briefing-on-covid-19---11-march-2020

World Health Organization (WHO) (2017). *Global action plan on the public health response to Dementia 2017-2025.* WHO Document Production Services. Retrieved from https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-Dementia-2017---2025

Zwaanswijk, M., Peeters, J.M., van Beek, A.P., Meerveld, J.H., and Francke, A.L. (2013). Informal caregivers of people with dementia: problems, needs and support in the initial stage and in the subsequent stages of dementia: a questionnaire Survey. *The Open Nursing Journal*, 7, 6-13.

Appendix A

Letter of Introduction for Directors/Directors of Care

Study Title: What is the psychosocial impact on the caregiver providing care to a loved one diagnosed with dementia?

Investigator: Robin Cheslock, M.S.W. Student

Supervisors: Dr. Diana Coholic and Dr. Leigh MacEwan, School of Social Work

As part of my M.S.W. studies at Laurentian University, I am proposing a qualitative research study to examine the psychosocial impact of being a caregiver to a loved one diagnosed with dementia. I am conducting this study to learn more about this question since it has not been studied much in the past and it's important to know people's experiences of caregiving. This study may assist community agencies, family doctors and health care professions with the design and availability of services for caregivers. In turn this may benefit the caregiver through the enhanced services that may be realized. The Laurentian University Research Ethics Board has approved this study.

I am hoping to recruit l0 participants to participate in a one-hour individual interview. The interviews will take place in a location of the participant's choosing or another location such as the Community Room at the Sudbury-Manitoulin Alzheimer's Society or the Quite Room at St. Joseph's Villa. I am asking you to help with recruiting by

(1) posting the Research Recruitment Poster on the Family Council bulletin board;

(2) posting the Research Recruitment Poster on the Resident Council bulletin board;

(3) allowing the distribution of the Research Recruitment Poster during group sessions where applicable.

When the study has been completed, I will prepare a summary of the research findings for those who participate. As the results of this study may be helpful to other social workers and health care professionals, I would also like to present the research findings at academic, community or gerontology conferences, and I may also want to publish the results in academic journals.

If you have any questions or require additional clarification, you may contact me at 705-918-XXXX or via email ra_cheslock@laurentian.ca

Sincerely,

Robin Cheslock, M.S.W. Student

School of Social Work, Laurentian University

Appendix B

LaurentianUniversity
UniversitéLaurentienne

RESEARCH RECRUITMENT POSTER

My name is Robin Cheslock and I am graduate student at Laurentian University School of Social Work. I am currently conducting research as a partial requirement for my Master of Social Work program.

The purpose of this study is to examine the psychosocial impact on caregivers when providing care to a loved one diagnosed with dementia.

My study requires the participation of people in the role of a caregiver providing care to a loved one diagnosed with dementia. Your participation in the study is valuable to other caregivers and the Greater Sudbury community as a whole.

This study may assist community agencies, family doctors and other professions with the design and availability of services for caregivers. In turn this may benefit you, the caregiver, through the enhanced services that may be realized.

This study will require approximately 1 to 1 ½ hours of your time to complete a one-to-one interview with me. Your responses and identity will be protected throughout the study and beyond.

If you, or someone you know, would be interested in participating in this much-needed research please contact me for further information.

Respectfully,

Robin Cheslock, RSW
Graduate Student
School of Social Work
Laurentian University

(705) 918-XXXX
Or email
ra_cheslock@laurentian.ca

Appendix C

LaurentianUniversity
UniversitéLaurentienne

LETTER OF INTRODUCTION FOR PARTICIPANTS

My name is Robin Cheslock and I am a Graduate Student in the School of Social Work at Laurentian University. Thank you for your interest in participating in my study that is looking to explore **The Psychosocial Impact on Caregivers of Persons with Dementia**. This is a qualitative study which means that you are able to relate your experiences as a caregiver in your own words.

If you decide to volunteer to participate in this study, for the most part the study will be directed by you, the caregiver, through the sharing of your experiences as a caregiver to a loved one with dementia. I would ask that you take part in one individual interview that will last for about an hour and a half. This interview will be in a place of your choosing.

Although this study is a partial requirement of my M.S.W. studies at Laurentian University School of Social Work the intended purpose of this study may assist agencies, counselors and other professions in the design and provision of service to caregivers of persons with dementia. Other caregivers of persons with dementia may also benefit from your experiences. When the study is complete, I will prepare a summary of the research findings and send it to you, if you want.

If you decide to participate, your confidentiality and anonymity will be protected at all times. I will not reveal who participates in this study nor what they have said during the interviews. I will not use your name at any time and, when I share information about the research, I will do so in such a way that you could never be identified.

If you have any questions about the study, or if you are interested in participating in this study, you can contact me at (705) 918-XXXX or email

ra_cheslock@laurentian.ca

I look forward to working with you,

Respectfully,

Robin Cheslock, RSW
Graduate Student
School of Social Work - Laurentian University

Appendix D

LaurentianUniversity
UniversitéLaurentienne

Consent Form

Study Title: What is the psychosocial impact on the caregiver providing care to a loved one diagnosed with dementia?

Investigator: Robin Cheslock, M.S.W. Student

Supervisors: Dr. Diana Coholic and Dr. Leigh MacEwan, School of Social Work

Thank you for participating in this study.

Before agreeing to participate in this research, we need to read, and agree with, the following explanation of this study. This statement describes the purpose and procedures of the study. Also described is your right to withdraw from the study at any time. This study has been approved by the Laurentian University Research Ethics Review Board.

Explanation of Process

This study is designed to examine the psychosocial impact of being a caregiver to a loved one diagnosed with dementia. I am conducting this study to learn more about this experience so that effective services and supports can be offered.

Participation in the study involves completion of a demographic questionnaire that asks you basic questions about yourself and a face-to-face individual interview; the face-to-face interview will last for approximately one to one and a half hours. The interviews will be conducted by me, the researcher, audio-taped and later transcribed (typed out) for the purpose of data analysis. I will interview you in the comfort of your home or in an alternate location such as the offices of the Alzheimer’s Society Sudbury-Manitoulin or in the Quiet Room of St. Joseph’s Villa Sudbury.

Risks and Discomforts

Potential risks or discomforts include possible emotional feelings that arise due to our conversation, such as sadness or stress. Should this occur and should you wish to talk to someone after our interview, I will provide you with a community resource list. Also, you could speak with the Chaplain or Social Worker at the long-term care home where your loved one currently resides.

Benefits

The anticipated benefit of participation is the opportunity to discuss feelings, perceptions, and concerns related to the experience of providing care to a loved one diagnosed with dementia, and to contribute to a better understanding of the psychosocial impact this role has on caregivers.

Confidentiality

The information gathered during this study will remain confidential in secure premises during this project. Only I, the researcher, along with my two supervisors, will have access to the study data and information. There will not be any identifying names on the interview transcripts. Your name and any other identifying details will never be revealed in any publication of the results of this study. The tapes will be destroyed 5 years after the completion of the study. The results of the research will be published in the form of a research paper and may be published in a professional journal or presented at professional meetings. The knowledge obtained from this study may help guide community agencies and other professionals to be more effective in service policy, design and delivery; thus, the findings are important to share with others.

Withdrawal without Prejudice

Participation in this study is strictly voluntary; refusal to participate will involve no penalty whatsoever. You are free to withdraw consent and discontinue participation in this project at any time without prejudice or penalty. You are also free to refuse to answer any question I might ask you.

Further Questions and Follow-Up

You are welcome to ask me any questions that occur to you during the interview. If you have further questions once the interview is completed, you are encouraged to contact me using the contact information given below. If, as a result of participating in this study you feel the need for further, longer-term support, you are welcome to contact Janet Bradley at 705-688-XXXX.

If you have other questions or concerns about the study please contact Dr. Jean Dragon in the Research Office at Laurentian University at (705) (705) 675-1151 ext. 3213 or, via e-mail, at JDragon@laurentian.ca. You can also contact my two supervisors at: Diana Coholic, 705-675-1151, 5053, dcoholic@laurentian.ca, or Leigh MacEwan, 705-675-1151, 5059, lmacewan@laurentian.ca.

By signing this form, you are indicating that you have read this form and agree to participate in this project.

I, ____ (name; please print clearly), have read the above information. I freely agree to participate in this study. I understand that I am free to refuse to answer any question and to withdraw from the study at any time. I understand that my responses will be kept anonymous.

____ ______________________

Participant Signature Date

Witness

If:

(a) you would like a copy of your interview transcript once it is available;
(b) you are interested in information about the study results as a whole; and/or
(c) you would be willing to be contacted again in the future for a possible follow-up interview,
please provide contact information below:

Check those that apply:

____ I would like a copy of my interview transcript

____ I would like information about the study results

____ I would be willing to be contacted in the future for a possible follow-up interview

Write your address clearly below. Please also provide an email address if you have one.

Mailing address: Email address:

Appendix E

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DEMOGRAPHIC QUESTIONNAIRE

Name of Participant: Address:

Age of Participant:

Marital Status: Phone Number(s):

Length of Relationship: ______years
Employment Status: Type of Employment:

Income Level: under $20 000 $20001 - $35000 $35001 - $50000 over $50000
(circle one)

Relationship to care recipient:

Are you the primary caregiver of your loved one? YES / NO

Do you have children/grandchildren/great grandchildren? YES / NO

Appendix F

SEMI-STRUCTURED INTERVIEW GUIDE

What has this caregiver journey been like for you as the caregiver of a person with dementia?

Since diagnosis what has been the response from family and friends;

Has there been an impact in your personal health related to the role as a caregiver; and

If you work outside the home, has there been an impact to your work related to the role as a caregiver?

Responsive Behaviors:

These are behaviors such as wandering, leaving home, repetitive questions, striking out, shouting, refusing care (such as bathing, eating, medication) or crying:

Have you experienced any responsive behaviors during the provision of care?

How prepared were you to manage the responsive behaviors?

What type of supports, if any, did you access to assist in the management of these responsive behaviors?

Quality of Life:

How has your caregiving experience influenced your current living arrangements?

Has your caregiving experience prevented your participation in any activities?
- Dining out?
- Attending movies?
- Family gatherings?
- Holiday celebrations?

Appendix G

Community Resources

Providing care to a person with dementia can lead to numerous feelings; feelings such as stress or frustration can be experienced when providing care. These feelings can come upon a person at any time; this is especially true when people discuss their personal caregiving experience(s). I have prepared a list of community resources that may be helpful if this should happen to you during the course of the study. I have also arranged for a counselor, Janet Bradley, to be available if you would want that form of service.

Community Resources

Alzheimer’s Society – Sudbury Manitoulin District	(705) 560-0603
Health Sciences North - Crisis Intervention	(705) 675-4760
211 Ontario (Provides information & referrals to community & social services in Ontario)	2-1-1
Community & Family Services (Salvation Army)	(705) 566-8151

Counselor

Janet Bradley, M.S.W. (705) 688-XXXX