Understanding Experiences and Support Needs of Families Caring for Older Adults with Depression

by

Chen Wang

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Rehabilitation Sciences Institute
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Abstract

**Background:** The experiences and needs of caregivers of older adults with depression are not well understood. This study aims to explore their experiences and desired resources from the healthcare system.

**Methods:** Eleven qualitative interviews were conducted with caregivers of older adults with a clinical depression diagnosis in Toronto, Canada. Findings were generated via thematic analysis.

**Findings:** Caregivers perceived a transformation in the person with depression’s behaviours and personality that also changed the relationship between them. Caregivers modified their lifestyle, perceived stigma towards their love one related to depression, and experienced declines in their own well-being. Caregivers’ personal and external resources helped with caregiving role and additional resources are needed from the healthcare system.

**Conclusion:** There is an immediate need for increased healthcare resources for older adults with depression and their family members. This study provides insight for clinicians and policy makers to implement resources to optimize the caregiving role.
Dedication

To Anderson, you angel, rest in paradise. And to everyone that is battling with mental illness –
you are not alone.
Acknowledgements

I would like to extend my greatest appreciation to the caregivers that participated in this study. Thank you for trusting me with your stories as many of them were incredibly heart-wrenching to tell – but need to be heard. Thank you for your time and your vulnerability, we will make a difference in mental health. Thank you Baycrest Health Sciences and staffs for connecting us.

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## Table of Contents

Acknowledgements ........................................................................................................ iv
Table of Contents ........................................................................................................... v
List of Tables ................................................................................................................... vii
List of Figures ................................................................................................................ viii
List of Appendices ......................................................................................................... ix
List of Abbreviations, Symbols, and Nomenclature ..................................................... x

**CHAPTER ONE: Family Caregivers of Older Adults with Depression and Factors Associated with their Well-being and Caregiving Needs** ........................................... 1

1.1. Introduction: An Aging Population ........................................................................ 2
1.2. Depression in Older Adults .................................................................................... 2
1.3. Role of Family Caregivers ...................................................................................... 4
1.4. Pearlin’s stress process model .................................................................................. 6
1.5. Experiences of caregivers of adults with depression .............................................. 8
1.6. Focus of thesis ........................................................................................................ 17

**CHAPTER TWO: Qualitative Design, Methodology and Research Questions** ............. 19

2.1. Outline .................................................................................................................. 20
2.2. Research Design .................................................................................................. 20
2.3. Participants .......................................................................................................... 21
2.4. Recruitment ......................................................................................................... 22
2.5. Data Collection ..................................................................................................... 23
2.6. Data Analysis ....................................................................................................... 25
2.7. Ethical Considerations .......................................................................................... 25

**CHAPTER THREE: Manuscript - “Understanding experiences and support needs of families caring for older adults with depression”** ..................................................... 29
1. Introduction ...........................................................................................................................................31
2. Methodology .......................................................................................................................................32
3. Results ..................................................................................................................................................34
4. Discussion ...........................................................................................................................................51

CHAPTER FOUR: Discussion, Limitations and Conclusion ..............................................................55
4.1. Discussion .......................................................................................................................................56
4.2. Limitations .....................................................................................................................................60
4.3. Conclusion ......................................................................................................................................61

References .............................................................................................................................................62
Appendices .............................................................................................................................................70
List of Tables

Table 2.1 – Sample Interview Guide ................................................................. 25

Table 3.1 – Demographic characteristics of caregivers ................................... 34
List of Figures

Figure 1.1 – Stress process model by Pearlin and colleagues (1990) ........................................ 6
List of Appendices

Appendix A: Consent Form........................................................................................................70
Appendix B: Recruitment Script............................................................................................73
Appendix C: Eligibility Checklist..........................................................................................74
Appendix D: Interview Guide..................................................................................................75
### List of Abbreviations, Symbols, and Nomenclature

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL</td>
<td>Activities of daily living</td>
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<tr>
<td>IADL</td>
<td>Instrumental activities of daily living</td>
</tr>
<tr>
<td>MDD</td>
<td>Major depressive disorder</td>
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<tr>
<td>PDD</td>
<td>Persistent depressive disorder</td>
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<tr>
<td>PWD</td>
<td>Person with depression</td>
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<tr>
<td>SPM</td>
<td>Stress process model</td>
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<tr>
<td>YLDS</td>
<td>Years lived with disability</td>
</tr>
</tbody>
</table>
CHAPTER ONE

Family Caregivers of Older Adults with Depression and Factors Associated with their Well-being and Caregiving Needs
1.1. Introduction: An Aging Population

As life expectancy continues to increase, a larger population is transitioning into old age. World Health Organization estimates our older adult population (i.e., individuals 65 years of age and older) will nearly double globally (from 12% to 22%) in the next 35 years (World Health Organization, 2017b). Currently, Canada has a higher proportion of older adults than the global average (16.1%) (Statistics Canada, 2015). With increasing life span and baby boomers reaching retirement age, the percentage of older adults in Canada is projected to surpass 20% by 2024 (Statistics Canada, 2015).

With the growing proportion of older adults in society, a greater proportion of individuals are likely to develop physical and psychological illnesses associated with disability and functional limitations (Angel & Angel, 2006; Arim, 2015). As well, aging and various age-related illnesses (e.g., dementia, cancer and stroke) often limit a person’s ability to perform activities of daily living (ADL) and instrumental activities of daily living (IADL) (Canning, Ada, Adams, & O’dwyer, 2004; Hewitt, Rowland, & Yancik, 2003; Tyson, Hanley, Chillala, Selley, & Tallis, 2006). ADL are personal maintenance tasks that are performed daily (e.g., bathing and toileting) and IADL are household maintenance tasks that support an independent lifestyle (e.g., cooking and managing medication) (Wolinsky et al., 2011). In Canada, 33.2% of older adults reported having a disability in 2012, and the prevalence increases steadily with age (Statistics Canada, 2013). Furthermore, individuals age 65 and older are more likely to develop one or more chronic illnesses, and a quarter of older adults reported having at least four chronic conditions (Statistics Canada, 2013). Age-related needs are the most common (28%) reasons that older adults require assistance, followed by cancer (11%), cardiovascular disease (9%) and mental illness (7%) (Sinha, 2013).

1.2. Depression in Older Adults

Following dementia, depression is the second most prevalent mental illness among older adults (World Health Organization, 2017a). Depression affects approximately 7% of older adults worldwide, and 15% of older adults experience clinically significant depressive symptoms (Fiske, Wetherell, & Gatz, 2009). Depression is believed to be underdiagnosed and undertreated in all ages (Takayanagi et al., 2014; World Health Organization, 2017a, 2017b), and older adults are more likely to underreport depressive symptoms than other age groups (Lyness et al., 1995).
In addition, several studies have demonstrated that over half of late-life depression cases are first onsets, including Brodaty and colleagues (2001) at 52% and Bruce and colleagues (2002) at 71%.

The most common depression diagnoses are major depressive disorder (MDD) and persistent depressive disorder (PDD, replaced dysthymic disorder in DSM-V), and the prevalence of MDD and PDD in North American older adults are approximately 2.6% (Østbye et al., 2005) and 2% (Devanand, 2014), respectively. MDD is a form of severe depression that is characterized by depressive mood and/or loss of interest or pleasure in activities over a two-week period or longer, accompanied by other depressive symptoms (e.g., fatigue or loss of energy, weight change, or sleep pattern disturbance) (Cole, McCusker, Sewitch, Ciampi, & Dyachenko, 2008). In contrast, PDD is characterized by a regularly low mood for over two years with less severe or fewer depressive symptoms than MDD (Devanand, 2014). In some cases, individuals can be diagnosed with both MDD and PDD, also known as double depression, which is prevalent in approximately a quarter of MDD cases (Katz, Robins, Scheftner, & Robert, 1982; Keller, Lavori, Endicott, Coryell, & Klerman, 1983).

Depression is the second leading cause of disability worldwide (Ferrari et al., 2013). According to the 2010 Global Burden of Disease study, MDD and dysthymia accounted for 8.2% and 1.4% of global years lived with disability (YLDs), respectively. YLDs is a measurement of the burden of disease that is calculated using the prevalence and loss of health associated with an illness. Depression can impact many facets of an individual’s life, including employment, social life, leisure activities and relationships with family (World Health Organization, 2017a). In worst cases, depression can lead to suicide, as depression was found in 60% of suicide victims (Cavanagh, Carson, Sharpe, & Lawrie, 2003; Lesage et al., 1994).

Older adults with depression have distinctive risk factors, symptoms, and consequences that are detrimental to their well-being. Depression is a leading complication that is frequently associated with chronic and other medical illnesses that are common in the aging population. For instance, prevalence estimates of MDD are much higher in individuals suffering from cardiovascular disease (20-25%) (Carney & Freedland, 2003), Type II diabetes (15%) (C. Li, Ford, Strine, & Mokdad, 2008) stroke (20-25%) (Park et al., 2007), Parkinson’s disease (15-20%) (Reijnders, Ehrt, Weber, Aarsland, & Leentjens, 2008) and Alzheimer’s disease (40%) (Alexopoulos, 2005;
Schweitzer, Tuckwell, O'Brien, & Ames, 2002) compared to the general older adults (1-5%) (Hasin, Goodwin, Stinson, & Grant, 2005). In addition, older adults often encounter stressful life events that are likely to contribute to depression. For example, older adults experiencing bereavement are three times more likely to develop depression (Cole & Dendukuri, 2003). Other stressful life events include physical and mental deterioration, activity reduction and financial burden following retirement (Fiske et al., 2009). On average, older adults are less physically active and more likely to be retired and socially isolated (Alexopoulos, 2005; Fiske et al., 2009). Depression’s disabling effect on an older adult’s daily functioning is higher than many chronic medical conditions, including lung disease, hypertension, and diabetes (Noël et al., 2004), and it often causes sleep disturbance (Cole & Dendukuri, 2003), alienation of social support (Hammen, 1991), increased mortality and chance of suicide (Conwell, Duberstein, & Caine, 2002) and poor adherence to treatment for depression and other medical conditions (Fiske et al., 2009). Besides lower mood and unstable emotions, older adults that are suffering from depression often report a cognitive decline, including poor memory and concentration and slower cognitive processing speed (Butters et al., 2004).

Depression is a prevalent mental illness affecting many older adults. The combination of age and depressive symptoms create unique difficulties for the person with depression (PWD) and their family members who are providing support. The following section will discuss the existing literature on family caregivers.

1.3. Role of Family Caregivers

The need for informal caregivers is concurrently growing with the aging population. Informal caregivers are defined as individuals who assist patients without financial compensation, often friends or family members (hereafter referred to as caregivers.). According to the 2012 General Social Survey, nearly half of Canadians (46%) aged 15 or older have provided or is providing assistance to a family member or friend with a long-term health condition, disability or aging needs (Sinha, 2013). The majority of family caregivers for the frail elderly are spouses (38.4%) and adult children (41.3%) (Wolff & Kasper, 2006), and women represented the slight majority of family caregivers in Canada at 54% (Sinha, 2013). The majority (60%) of caregivers are working in a paid position in Canada (Sinha, 2013).
Family members often assume the caregiver role and responsibilities of older adults, and the majority of older adults that reside in the community rely on them for assistance with ADL and IADL (Smith & Smith, 2000). Older adults with functional limitations may require a wide range of supports. Providing transportation and doing household chores are performed by over half of caregivers (Smith & Smith, 2000), while coordinating appointments, managing finances, helping with medical treatment and providing personal care are also common activities among Canadian caregivers. In 2009, family members’ unpaid care for older adults was estimated to save the Canadian healthcare system $25 to $26 billion (Hollander, Liu, & Chappell, 2009). Caregiver demand is expected to increase as more individuals transition into old age, and the role often affects multiple aspects of caregivers’ daily lives.

Caregivers are often required to adjust their lifestyle to fulfill their caregiving duties. In Canada, 10% of caregivers devote 30 hours or more offering assistance (Sinha, 2013). In these more time demanding cases, caregiving becomes close or equivalent to a full-time job, and caregivers commonly reduced their time spent on leisure activities and time with friends and other family members (Beesley et al., 2011; Cameron, Cheung, Streiner, Coyte, & Stewart, 2006; Cameron, Franche, Cheung, & Stewart, 2002; Pearlìn, Mullan, Semple, & Skaff, 1990; Periard & Ames, 1993). As well, caregivers’ career growth is often disrupted by caregiving responsibilities, as they are more likely to turn down promotions, retire early, and take more time off to fulfill their caregiving duties (Fast, Keating, Lero, Eales, & Duncan, 2013). In addition, studies have suggested that the lower well-being and depression commonly observed in caregivers are associated with reduced employment productivity (Lamb et al., 2006; Simon et al., 2001), which can further impede their career trajectory.

Therefore, in collaboration with a librarian from Toronto Rehabilitation Institute, a narrative literature review on the topic of caregivers of adults with depression was conducted. A search of caregivers of older adults with depression yielded a limited number of articles so the search was expanded to caregivers of adults with depression. The quality of the studies was not examined as the goal was to gain a better understanding of the available research in this field. Past literature on caregiving suggested factors that influence caregiver well-being are complex, and a theoretical model may assist in delineating their experiences. The following section will introduce Pearlìn’s stress process model (SPM) and its use in guiding caregiving research.
1.4. Pearlin’s stress process model

Pearlin’s SPM has demonstrated its effectiveness in providing a comprehensive assessment of factors that influence caregiver outcomes (Pearlin, 1999; Pearlin et al., 1990). The model was originally created by examining factors that affect well-being in caregivers of Alzheimer’s patients’, and its framework and components have since being tested in a variety of populations, such as cancer (Fletcher, Miaskowski, Given, & Schumacher, 2012; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Schumacher et al., 2008) dementia (Haley et al., 2003; Judge, Menne, & Whitlatch, 2010; Son et al., 2007), stroke (Cameron et al., 2006; Schreiner & Morimoto, 2003) and organ transplant (Bolden & Wicks, 2008). SPM provides a conceptual representation of the interactions between each component (Pearlin et al., 1990). The components and their relationships are illustrated in Figure 1.1.

Figure 1.1 – Stress process model by Pearlin and colleagues (1990). The model aims to understand factors that are associated with caregiver well-being; it consists of background and context, stressors, mediators and outcomes.

SPM identified three major domains (i.e., background and context, stressors, mediators) that affect caregiver outcomes (Pearlin et al., 1990). SPM defines caregiver outcomes to include caregivers’ physical (e.g., limitations in their ability to engage in usual activities) and mental
(e.g., depression, anxiety, cognitive disruption) health. Background and context describe the caregiver’s environment (e.g., family composition) as well as their demographic characteristics and ascribed statuses (e.g., level of education, racial minority) that may affect stressors and caregiver outcomes. Stressors are defined as conditions, experiences, and activities that are potentially problematic for the caregiver (e.g., IADL dependencies). Stressors encompass the nature of the patient’s illness and tasks performed by the caregiver to meet illness’s demands. Mediators are factors that explain why caregivers are exposed to similar stressors but are affected by them in dissimilar ways (e.g., coping strategies, social supports). Thus, the same stressors can affect each caregiver’s well-being differently depending on the mediators available.

The present study adopted Pearlin’s SPM to guide literature organization and data collection. The model was chosen because it has been widely cited in various caregiving populations and has shown robust findings (e.g., establishing associations) across studies. As well, Pearlin’s SPM has identified many factors that are associated with caregiver well-being. The present study will consider items from context and background, stressors and outcomes when examining caregiver’s experiences, and consider items from mediators when examining caregiver’s resources and support needs.

For the present study, we adapted the model to enhance the simplicity and relevance to current related research. Firstly, primary and secondary stressors are collapsed into stressors. The terms primary and secondary are used to indicate the temporal order in which the stressors occur rather than their importance, and past studies have used quantitative measurements to examine their associations between one another and caregiver outcomes (Pearlin et al., 1990). However, the present study applied a qualitative approach, and the aim was to identify the stressors rather than examining their associations with each domain. Secondly, mastery, or the sense of control the caregiver feels they have in their life or caregiving, was moved from the stressor to mediator domain. Pearlin’s SPM considered mastery as a stressor when it is diminished in a caregiver. However, past studies have found that mastery was associated with a reduction in caregiver stress (Gaugler et al., 2005; Mausbach et al., 2012), suggesting its positive effects on caregiver well-being and its potential fit as a mediator rather than a stressor. Lastly, stigma, or the negative perception and attitude, was added as a stressor due its prevalence in mental illness and negative effects on caregiver well-being (Bottorff, Oliffe, Kelly, Johnson, & Carey, 2014; González, Romero, López, Ramírez, & Stefanelli, 2010; Highet, Thompson, & McNair, 2005). In the
following section, Pearlin’s SPM is used to organize the present literature on caregivers to adults with depression.

**1.5. Experiences of caregivers of adults with depression**

Currently, the literature on caregivers of older adults with depression is limited, but several studies have begun to explore caregiving to younger adults with depression. Qualitative studies examining caregivers’ experiences revealed the difficulties and obstacles they encountered while caring for a family member with depression. In addition, caregivers commonly discussed the impact of caregiving on their well-being. Several studies also focused on the effect of mediators, characterized by caregivers’ resources (i.e., personal and social resources, healthcare system) available. Using Pearlin’s SPM (Pearlin et al., 1990), the following sections will summarize the qualitative literature examining caregivers of adults with depression as well as some general caregiving studies that include components of the SPM.

**Background and Context.** Sex and ethnicity both play an important role in the context of caregiving. In a meta-analysis of 229 caregiving studies that include analyses on gender differences, Pinquart and Sorensen (2006) revealed that women reported significantly higher levels of burden and depression, as well as provided more caregiving tasks than men. The review also suggested women had lower levels of subjective well-being and physical health and provided more hours of care, but gender differences in these factors were deemed small or very small in magnitude according to Cohen’s criteria (Cohen, 1992; Pinquart & Sörensen, 2006). The review also demonstrated that there were no differences in caregivers’ use of formal and informal support. In a separate meta-analysis, Pinquart and Sorensen examined caregiver ethnicity and revealed its influence on caregiving outcomes (Pinquart & Sörensen, 2005). Overall, ethnic minorities (e.g., Asian, African, Hispanic and Native American) were more likely to receive informal support, provide more care, and have stronger filial obligation beliefs and worse physical health in contrast to their Caucasian counterparts. Regarding psychological health, Asian- and Hispanic-Americans reported more depressive symptoms than White-Americans. In contrast, African-Americans had lower levels of burden and depression than White-Americans. These studies highlighted the importance of sex and ethnicity when considering caregiving outcome.
Familial relationship between caregiver and care recipient is an important factor affecting their caregiving circumstances and well-being. Currently, spouses and adult children represent the majority of caregivers to older adults who require assistance (38.4% and 41.3%, respectively) (Pinquart & Sörensen, 2011). Pinquart and Sørensen’s meta-analysis (2011) on caregivers for older adults revealed that spouse caregivers reported higher levels of depressive symptoms and lower levels of positive psychological well-being in comparison to adult children. In addition, spouses experienced greater physical and financial burden in their caregiving roles than adult children and a greater level of relationship strain (i.e., problems with relation to care recipient). Spouse caregivers are more likely to reside with the care recipient, and they provide more caregiving hours and assist with more caregiving tasks. In contrast, adult child caregivers often experience conflicting responsibilities, such as employment and their own immediate family that requires attention. In terms of support availability and utilization, spouses reported a lower level of informal support (informal helpers or hours of help received) but the same level of formal support (use of healthcare services) as adult children. The literature on caregiving to older adults has highlighted the importance of familial relationship and its potential to contribute to caregiving experiences and outcomes.

**Stressors.** The literature on caregivers to PWD revealed that as depressive symptoms were exhibited by the PWD, caregivers expressed interacting with a different person and experiencing a shift in family dynamic. Studies examining depression as compared to other psychiatric illnesses (e.g., bipolar disorder, schizophrenia, and alcohol dependence) showed depressive symptoms, such as social withdrawal, anhedonia and hopelessness, created more disruption in family functioning (Coyne et al., 1987; Keitner et al., 1987; Keitner et al., 1990). Communication disruptions between the PWD and family members were prevalent. Caregivers commonly reported the PWD’s unresponsiveness and self-isolating tendency as major barriers to communication (Harris, Pistrang, & Barker, 2006; Highet et al., 2005; Muscroft & Bowl, 2000), and caregivers reported feelings of loneliness and distress. Caregivers expressed frustration because they did not know how to help the PWD when they did not receive feedback. In addition, the PWD was less inclined to express gratitude, which at times left the caregivers feeling unappreciated (Bottorff et al., 2014; Highet, McNair, Davenport, & Hickie, 2004; Muscroft & Bowl, 2000). Caregivers were also reluctant to communicate with the PWD because they were afraid of potentially exacerbating the PWD’s distress or anger. Facing poor
Communications and the PWD’s symptoms, caregivers expressed a sense of lost emotional connection and difficulties in continuing with caregiving duties.

Caregivers reported the changing needs of the PWD at different time points made providing care more difficult. As caregivers accompanied the PWD through their illness trajectory, caregivers went through a caregiving trajectory from not recognizing depression to eventually adapting and adjusting to the illness. Initially, caregivers noticed depressive symptoms but often attributed them to reasons other than depression. Caregivers were often confused or surprised by the illness diagnosis due to the PWD’s lack of communication about their health (Hansen & Buus, 2013; Stjernswärd & Östman, 2008). They often had difficulties in discriminating between depressive symptoms and the PWD’s personality or circumstances, and they attributed the symptoms to work-related stress, other somatic illnesses, weak personal character, boredom, laziness, or reactions to caregivers’ behaviours (Bottorff et al., 2014; González et al., 2010; Hansen & Buus, 2013; Hight et al., 2005). As symptoms persisted or became more severe, caregivers realized the PWD was experiencing depression and attempted to help. Since caregivers had limited knowledge about depression, they described the process of learning helpful actions as challenging and confusing (Harris et al., 2006). The complexity of care was compounded by the PWD’s changing needs along the illness trajectory. For instance, the PWD may welcome caregivers’ help with activity planning during mild phases of depression, but they may reject such activity during severe depressive episodes. As the PWD’s symptoms subsided, some caregivers reported a strengthened familial relationship and greater closeness (Harris et al., 2006; Muscroft & Bowl, 2000; Stjernswärd & Östman, 2008). These changes encouraged them to continue with the caregiving role, and they felt less concerned about depression relapse as they believed they developed expertise in dealing with similar situations in the future. Overall, caregivers needed time to adjust to the PWD’s illness, and they often felt obligated to take on the caregiving responsibilities (González et al., 2010; Hansen & Buus, 2013; Harris et al., 2006).

Caregiving responsibilities were accentuated depending on the caregiver’s employment status, the severity of depression and the PWD’s illness trajectory. Caregivers commonly reported consoling and spending time with the PWD (Bottorff et al., 2014; González et al., 2010), participating in the PWD’s activities (González et al., 2010; Nosek, 2008) and seeking support on their behalf (Hight et al., 2004; Nosek, 2008; Stjernswärd & Östman, 2008). Caregivers, especially the ones that were unemployed, close to and/or residing with the PWD, took on the
financial and domestic workloads that the PWD was unable to maintain. For caregivers that were employed and had other family members to attend to, they described caregiving responsibilities as working double shifts, and they sometimes neglected other family members as a result (Higet et al., 2004; Radfar, Ahmadi, & Fallahi Khoshknab, 2014; Skundberg-Kletthagen, Wangensteen, Hall-Lord, & Hedelin, 2014; Stjernswärd & Östman, 2008). Caregivers’ involvement changed depending on the PWD’s illness trajectory that alternated between acute and mild phases. In the acute phase, the PWD showed prominent depressive symptoms (e.g., suicide attempts). Caregivers described the situation as “all hands to the pump” (Harris et al., 2006), and they sought help on the PWD’s behalf and adjusted their own lifestyle as needed. During the mild phase, depression was stabilized and the PWD showed minor (e.g., low mood) or no symptoms. Caregivers reported constant worries as a major stressor to their daily lives, and the concerns persisted even after the PWD’s symptoms subsided as they feared the possibility of relapse. Concerns about the PWD’s safety and self-harming behaviours were common among caregivers (Higet et al., 2004; Nosek, 2008; Skundberg-Kletthagen et al., 2014; Stjernswärd & Östman, 2008). They felt the need to closely monitor the PWD’s schedule and were always on call. In particular, caregivers had difficulties trusting the PWD with a history of suicide attempts and were vigilant about abnormal signs and behaviours at all times. As well, caregivers commonly described the daily interaction with the PWD similar to “walking on eggshells” (Bottorff et al., 2014; Harris et al., 2006; Higet et al., 2004; Muscroft & Bowl, 2000; Skundberg-Kletthagen et al., 2014). The experience of interacting with the PWD was fear and anxiety provoking at times because caregivers perceived the PWD as acutely sensitive, and they worried about making the PWD to feel worse through their behaviour. When the PWD was in remission, fear of relapse was a source of concern for the family (Harris et al., 2006; Muscroft & Bowl, 2000; Nosek, 2008; Radfar et al., 2014; Skundberg-Kletthagen et al., 2014) which encouraged caregivers to remain vigilant. Caregivers had various worries about the PWD’s future, including their health (Bottorff et al., 2014), difficulties in having a normal life (Radfar et al., 2014; Stjernswärd & Östman, 2008) and familial relationships (Radfar et al., 2014), and caregivers felt they do not have control of the future (Radfar et al., 2014). Caregivers’ constant state of vigilance was emotionally draining and thus negatively impacted their well-being. Financial burden, or the additional economic expenses caregivers accrue due to providing care and loss of income due to decreased work hours, is not well-documented in caregivers of PWD.
Some studies suggested caregivers took on more work hours to compensate for the PWD’s treatment costs and reduction of household income (Muscroft & Bowl, 2000; Radfar et al., 2014). Concurrently, caregivers utilized partial sick leaves and adjusted work hours to make themselves more available to assist with caregiving tasks and emergency situations (Skundberg-Kletthagen et al., 2014; Stjernswärd & Östman, 2008). Some illness populations had observed a strong financial burden, such as dementia and cancer (Coen, O’Boyle, Coakley, & Lawlor, 2002; Grunfeld et al., 2004). There is a considerable financial burden to family members to a person with dementia when the care is provided at home or in unsubsidized institutions (Dunkin & Anderson-Hanley, 1998), and caregivers consider finances as an important domain that contributes to their quality of life (Coen et al., 2002). Similarly, financial burden was found in caregivers of cancer patients, with prescription drugs and home help being the most significant expenses (Grunfeld et al., 2004). Caregivers of terminally ill patients with substantial care needs reported a high likelihood of experiencing economic burden, obtaining loans or mortgages, spending their savings, and working additional jobs (Emanuel, Fairclough, Slutsman, & Emanuel, 2000). These caregivers were also more likely to experience depressive symptoms.

To accommodate the caregiving responsibilities and unpredictability of depressive episodes, caregivers also modified their social and leisure activities. Although caregivers recognize the importance of social and relaxation time, they felt guilty for leaving the PWD alone (Bottorff et al., 2014). Caregivers’ social circle often diminished in size while they spent time with the PWD (Bottorff et al., 2014; Hightet et al., 2004; Muscroft & Bowl, 2000; Stjernswärd & Östman, 2008). Many caregivers expressed being tied up (Muscroft & Bowl, 2000; Nosek, 2008; Skundberg-Kletthagen et al., 2014) and unable to live their own life because their plans, especially family activities, were interrupted whenever the PWD’s symptoms intensified (Ahlström, Skärsäter, & Danielson, 2009; Bottorff et al., 2014; Radfar et al., 2014; Stjernswärd & Östman, 2008). Additionally, caregivers feared for their safety when depression was manifested as volatile and unpredictable moods and behaviours (e.g., outburst of anger, violence), which discouraged caregivers from spending time with the PWD and continuing to provide care (Bottorff et al., 2014; Harris et al., 2006; Oliffe, Kelly, Bottorff, Johnson, & Wong, 2017; Radfar et al., 2014). Caregivers relinquished control of everyday life due to the unpredictability of depressive episodes.
Familial relationships were often challenged. While Muscroft and Bowl (2000) suggested that spouses’ lives were taken over by depression more than parents’ and children’s lives, Nosek (2008) proposed that familial relationships did not play a role in caregiving experiences. For romantic relationships between the healthy individual and PWD, a true partnership was sometimes lost and transformed into a nurse-patient or parent-child dynamic (Bottorff et al., 2014; Stjernswärd & Östman, 2008). In addition, the PWD often had a much lower sexual desire (Bottorff et al., 2014; Oliffe et al., 2017; Stjernswärd & Östman, 2008), which caused their partners to feel frustrated and unfulfilled. In the cases of parents with depression and child caregivers, the roles were often reversed and the ill parent became similar to a child in need of care (Stjernswärd & Östman, 2008).

Although not commonly reported in caregivers of PWD, role captivity, or the involuntary participation the caregivers feel towards the caregiving role, was observed to be a major contributor to perceived stress by caregivers of cancer patients (Gaugler et al., 2005). As well, in a study of dementia caregivers, role captivity and problematic behaviors of patients mediated caregivers’ depressive symptoms (Givens, Mezzacappa, Heeren, Yaffe, & Fredman, 2014), and other studies have demonstrated similar associations (Alspaugh, Stephens, Townsend, Zarit, & Greene, 1999; Pioli, 2010). In addition, a qualitative study on caregivers of mentally ill older adults found that perceiving caregiving as a freedom of choice was the key determinant for positive caregiving experience (Zegwaard, Aartsen, Grypdonck, & Cuijpers, 2013).

Caregivers often had mixed feelings about their supporting role, and some caregivers considered taking time away from caregiving or leaving the PWD in difficult situations. Caregivers reported feeling irritated and exhausted by their caregiving responsibilities, and some caregivers thought they were unable to continue care (Bottorff et al., 2014; González et al., 2010; Skundberg-Kletthagen et al., 2014). In contrast, the feelings of obligation, love and guilt encouraged caregivers to continue with caregiving activities (González et al., 2010; Hansen & Buus, 2013; Harris et al., 2006). However, for caregivers that were unable or unwilling to continue in their role, they chose to separate (e.g., divorce) or take a break (e.g., go on vacation) from the PWD as a coping mechanism to preserve their well-being (Bottorff et al., 2014; González et al., 2010; Muscroft & Bowl, 2000; Nosek, 2008). Caregivers distanced themselves to gain their own space and stopped engaging in caregiving activities. While some caregivers decided to return to their caregiving role (Bottorff et al., 2014; Nosek, 2008), others chose to stay away resulting in a
permanent break in the relationship (Highet et al., 2004; Muscroft & Bowl, 2000). Caregivers were often caught in the struggle of ambivalent feelings, and the unpredictable length and intensity of depression challenged their capacity to remain supportive.

Caregivers’ narratives suggested that stigma of depression was a barrier to caregiving and social support. Caregivers’ own stigma delayed or prevented them from accepting the illness. In some cases, caregivers refused to accept the diagnosis as a defense mechanism to live “blinded” from what was happening and prevented the diagnosis from affecting the PWD and themselves (Bottorff et al., 2014; González et al., 2010; Highet et al., 2005). Caregivers’ delayed realization or acceptance of depression postponed their action in seeking treatment to help the PWD, and depressive symptoms were often exaggerated when left untreated (Radfar et al., 2014). Caregivers also reported encountering other people’s stigma on depression. The PWD and caregivers received negative or unsupportive attitudes and behaviours from their friends, relatives, and colleagues due to their lack of understanding of depression (Bottorff et al., 2014; Stjernswärd & Östman, 2008). To avoid judgment from the society, caregivers felt it was necessary to make excuses for the PWD’s behaviours and social absences (Bottorff et al., 2014; Highet et al., 2004). Caregivers identified stigma of depression as a factor that delayed the PWD’s illness diagnosis and treatment and diminished the PWD and caregivers’ social support.

**Mediators.** Throughout their caregiving to PWD journeys, caregivers reported adopting coping strategies. Caregivers learned to not take the PWD’s mood and negative comments personally (Bottorff et al., 2014; Harris et al., 2006), stop blaming themselves for their family’s depression (Bottorff et al., 2014), and lower their expectations of the PWD (Bottorff et al., 2014). Hope was a strong motivator that encouraged caregivers to maintain their role (Ahlström et al., 2009; González et al., 2010; Stjernswärd & Östman, 2008) as they believed the situation would eventually become better. By recognizing their limits and needs for self-care, caregivers made time for themselves to pursue their hobbies and social network while not being available to the PWD and others (Bottorff et al., 2014; Hansen & Buus, 2013; Skundberg-Kletthagen et al., 2014; Stjernswärd & Östman, 2008). Some caregivers also embraced their time at work as they perceived employment as a “valid” reason to be free from caregiving responsibilities (Skundberg-Kletthagen et al., 2014; Stjernswärd & Östman, 2008). Caregivers valued opportunities to share their difficulties and feelings, and they often disclosed these suppressed experiences with friends (Hansen & Buus, 2013; Harris et al., 2006; Muscroft & Bowl, 2000),
health professionals (Stjernswärd & Östman, 2008), and individuals with similar experiences (Stjernswärd & Östman, 2008).

Although mastery has not been examined in caregivers to PWD, it has been associated with positive outcomes in other caregiving populations. Mastery is defined as the caregivers’ perception of control over their life circumstances (Pearlin et al., 1990). Increased mastery had been associated with decreased perception of stress in caregivers of Alzheimer’s patients (Mausbach et al., 2012), as well as less depressive symptoms, higher psychological well-being, and better mental health in caregivers of critically ill patients (Cameron et al., 2016). In addition, mastery was observed to moderate the effect of perceived caregiving demands on depression and anxiety in caregivers of Alzheimer’s patients (Pioli, 2010). Furthermore, high mastery in caregivers of cancer patients is highly associated with a reduction in emotional distress (Gaugler et al., 2005).

Caregivers commonly reported negative experiences when seeking resources for themselves or the PWD. Caregivers were frustrated with the scarce resources that were available (Highet et al., 2004; Stjernswärd & Östman, 2008) and the hardship in navigating through the healthcare system on their own. They questioned the healthcare system’s ability to respond during crisis situations (Highet et al., 2004) and the lack of flexibility and continuity of care, which further compounded their stress and feelings of helplessness (Hansen & Buus, 2013; Harris et al., 2006). Caregivers were often not included in the PWD’s treatment or care planning due to confidentiality regulations (Hansen & Buus, 2013; Nosek, 2008; Stjernswärd & Östman, 2008), which rendered them feeling unimportant and limited their capacity to share the PWD’s progress at home with the health professionals. As well, some caregivers felt they were being ignored by the health professionals and this contributed to caregivers’ feelings of unimportance and prevented them from requesting assistance for themselves (Hansen & Buus, 2013; Stjernswärd & Östman, 2008). Caregivers were sometimes held responsible by the health professionals when the PWD was not following treatment programs, or they were asked to decide on the PWD’s behalf when they were not fully informed about the choices (Hansen & Buus, 2013; Stjernswärd & Östman, 2008). They felt uncomfortable in these situations and desired more guidance. In instances where caregivers perceived health professionals as helpful, they experienced less stress and emotional burden due to the sense of shared responsibilities and the impression that the PWD was under good care (Stjernswärd & Östman, 2008). Despite the importance of having
supportive health professionals, caregivers went through the healthcare system’s lottery effect (paired with health professionals with various levels of supportiveness based on chance) that left some caregivers to feel well-supported while others to feel alone with their difficulties (Muscroft & Bowl, 2000).

Caregivers suggested several resources they wished to have access to in the healthcare system. They hoped for a contact person to obtain information about regulations and available resources for both the PWD and themselves (Stjernswärd & Östman, 2008), as they often felt lost navigating the healthcare system and were uncertain about available benefits and assistance (Muscroft & Bowl, 2000). As well, not knowing how to help the PWD and interpret their behaviours caused caregivers to feel frustrated and insecure, and they wished to receive more information and training (Highet et al., 2005; Muscroft & Bowl, 2000; Nosek, 2008; Skundberg-Kletthagen et al., 2014). They wanted to understand the illness trajectory of depression and learn ways to assist and communicate with the PWD in different situations without upsetting them. Some caregivers requested counselling service for themselves to have open communications and receive advice on coping strategies (Muscroft & Bowl, 2000; Skundberg-Kletthagen et al., 2014). However, the cost of counselling, fear of breach of confidentiality and shame of seeing oneself as mentally ill prevented them from pursuing professional help. Caregivers viewed support groups as a beneficial opportunity to mingle with others in similar situations and share feelings without judgment (Bottorff et al., 2014; Highet et al., 2004). In addition, they desired healthcare plans to be more inclusive of family members (Stjernswärd & Östman, 2008). As well, caregivers wanted professionals to listen to their inputs and understand their difficulties as they often felt unheard in relation to care planning (Muscroft & Bowl, 2000). Caregivers also craved support that revolved around the PWD rather than their own well-being, including hopes for more effective depression treatment and shorter waiting queue for psychiatric care (Bottorff et al., 2014; Stjernswärd & Östman, 2008). In general, caregivers wished the healthcare system was more inclusive of family members of the PWD in the treatment plan, such as offering counselling services, support groups, education classes and a point of contact for families, so they are more prepared for the complexity of the role.

Social support has been demonstrated as a key mediator of caregiver distress (Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2001; Rossi Ferrario, Zotti, Massara, & Nuvolone, 2003) and caregiver well-being (Cameron et al., 2016). As a mediator, it has been
shown to decrease the effect of stressors (e.g., caregiver demands) on caregiver well-being (e.g., caregiver depression) (Thielemann & Conner, 2009). In addition, lack of social support is also linked to depression in caregivers of Alzheimer’s patients (Roth, Mittelman, Clay, Madan, & Haley, 2005).

Outcomes. Providing care to the PWD was associated with caregivers reporting psychological and physical complications. Caregivers felt their emotional state was sometimes dependent on the PWD’s mood, and they described feelings of sadness and loss when the PWD demonstrated no symptom improvement (González et al., 2010; Hight et al., 2004; Muscroft & Bowl, 2000; Nosek, 2008; Radfar et al., 2014; Skundberg-Kletthagen et al., 2014). Some caregivers reported experiencing depressive symptoms themselves. Caregivers commonly reported exhaustion due to the chronic and unstable nature of depression, which required constant vigilance and flexibility in caregivers’ schedule (Ahlström et al., 2009; González et al., 2010; Hansen & Buus, 2013; Hight et al., 2004; Oliffe et al., 2017; Radfar et al., 2014; Skundberg-Kletthagen et al., 2014; Stjernswärd & Östman, 2008). As a result, they became socially isolated due to exhaustion (Ahlström et al., 2009; Hansen & Buus, 2013), which made the caregiving process more lonely and difficult (Stjernswärd & Östman, 2008). Similar to the PWD, some caregivers reported feelings of anger and resentment, as they thought the PWD was not putting in the effort to recover or they were prohibited to live their own lives due to caregiving responsibilities (Bottorff et al., 2014; González et al., 2010; Skundberg-Kletthagen et al., 2014). Caregivers felt helpless when they were unable to provide meaningful assistance and foresee improvements in the PWD’s symptoms (Ahlström et al., 2009; Harris et al., 2006; Muscroft & Bowl, 2000). Furthermore, caregivers experienced guilt as they believed they were the cause of illness or could have done more for the PWD (Hight et al., 2005; Muscroft & Bowl, 2000), and they felt incompetent for not being able to remedy the PWD’s illness (Bottorff et al., 2014; Harris et al., 2006; Hight et al., 2005). In addition, caregiving was demanding on a person’s physical health, as caregivers reported sleeplessness (Ahlström et al., 2009; González et al., 2010; Oliffe et al., 2017; Skundberg-Kletthagen et al., 2014) and high blood pressure (Skundberg-Kletthagen et al., 2014). Caregivers experienced a range of psychological and physical complications that also turned them into subjects who demanded care.

1.6. Focus of thesis
Previous research has begun to delineate how providing support to a PWD affects caregivers. Following Pearlin’s SPM, various stressors (e.g., PWD’s symptoms, lifestyle modification), mediators (e.g., coping strategies, social support) and outcomes (e.g., psychological and physical complications) were reported by this caregiving population. As well, previous research highlighted the lack of resources caregivers receive from the healthcare system and their desire for additional support. Past studies have focused on family members’ caregiving experiences in the context of younger adults with depression and various medical illnesses in older adults (e.g., cancer, dementia), but depression in older adults is under-researched despite its high prevalence.

To date, the experiences and support needs associated with providing care to an older adult with depression are unclear. As discussed above, older adults with depression have a variety of unique characteristics (e.g., comorbidities, less active, more isolated) which may present distinct challenges to family members involved in providing care and support. The present research examined caregivers’ experiences and support needs to highlight how these unique characteristics can affect caregiving. As well, this study used Pearlin’s SPM to guide research directions and explore factors from the SPM that were not discussed in past studies on caregiving to adults with depression (e.g., PWD’s ADL and IADL dependencies, caregiver’s sense of mastery).

Both experience and support are difficult constructs to define since they include a broad range of factors. For the purpose of the present study, experience will be conceptualized as the background and context (e.g., demographic factors), stressors (e.g., problematic conditions and factors) and well-being (e.g., physical, psychological and financial health) from Pearlin’s SPM (Pearlin et al., 1990), with the addition of positive aspects of caregiving (e.g., satisfaction from fulfilling caregiving duties). Support will be conceptualized as the personal (e.g., coping strategies, mastery) and social (e.g., friends and family, healthcare system) resources that caregivers utilize.

Therefore, this thesis aimed to use a qualitative descriptive approach to explore the experiences and support needs of caregivers to older adults with depression, and the goal was to inform intervention and/or system change.
CHAPTER TWO

Qualitative Design, Methodology and Research Questions
2.1. Outline

This chapter describes the use of a qualitative descriptive approach and discusses the appropriateness of this methodology, in relation to other qualitative approaches, to address the research objective. In addition, the chapter provides a detailed description of the participant selection process and recruitment strategies. The data collection process of semi-structured interviews is described, and interview strategies and questions are discussed in detail. Lastly, this study’s use of Braun and Clarke’s thematic analysis to generate themes is delineated.

2.2. Research Design

A qualitative descriptive approach was selected to understand the experiences and support needs of family caregivers of older adults with depression. This qualitative study aligns with constructivism and believes that individuals create their own subjective representations of the objective reality, and the goal of the research was to explore the multiple realities embodied by participants in this study population (Ivankova, Creswell, & Plano Clark, 2007). A qualitative descriptive approach was used as opposed to ethnography, phenomenology, narrative or grounded theory to present study findings due to its use of everyday language and low-inference descriptions from the researchers (Sandelowski, 2000, 2010). Low-inference descriptions of the study findings allow policy makers and key stakeholders to interpret participants’ own words and create resources for this caregiving population. Researchers that employ an ethnographical approach focus largely on the study population’s culture and criteria of being part of this particular group (Oliffe, 2005). However, the goal of this study was not to distinguish between this caregiving population and others. Phenomenology aims to construct a gestalt of a prototypical experience of participants from their perspectives (Creswell, 2012; Lester, 1999). This approach does not align with the objective of this study, which aims to describe different facets of caregivers’ experiences and support needs in a concise manner with rich descriptions from the participants and few interpretations from the researcher. A narrative approach consists of researchers categorizing data and developing themes based on stories told by participants (Creswell, 2012; Piana et al., 2010). This methodological approach has demonstrated its effectiveness in helping health practitioners understand an individual’s experiences and perspectives (Overcash, 2004; Sparkes & Holloway, 2005). However, it is difficult to communicate multiple individuals’ stories concisely to policy makers and health professionals. A
grounded theory approach aims to construct a theory or conceptual model (Creswell, 2012). Currently, few studies exist on this research topic, and the goal of this study is to start at a basic and exploratory level instead of developing a theory. A qualitative descriptive approach produces data analysis that can be easily interpreted by policy makers and health professionals, thereby allowing the researchers to communicate the study findings to these key stake holders for potential health care improvements (Sandelowski, 2010).

The power relation between researcher and participant is an important consideration in qualitative interviews, as an imbalanced social dynamic may influence the course and content of interviews (Manderson, Bennett, & Andajani-Sutjahjo, 2006; Nicholls, 2009; Speziale, Streubert, & Carpenter, 2011). Participants were able to select interview locations (e.g., their home or telephone) for this study, which may increase their comfort and attendance rate and result in a more productive interview (Gill, Stewart, Treasure, & Chadwick, 2008; Kvale, 1996). In addition, it also helps balance the power relations between researcher and participants when participants are the ones in control of selecting their preferred interview location (Elwood & Martin, 2000). Additionally, semi-structured interviews render participants some power to dictate the direction and information disclosed during interviews (Nicholls, 2009).

2.3. Participants

This qualitative study aimed to interview family members of an older adult with depression. Family members were eligible for this study if they were: 1) an immediate family member of the care recipient; 2) currently providing assistance with at least one activity or instrumental activity of daily living per week; 3) not financially compensated; 4) being a caregiver for at least 90 days; and 5) able to communicate in English. In addition, in order for the family member to be eligible, the care recipient had to be: 1) over the age of 65; 2) diagnosed with MDD or PDD; 3) living in the community; and 4) depression had to be the primary reason for care. Family members were required to have at least 90 days of caregiving to ensure they had some experiences as a caregiver. MDD and PDD were both included to better understand caregivers that were caring for someone with serious depression in terms of severity and longevity. Lastly, only care recipients that lived at home (e.g., not hospitalized, in respite care or living in a nursing home) were included in the study to ensure that family members were providing care in the community to the person with depression.
Convenience sampling was employed in this qualitative research, and data collection continued until data saturation was reached. The number of participants required to reach theme saturation varies among qualitative studies. Some studies suggested 20 participants were necessary to achieve theme saturation (Green & Thorogood, 2013), while others proposed fewer participants were required (Reimer, De Haan, Rijnders, Limburg, & Van Den Bos, 1998; Starks & Trinidad, 2007). Data collection and analysis happened concurrently, and recruitment ended when theme saturation was reached (i.e., no new ideas were appearing in the interviews).

**2.4. Recruitment**

Prior to study recruitment, the study obtained ethics approval from the research ethics boards of Baycrest Health Sciences and the University of Toronto. Baycrest Health Sciences was first founded as the Toronto Jewish Old Folks Home, and it has since transitioned into a hospital that focuses on brain health, aging and education while maintaining some Jewish traditions. Baycrest Health Sciences was chosen as the recruitment site since the graduate student’s supervisor and program advisory committee members had affiliations with outpatient programs that served seniors with depression at the facility. The graduate student collaborated with health professionals (i.e., psychiatrists, psychologists, occupational therapies, social workers and nurses) at Baycrest Health Sciences and provided information about the study goals and inclusion and exclusion criteria. Health professionals identified eligible outpatients (i.e., patient over the age of 65 with a diagnosis of MDD or PDD) and their immediate family members through their clinical practice or health record database, obtained information about family members involved in their care, and asked for permission to contact their family members about the study. Next, they provided the graduate student with the family member’s contact information. The graduate student screened family caregivers to ensure that they satisfied the inclusion and exclusion criteria and assessed their willingness to participate in the study. If family members were eligible, the graduate student explained the study in detail, including the purpose of the study, participation commitment, potential risks and benefits, conditions for participation, and contact information of the graduate student, his supervisor, and the ethics board (see Appendix A for complete consent form). If the individual agreed with the terms and conditions, the graduate student obtained consent and scheduled an in-person or telephone interview.
Recruitment of caregivers of the PWD was challenging and recruitment took longer than anticipated as it lasted 11 months in total (February to December 2017). It is worth noting that 8 out of 11 participants came from two healthcare professionals, and the healthcare professionals commented that their success in recruitment was due to their established rapports with the caregivers. It was difficult to recruit through the care recipients as they were reluctant to identify their family members or pass the study information to their family members. Some care recipients commented that they did not want to put additional burden onto their family members by asking them to participate in the study, and a few care recipients were not interested in the study in general and did not want their families to be involved. As a result, the graduate student and his recruitment team had difficulties reaching out to the caregivers or getting their contact information. Two other recruitment strategies were used for the study but did not yield any participants. First, flyers regarding the study information and graduate student’s contact information were posted on bulletin boards of Baycrest Health Sciences’s geriatric psychiatry and mood clinic. Second, the graduate student was invited to speak to care recipients and caregivers at Baycrest Health Sciences’s depression day program (an outpatient program for older adults with depression). It is recommended for future studies of caregivers to older adults with depression to collaborate with healthcare professionals who have established clientele to facilitate recruitment.

2.5. Data Collection

The study employed a semi-structured interview approach to collect data. It consisted of pre-defined broad questions but allowed deviations when participants had information to share regarding the study objectives (Nicholls, 2009). This interview approach does not assume the researcher anticipated enough of the responses to pre-format a complete interview guide, but it includes a guideline of questions and topics to ensure the interview contents were relevant to the research objective. Open-ended questions were used to lead the conversation towards a certain topic (e.g., how does caregiving affect your life?) and allowed general answers, and probing questions encouraged more specific or additional responses that helped to answer the research question (e.g., how does caregiving affect your work?). For instance, when participants were describing how caregiving affected their life, they were asked to elaborate on different aspects of life (e.g., work life and social life). When participants described each life aspect in detail, the probe was successful and the interview was able to extrapolate a more comprehensive
understanding of how participants’ lives were influenced by their caregiving role and responsibilities. The conversation-style of these questions allowed the participant and graduate student to establish rapport, which encouraged participants to openly share caregiving details (Nicholls, 2009). The graduate student recorded field notes during the interviews to capture information that was not available through audio recordings and could be incorporated during data analysis. For instance, a participant who was visibly shaken when discussing a certain topic may be reflecting the degree of impact the topic has on the participant, which can influence how researchers interpret such data.

During the consent stage of the interview, each participant reviewed a physical copy of the consent form. Prior to in-person interviews, participants reviewed the consent form with the graduate student and signed the consent form once all their questions were answered and they agreed to the terms and conditions. In the case of a phone interview, a consent form was mailed to the participant with a postage-paid self-addressed envelope so the participants could return the signed consent form. The interview was only conducted after the signed consent form was received.

Interviews were informed by Pearlin’s SPM (Pearlin, 1999; Pearlin et al., 1990) (See Chapter One for more information on Pearlin’s SPM). Consistent with the SPM, interviews probed caregiving stressors (e.g., caregiving assistance, economic stressors and lifestyle changes), mediators (e.g., social support and coping mechanisms) and outcomes (e.g., physical and psychological health). Therefore, the interview explored these factors in detail. Interviews were guided by open-ended questions and probes that asked the participants to describe: a) care recipient’s conditions; b) caregiver’s caregiving history and current situation; c) caregiver’s experiences in their caring role; d) how caregiver’s life was affected by their caring role and responsibilities; e) caregiver’s social support and support needs; f) caregiver’s coping mechanisms; and g) caregiver’s demographic information (see Table 2.1 for sample questions; see Appendix D for complete interview guide). These questions provided context regarding participants’ situation and oriented the graduate student to their circumstances.
Table 2.1 – Sample Interview Guide

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<tr>
<td>a.</td>
<td>Can you describe things you help your family member with?</td>
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<td>b.</td>
<td>In what ways do you adjust your daily schedule for these responsibilities?</td>
</tr>
<tr>
<td>c.</td>
<td>How do you manage all the responsibilities?</td>
</tr>
<tr>
<td>d.</td>
<td>Does providing care affect your health?</td>
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To capture participants’ demographic information, a short questionnaire was administered at the end of the interview. It assessed the participant’s age, primary daily activity, employment status, income, education and caregiving history. The majority of the questionnaire was in multiple choice format, and participants had the option to either complete it independently or with the graduate student (i.e., interview format).

Although there were concerns that phone interviews can compromise the quality of the conversation in the absence of visual cues (Novick, 2008), recent studies have suggested limited evidence that phone interviews compromise data quality (Novick, 2008; Sturges & Hanrahan, 2004; Vogl, 2013). Interviews were audio-recorded and transcribed verbatim by the graduate student after each interview, and field notes regarding impressions gained during the conversation were recorded.

Confidentiality was maintained by providing each participant with an identification code upon consent. Participants were identified by their ID code in all records and transcripts. Personal information and audio recordings of the interviews were stored on institutional desktops that had a password, firewalls, and security measures in place. Physical copies of consent forms and interview notes were stored in the institution’s locked filing cabinets. Only the graduate student and his supervisor had access to the master linking log containing participants' names and ID codes. The master linking log was stored separately from the study data and will be destroyed 5 years after publication. All identifying information was removed from the transcripts.

2.6. Data Analysis
Initial attempts to map findings onto Pearlin’s SPM were made as the study direction and data collection were informed by the model. Data were placed into the four domains (i.e., background and context, stressors, mediators and outcomes), and themes were explored. However, the majority of the findings did not map onto a single domain and, in some situations, crossed domains. Additionally, the data mapped onto certain domains more heavily than others. For example, caregivers discussed facets of stressors much more than mediators, resulting in an imbalance in the data across domains. As a result, Braun and Clarke’s thematic analysis was chosen to analyze the data as it allows the researcher to stay close to the interview contents when deriving the themes and provides a more holistic view of the data (Braun & Clarke, 2006). The steps include: (1) familiarize oneself with the data by reviewing recordings and transcripts; (2) generate initial codes; (3) develop themes based on generated codes; (4) review themes by deleting themes with limited data support, combining similar themes, and make adjustments to existing themes; (5) name and define themes when a satisfactory thematic map is achieved; and (6) producing the report (Braun & Clarke, 2006). Braun and Clarke’s thematic analysis is a recursive iterative process (Braun & Clarke, 2006; Clarke & Braun, 2013), and the graduate student and his research team had gone back and forth between steps one to five before producing the final report. The discussion addresses the strengths and limitations of using Pearlin’s SPM in the analyses.

To ensure the graduate student was immersed in the data, he first transcribed the audio recordings verbatim and familiarized himself with the audio recordings, transcripts and field notes. As well, initial analytic observations were noted. Next, the graduate student and his supervisor generated initial codes, which systematically labelled concepts and themes throughout the transcripts that were relevant to the research question (Bryman, 2001). The coding process was assisted by NVivo, a qualitative research software that allowed the graduate student to code and label sections throughout transcripts (Gibbs, 2002). Codes and relevant data were then extracted and collated, and potential themes were developed by the graduate student and his supervisor. Themes were established when they consisted of distinct ideas. Based on the content richness and relationship between each theme, they were labelled as a main theme, sub-theme or preliminary theme. This step helped compartmentalize large and complex themes into smaller categories. Sub-themes that had commonalities were grouped and placed under a main theme. Data that did not appear to link to the research objective was coded as “miscellaneous”. In the
case of disagreement, the graduate student and his supervisor compared their interpretations of the data and worked towards consensus before proceeding. All codes and relevant data were then placed into a thematic map, as it offered a visual representation of relationships between themes and information available inside each theme (Braun & Clarke, 2006). Following the initial construction of a thematic map, the graduate student sent his Program Advisory Committee (i.e., his supervisor, a qualitative researcher in mental health and occupational therapy and a psychiatrist) three de-identified interview transcripts. He presented the themes and the Program Advisory Committee offered feedback. Themes and codes were reviewed and revised (i.e., deleted, created, combined or broken down) for clarity and coherence. In addition, transcripts and “miscellaneous” codes were reviewed to ensure all relevant data were included in the analysis. Once a satisfactory thematic map was developed, each theme was defined, described, and their connections with each other were delineated. In addition, quotations from the interviews that captured the essence of each theme were used as examples. Next, themes and interpretations were again reviewed by the graduate student and his Program Advisory Committee and were revised accordingly. See Chapter Three for the complete thematic analysis.

Three strategies, including reflexive journal, multiple analyst triangulation and peer debriefing, were used to enhance the rigour and trustworthiness of study findings. A study’s rigour, or the credibility of the study and the thoroughness of the researcher’s methods before reaching their assertions, is often challenged in qualitative research (Morse, Barrett, Mayan, Olson, & Spiers, 2002; Nicholls, 2009). First, to increase confirmability, or the degree to which results can be confirmed by others, a reflexive journal was used. An entry consisted of the graduate student’s perspectives and positions were documented before and after each interview. Prior to an interview, reflexive journal entries helped the graduate student to recognize his own preconceptions and increase self-awareness regarding his background and interests (Finlay, 2002; Lincoln & Guba, 1985), and it acted as a reminder to not guide the interview based on his own caregiving experiences or knowledge (Anney, 2014; Nicholls, 2009). For instance, his personal caregiving history may influence him to ask leading questions to confirm that others had similar caregiving experiences. An entry after the interview offered the graduate student the opportunity to reflect on the interview and implement any changes for future interviews. Second, to minimize potential bias from having only a single researcher’s perspective, this study used multiple analyst triangulation throughout data analysis to include perspectives of researchers and
health professionals from various disciplines (i.e., family caregiving, occupational therapy, mental health and psychiatry) (Patton, 1999). As described above, the graduate student and his supervisor reviewed the data, developed codes and themes, and met regularly to ensure consistency in codes, themes, definitions and interpretations. Additionally, the graduate student’s Program Advisory Committee helped critically review the themes and interpretations with their expertise in their perspective fields. Last, the graduate student utilized peer debriefing by presenting the research findings in team meetings of health professionals in the Greater Toronto Area to receive feedback (e.g., overlapping themes) and consider an alternative interpretation of the data (Morse et al., 2002).

In reflecting on my own positionality, I am a student and health practitioner in the field of mental health, and a caregiver to a family member with depression. Positionality is crucial in shaping the subjectivity of the researcher (Bourke, 2014). My past experiences in providing counselling services may create distractions during interviews (e.g., giving participant advice about their relationship with the care recipient). As well, being a caregiver to a family member with depression myself can encourage me to interpret participants’ words based on my own situation. However, my experience as a caregiver can also help me empathize with the participant and understand their experiences. Thus, reflexive journal, multiple analyst triangulation and peer debriefing were extremely important in completing this study. Writing reflective journal entries before and after each interview highlighted my positionality and the objectives of this study, and they reminded me to use my experience and knowledge to achieve the study goals. Multiple triangulation and peer debriefing allowed me to discuss the study findings with other researchers and health professionals, and they can reduce the effects of my subjectivity and positionality influencing the finding outcomes.

2.7. Ethical Considerations

The present study obtained ethical clearance from Baycrest Health Sciences (REB #16-42) and the University of Toronto (#33933). All participants received a study information document and were required to provide informed consent prior to each interview. All physical documentations collected are stored in a secure location at the University of Toronto, and all digital participant information is located on the password encrypted hard drive of the student researcher and his supervisor’s computers.
CHAPTER THREE

Manuscript:

“Understanding experiences and support needs of families caring for older adults with depression”

Note: As this chapter is intended to be a stand-alone manuscript prepared for Journal of Affective Disorder, there is some repetition from other chapters
Abstract

Background: Caring for a person with depression is associated with worse physical and mental well-being in caregivers, but the experiences and needs of caregivers to an older adult with depression are unclear. This study aims to explore their experiences and desired resources from the healthcare system.

Methods: A qualitative descriptive approach was used and eleven individual qualitative interviews were conducted with caregivers to older adults with a clinical depression diagnosis in Toronto, Canada. Participants were recruited by health professionals through clinics and health record database. Findings were generated via thematic analysis.

Results: Caregivers perceived a transformation in the person with depression’s behaviour and personality that also changed the relationship between them. Caregivers modified their lifestyle, perceived stigma towards their love one related to depression, and experienced declines in their own well-being. Caregivers’ personal and external resources helped with the caregiving role. They desired additional resources from the healthcare system, including instrumental support for older adults with depression, centralized information, and caregiver access to health professionals.

Limitations: Most participants were women and had high family income, and no separate analysis was used for different caregiver and care recipient familial relationships.

Conclusion: There is an immediate need for increased healthcare resources for older adults with depression and their family members. This study provides insight for clinicians and policy makers to implement resources to optimize the care of older adults with depression and their caregivers.
1. Introduction

The need for informal caregivers (individuals who provide assistance to patients without financial compensation, often friends or family members; hereafter referred to as caregivers) is concurrently growing with the aging population. Following dementia, depression is the second most prevalent mental illness among older adults (individuals 65 years of age or older) (World Health Organization, 2017b). Older adults with depression encounter distinctive circumstances, as they are more likely to have comorbidities (Carney & Freedland, 2003) and be less active, retired, and socially isolated (Alexopoulos, 2005; Fiske et al., 2009). Family members often assume the caregiver role to assist with activities of daily living (ADL) and instrumental activities of daily living (IADL). However, caregivers report lower physical and psychological health compared to non-caregivers (Berglund, Lytsy, & Westerling, 2015; L. Smith et al., 2014).

Several studies have examined the experiences and support needs of caregivers of younger adults with depression, but there is very limited literature on caregivers of older adults with depression. Caring for a person with depression (PWD) was associated with physical and mental fatigue in caregivers (Ahlström et al., 2009; González et al., 2010; Radfar et al., 2014). In addition, they discussed encountering financial and employment difficulties, and some caregivers work additional hours or take time off to fulfill their caregiving duties (Muscroft & Bowl, 2000; Radfar et al., 2014). As well, caregivers commonly reported having less time for social and leisure activities (Bottorff et al., 2014; Hight et al., 2004; Muscroft & Bowl, 2000; Stjernswärd & Östman, 2008). They had difficulties understanding depression and living or spending time with the care recipient due to their unpredictable mood swings (Bottorff et al., 2014; González et al., 2010; Skundberg-Kletthagen et al., 2014). They wished they were more prepared and trained for their caregiving roles to provide helpful and proper support to the older adult with depression (Hight et al., 2004; Stjernswärd & Östman, 2008).

1.2. Theoretical Framework

Pearlin’s stress process model (SPM) has demonstrated its ability to make a comprehensive assessment of factors that influence caregiver outcomes (Pearlin, 1999; Pearlin et al., 1990). SPM identified three major domains (i.e., background and context, stressors, mediators) and suggested components from each domain that contribute to caregiver outcomes
(e.g., caregiver well-being) (Pearlin et al., 1990). The present study adopted Pearlin’s SPM to guide data collection. The model was chosen because it has been widely cited in various caregiving populations (e.g., dementia, cancer and stroke) and has shown robust findings (e.g., establishing associations) across studies. The present study explored items from context and background (e.g., income), stressors (e.g., IADL dependencies) and outcomes (e.g., psychological well-being) when examining caregiver’s experiences, and consider items from mediators when examining caregiver’s resources (e.g., healthcare system) and support needs.

As discussed above, older adults with depression have a variety of unique characteristics (e.g., comorbidities, less active, more isolated) which may present distinctive challenges to family members involved in providing care and support. Past studies have focused on family members’ caregiving experiences in the context of various medical illnesses in older adults (e.g., cancer, dementia), but depression is under-researched despite its high prevalence. To date, the experience and support needs associated with providing care to an older adult with depression are unclear.

Therefore, this study aimed to use a qualitative descriptive approach to explore the experiences and support needs of caregivers to older adults with depression, and the goal was to inform intervention development and/or system change.

2. Methods

2.1. Research Design

A qualitative descriptive approach was selected to understand the experiences and support needs of family caregivers of older adults with depression. Currently, few studies exist on this research topic, and the goal of this study is to start at a basic and exploratory level instead of developing a theory. A qualitative descriptive approach offers rich descriptions from participants and few researcher interpretations in a concise manner. This approach produces data analysis that can be easily interpreted by policy makers and health professionals, thereby allowing the researchers to communicate the study findings to these key stakeholders for potential health care improvements (Sandelowski, 2010).

2.2. Recruitment
This qualitative study aimed to interview family members of an older adult with depression. Caregivers were eligible for this study if they were: 1) an immediate family member of the care recipient; 2) currently providing assistance with at least one activity or instrumental activity of daily living per week; 3) not financially compensated; 4) being a caregiver for at least 90 days; and 5) able to communicate in English. In addition, in order for the family member to be eligible, the care recipient had to be: 1) over the age of 65; 2) diagnosed with major depressive disorder (MDD) or persistent depressive disorder (PDD); 3) not currently hospitalized; and 4) depression had to be the primary reason for care. Family members were required to have at least 90 days of caregiving to ensure they had some experiences as a caregiver. MDD and PDD were both included to better understand caregivers that were caring for someone with serious depression in terms of severity and longevity. Lastly, hospitalized care recipients were not included in the study to ensure that friends and family members were providing the majority of assistance to the person with depression.

2.3. Data Collection

The interview explored the domains of Pearlin’s SPM in detail to understand caregivers’ experiences and needs. Interviews were guided by open-ended questions and probes that asked the participants to describe: a) care recipient’s conditions; b) caregiver’s caregiving history and current situation; c) caregiver’s experiences in their caring role; d) how caregiver’s life was affected by their caring role and responsibilities; e) caregiver’s social support and support needs; f) caregiver’s coping mechanisms; and g) caregiver’s demographic information.

2.4. Data Analysis

Interviews were audio-recorded and transcribed verbatim after each interview, and the accuracy of transcripts was reviewed by the interviewer. Themes were presented as derived from Braun and Clarke’s thematic analysis. The steps include: (1) familiarize the data by reviewing recordings and transcripts; (2) generate initial codes; (3) develop themes based on generated codes; (4) review themes by deleting themes with limited data support, combining similar
themes, and make adjustments to existing themes; (5) name and define themes when a satisfactory thematic map is achieved; and (6) producing the report (Braun & Clarke, 2006).

2.5. Trustworthiness

Three strategies, including reflexive journal, multiple analyst triangulation and peer debriefing, were used to enhance the rigour and trustworthiness of study findings. Journal entries, consisting of the researcher’s perspectives and positions, were documented before and after each interview. This was done to increase the researcher’s self-awareness regarding their background and interests (Finlay, 2002; Lincoln & Guba, 1985) and avoid guiding the interview based on their own caregiving experiences or knowledge (Anney, 2014; Nicholls, 2009). The present study also utilized multiple analyst triangulation to include perspectives of researchers and health professionals from various disciplines (e.g., occupational therapy, mental health and psychiatry), and the authors met regularly to generate ways to present the findings. As peer debriefing, the research findings were presented in team meetings of health professionals and health and rehabilitation researchers in the Greater Toronto Area to receive feedback and consider alternative interpretations of the data (Morse et al., 2002).

3. Results

Eleven individual interviews (either in-person or over the phone) were conducted with caregivers to older adults with a clinical diagnosis of depression in Toronto, Canada, over an 11-month period (February to December 2017). Data saturation was reached after nine interviews and two additional interviews were conducted to ensure saturation. The age ranged from 40 to 73 years old and the majority of caregivers were women (n = 10/11). Caregivers consisted of partners (n = 3/11), adult children (n = 7/11) and sibling (n = 1/11). Refer to Table 3.1 below for more detail.

Table 3.1 – Demographic characteristics of caregivers

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Participants (n=11)</th>
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<tr>
<td>Age (range, years)</td>
<td>40-73</td>
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<td>Sex</td>
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The findings revealed four key themes that reflect the experiences, available supports and needs of caregivers. Firstly, caregivers observed changes in the PWD’s character, and they felt their relationship with the PWD became different. Secondly, the caregiving role and responsibilities affected caregivers’ lifestyle and well-being. Thirdly, caregivers revealed the resources they utilized to help with caregiving and their own well-being, and they discussed additional resources that they would like to receive from the healthcare system. Lastly, the stigma of depression in older adults and its relationship with caregiving was discussed. These themes will be described in detail in the following sections including participant quotations to exemplify specific points.

3.1. “Not the Person I Used to Know”
As depression manifested in the PWD, caregivers witnessed what they perceived to be a transformation in their personality. The depressive symptoms increased the complexity of care as caregivers reported adjusting to the changes of the PWD’s character and the impact on their family dynamic.

3.1.1. Symptoms of depression. Caregivers reported the PWD had a lower mood in general, was more lethargic and had difficulties in taking actions and conducting daily activities. As well, they described the PWD as more critical and frequently complained about their surroundings, and they thought the PWD had difficulties in finding joy in things they previously enjoyed. Caregivers also found the PWD to be more easily upset or irritated compared to before, and that they were sometimes the recipients of the PWD’s criticisms. As a result, caregivers didn’t enjoy being with the PWD.

“When I go to the [PWD’s] house… it feels like walking into a morgue. It really, it’s like such a depressing situation to walk into that house every week” (P7, son of the PWD).

“And just, you know, like little stuff. Like oh, I don’t know, complaining about the TV show. Just constant, you know? Like my god. Is there anything you can say something nice about” (P10, wife of the PWD)?

Caregivers thought the PWD demonstrated more self-centered and unappreciative behaviours. Many caregivers reported their interactions and conversations centered around the PWD (e.g., the PWD complaining about their day, the PWD’s concerns and worries), and they felt the PWD was less cognizant of other people’s needs. As well, caregivers commented on the PWD not expressing much appreciation, and instead, they demanded more help. Although they suspected these actions as manifestations of depression, some caregivers still felt taken for granted and were deterred from interacting with the PWD.

“He can be negative. He’s also very self-centered right now. Everything that’s happening has to happen around him, for him. Um, he’s uh, he hasn’t been very conscious about
other people’s needs or concerns, which is unlike him, because he is a very sensitive man” (P2, wife of the PWD).

Caregivers also observed a lack of motivation in the PWD, leading to inactivity and treatment non-compliance. Some caregivers were frustrated because they thought the PWD was not putting in the effort to improve their situation or take care of themselves.

“She has difficulties in initiating and just getting up and doing stuff. She says that she can’t get up and get dressed and has a really hard time just even doing things like seeing something on the floor and picking it up” (P3, daughter of the PWD).

Caregivers felt the PWD was heavily dependent on them, and the sense of responsibility sometimes made the role suffocating. The feeling was further compounded when the caregivers thought they were the sole social support of the PWD.

“He didn’t like the separation. He is very clingy. I couldn’t leave him for very long periods, if I had to do groceries or go to the drug store and pick up medications or anything, I have to keep calling him every fifteen minutes… I thought I was in a cell, I couldn’t escape” (P2, wife of the PWD).

Caregivers described feelings of interacting with a different person due to the manifestation of depression, and many characteristics deterred them from continuing their caregiving role. Consequently, caregivers felt these depressive symptoms affected their relationship with the PWD.

3.1.2. Family life. In general, caregivers felt their relationship with the PWD became unbalanced, and they were offering support and care without reciprocation from the PWD. Caregivers adapted to the care provider role regardless of their familial relationship or previous dynamic, and they felt the need to take charge in most situations. Caregivers commented on spending more time with the PWD due to caregiving responsibilities, but the interactions were more often related to caregiving (e.g., driving to doctor’s appointment) than leisure activities (e.g., playing board games). As well, caregivers thought it was harder to communicate with the PWD.
Caregivers had difficulties in getting the PWD to openly share themselves, and caregivers felt their voices and feelings were not heard by the PWD. They expressed feelings of loneliness when reciprocations were absent. In addition, some caregivers commented that families had disagreements over how caregiving responsibilities (e.g., taking the PWD to doctor’s appointments, spending time with the PWD) should be divided among the family members which increased family tension.

“I think it’s the feeling of being alone in it. You know? Like when you’re the one looking after the bills, investments, and the future of this property, the family stuff, the kids… You kind of feel alone in it, because he is like “I don’t care, don’t tell me”. Like I’m on the board of directors and he has no interest in what’s happening and what I’m doing” (P10, wife of the PWD).

Few caregivers reported that the care recipient’s illness brought the family closer together and they spent more time with each other. However, caregivers said the PWD’s negative attitude did repel them after a prolonged period of time.

3.2. “My Life Has Changed”

Caregivers reported changes in their lifestyle and well-being as they took on the caregiving role and responsibilities. Caregivers discussed experiencing symptoms similar to depression (e.g., low mood, anger), neglecting own health and constantly worrying about the PWD.

3.2.1. Caregiving responsibilities. Caregivers helped the PWD with IADL and spent more time with them to ensure their well-being. Caregivers commonly reported driving the PWD places, accompanying the PWD to doctor’s appointments, navigating the healthcare system on the PWD’s behalf, doing household chores, paying bills, creating schedules for the PWD to keep them active, and taking on responsibilities formerly held by the PWD.

As well, caregivers reported being with the PWD much more frequently (e.g., everyday activities, chatting), both in-person and remotely (e.g., telephone and FaceTime). They spent time with the PWD when they had openings in their schedule and tried to alleviate the PWD’s
depressive symptoms by keeping them active and accompanied. Many caregivers took on the counselling role in these situations and offered the PWD encouragements to follow treatment plans and listened to the PWD’s problems and complaints. During severe phases of depression, caregivers described the PWD becoming completely paralyzed and unwilling to get out of bed. In these instances, caregivers helped them with ADL to ensure their wellness, including bathing, dressing, toileting and eating.

“I go to the doctor with her. I can help her pay her bills. I had to sleep with her, get her up, take her to the bathroom. Living with her all day, cooking for everybody. And then we would go to her house and clean” (P1, daughter of the PWD).

3.2.2. Lifestyle modification. Caregivers often modified their lifestyle to fulfill caregiving duties. Outside of caregiving, caregivers commonly reported having to attend to employment, volunteer positions and other family members, and they experienced difficulties in accomplishing caregiving tasks in addition to their pre-existing responsibilities. For caregivers that were retired or had flexible work schedules, they planned their daily activities around the PWD’s needs. Since taking on the caregiving role, some caregivers worked fewer hours, took leaves of absence or retired from their previous job to create time for caregiving activities.

“I’ve taken most of the year off. I was her primary caregiver and she could not be alone, so I had to do everything for her… I would have to take a leave of absence from work because there would’ve been no one” (P1, daughter of the PWD).

Some caregivers spent less time with other family members, but they recognized that other family members also required attention and ensured some time was reserved for them.

“Just trying to find the time to balance my brother and my husband was demanding. I would say that all filters down into stress” (P9, sister of the PWD).

In contrast, caregivers’ social life and leisure activities were often neglected when they were busy. Besides not having time, caregivers also commented on being too exhausted to socialize. As well, some caregivers reported strong feelings of guilt when they socialized or
spent time on their hobbies instead of accompanying the PWD. As a solution, some of them invited the PWD to join their social functions or leisure activities.

“It’s no time and not only time, but socially I’m exhausted a lot of the times, so I don’t really feel like hanging out. You get sucked into the vortex of this [caregiving] world, you just get caught in it” (P7, son of the PWD).

When the PWD was experiencing severe symptoms, caregivers made drastic changes to their life schedule and became fully involved. One participant described the situation as “all hands on deck” (P10, wife of the PWD), and they put the rest of their life on hold and attended strictly to caregiving activities. The sudden onset of depressive episodes or the possibility of them deterred the caregivers from planning extended trips or time away from the PWD.

“When we’re in crisis mode… my Christmas went out the window, and anything we have planned, like New Years, any events we have planned went out the window. It was all about taking care of my mother” (P1, daughter of the PWD).

3.2.3. Well-being. Caregiver’s health was often negatively impacted by their caregiving role. Specifically, caregivers reported a decline in their mental and physical well-being, while their financial well-being is affected to a lesser degree.

Caregivers identified several psychological stressors since taking on the caregiving role. Constant worrying was noted by the majority of caregivers, and they reported having repetitive thoughts about the PWD’s safety (e.g., self-destructive and suicidal behaviours) and their future (e.g., symptom improvement). Caregivers experienced stress and exhaustion in these instances.

“I’m worried about his state of mind, I’m worried about his health, I’m worried about whether he’s going to pull through this. I’m worried about whether he’s going to be okay… I think the worst part was just watching him go through that. Just having to watch. So a lot of time I would be at home worrying about he was doing all day because I knew he was very unhappy and had nothing to do” (P9, sister of the PWD).
Many caregivers revealed experiencing depressive feelings in their caregiving role. Caregivers noted that their mood was heavily influenced by the PWD’s emotions, and their well-being felt dependent on the PWD’s condition. As well, the feeling of helplessness and inability to assist the PWD further enhanced their depressive feelings.

“Sometimes I come home and I just wanted to scream or cry. I have a lot of friends and wonderful kids, but in between I am really depressed. Thinking about it and trying to help [the PWD]… Sometimes I wonder how much I am helping them because I’m dragging myself down. My well-being depends on how her mood is and how depressed she is” (P5, daughter of the PWD).

“Does depression breed? If you’re looking after someone who’s depressed, can you end up getting depressed” (P10, wife of the PWD)?

Frustration and resentment were also noted by several caregivers. These feelings arose when caregivers had to make undesirable changes to their lifestyle, and the feelings were further compounded when they did not feel appreciated for their efforts. Caregivers also described feelings of frustration when the PWD was not following treatment plans.

“I get very frustrated at her at times… I keep reminding myself that I have to do more for myself during the day or else it’s not gonna happen and I start to feel resentful. I do feel frustrated when my mom feels like [my help] is not enough” (P3, daughter of the PWD).

As well, caregivers commented on a decline in their physical health. Caregivers felt physically exhausted from helping the PWD with IADL and not getting enough rest. Specifically, caregivers commonly reported doing house chores for the PWD and driving them to places as tiresome activities. Additionally, caregivers placed their own physical health on the backburner and neglected exercising and rehabilitation, and they experienced physical discomforts or illnesses as a result.

“I cut my [rehabilitation] short… I put my own health on the backburner and I shouldn’t have done that. Because I have issues that I’m trying to deal with that had I taken steps a
few months ago I wouldn’t have the problems that I have right now” (P2, wife of the PWD).

Caregiving did not have a large impact on the majority of caregivers’ financial well-being. Most caregivers commented that their families were in good financial standing and they were able to afford help when necessary (e.g., homemaking services). However, for caregivers that were financially dependent on their employment, reduction in working hours negatively impacted their financial well-being and led to stress. In addition, few caregivers commented on not being able to perform at work due to constant worrying and exhaustion.

“The hours I should be working are spent with my folks or dealing with those [caregiving] issues, then I’m not making money” (P7, son of the PWD).

3.3. Available and Desired Support

Caregivers described resources they utilized to help with their caregiving role including their own internal personal resources, their surrounding social support (external personal resources) and the healthcare system. As well, caregivers discussed services they wished were available from the healthcare system.

3.3.1. Internal personal resources. Caregivers rely on coping strategies, including mindsets and activities, to sustain their caregiving roles. Some caregivers accepted the chronic nature and symptoms of depression and did not expect the PWD to immediately recover or to receive additional resources. As well, accepting the illness and understanding the negative tendencies of PWD allowed caregivers to avoid taking depressive symptoms (e.g., anger and sadness) personally.

“When [the PWD] is directing his anger at me, I just go “oh okay you’re feeling particularly bad today”. You know you’re the only other person that the negativity can be directed at… I’m smart enough to know that that’s just an emotion for an instant” (P10, wife of the PWD).
“I get frustrated, but then I think I’m able to push it aside a little bit and realize it’s not her per se, it’s not me per se, it’s just unfortunately right now and try not to take it too personally” (P3, daughter of the PWD).

Caregivers’ own confidence in being a good caregiver also contributed to their ability to cope. They described gaining confidence from past successful caregiving experiences and their personality traits (e.g., patient, gentle, caring) that were suitable for caregiving. They commented on feeling in control of the situation and focused on taking actions to improve the present situation rather than reminiscing about the past or worrying about the future.

“I’m a good caregiver and I’m the one that gets things done” (P5, daughter of the PWD).

“I’m a firm believer in you deal with what you got, and you make the best of it” (P10, wife of the PWD).

Caregivers’ personal motives encouraged them to continue providing care. Many caregivers expressed their love for the PWD and commented that although it’s not always pleasant, they would provide care for as long as needed.

“Being a caregiver… I don’t resent it. Well, maybe a little. I wouldn’t not do it. I love this man with all my heart. But it wouldn’t be my choice, no” (P10, wife of the PWD).

For caregivers that did not have a positive relationship with the PWD or who were the PWD’s only social support, they continued to provide care due to the sense of duty as a family member. Caregivers were also inspired to offer support as they experienced satisfaction from feeling needed and fulfilling their duties as a family member.

“I guess there is a certain satisfaction to fulfilling your responsibilities. You feel that you’re doing the right thing for whatever that’s worth… It’s being put in a position where you feel you’re absolutely trapped, like I’m really the only [caregiver]. But I care. I care for their well-being” (P7, son of the PWD).
After several months of care, many caregivers recognized their own limits and the importance of self-care. Most caregivers scheduled physical activities into their weekly routine as a form of self-care, and some caregivers described doing other hobbies or going to work as a temporary break from their caregiving duties. As well, caregivers described hobbies and employment as opportunities to reclaim their individuality and remind themselves who they were outside of caregiving. When discussing coping strategies, few caregivers commented on the use of sleeping pills, alcohol, cigarettes or marijuana to combat the pressure and acquire a temporary relief.

“You have to nurture yourself if you’re going to be able to take care of another person” (P8, daughter of the PWD).

Some caregivers reported having a sense of detachment from the PWD. By seeing the self as a separate entity from the PWD, they found themselves less likely to be swayed by depressive mood and found it easier to maintain a balanced lifestyle.

“[Caregiving] wasn’t going to change my life except being a caregiver” (P11, wife of the PWD).

Caregivers’ knowledge regarding depression and the healthcare system also contributed to caregiving. Caregivers that had an understanding of depression expressed patience and were less irritated by depressive symptoms. As well, they often had ideas on how to help. Most caregivers that had extensive knowledge of the healthcare system obtained the information from their job or past experiences in navigating the system. Caregivers that worked in healthcare understood the resources that were available and had multiple connections to health professionals where they could obtain help (e.g., connection to resources).

“If I didn’t work here, honestly, I don’t think I would know what to do. Her family doctor is not all that responsive, she’s very busy, right? So she doesn’t have the time. If I didn’t work here I think it’d be difficult. Like if – to find things. Like I wouldn’t know what to do” (P6, daughter of the PWD).
3.3.2. External personal resources. Caregivers reported reaching out to their social circle, mostly family and friends, to share caregiving responsibilities and receive emotional support. In instances where other people were involved in the PWD’s care, caregivers described a sense of relief because the caregiving duties were not their sole responsibility. In addition, having the social support allowed caregivers to share their frustrations and sometimes gain new perspectives. Similar to hobbies and employment, time spent interacting with their social circle offered caregivers a rest from their caregiving role. Caregivers also viewed the PWD receiving support from others and their ability to self-care as valuable resources. Specifically, caregivers reported feeling less worried when the PWD had help from others, followed treatments and conducted activities that were beneficial to their mental states and well-being.

“I have a very supportive immediate family. My own kids and husband are amazing. So, um, when they’re living here, they would do things for [PWD]… So yeah, everybody kind of chips in” (P1, daughter of the PWD).

In contrast, some caregivers had little social support or they realized the limitations on what others were able to do. In these instances, caregivers felt like they were fighting an uphill battle alone.

“I can phone and complain to someone and they’ll listen to me. But nobody’s moving in. And at the end of the day it’s still me living with [the PWD]” (P10, wife of the PWD).

“It’s a pretty shallow pool. I don’t have a lot of social support, I don’t have a lot of extended family support, it’s pretty much just me, yeah… And just very practically I haven’t had people to delegate to and share responsibilities with” (P7, son of the PWD).

Caregivers’ wealth was a key determinant of their ability to utilize private care. Caregivers who were financially able reported hiring nurses, homemakers and housekeepers to deliver home care services for PWD and accessed respite care during crisis situations. These resources lessened the caregiving responsibilities (e.g., IADL, ensured the PWD’s safety). Many caregivers that were employed reduced their work hours to transition into their caregiving role.
With this decision, some caregivers placed themselves in a difficult financial situation by supporting unmet care needs.

“We did get [PWD] a full-time housekeeper for the physical things… I think it’d be a different thing if you couldn’t afford some of the help. I think it’s very helpful to have the money to have this support system” (P8, daughter of the PWD).

3.3.3. Healthcare system. Caregivers expressed conflicting feelings towards the public healthcare system. Some caregivers encountered helpful healthcare professionals that fully addressed their concerns and the PWD’s needs. Caregivers described these health professionals as navigators that connected the PWD and caregivers to resources, and they frequently followed up on the PWD’s condition. In these cases, caregivers reported a sense of shared responsibilities and they experienced less burnout. As well, they had the freedom to spend more quality time with the PWD.

“Getting my mom connected with [health professional] has been great because [health professional] has opened the door to a lot of different things as far as my mom having a full geriatric assessment at [hospital] and getting connected with physio and all that sort of stuff. So I think that if I didn’t have that connection I feel like we would be kind of drowning a little bit and don’t know what to do” (P3, daughter of the PWD).

In contrast, some caregivers interacted with healthcare professionals that were dismissive, did not address the PWD’s and caregiver’s concerns and were not knowledgeable regarding the resources available. Caregivers perceived these health professionals as non-caring and belittling. They understood health professionals’ busy caseloads but reported feeling frustrated and helpless in these circumstances.

“I had to fight with doctors. I wasn’t happy with the family doctor. I had the right to ask for a second opinion… When I gave the information to the family doctor, she tore the piece of paper with the information on it from my hands, was very rude, very um, belittling” (P2, wife of the PWD).
“Unfortunately I think quite often family physicians, they’re overworked and they’ve got about 15-minute time slot to see their patients. And somebody like my mother – she has actually been told that she reached the max of what she is allowed to talk about… But she doesn’t have anybody else, there aren’t a lot of doctors” (P3, daughter of the PWD).

In cases where the PWD had comorbid conditions that inhibited their ability to perform ADL and IADL (e.g., hip fracture, cognitive impairment), they were able to receive substantial homemaking services from the public system that alleviated some caregivers’ responsibilities. Many caregivers also compared their current caregiving situation with past caregiving experiences, such as providing care to an individual with hip fracture or dementia, and they reported that older adults with depression and their families received much fewer services. For the PWD that had comorbidities that did not strongly affect their ability to perform ADL or IADL (e.g., diabetes, hearing impairment), caregivers reported receiving very little to no homemaking services and had to pay out of pocket for additional help.

3.3.4. Desired support

Caregivers expressed frustration and wished more resources were allocated to older adults with depression. As for caregivers’ desired support, they mostly wished for resources that would improve the PWD’s well-being rather than supports for themselves.

3.3.4.1. Additional resources for the PWD. In general, they wished the healthcare system had more resources for the PWD so the caregiving responsibilities were shared and they could be more confident the PWD was receiving proper care. Caregivers asked for shorter waiting times for services (e.g., doctors’ appointments and therapy sessions), and more affordable homemaking services and respite care. Caregivers believed the current healthcare system was not tailored to older adults with depression, who they described as a population that could greatly benefit from additional services due to lethargic symptoms and difficulties in performing some ADL and IADL. When caregivers observed severe depression in the PWD, they reported not knowing what to do and often sent the PWD to emergency rooms or respite care services. In these cases, caregivers often had to pay a portion of the fees out of pocket, and they wished the healthcare system could provide greater coverages.
“I wish my mom had more medical attention, but it takes forever, getting referrals are hard. Even getting her family doctor is hard. Resources are limited” (P3, daughter of the PWD).

“It would be easier for caregivers if the patient was able to get more services. Then caregivers can spend more time just hanging out and talking or doing fun things as opposed to trying to look up services or trying to take them to appointments” (P5, daughter of the PWD).

“The better she is, the [more] independent she is, the more she has things to do and is happy with her surroundings, you know, better my life is by far. I just need her to be okay. And if she’s okay then I can live my life and find my own, her situation directly affects mine” (P7, son of the PWD).

“The only help that would’ve helped me would’ve been something to help him” (P9, wife of the PWD).

3.3.4.2. Service navigation. The majority of caregivers complained about the difficulties in finding resources in the healthcare system, and they wished for a one-stop shop that has a comprehensive list of supports and services available. Caregivers reported the PWD often gave up looking for support for themselves because of how complicated the system was, so the caregivers had to explore the system on their behalf. Caregivers imagined this service in the form of a helpline or an information centre that can provide medical advice, assistance, and connect the PWD and caregivers to relevant help.

“I find depending on the family physician of the person, they may or may not know the services that are available… So if there was some way that there is a central place that you can access information and services. Because I think a lot of people don’t know where to start” (P3, daughter of the PWD).
“Make [the healthcare system] easier. Easier to access and understand. Think about the position they’re in, again both with depression and being older. Waiting on the line forever or being referred to a website that is complicated and – somebody’s already not in a great state, they’ll be turned off, or they’ll just give up” (P7, son of the PWD).

3.3.4.3. Caregiver access to health professionals. Caregivers wished the health professionals were more accessible to them so that they can receive information on the PWD’s progress and guidance for their caregiving role. Caregivers expressed frustration when both the PWD and health professionals refused to provide updates on the PWD’s condition. They described feeling like the only person in the dark and wished the healthcare system would be more inclusive of family members in the PWD’s treatment plan.

“I found it very difficult to get information from anybody. Phone calls weren’t returned, I was trying to find out how [PWD] was doing… I found it very frustrating. And that added to my stress because I didn’t really know what his condition was at any given time” (P9, wife of the PWD).

Additionally, many caregivers reported feeling lost on how they can help the PWD. They did not know how to react to depressive symptoms, and they wished for advice on things they can do to help the PWD to alleviate depressive symptoms. Few caregivers mentioned the desire for support groups to obtain emotional support and education.

“I don’t know if I should be here, or not be here or do things for him or not. Like I – you know, I’m sort of in a quandary about what my job is” (P11, wife of the PWD).

3.4. Stigma of Depression

Interviews suggested some of the PWD, caregivers, and society expressed attitudes and behaviours similar to stigma towards depression. Caregivers thought this feeling of disapproval, non-acceptance or lack of empathy toward depression hindered the PWD’s and their own ability to reach out for help and reduced their social support, which increased the difficulties associated with providing care.
3.4.1. Stigma from the PWD

Caregivers reported seeing the PWD attributing their depressive symptoms as a weakness rather than an illness, and it delayed the PWD to seek treatment or ask caregivers for help. As well, caregivers thought the PWD was worried about other people’s judgment if they disclosed their mental illness, so the PWD isolated themselves and hid their depressive symptoms from others.

“We have lots of supports in our community, but she won’t use them. You know, it [seems like] everything is great, and she wants to maintain that… there’s so much stigma around mental health. You can’t see a cast around it, so people stigmatize it, right” (P1, daughter of the PWD)?

“The number of people who came to my husband who said, “I suffer from depression and my family doesn’t know, when I get really sick I go away on a business trip for a month.” I mean, hidden, completely hidden, unable to own up. Unable to acknowledge even for themselves that they, you know, couldn’t get their act together so to speak” (P11, wife of the PWD).

3.4.2. Stigma from caregivers

Similarly, some caregivers attributed symptoms of depression, for example, lethargic behaviours and inactivity, as the PWD’s choice to be difficult and lazy. As a result, caregivers felt frustrated and impatient when the PWD refused to reach out for help or follow the treatment plan, and caregivers expressed little to no empathy for the PWD in these instances. The lack of understanding of depression discouraged caregivers from seeking support on the PWD’s behalf and diminished their motivation to help.

“Her thing is “I got nobody, I’m all alone”, she’s not all alone. She’s actually got a team of people around her. She’s got all the resources she needs, both financial and otherwise. She acts like she’s chained to the chair. No one is stopping her from taking a cooking
class, or getting some exercise, or having a coffee with a friend or doing all this. She just refuses to” (P7, son of the PWD).

“He saw the doctor, told her that he was going home. And then I just lost it with him. I said ‘You gotta reach deep within yourself here, you have to pull up your socks and you have to go to the hospital’” (P2, wife of the PWD).

3.4.3. Stigma from the society

Caregivers also experienced a lack of understanding and acceptance of depression from members of their social network and society. Caregivers described interacting with people who wondered why the PWD couldn’t just get better or shake off the laziness, and they had to defend the PWD and explain depression. As well, some caregivers witnessed people from their social network becoming distant, and they suspected the reasons being they didn’t know how to interact with the PWD or were unwilling to be around someone with a low mood that was easily irritated. Caregivers thought the society’s negative perception of depression caused the PWD to have less social support and become more reliant on them as a result.

“One of our daughter’s sort of said at the time ‘well, why can’t he just, you know, get his act together and come home?’ … Even my husband himself sort of said ‘you know, I ought to be able to just pull up my socks and get going and you know, I’m weak, not sick’” (P11, wife of the PWD).

4. Discussion

4.1. Main findings

The present study explored the experiences and support needs of caregivers to older adults with a formal depression diagnosis. Caregivers discussed adjusting to the PWD’s symptoms and the changes depression brought to their lives, in areas including family dynamic, lifestyle and well-being. Some caregivers found beneficial resources from the healthcare system,
while others wished for additional support for the care recipient and themselves. Stigma towards depression from the care recipient, caregiver and society was also discussed.

The findings of the present study were comparable to studies on caregiving of adults with depression, as this study highlighted the negative impact of caregiving on family members’ psychological and physical well-being. Sewitch and colleagues’ (2004) quantitative study suggested that caregivers of older adults with depression provided more care and had worse mental health and perceived quality of life compared to caregivers of non-depressed older adults. As well, qualitative studies on caregivers of younger adults reported that caring for a PWD is both physically and mentally demanding as exhaustion (Ahlström et al., 2009; Hansen & Buus, 2013) and depressive feelings (González et al., 2010; Highet et al., 2004; Muscroft & Bowl, 2000; Nosek, 2008; Radfar et al., 2014; Skundberg-Kletthagen et al., 2014) were common. However, caregivers in this study highlighted the disabling effect of depression on older adults’ ability to perform ADL and IADL, and caregivers were often responsible for the care recipients’ unmet needs. Participants in this study took on extra household chores, which was not frequently reported in caregivers of younger adults with depression (Priestley & McPherson, 2016). The household tasks were especially strenuous when caregivers had physical health concerns, adding to the difficulties of the caregiving role. This study emphasized the similarities between caregivers of older and younger adults, and it also highlighted the additional caregiving responsibilities that caregivers of older adults often managed.

The findings suggested each caregiver received varying amounts of help from the healthcare system and highlighted the lack of standardized care for families. Participants that were not satisfied with the healthcare system discussed insufficient resources for the PWD and themselves contributing to feelings of distress, frustration and helplessness. Caregivers reported that the PWD received very little (e.g., 2 hours per week) to no homemaking services, and many caregivers used their own finances to hire private care and cleaning services as a result. They expressed the desire to have additional subsidized homemaking services to share caregiving responsibilities and support the PWD to maintain an independent lifestyle. Past studies on families of frail older adults have demonstrated that receiving home making services was associated with lower caregiver burden (Graessel, Luttenberger, Bleich, Adabbo, & Donath, 2011; Mason et al., 2007). Some caregivers in the present study had health professionals that connected them to resources, while others had difficulties navigating the healthcare system to identify the limited help that was available to the PWD and themselves. These caregivers wished
for an information centre that has a comprehensive list of supports and services available. In comparison, individuals with dementia and their caregivers have established organizations, such as the Alzheimer Society’s First Link program, that provides the element of service navigation (Woods & Tadros, 2014). In Woods and Tadros (2014) study, both the health professionals and caregivers found the Alzheimer Society beneficial and supportive. Policy makers that are looking to implement system changes for older adults with depression and their caregivers can consider providing additional homemaking services and creating establishments similar to the Alzheimer Society’s First Link program or having designated health professionals to guide caregivers.

The findings also emphasized the need to consider family members in the PWD’s treatment plan. Specifically, some participants in the study were uncertain how to react to PWD’s self-destructive or suicidal behaviours, and they experienced stress and helplessness as they constantly worried about the PWD’s safety.Caregivers desired to receive guidance on ways to assist the PWD when they were depressive, unmotivated or in a self-destructive mind state. As well, caregivers wanted to receive updates on the PWD’s health condition, and they often felt frustrated, unimportant and isolated when they were not included in the treatment plan and unable to contribute. Recent studies on family-centered care in mental health suggested involving the family members in patient’s treatment plan may be the best practice for supporting the well-being of both the individual with mental illness and their families (Heru, 2015; MacFarlane, 2011; McNeil, 2013). Policy makers that aim to implement family-centered care for older adults with depression may consider implementing exist models and resolving the challenges (e.g., billing structure, training for family-centered care) that clinicians and organizations encountered when trying to apply similar changes in other illness populations (Leonard, Linden, & Grant, 2018; Wong, Wan, & Ng, 2016).

4.2. Limitations and Conclusion

Although caregivers of an older adult with depression were interviewed, there were some limitations surrounding the demographic diversity of subjects. Firstly, the interviews of all participants were analyzed together regardless of caregiver and care recipient’s familial relationship. Past studies have suggested that caregivers in different familial roles may also have very different life circumstances (e.g., spouse caregivers are more likely to reside with care recipient). This limited the current study’s ability to examine similarities or differences in
caregiving associated with the familial role. As well, the majority of participants for the present study were women. Past studies have observed differences between male and female caregivers, and the findings did not explore any gender comparisons. Another limitation of the study may result from the high income of our study population. Many participants were able to afford additional homemaking and/or respite care services, and the perspectives of caregivers that experience financial struggles may be absent from the study findings. Future research may further consider caregivers’ demographic factors and familial relationship and their impact on the caregiving experience to PWD.

This study provides evidence that an older adult’s depression has a profound effect on their family caregivers, as they are at risk of developing their own health concerns. The findings highlighted the disabling effect of depression on older adults and their needs for additional help with ADL and IADL compared to younger adults. The findings emphasized the need for a formal and structured approach to help families, as caregivers were often responsible for older adults’ unmet needs. Additional resources from the healthcare system may be a key element in reducing the psychological and physical stress that caregivers experience. This study provides the unique perspectives of Canadian caregivers, and an understanding of these caregivers’ experiences and desired services provide insights for clinicians and policy makers to implement resources to optimize the caregiving role.
CHAPTER FOUR

Discussion, Limitations and Conclusion
4.1. Discussion

The present study explored the experiences and support needs of caregivers to older adults with a formal depression diagnosis. Caregivers discussed adjusting to the PWD’s symptoms and the changes depression brought to their lives, in areas including family dynamics, lifestyle and well-being. Some caregivers found beneficial resources from the healthcare system, while others wished for additional support for the care recipient and themselves. Stigma towards depression from the care recipient, caregiver and society was also reported.

The final themes presented were derived through a thematic analysis and were not mapped onto Pearlin’s SPM. Initial attempts were made to map the themes onto Pearlin’s SPM but it did not enhance the findings. Although the study direction and data collection were informed by Pearlin’s SPM, a general thematic analysis was used as it best represented the key themes arising from the study. The interviews went beyond the discussion topics included in the model (e.g., stigma, desired support) and provided a rich dataset for analysis. Additionally, Braun and Clarke’s thematic analysis offers the option to analyze the data inductively, or a “bottom up” approach. An inductive approach stays closer to the data as opposed to organizing the findings using a theoretical model or the researcher’s interpretations (Braun & Clarke, 2006), which aligns with the choice of qualitative descriptive approach (Sandelowski, 2010). In contrast, using Pearlin’s SPM in the data analysis would likely require applying a deductive approach and fitting the collected data into Pearlin’s SPM instead of constructing themes based on the interviews.

The objective of this study was to obtain a better understanding of the experiences and support needs of this caregiving population that is under-researched. Pearlin’s SPM has not been used previously with this caregiving population and we do not know if the SPM accurately represents or fully captures their experiences and needs. However, it was helpful to organize the existing literature using the model as it captures key aspects of caregiving as identified in other caregiving populations. It is important to note that using Pearlin’s SPM to inform data collection does not align with the inductive approach of qualitative descriptive methodology, and this could be a limitation of the research. Nonetheless, the model was a helpful starting point for the graduate student, who was new to qualitative research that was studying an under-researched population (i.e., caregivers of older adults with depression), to begin the research.
The present study contributed to the robustness of Pearlin’s SPM and identified factors that may be unique to this caregiving population. The study utilized Pearlin’s SPM to guide the data collection process, and the findings included several stressors (e.g., problematic behaviours, ADL and IDAL dependencies, lifestyle adjustments), mediators (e.g., coping strategies, social support) and outcomes (e.g., psychological and physical well-being) that were originally included in the model. As well, the present study and past research identified additional factors unique to this population that are not elements of the model but align with its domains, such as stigma and constant vigilance as stressors. This study adopted a qualitative approach because there is very limited research on caregivers of older adults, and we were uncertain which factors are relevant to this population. By using Pearlin’s SPM in a qualitative study, we identified aspects that are important to this caregiving population, but the goal was not to examine associations between these factors. It may be interesting for future research to examine the relationships between specific factors using quantitative measurements (e.g., the PWD’s IADL dependencies and caregivers’ depression), as such research may help policy makers to identify variables that negatively affect caregiver well-being and create resources accordingly.

The study highlighted the lack of standardized care for families as the participants reported receiving various amount of help from the healthcare system. Participants in the study commonly discussed worse psychological and physical outcomes since taking on the caregiving role, and most caregivers wished for more supports and services. Three key categories of desired support were identified in this study, including 1) additional resources for the PWD, 2) service navigation, and 3) caregiver access to health professionals.

Participants discussed a lack of resources from the healthcare system for the PWD, and they reported feelings of distress when they thought the PWD were not receiving the best care available. This is in line with past findings that inadequate support from the healthcare system can increase frustration and helplessness (Harris et al., 2006; Highet et al., 2004; Stjernswärd & Östman, 2008). Compared to older adults with dementia, both populations have difficulties in maintaining their own well-being (e.g., dementia due to cognitive impairment, depression due to lack of motivation and some cognitive impairment). In terms of treatment options, antidepressant and multidisciplinary interventions are available to individuals with depression, and no standardized help is available for caregivers (Prince, Livingston, & Katona, 2007). In contrast, individuals with dementia have the options of behavioural management strategies, nurse-led
collaborative care, pharmaceutical treatments and psychosocial interventions for caregivers (Prince et al., 2007). As mentioned in the previous chapter, participants reported using their own finances to hire private care, homemaking services and respite care. However, most participants in this study had high family income, and they believed caregiving would have been much more difficult if their family was not able to afford the additional help. They expressed the desire to have additional subsidized homemaking services to share caregiving responsibilities and support the PWD to maintain an independent lifestyle. Similarly, caregivers thought the respite care was expensive and not subsidized by the healthcare system, or some caregivers were not aware of such a service. A systematic review on respite care programs for individuals with dementia showed that temporary residential admissions were commonly associated with a reduction in caregiver stress (Vandepitte et al., 2016). Temporary respite care services for older adults with depression could be beneficial to both caregiver and care recipient outcomes.

The current study found inconsistent quality of help caregivers received from the healthcare system and highlighted the lack of standardized care for families. Specifically, the majority of caregivers had difficulties navigating the healthcare system to identify the limited resources that were available to the PWD and themselves, while a few caregivers encountered resourceful health professionals who connected them to available support. The participants that had problems locating existing resources wished for a one-stop shop with a comprehensive list of available supports and services. In comparison, individuals with dementia and their caregivers have established organizations, such as the Alzheimer Society, that have a compilation of resources and can direct and connect patients and their caregivers to these resources (Woods & Tadros, 2014). For instance, the First Link program from the Alzheimer Society partners with local healthcare professionals to ensure patients and their caregivers are connected to resources and supports provided by the organization and other community services in the city. In Woods and Tadros (2014) study, both the health professionals and caregivers found the services beneficial and supportive. Policy makers aiming to implement system changes for older adults with depression and their caregivers can consider programs, like First Link, offered by the Alzheimer’s and other societies as models to serve this population.

The findings also emphasized the need to include family members in the PWD’s treatment plan. Recent studies on family-centered care in mental health suggested involving the family members in patient’s treatment plan (e.g., regular meetings with caregivers to follow-up with care
recipient’s progress, educate caregivers on mental illness) may be the best practice for supporting the well-being of both the individual with mental illness and their family (MacFarlane, 2011; McNeil, 2013). Specifically, family-centered care in outpatient psychiatry has been associated with improvements in caregiver and patient outcomes (e.g., less caregiver burden, improvements in patients and caregiver health) (Heru, 2015). By including families in the patient’s treatment plan, they can assist patients with appointment attendance, medication adherence and emotional support. As well, families become more knowledgeable about care recipient’s illness and understand ways they can support the care recipient, thus reducing their own caregiving stress. Policy makers that aim to implement family-centered care for older adults with depression may consider resolving the challenges (e.g., billing structure, training for family-centered care) that clinicians and organizations encountered when trying to apply similar changes in other illness populations (Leonard, Linden & Grant, 2018; Wong, Wan & Ng, 2016).

Although only a few participants in the present study discussed the desire for support groups, past research on support groups for caregivers of individuals with dementia have demonstrated their benefits. Caregivers who participated in support groups reported becoming more knowledgeable about dementia (Küçükgüçlü, Söylemez, Yener, & Işık, 2018) and decreased caregiver depression and burden (Chien et al., 2011). Policy makers may consider implementing support groups as the best practice for caregivers of older adults with depression.

The findings reported that PWD, caregivers and the society expressed negative stereotypes toward depression that resemble stigma. Stigma was a key barrier for caregivers to providing support to the PWD and seeking resources, as it often led others to perceive the patient as weak and unreliable (Norman, Windell, & Manchanda, 2012). In the present study, caregivers discussed the stigma that they experienced as they interpreted the PWD’s lethargic symptoms and treatment incompliance as laziness. This often led caregivers to be impatient and frustrated when assisting the PWD. As well, the presence of stigma was a barrier to caregivers seeking help for the PWD and themselves, as they were uncomfortable discussing the topic with others. Past studies have suggested that stigma associated with depression is often due to the lack of knowledge regarding the illness. Many educational interventions have demonstrated their ability to reduce the stigma associated with depression (Lu, Winkelman, & Wong, 2016; Shann, Martin, Chester, & Ruddock, 2018). The addition of depression education for caregivers can potentially
reduce their feelings of frustration and allow them to have a better understanding of the illness, and thus improving the care they provide and the caregiver-recipient relationship.

Depression has higher prevalence with several age-related illnesses, such as hearing (Li et al., 2014) and vision impairment (Eramudugolla, Wood, & Anstey, 2013), stroke (Robinson & Jorge, 2015), cancer (Krebber et al., 2014), and dementia (Goodarzi, Mele, Roberts, & Holroyd-Leduc, 2017), and it would be interesting to examine the experiences and needs of caregivers to people that have depression and other medical conditions. The current study explored caregivers of older adults that had depression as their primary reason for care to ensure the interviews were capturing caring for someone with depression. As all the PWD in this study had other health complications (mostly age-related conditions) in addition to depression, it is worth noting that this is a study of depression in the context of other conditions. Although the comorbidities were not the primary reason of care, they may still affect the PWD’s ability to perform ADL and IADL. Due to the high prevalence of depression as a comorbidity, studying caregivers of patients with only depression can limit the transferability of findings. Future research can consider examining illness populations that commonly has depression as a comorbidity. As well, some symptoms of depression can be more prominent in the presence of other illness, such as suicidal ideation in PTSD (Gonzalez, Novaco, Reger, & Gahm, 2016) and low mood and irritation in chronic pain (Fitzgibbon, Finn, & Roche, 2016), and caregivers that offer support to care recipients with these prominent symptoms may face distinctive challenges. Caring for a person with a serious illness and depression can be complex, and future research can build on the current study to help such populations by delineating their experiences and support needs.

4.2. Limitations

Although caregivers of an older adult with depression were interviewed, there were some limitations surrounding the demographic diversity of subjects. We had difficulties in finding caregivers, and older adults with depression did not refer them to the study. We aimed to use purposive sampling but were not able to recruit a large enough or diverse sample to explore similarities and differences across caregiving populations (e.g., spouse versus adult child). As a result, the interviews of all participants were analyzed together regardless of caregiver and care recipient’s familial relationship or gender. Past studies have suggested that caregivers in different familial roles may also have very different life circumstances (e.g., spouse caregivers are more
likely to reside with care recipient). The majority of participants for the present study were women. Past studies have observed differences between male and female caregivers, and the findings did not explore any gender comparisons. Additionally, the majority of participants were Caucasian. Although research suggested a potential difference in caregiver outcome between ethnicities, the study did not include enough participants from different ethnic backgrounds to analyze each race independently. Another limitation of the study may result from the high income of our study population. Many participants were able to afford additional homemaking and/or respite care services, and the perspectives of caregivers that experience financial struggles may be absent from the study findings. Future research may further consider caregivers’ demographic factors and familial relationship as they can impact caregiving experience.

4.3. Conclusion

This study provides evidence that caregivers of older adults with depression are vulnerable to developing their own health concerns and require additional supports and services from the healthcare system. Pearlin’s SPM assisted in answering our research question as it suggested aspects of caregiver experiences to explore. This is the first study on caregivers of individuals with depression that utilized Pearlin’s SPM to guide the research, and the findings suggested additional factors (e.g., stigma and constant vigilance) that can be added to Pearlin’s SPM for future studies of other illness populations (e.g., schizophrenia). To our knowledge, only one previous study has explored the experiences of caregivers to older adults with depression that was conducted in Chile (González et al., 2010), and no studies have examined these caregivers’ support needs. This study provides the unique perspectives of Canadian caregivers, and the findings highlighted the disabling effect of depression on older adults and their needs for additional help with ADL and IADL compared to younger adults. The interviews emphasized the need for the healthcare system to develop a formal and structured approach to help family caregivers assisting older adults with depression. Additional resources from the healthcare system may benefit caregivers and reduce their psychological and physical stress. The study helped caregivers to express their experiences and desired needs from the healthcare system, thus providing insights for clinicians and policy makers to implement resources to optimize the caregiving role and the care of older adults with depression.
References


Anney, V. N. (2014). Ensuring the quality of the findings of qualitative research: looking at Trustworthiness Criteria.


Appendices

Appendix A: Consent Form

Title of Study: Understanding Support Needs in Spouses and Adult Children caring for seniors with Depression

Student Researcher:
C. Daniel Wang  MSc Student, Rehabilitation Sciences Institute, University of Toronto

Supervisors:
Dr. Jill Cameron  Associate Professor, Department of Occupational Science and Occupational Therapy, University of Toronto

Dr. David Conn  Vice-President, Education & Director, Centre for Education, Department of Psychiatry, Baycrest

Dr. Bonnie Kirsh  Associate Professor, Department of Occupational Science and Occupational Therapy, University of Toronto

Background and purpose of the study:
Following dementia, depression is the second most prevalent mental illness among seniors, and family members often assume the role of caregiver. Due to depressed seniors' tendency to withdraw from their environment, caregivers are often their primary sources of support. Unlike trained professionals, caregivers have limited knowledge regarding the patients' illnesses or care requirements, are not financially compensated, and may have other responsibilities, like employment, to attend to. Thus, caregivers struggle to find time, energy and financial resources necessary to support the care recipient and their own health and well-being may suffer as a result. Very limited research has specifically examined the experience of providing care to a
senior with depression. This population has unique risk factors, symptoms, and consequences, and often occurs with other illnesses, which may present distinctive challenges to family members providing support. In addition, studies often view family caregivers as a homogenous group, when in fact they may experience different challenges.

Who is invited to participate in this study?

Spouse and adult child caregivers of seniors that have been diagnosed with major depressive disorder and persistent depressive disorder are invited to participate in this study. A caregiver is defined as an unpaid person that provides assistance to patients with daily activities. The senior (care recipient) must be 65 years of age or older, lives in the community, and has not been diagnosed with dementia.

What does participation in this study involve?

You are invited to participate in an interview to share your caregiving experiences. The interview will take approximately an hour to complete and will be scheduled at a time and place of your convenience. For the first part of the interview, you will be asked about general demographic information and your caregiving history. Next, you will be asked questions regarding your caregiving experience, support you have received and the need for additional assistance. To protect your confidentiality, you are provided with an identification code, and it will be used for all records and transcripts. No one will have access to your interview content except member of the research team. For data analysis purposes, the interview will be audio recorded and notes will be taken. Your personal information and audio recordings will be deleted 5 years from publication.

Potential Risks:

Due to the sensitivity of the interview topic, you may experience emotional discomfort during the process. You can skip any questions that you don’t feel comfortable answering, take breaks as needed, and terminate the study at any given time during the interview.

Potential Benefits:

You will have the opportunity to share their experiences and feelings with the researcher. Participants have reported feeling less isolated and distressed by talking openly and honestly about their feelings with someone in research interviews, and you may discover additional resources available (e.g., support group). In addition, you will be presented with study findings that may inform intervention and/or system change for future caregiving.
Conditions for participation:

Your participation in the study is voluntary. You may withdraw at any point in time without receiving any consequences. If you choose to withdraw from the study, any information that has been collected up to the time of withdrawal will be used in the research. However, if you feel uncomfortable with us using your interview content, please inform us within a week after the interview, and we will remove your interview content from our data analysis.

Contact information:

If you have any additional questions or concerns regarding the study, or would like to know the study results once it is complete, please contact Dr. Jill Cameron at

500 University Avenue, Toronto, ON M5G1V7
Rehabilitation Sciences Institute
University of Toronto
Email: jill.cameron@utoronto.ca | Tel: 416-978-5694

If you wish to contact someone not connected with the project about your rights as a research participant, feel free to call Dr. Ron Heslegrave, Chair of the Research Ethics Board at (416) 785-2500 ext. 2440.

By signing below, I acknowledge that I have read and understood the above information, and had the opportunity to ask questions regarding my involvement in the research and agree to participate.

Name of Participant: __________________________________________________________
Telephone: _____________________ Email: __________________

Signature: ______________________________ Date: ____________________________

Person obtaining consent:

Signature: ______________________________ Date: ____________________________
Appendix B: Recruitment Script

Hi Mr. / Ms. ____________

My name is Daniel Wang and I am a student researcher from the University of Toronto, how are you today? Currently we are conducting a study to explore caregiving experience of spouses and adult children caring for seniors with depression. We would like to know if you would like to participate. As a caregiver, your participation would involve taking part in a one-on-one interview and discuss your caregiving experience with us. The interview will take approximately an hour and you have the choice to participate either in-person or via phone. For in-person interviews, you can select a time and location that is convenient for you.

Are you interested in participating?

If yes on phone, go through the criteria for participation to determine their eligibility, review the full consent form with them and schedule a time and place for the interview. In addition, send a copy of the consent form and a paid self-addressed envelope where participants can mail back the signed consent form. The interview can only be conducted after the researcher receives the signed consent form.

If yes in person, go through the criteria for participation to determine their eligibility, review the full consent form with them and schedule a time and place for the interview if necessary, or proceed with the interview by obtaining signed consent.

If they need more time to consider participating, let them know that you will call back at a later date.

If no, thank them for their time, let them know that they can call or e-mail you if they have any questions or if they re-consider participation.
## Appendix C: Eligibility Checklist

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>Care Recipient</th>
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</thead>
<tbody>
<tr>
<td>Immediate family member of the care recipient</td>
<td>65 years of age or older</td>
</tr>
<tr>
<td>Provide assistance with at least one activity or instrumental activity of daily living per week</td>
<td>Diagnosed with MDD or PDD</td>
</tr>
<tr>
<td>No financial compensation for caregiving activities</td>
<td>Lives in the community</td>
</tr>
<tr>
<td>Able to communicate in English</td>
<td>Depression is the primary reason of care</td>
</tr>
</tbody>
</table>
Appendix D: Interview Guide

Screen for inclusion & exclusion criteria

To ensure that potential participant satisfies all inclusion & exclusion criteria

- What’s your relationship with the care recipient?
- Do you provide or interact with the care recipient on a weekly basis?
- Just to make sure, you are not a professional care provider nor are you financially compensated for providing care, correct?

Interview

Thank you for your interest in being a part of this study. We are looking to understand experiences and support needs of family members that are providing care to a senior family member suffering from depression. Your participation today is strictly voluntary. I would like to remind you that when you consented to participate in this study, you volunteered to engage in a discussion about your experience providing care to [insert name of care recipient]. This interview will likely take 60-90minutes in total and the interview session will be recorded so we could review the data at a later time. Everything we discuss today will be kept confidential. Are you still able and willing to participate in this interview? Do you have any questions before we get started?

*If “yes”, continue with the interview below. If “no”, ask if they have any further questions or concerns that you can address. If they remain not interested in participating, thank them for their time.*

Obtain consent

By telephone: To make sure you can speak as freely as possible, are you in a private room at the moment? If not, I could give you a call back once you are.
Caregiving experience

1. I understand your (insert care recipient) is experiencing depression. Could you tell me about him/her?

2. Could you tell me about his/her depression? How long has it been?

3. Does he/she have any other health concerns?

4. Can you describe a typical day of caring for your family member?

5. What are some of the ways you help your family member?
   - What skills help you with your caregiving role? Any additional skills you would like to have?

6. Who else is involved in your family member’s care?

7. How does providing care make you feel?
   - Affect your life? In what ways do you adjust your daily schedule for these responsibilities?
   - Affect your health and well-being (physically and mentally)? Are you generally healthy? Do you have any health conditions that affect you?

8. Any aspects of caring that is positive or that you enjoy? Why?

9. What do you find the most difficult as a caregiver? Why are they difficult?

10. How does providing care to (insert care recipient) affect your financial situation?

11. How do you cope with all the responsibilities?

12. What supports have you received? What did you find the most helpful?

13. What additional supports would you like to receive? How would they benefit you or your family member?

14. Please tell me about your unmet needs
   - In terms of the help you receive from the health care system (e.g., hospital)
   - In terms of personal needs / outside of the health care system (e.g., lack of social and financial support)

15. If you could make one change to help caregivers in your situation, what would that be?

16. If you could give advice to caregivers in your situation, what would that be?
17. As our interview is coming to a close, do you have any additional caregiving experience you would like to share?

**Demographic information & caregiving history**

18. May I have your age?

19. What is/was your profession? What is your current primary daily activity?

20. What is the highest level of education you have completed?

21. Which category best describes your family income?

   - Under $5,000
   - $5,000 and over
   - $10,000 and over
   - $15,000 and over
   - $20,000 and over
   - $25,000 and over
   - $35,000 and over
   - $50,000 and over
   - $75,000 and over
   - $100,000 and over
   - $150,000 and over
   - $200,000 and over
   - $250,000 and over

22. Besides the family member you’re currently caring for, have you provided assistance to anyone else in the past? If yes, for whom and how long?