SUPPORTING INFORMAL CAREGIVERS THROUGH THE DEMENTIA JOURNEY:
A PRIMARY CARE APPROACH

by

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Abstract

Informal caregivers of persons with dementia often experience significant stressors which may result in detrimental physical, psychological, social, and financial consequences. In order for primary care providers to adequately support this burgeoning group of caregivers a greater understanding of their experiences and needs is essential. This literature review seeks to determine how primary care providers can best support informal caregivers of persons with dementia through the dementia journey. Studies were included that examined the needs or experiences of informal caregivers of persons with dementia. Additionally, studies that examined primary care-based interventions aimed at improving the caregiving experience for these individuals were also included. Four themes emerged from analysis of the literature: the health system; family and community; relationship with the care recipient; and personal journey. Findings from the literature are discussed and recommendations made in the context of creating strategies to increase awareness and care for informal caregivers of persons with dementia. Implications for primary care provider practice include ensuring timely diagnosis, collaborating with a multidisciplinary team, conducting informal caregiver assessments, providing education, raising public awareness, and providing anticipatory guidance. Further research is needed to explore the experiences of male and culturally diverse caregivers. It is through the identification and validation of informal caregiver's needs that appropriate interventions can be developed and implemented, thus providing commensurate support for informal caregivers of persons with dementia through their dementia journeys.

Keywords: informal caregiver, dementia, primary care, support, journey

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Introduction

Former First Lady Rosalynn Carter once stated, "there are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who will need caregivers" (Carter & Golant, 1994, p. 3). This statement acknowledges the significance of the caregiving role, as well as the importance of recognizing and supporting individuals who provide this care. Policy makers, researchers, and health care providers are increasingly acknowledging the value and benefit of informal care provision to both care recipients and to society as a whole (Peacock et al., 2010; Rosa et al., 2010; Schultz & Matire, 2004). However, Salfi, Ploeg, and Black (2005) reported that informal caregiver needs are often unarticulated and unmet. Further, evidence-based information about the application of both informal caregiver needs assessments and supportive informal caregiver interventions in the primary care setting is notably lacking (Feinberg, 2002; Schulz & Matire, 2004).

People of all ages and with diverse health care needs will potentially require care at some point in their lives; however, it is older adults who predominantly provide and receive informal care. As the number of older adults in our population continues to rise, the need for informal caregivers will concurrently increase. The aging population is, in fact, the fastest growing sector of our population (Kane, 2011). The increase in the number of seniors in our communities means that the number of individuals with dementia will continue to rise as well. The Government of Canada (2016) reports that approximately 395,000 Canadians over the age of 40 live with dementia, and the number of people diagnosed with dementia is predicted to double by 2030 and more than triple by 2050 (Canadian Institutes of Health Research [CIHR], 2015).

Health conditions such as dementia, which are most often associated with such an aging population, are causing an increased demand for residential care beds and formal care services (Canadian Institute for Health Information [CIHI], 2010a). This then results in an increased need for government-funded health care expenditures. The sustainability of the health care system is dependent on a network of informal caregivers who provide care and support to seniors at home in order to avoid the prospect of institutionalization for as long as possible (CIHI, 2010b). Health care systems within Canada are currently shifting the focus away from residential and acute care toward community-based care for seniors in order to ensure a sustainable health care system for Canadians (CIHI, 2010a). However, this shift has the simultaneous effect of placing increasing pressure on informal caregivers, including informal caregivers of persons with dementia (ICPWD), to provide care for their loved ones for longer periods of time in the home environment.

Although care provision by ICPWD most often benefits both the care recipient and society as a whole, the negative effects of caregiving on ICPWD can also be considerable and should not be discounted (Schultz & Matire, 2004). Thus, there is a crucial need to find the most effective ways by which to support these informal caregivers (Duggleby, Swindle, & Peacock, 2014; Winter & Gitlin, 2006). Finding ways to meet the needs of ICPWD throughout their caregiving journeys is a critical contribution that primary care providers (PCPs) must endeavour to achieve.

Issues that ICPWD face are of particular importance in primary care (Nichols et al., 2009), as most individuals with dementia and their family members receive care via primary care clinics (Austrom et al., 2004). PCPs, such as Family Physicians and Nurse Practitioners (NPs), are often the first and recurrent contact for ICPWD (Belle et al., 2006; Fillit, Knopman, Cummings, & Appel, 1999; Greenwood, Pelone, & Hassenkamp, 2016). PCPs are most often in an ideal position to connect with informal caregivers, identify the changing needs of those caregivers, and to develop and implement supportive interventions that are most appropriate for each individual caregiver. This is a profoundly important topic for PCPs to consider since maintaining the well-being of informal caregivers is not only beneficial to the caregiver, as it generates favourable outcomes for the care recipient with dementia, but it also more broadly supports a sustainable health care system. For instance, the well-being of the ICPWD is often fundamental to the care recipient being able to receive supportive services in the community instead of being placed in residential care (Family Caregiver Alliance, 2003). Wilz, Schinköthe, and Soellner (2011) agree, stating that it is "a social necessity" (p. 115) to provide support to ICPWD in order to maintain a good quality of life (QOL) for both ICPWD and their care recipients. ICPWD who successfully manage the caregiver role not only provide better care to the care recipient but they also act as a valuable source of information for the PCP and can thereby assist in more effectively guiding the care of the patient with dementia. For example, contributions by ICPWD often provide the infrastructure upon which dementia care plans for patients are built (Anderson & Jehaanandan, 2011). Berthelsen and Kristensson (2015) agree, stating that ICPWD are now frequently acting as an essential resource to the patient as well as to the health care providers.

The purpose of this integrative literature review is to answer the research question: how can PCPs best support ICPWD through the dementia journey? In order to answer the above question, literature was identified through an extensive search that addressed either the lived experiences and needs of ICPWD or the primary care-based interventions aimed at improving the caregiving experiences for ICPWD (it is to be noted that, although not a formal acronym, ICPWD was chosen for use to add brevity to the review). The findings of the literature will be synthesized and discussed. Following the discussion, recommendations for practice, education, and research will be documented.

The following chapter seeks to provide insight into the personal, societal, and health system challenges that ICPWD can face throughout their often long and arduous caregiving journeys, as well as the challenges that PCPs may encounter while striving to support this unique group of caregivers. First, my own family members' experiences as ICPWD will be shared to provide an example of informal caregiving in a Canadian context and to juxtapose their experiences with other ICPWD from different geographical areas. Literature will then be discussed that illustrates the caregiving role and the impact that caregiving can have on ICPWD. The fundamental role PCPs play in supporting ICPWD in the community will be presented. Then, the effects that supportive interventions for ICPWD may have on the lives of ICPWD will be highlighted.

Chapter 1: Background and Context

The Caregiving Journey

An odyssey can be defined as "a long series of wanderings or adventures, especially when filled with notable experiences [or] hardships…" ("Odyssey", 2016). The caregiver's experiences in caring for a person with dementia can certainly be equated to this type of journey. It is the type of journey that no one books in advance, no one packs for, and no one wishes to take, but it is an adventure nonetheless. For some, it is a form of spiritual journey, as virtuous steps are taken down an uneven path with the enticement of personal enlightenment shining at the destination. However, it can also be a challenging and seemingly unrelenting trek for others as they endeavour to just make it through to the end in one piece. Although the journey may seem formidable at times, several factors, including the level of social support available, previous caregiving experiences, and the caregiver's own personal characteristics, can help caregivers to make it through yet another day of the caregiver odyssey.

Members of my own family have embraced the caregiving journey in order to support my paternal grandfather, who was diagnosed with dementia at the age of 82. Grandpa was diagnosed with Alzheimer's disease and vascular dementia (mixed dementia) in 2010, approximately two years after problems with his memory first became apparent to my Grandma. Just prior to my grandparents moving out of their home of 42 years into an apartment, Grandma began noticing small noticeable cognitive changes in Grandpa. Although Grandpa's physical functioning deteriorated fairly rapidly since 2014, his cognitive impairment steadily deteriorated from diagnosis to death. He suffered from several falls at home. He surrendered his driver's license and became increasingly dependent on my

Grandma. Over the years, he became unable to manage his finances or medication. Grandma's roles and responsibilities increased as Grandpa's needs regarding management of the household, finances, shopping, medication management, transportation, and personal care increased. Grandpa did not willingly accept home support services due to frequent changes in support staff; therefore, after accepting help for a short period of time, the services were cancelled. Grandma suffers from her own health issues, including heart failure, asthma, anemia, chronic pain, and fairly recently, a fractured cervical spine after tripping and falling at a shopping centre. Although my Grandma has a warrior spirit, her own ailing health meant that she was unable to provide care to Grandpa single-handedly. My Aunt then made the decision to move away from her grown children in Ontario in order to assist my grandparents with their needs. She and my Uncle sold their house in Ontario and moved to a house within two blocks of my grandparents. My Aunt began working soon after arriving in British Columbia and continued to work while also providing care to my grandparents. The following is an excerpt from the lived experience of my Grandma and Aunt about their experiences with my Grandpa after he had been diagnosed with dementia. The repetitive nature of the following anecdotes reflects the repetitive nature of his behaviours and the issues that they were required to confront on an almost daily basis.

Yet another day of laughter, as they reminisce about Caribbean holidays with their family and good times with friends. Old stories that have been told again and again. Stories that, as he tells them, often become convoluted or trail off without an ending as distraction sets in. Yet another day of arguing as Grandma asks him the same question repeatedly, and after minutes of searching the depths of his memory, he can't find the words he is searching for, then forgets the question entirely. Yet another day he is awake at three a.m. making *coffee, getting dressed, believing that he is on his way to work. Yet another day of broken sleep, of ongoing fatigue. Yet another day of frustration and agitation as he tirelessly combs through his financial statements, certain that the banks are stealing from him. Yet another day that my Aunt misses work to drive them to appointments, where they sit and try to make sense of increasingly complicated diagnoses and treatment plans. Yet another day as Grandma leaves to pick him up from his respite day program, and she tells me "do not call it daycare, or he will never go again". "Some days he likes it, some days he doesn't". "He doesn't like the food". "I feel guilty sending him when he doesn't want to go", she says. Yet another day that Grandma has tears in her eyes, unsure if he will remember the name of his grandchildren when they call. Yet another day in which Grandma clamps the lock on the steering wheel of the car for fear he may forget he can no longer drive and attempt to get behind the wheel. She feels that she can't take his keys away, can't take away what little independence remains. Yet another day where Grandma is at a specialist appointment for her own health issues. Yet another day where she signs herself out of the hospital prematurely in order to get home to care for her husband. Yet another day in which he is in the back of an ambulance with severe hypoglycemia after inadvertently mixing up his long and short acting insulin. Yet another day when they sit in the hospital feeding him food from home to ensure he eats. Yet another day where he is heavily sedated after the nursing staff administered medication to deal with his agitation. Yet another day that my Aunt aimlessly wanders around her home, so overwhelmed with growing responsibilities and stress that she is unable to complete the simple task that she originally set out to do. Yet another day that they struggle to navigate the health care system, juggling perpetual medical appointments, assessments, and community services. Yet another day in which, although he is physically* *present, they grieve the loss of the husband and father they once knew. Yet another day in which they experience utter loneliness as friends and family stop visiting because people do not know how to help or what to say to the "crazy old coot". Fifty-five year-old friendships have dissipated, with only fading memories to cling to now. "If someone is diagnosed with cancer, people bring casseroles and hugs. When someone is diagnosed with dementia, people stop coming". That's the hardest part of this disease" she tells me, "feeling so alone".*

The events presented above illustrate just some of the many challenges that my own Grandmother and Aunt faced in the context of being the informal caregivers of my Grandpa. However, such experiences are not uncommon for many ICPWD. The caregiving experience is dynamic and complex, yet dementia caregivers often face such daily struggles either alone or with minimal outside support. This often leads to the caregiver taking the care recipient to the hospital as a form of respite when the informal caregiver becomes unable to cope with the tremendous demands of the caregiving role or with an acute change in the care recipient's health status. Rose and Lopez (2012) agree, stating that individuals with dementia experience more hospital and nursing home stays compared to other elderly adults.

Throughout my 12-year career as a Registered Nurse, I have witnessed many patients with dementia admitted to the hospital with a vague diagnosis of "failure to thrive" or "caregiver burnout". I often felt helpless watching exhausted caregivers contend with the demands of their responsibilities, as well as watching patients themselves struggle with being in an unfamiliar and over-stimulating acute care environment. These patients consistently experienced prolonged hospital admissions, eventually followed by a transfer to a residential care facility as their caregiver became either unable or unwilling to have the patient return home. Such lengthy "social admissions" not only have negative implications for the patients and caregivers, but also place a significant economic burden on the health care system (Axam, Hasnip, & Luxford, 2013).

Throughout my nursing career, I have witnessed these "social admissions" in both rural and large urban centres in Australia, England, and Canada. Although informal caregivers in rural settings may face challenges with regards to more limited availability for resources and supportive services, many of the challenges associated with caregiving are similar to those experienced by caregivers in urban settings (Bedard, Koivuranta, & Stuckey, 2004). For example, rural caregivers in Bedard et al.'s (2004) study reported similar health status, levels of burden, and unhealthy behaviours compared to urban caregivers. Lilly et al. (2012) argued that, although challenges associated with service provision in isolated communities do exist, health system rationing in urban areas has also affected their supportive services and has similarly led to detrimental impacts on caregivers (Wiles, 2003). Overall, although ICPWD from different geographical areas may be confronted with particular challenges related to service provision, many ICPWD share similar experiences in the caregiving context.

Dementia: The Impetus of the Journey

A clear understanding of dementia as a diagnosis provides insight into the ways in which symptom manifestations can affect the informal caregiving experience and can contribute to changing caregiver needs. First, it is important to recognize that dementia is not a specific disease in itself but is instead a group of symptoms caused by disorders that affect the brain (Alzheimer Society of Canada, 2015). Specifically, dementia presents as "an acquired persistent and progressive impairment in intellectual function, with compromise of memory and at least one other cognitive domain" (Harper, Johnston, & Landefeld, 2014, p. 56). The four domains of dementia are often referred to as the "four A's" (Alzheimer's Foundation of America [AFA], 2016). These four key terms are defined below:

- *Amnesia*: short term or long term memory loss, although short term memory is primarily affected first (AFA, 2016);
- *Aphasia:* the inability to communicate capably, either through the inability to understand written or spoken language, or the inability to form spoken words (AFA, 2016);
- *Apraxia*: the inability to carry out inherent motor skills such as brushing one's teeth, due to neurological dysfunction in the brain (National Institute of Neurological Disorders and Stroke [NINDS], 2015);
- *Agnosia*: alterations in sensory perception, causing poor recognition of signals, such as pain or a full bladder (AFA, 2016).

Individuals with dementia may be affected by any or all of these four conditions during different stages of their disease; however, they are most often evident in the later stages and have been found to develop more rapidly in those diagnosed with Alzheimer's disease (AD) compared to other forms of dementia (Weiner, 2009).

Although AD, vascular dementia, and dementia with Lewy bodies together comprise up to 90% of dementia diagnoses (Sheehan, 2012), several other disorders can also cause dementia. Less common causes of dementia may have reversible etiologies; however, dementia is most often irreversible, progressive, and caused by degenerative or neurodegenerative processes. Degenerative dementia can be related to infectious processes (such as Creutzfeldt-Jacob disease [CJD], post-encephalitic dementia, and human immunodeficiency virus), vascular disorders (such as infarcts, vascular dementia, amyloid angiopathy, and Binswanger disease), or neurodegenerative disorders (such as Parkinson disease, Huntington disease, Pick disease, frontotemporal dementia, dementia with Lewy bodies, and AD) (Boss, 2010). Further descriptions of the most common forms of dementia listed above can be found in Appendix A. For the purposes of this review, the term dementia will be used in reference to the most common forms of progressive dementia: AD, vascular dementia, mixed dementia, frontotemporal dementia, and dementia with Lewy bodies (see Figure 1).

Figure 1: Sub-types of dementia commonly seen in Canadian memory clinics.

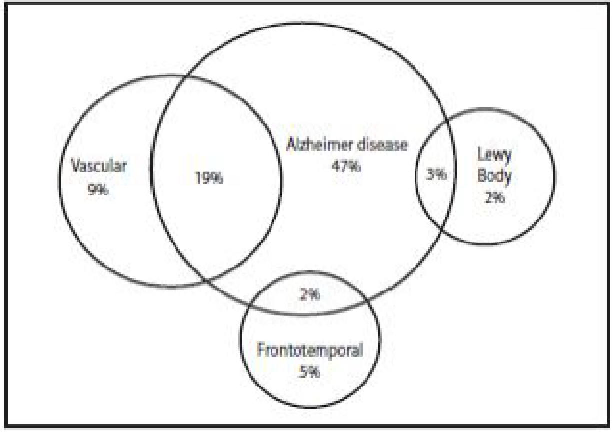

Figure 1. Common sub-types of dementia. Adapted from “Cognitive Impairment - Recognition, Diagnosis and Management in Primary Care”, by The Guidelines and Protocols Advisory Committee, 2014, *BCGuidelines.ca,* para. 3. Copyright 2016 by Province of British Columbia.

Regardless of the type of progressive dementia that a person has, clinical manifestations such as memory loss, erroneous executive functioning, poor concentration, poor judgment, mood changes, emotional lability, aggressive behaviours, language deficits, or decreasing mobility, may become evident over time (Boss, 2010). Additionally, problems with successfully accomplishing activities of daily living (ADLs), such as dressing, bathing, and toileting, or instrumental activities of daily living (IADLs), such as grocery shopping, banking, cleaning, medication management, or driving, frequently occur (Boss, 2010). It is valuable for caregivers to understand the symptoms that their loved one may experience, as well as the behaviours they may exhibit, in order to best anticipate and prepare for the often-distressing symptomology. The progressive nature of the disease means that the health care and functional needs of the affected individuals tend to escalate throughout the disease progression, most often requiring constant supervision and assistance with all ADLs and IADLs by the end of the disease trajectory.

Rose and Lopez (2012) ascertained that, although the rate of progression and symptoms of the disease does vary between patients, there are several characteristic transitions that occur as part of the dementia pathway. Providing a clear understanding of the stages of dementia to ICPWD may help them to better understand the expected progression of dementia and to anticipate the transitions that they may face. Despite different clinical manifestations between the types of progressive dementia, cognitive and functional deterioration are hallmark signs of all of them. Validated dementia staging scales have therefore been developed to help guide management and treatment in primary care practice, including the Clinical Dementia Rating (CDR) (Morris, 1993), Functional Assessment Staging (FAST) (Sclan & Reisberg, 1992), and the Global Deterioration Scale (GDS) (Reisberg et al., 1982). No literature has been found describing whether these scales are used more often in primary care settings compared to specialist settings. However, the use of the GDS is suggested in the BC Guidelines for use in primary care settings to help with diagnosis (Guidelines and Protocols Advisory Committee, 2014). The stages of dementia listed in these staging scales can be applied to all progressive dementias and can be used to describe the different stages to ICPWD. The scales are similar, describing the degree of cognitive and functional decline in either five stages (CDR) or seven stages (GDS and FAST) in accordance with the degree of cognitive and functional decline. In order to illustrate the stages of dementia, the three scales described above are compared in Appendix B.

Some authors (Montgomery & Kosloski, 2000; Wald, Fahy, Walker, & Livingston, 2003) suggest that highlighting the stages of caregiving rather than the stages of dementia will better prepare PCPs to concentrate on the needs of ICPWD. Rose and Lopez (2012) disagree, arguing that the consideration of the stages of dementia allows PCPs to provide anticipatory guidance, as well as other supportive interventions, to the ICPWD at appropriate junctures of the disease process (Rose & Lopez, 2012). Amalgamating both the stages of caregiving, such as the Elizz Five Life Stages of Caregiving (Elizz, 2015), with the stages of dementia may prove valuable for both ICPWD and PCPs. The five stages of caregiving progress through the helping stage, involved stage, intensive stage, all-encompassing stage, and closing stage. Developing a consolidated understanding of the disease process and anticipated trajectory will help PCPs to choose the appropriate supportive interventions, and can help both ICPWD and care recipients successfully transition through the different stages of the dementia journey.

Getting to Know the Travelers: Who are The Caregivers and What is the Role of Each Type?

Patients with dementia will inevitably require care provision from either informal or formal caregivers, or both. The term "formal caregivers" refers to paid health care professionals, such as care aides, nurses, and PCPs, who fulfill the vital role of providing care to clients in residential care facilities, acute care facilities, hospices, or within the client's home (Gallagher-Thompson et al., 2009). These formal caregivers may be hired and paid by a private company, by a public body such as a provincial Health Authority, or by the client directly. In comparison, informal caregivers are most often family members, usually the spouse or an adult child of the individual affected, although such caregivers may also be the care recipient's friends or neighbours. Informal caregivers are generally unpaid; however, they may receive a government subsidy, tax benefit or other compensation in exchange for providing care. In the early stages of the disease in particular, the majority of care provided to people with dementia tends to be delivered by informal caregivers (Daly, McCarron, Higgins, & McCallion, 2012; Rose & Lopez, 2012) who often have little or no prior experience in dementia caregiving (Savva & Brayne, 2009). Both formal and informal caregivers can play essential roles in assisting those in need of care and both types of caregivers will often concurrently provide care to individuals with dementia, especially in the later stages of the disease process. Figure 2 illustrates the common progression from informal to formal care within the context of dementia.

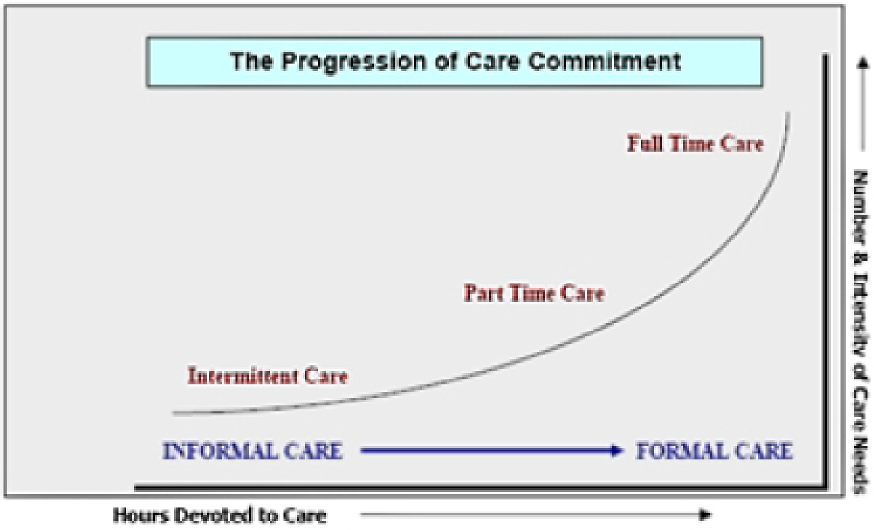

Figure 2. *The progression of care during the progression of dementia. Adapted from* "The Four Steps of Long Term Care Planning", by The National Care Planning Council, 2013, *The Accidental Caregiver*, para. 13. Copyright 2016 by The National Care Planning Council.

Both types of caregivers may hold varied responsibilities, including cleaning, meal preparation, running errands, driving, medication supervision, personal care, and emotional support (Fast, Niehaus, Eales, & Keating, 2002). However, in addition to the expectation of such routine types of tasks, caregivers of those with dementia must often contend with the care recipient's disease-induced reactions to care, such as care resistance, a diminished ability to communicate, and further concerns such as wandering, perseveration, agitation, paranoia, significant personality changes, and insomnia (Austrom et al., 2004; Family Caregiver Alliance, 2015). Informal caregivers may find managing these behaviours more difficult than formal caregivers, as they often lack the knowledge, skills, and experience in dementia care that formal caregivers possess (Sadavoy & Wessen, 2012). This contention is supported by Czaja et al. (2013) who found that many informal caregivers report feeling insufficient competence to effectively fulfill the caregiving role. Informal caregivers (if a spouse or adult child) must often learn to adapt and provide care within a complicated emotional environment, resulting in such feelings as apprehension, loneliness, and grief. In contrast, formal caregivers may not experience such emotional conflict because of the lack of a pre-existing relationship with the individual requiring care (Sadavoy & Wessen, 2012). Further, many ICPWD face the responsibility of having to provide care 24 hours per day, seven days per week, with limited access to respite care, and confinement within the home when the care recipient is unable to be left alone.

Levine (2006) adds that the biggest challenge she faced as an informal caregiver was not what she had to do but rather lacking adequate time in which to do it. For example, she often found herself cleaning or paying bills late at night since she had no time during the day to perform these tasks. She found it frustrating that assessments for formal care services included questions about the personal activities with which her husband needed help, but they failed to ask about many of the associated issues, such as the difficulty associated with such tasks, her own resulting sleep deprivation, and how she was able to complete all of her responsibilities during the day. Levine (2006) recalls that much of her time as a caregiver was spent waiting, "just being there, waiting for the next time to do something, the next time there is a call for water, changing the TV channel, fixing the pillow, or any of countless uncategorizable requests" (p. 9).

It is often the persistent demands of care, such as those in the above examples, as well as having to provide ongoing care every minute of every day, that predispose caregivers to distress, poor adaptation, or placement of care recipients in residential care (Gaugler, Kane, Kane, Clay, & Newcomer, 2003; Pinquart & Sorensen, 2003). Experiences such as Levine's (2006) highlight some of the difficulties that informal caregivers face. Thus, the importance of informal caregiver needs assessments becomes increasingly evident if a PCP is to choose and implement the most appropriate interventions for a given caregiver.

In addition to gaining an understanding of the tasks involved with informal caregiving, it is useful for PCPs to have an understanding of informal caregiver demographics in order to most appropriately tailor interventions to individuals and to proactively identify any high risk groups. Sadavoy and Wesson (2012) have identified that, in Canada, 97% of persons with dementia have at least one informal caregiver, with 50% of those caregivers being over the age of 65. The majority of these informal caregivers are women (Sadavoy & Wesson, 2012; Sinha, 2012). The Alzheimer's Association (2016) reports that 75% of ICPWD have been providing care for at least one year while 33% have been providing care for five or more years.

Although female informal caregivers outnumber males (59% women compared to 41% men), there are a significant number of male caregivers in Canada (Eales, Kim, & Fast, 2015). This may, in part, be related to the fact that more women (72%) are diagnosed with dementia than men annually, and these women are often then cared for by their husbands (Alzheimer Society of Calgary, 2013). The greater number of female caregivers overall is likely due to the number of women providing care to elderly parents or other relatives in addition to their spouses. Compared to their male counterparts, it has also been found that wives and daughters spend more time on caregiving responsibilities per week (Family Caregiving Alliance, 2011; Sinha, 2012). Sinha (2012) proposes that the greater number of caregiving hours that women provide may partly be related to the type of tasks routinely performed. Women are more likely to help with the provision of personal care, dressing, toileting, medical treatments, and housework, whereas men are more likely to assist with outdoor work or maintenance (Sinha, 2012).

A trend towards delayed childbearing, as well as the increased number of women in the workforce, suggests that an increasing number of women are also involved in the "sandwich generation" who provide care for children and elderly relatives while simultaneously working outside the home (Alzheimer's Association, 2015b; Dang, Badiye, & Kelkar, 2008). My Aunt is an example of a person in this situation, as she was subjected to numerous competing and concurrent employment, family, and caregiving demands. She frequently had to request time off of work to attend to the needs of my grandparents. Additionally, she would have to fly back to Ontario for other family commitments for her sons or husband's family. Aw (2013) reports that three large-scale work-life surveys were conducted by Duxbury and Higgins (2012) over the past 20 years. The researchers found that the number of Canadians in the workforce providing care to elderly relatives significantly increased from 5% in 1991 to 73% in 2012. One in three respondents to these surveys belonged to the sandwich generation, of which 21% reported feeling overwhelmed at least weekly. Once again, this was illustrated in my Aunt's experiences with caregiving, as she often felt overwhelmed with the situations that she faced as part of the caregiver experience.

The Road Less Traveled: The Impact of Caregiving on Informal Caregivers

For ICPWD, the dementia journey can be compared to traveling down a steep, winding, bumpy road with no firm idea of the direction in which one is actually headed. Informal caregiving for individuals with dementia can be characterized by unique challenges and prolific stress that often increase over time due to the progressive nature of the disease (Cotrell, 1997; Czaja et al., 2013; Davis, Hendrix, & Superville, 2011). A significant amount of research has demonstrated that informal caregivers may suffer adverse physical and mental health outcomes (Belle et al., 2006; Blom et al., 2015; Croog, Burleson, Sudilovsky, & Baume, 2006; Diamond, Gleuckauf, & Loomis, 2003; Ferreira, Aguiar, & Meneses, 2014; Simon, 2001; Tremont, 2011), as well as negative social and financial consequences, as a result of caring for patients with dementia (Lai, 2012). A study by Schulz and Beach (1999) reported that mortality related to psychological strain was found to be 63% higher in informal caregivers than in non-caregivers. Further, a study by Schoenmakers et al. (2010) found that ICPWD in the community experience more burden, both psychosocial and physical, than informal caregivers of individuals with other chronic diseases.

Stressors. It is well known that chronic stress can lead to physical and emotional consequences, significantly impacting the health and well-being of an individual. Khalsa

(2010) reports that, "caregivers are twice as likely to report physical strain and high levels of emotional stress as a direct result of caregiving responsibilities" compared to non-caregivers (p. 1025). Schubert et al. (2008) reported on a national survey conducted in the United States that included over 1,500 informal caregivers. These authors determined that, in comparison to informal caregivers of those with physical disability but not dementia, more informal caregivers described their role as "exceedingly stressful".

As the disease trajectory of dementia can be lengthy, ICPWD often become highly vulnerable to various stressful occurrences (Cohen & Lee, 2007). Primary and secondary stressors may lead to further caregiver distress, affecting both health and well-being and impeding the informal caregiver's ability to effectively provide care to another person. Primary (objective) stressors that are particularly relevant to a dementia diagnosis would include physical caregiving demands that become more challenging as the disease progresses. Relevant secondary (subjective) stressors would include financial burden through loss of wages, family conflicts, relationship hardships, and increasing social isolation as the needs of the care recipient increase (Emlet, 1996; Farcnik & Persyko, 2002; Savva & Brayne, 2009). Further, as dementia is a neurodegenerative condition with no cure, uncertainty about what the future holds after diagnosis can be exceedingly stressful. If the informal caregiver becomes unable to cope with the chronic strain and stress associated with caregiving, he or she may become distressed and unable to continue to provide care for the person with dementia.

Physical impacts. Although many informal caregivers may rate their health as good or even excellent, the stress involved with dementia caregiving has been associated with numerous negative implications regarding physical health, including fatigue, weight changes, and insomnia (Gallant & Connell, 2003; Krach & Brooks, 1995; Sansoni et al., 2004). Additionally, it has been hypothesized that cardiovascular problems, such as hypertension and coronary artery disease, are associated with caregiving (Vitaliano et al., 2002). Physiologically, chronic stress "… impairs hippocampal-dependent cognitive function, suppresses neurogenesis, and causes dendritic shrinkage, which serves as a mechanism in the pathogenesis of human depressive illness and cognitive decline" (Khalsa 2010, p. 1025). This can manifest as poor decision-making and care provision by the informal caregiver (Khalsa, 2010). A meta-analysis conducted by Vitaliano, Zhang, and Scanlan (2003) found that caregivers can have decreased antibody responses in comparison to non-caregivers, as well as greater levels of circulating stress hormones. Increased levels of stress hormones such as cortisol, adrenocorticotropin (ACTH), 8-lipotropin and 3-endorphin, as well as catecholamines released during prolonged stress, can lead to damaging systemic affects (Ranabir & Reetu, 2011). Chronic stress can also cause altered endocrine responses, such as increased dissemination of vasopressin, gonadotropin suppression, suppressed thyroid function, a deficiency of growth hormone secretion, changes in prolactin levels, and decreased insulin secretion (Ranabir & Reetu, 2011).

Chronic stress can lead to the development, or exacerbation, of numerous disease states and can adversely affect immune and inflammatory responses (Forshee, Clayton, & McCance, 2010). In their study investigating the relationship between caregiver stress, immune system suppression, and sympathetic nervous system activation, Mills et al. (2004) concluded that immunity was suppressed in at-risk caregivers, as demonstrated by their decreased beta-2 adrenergic receptor sensitivity and density. Elderly informal caregivers may be at even higher risk for poor adaptation to stress due to neurohormonal, cellular, and immune changes which are collectively referred to as "stress-age syndrome" (Forshee et al., 2010, p. 365).

As dementia progresses, the level of required assistance with ADLs and IADLs by the individual with dementia often increases, resulting in the informal caregiver taking on ever-greater responsibilities (Nguyen, 2009). These physical demands along with the increased morbidity associated with aging places elderly caregivers at particular risk for poor physiological outcomes (Au et al., 2010; Pinquart & Sörensen, 2006; Schulz & Patterson, 2004; Vitaliano et al., 2003). In addition to the risk for injury that is related to the physically challenging tasks involved in caregiving, ICPWD may also be at risk of injury from aggressive and impulsive behaviours inflicted upon them by the care recipient. The relationship between long-term caregiving, chronic stress and detrimental physical effects have important clinical significance as it can provide one measure by which to identify at-risk ICPWD as well as to guide the choice of appropriate interventions (Schulz & Patterson, 2004).

Psychological impacts. In addition to the physical effects of chronic stress related to the different aspects of caregiving, mental and emotional effects can also greatly impact ICPWD, leading to distress and poor adaptation to the caregiver role. Negative psychological effects related to personal sacrifice, having to perform the many tasks involved with caregiving, increasing risk of social isolation, and feelings of burden, burnout, guilt, frustration, and fear (related to either personal safety or the safety of the care recipient), may manifest in the caregiver as depression, anxiety, anger, and burden (McKibbin, Walsh, Rinki, Koin, & Gallagher-Thompson, 1999; Schulz & Patterson, 2004). There is formidable concurrence throughout dementia caregiving literature, indicating that providing care for a person with dementia can lead to these types of negative impacts on the informal caregiver (Schulz & Patterson, 2004). Increased levels of stress and anxiety may be expressed by ICPWD when there are reports of sleep deprivation, frequent sleep interruptions at night, or verbal or physical abuse (Dury, 2014).

The stress involved with caregiving also places ICPWD at increased risk for mental health issues, particularly depression (Cuijpers, 2005; Epstein-Lubow, Davis, Miller, & Tremont, 2008; Owen et al., 2002; Schoenmakers et al., 2010; Schubert et al., 2008). Numerous studies have found that depression tends to be connected to several factors involved in caregiving, including degree of perceived burden, level of health, income of the caregiver, and degree of life satisfaction (Cuijpers, 2005; Schubert et al., 2008; Owen et al., 2002). The incidence and prevalence of depression is greater in ICPWD compared to non-caregivers (Cuijpers, 2005; Nguyen, 2009; Schubert et al., 2008). Similarly, Schoenmakers et al. (2010) found that ICPWD have more diagnoses of depression than others of their age, with caregiver rates ranging from 30% to 80%.

Aw (2013) states that informal caregivers in the sandwich generation are also at particular risk for “compassion fatigue”. Compassion fatigue represents a syndrome that was originally used to describe the physical and emotional exhaustion experienced by medical professionals who provide a great deal of empathy and caregiving in the workplace. Research has now demonstrated evidence of compassion fatigue in ICPWD (Day, Anderson, & Davis, 2014). The syndrome is characterized by physical, emotional, and spiritual collapse related to constant caregiving and can lead to feelings of anxiety, apathy, depression, resentment, and helplessness (Aw, 2013; Day et al., 2014).

Social impacts. In addition to the physical, mental, and emotional impact that caregiving can have on ICPWD, such caregivers also report frequent feelings of isolation and pressure. These negative feelings can result in financial and social implications as well (Schoenmakers et al., 2010). Cotrell and Engel (1999) concur, stating that, as caregiving demands accumulate, the informal caregiver can simultaneously become increasingly socially isolated from outside resources and supports. Furthermore, loneliness in such situations is common and has a proven association with increased morbidity and mortality (Charlesworth et al., 2008). Many adult children providing care to an elderly parent find that they must decrease the number of working hours that they can perform per week in order to continue to provide care. The resulting loss of income may affect their family and become a significant additional source of strain.

Financial impacts. The economic implications related to caregiving can be detrimental to many ICPWD. The costs associated with acquiring supportive services, or placing a family member in a residential care facility, can be exorbitant and prohibitive. The financial costs of caring may also include direct non-reimbursable health care costs for the care recipient, as well as the cost of forgone wages (Lai, 2012). The financial impact on younger ICPWD who remain in the workforce can be considerable as many informal caregivers find that they must necessarily decrease the amount of hours that they are able to work each week. Farcnik and Persyko (2002) state that a substantial number of informal caregivers are actually forced to quit working entirely in order to take on the caregiving role. The financial impact of caregiving can also be particularly significant for elderly spouses who are no longer in the workforce or who are receiving limited pensions.

Burden. Emlet (1996) describes burden as a complex phenomenon involving numerous objective and subjective factors. Similarly, Tebb (1995) states that burden, "or the inability to be resilient, is the extent to which the caregiver perceives that his or her physical, social, mental, and spiritual status is suffering as a result of providing care" (p. 88). Determining a caregiver's level of perceived burden is essential, not only for the purpose of ensuring the health and well-being of ICPWD, but also to identify any negative impact on the care recipient. Inordinate caregiver burden has been associated with negative implications for the care recipient, including an increased risk of residential care placement as well as a higher potential for elder abuse (Emlet, 1996; Yaffe et al., 2002).

Several forms of burden, such as physical, psychological, social, emotional, and financial burden, may be experienced by ICPWD (Donaldson & Burns, 1999; Emlet, 1996). Such caregivers often experience a multifaceted response to numerous stressors associated with the caregiving experience (Epstein-Lubow et al. 2008; Kasuya, Polgar-Bailey, & Takeuchi, 2000). Caregiver burden can be further influenced by other factors, including the ICPWD's perception of family relationships, culture, and social impacts (Etters, Goodall, & Harrison, 2008). The cultural background of the individuals involved can influence a caregiver's perception of familial obligations and consequently influence their perception of the burden they carry related to the caregiving role (Etters et al., 2008). For example, first-generation Chinese Canadians with a strong sense of filial responsibility may perceive less burden associated with caregiving than an acculturated third-generation Chinese Canadian whose experiences have been influenced by Western culture (Miyawaki, 2015). It is critical for PCPs to acknowledge that a caregiver's perception of burden is a major risk factor for poor adaptation to the caregiver role and most often presents in primary care as poor health and depression (Donaldson & Burns, 1999; Epstein-Lubow et al., 2008).

Numerous stressors, such as challenging behaviours by the patient with dementia, correlate with all facets of caregiver burden, whereas increasing limitations of ADLs and IADLs in the dementia patient correlate with greater personal burden for the informal caregiver (Diwan, 2004). As the disease progresses and care needs increase, so does the level of caregiver burden since the informal caregiver will necessarily have less ability and time to address their own needs and personal health requirements (Nguyen, 2009). Croog et al. (2006) state that higher levels of perceived burden may manifest as anxiety, anger or resentment towards the care recipient in addition to feelings of constraint, feelings of inadequacy in care provision, and feelings of social restriction.

Without adequate support, subsequent role strain and burden can lead to distress, generating poor outcomes for the informal caregiver as well as for the care recipient (Fowler, Haney, & Rutledge, 2014). Aggarwal et al. (2003) agree, stating that inadequate caregiver support can adversely affect the quality of care that ICPWD are able to provide. Furthermore, if ICPWD become incapable of continuing their role due to distress, there is an increased risk for institutionalization, conceivably for both the client and the informal caregiver (CIHI, 2010b). Consequently, the effects of caregiving on the health of ICPWD "continue to be important at both the individual and societal level" (Gonzalez, Polansky, Lippa, Walker, & Feng, 2011, p. 528; Schubert et al., 2008, p. 1737).

Changing Weather Along the Journey: Factors that Influence Burden

Understanding those factors that influence an informal caregiver's level of burden, well-being, and adaptation has significant implications for PCPs, particularly with respect to the identification and utilization of a caregiver's own resources to provide support and direct interventions. There are several determinants that may positively or negatively influence caregiver burden, well-being, and adaptation in ICPWD. Demographic factors include caregiver age, gender, living arrangements, relationship with the patient (Donaldson & Burns, 1999; Emlet, 1996), and cultural characteristics (Etters et al., 2007). Important contextual factors include caregiver characteristics (Donaldson & Burns, 1999; Emlet, 1996), accessibility or retention of social support, and behavioural issues that may be demonstrated by care recipients (Cotrell and Engel, 1999; Donaldson & Burns, 1999; Emlet, 1996; Tremont, 2011). These factors will be discussed in more depth in the following sections.

Ethnicity. It is important to consider ethnicity and culture in any discussion of the experiences of ICPWD as it can be influential through the entire dementia journey. Cultural values, such as filial responsibility and familism can either positively or negatively impact the caregiving experiences of culturally and linguistically diverse (CALD) ICPWD (Boughtwood, Adams, Shanley, Santalucia, & Kyriazopoulos, 2011; Miyawaki, 2015). For example, filial responsibility has been identified as a prevailing coping mechanism (Boughtwood et al., 2011); however, a strong sense of familism (a cultural value "…in which the needs of the family as a group are more important than the needs of any individual family member" ["Familism", 2016]), has been associated with negative impacts on informal caregiver health and higher accounts of burden and distress (Knight et al., 2002).

Interestingly, not all studies have found a significant connection between familism and health outcomes. A study by Knight and Sayegh (2010) found no evidence to support an association between familism, burden, and health outcomes in any of Spanish, Korean, African American, Caucasian American, or Korean American situations. It was instead found that individual coping styles, which admittedly can be influenced by culture, had a greater impact on burden and health outcomes.

Studies have found that the perception of burden is influenced by ethnicity. The study by Knight et al. (2002) determined that African American caregivers reported less burden than their Caucasian counterparts. This finding is further supported by Dilworth-Anderson et al. (2002), who found that depression and burden were higher amongst Caucasian caregivers than amongst African American caregivers. The latter authors state that this may be attributed to the cultural socialization within African American communities that shape expectations and feelings towards caregiving (Dilworth-Anderson et al., 2002), such as the development of interdependence and expected reciprocity within family members (Franklin, 1997). African American families may also identify more with traditional values that encourage care provision for dependent relatives (Lawton, Rajagopal, Brody, & Kleban, 1992). Likewise, a study by Roff et al. (2004) posits that African American informal caregivers experience more positive aspects of caregiving than their Caucasian counterparts as well as lower reported levels of anxiety and distress in response to behavioural and psychological symptoms of dementia (BPSD) in the care recipient.

Age and gender. Although a study by CIHI (2010b) found that the gender and age of the informal caregiver did not greatly impact the level of their distress, previous research has shown a greater association between burden and distress in female informal caregivers compared to their male counterparts. For example, a longitudinal study by Grafstrom and Winblad (1995) found that daughters reported more burden and negative physical effects from caregiving than sons. Donaldson, Tarrier, and Burns (1998) also found that female

ICPWD experience greater distress and subjective burden than male ICPWD. Similarly, in a study by Brodaty et al. (2014), female ICPWD reported higher levels of burden than their male counterparts. This is supported by more recent research by Pöysti et al. (2012) who found that male ICPWD experience less burden that female ICPWD regardless of the severity of the care recipient's dementia. Compared to male informal caregivers, female informal caregivers had increased reports of poor psychosocial health and well-being (Chiou, Chen, & Wang, 2005; Schulz & Beach, 1999), higher levels of stress (Meller, 2001), and higher rates of depression (Chiou et al., 2005; Dura, Stukenberg, & Kiecolt-Glaser, 1991; Fudge, Neufeld, & Harrison, 1997). Higher reports of burden in younger female ICPWD may in part be related to the numerous competing demands many such women face, since they may be caring for an elderly relative, be the primary caregiver for their own children, be maintaining a household, and hold employment commitments.

Relationship between the caregiver and care recipient. The nature of the relationship between the ICPWD and care recipient has also been found to correspond to levels of stress in the informal caregiver. As could be expected, a poor relationship between the informal caregiver and care recipient prior to the commencement of caregiving correlated with increased caregiver burden (Rinaldi et al., 2005). A cross sectional study by Campbell et al. (2008) identified that a poor relationship between the informal caregiver and care recipient, as evidenced by poor communication or a lack of affection and rapport, to be a significant predictor of burden. Spouses have also been found to be at increased risk for burden compared to other informal caregivers (Emlet, 1996). As support for this assertion, CIHI (2010b) found that it is more likely for spouses to experience distress and burden than other informal caregivers for several reasons: they often live with the care recipient, provide more care, act as the primary caregiver, and are often elderly themselves.

Caregivers' own traits. It has historically been assumed that only the cognitive changes and incapacities of the patient with dementia would impact the level of burden and stress experienced by their informal caregivers. However, recent literature has explored the ways in which the caregiver's own attributes and traits can affect their perceptions of burden (Donaldson & Burns, 1999). Au et al. (2010) stated that the impact of caregiving that has been caused by the care recipient's disease may actually be modulated by an informal caregiver's own personal characteristics. A study by Gaugler, Kane, and Newcomer (2007) suggests that caregiver resilience (measured by high caregiving demands associated with low burden) is a positive factor in adaptation, with greater proficiency in the caregiving role and with delayed nursing home placement of the care recipient. Additionally, Campbell et al. (2008) determined that decreased confidence in the informal caregiver is predictive of increased burden and distress. In comparison, those informal caregivers who demonstrate a more positive coping style and a higher level of perceived self-efficacy were more likely to express a reduced level of caregiving burden (Van Den Wijngaart, Vernooij-Dassen, & Felling, 2007).

Severity of disease and care recipient behaviours. CIHI (2010b) found that cognitive impairment and the number of informal care hours received were inversely related to caregiver distress. In fact, CIHI (2010b) found that those care recipients who received 21 or more hours of informal care per week were four times more likely to have an informal caregiver in distress than those who received less than 10 hours per week. This is likely related to the the fact the care recipient is in a later stage of dementia, placing greater strain on the caregiver in terms of physical care and managing BPSD, which increases throughout the disease trajectory. Feelings of burnout related to caregiving demands place caregivers at high risk for burden. However, Schubert et al. (2008) argue that the care recipient's decline in cognitive function does not contribute to caregiver burden as much as BPSD does. A correlation has been found in numerous studies between the feeling of caregiver burden and the incidence of challenging behaviours exhibited by the care recipient, such as resistance to personal care or physical abuse of the informal caregiver (Brodaty et al., 2014; CIHI, 2010b; Yaffe et al., 2002).

Social support. Social support, or lack thereof, can also considerably impact the experiences of ICPWD through the dementia journey. It can be divided into three elements: (a) a support network comprised of resources; (b) functional support, as in home supports; and (c) perceived support, as in the caregiver's satisfaction with, and subjective evaluation of the support available to him/her (Barrera, 1986; House, Umberson, & Landis, 1988; Vaux, 1988). Of the three, the level of perceived support has been suggested to be the greatest moderator of caregiver health outcomes (Lubben, 1988; Turner & Marino, 1994). A study by Wilks and Croom (2008) found that social support not only affects health outcomes, but likely also contributes to resilience in ICPWD during stressful times. The authors found that informal caregivers were "4.9 times more likely to experience high resilience with high family support; 1.8 times more likely to experience high resilience with high friend support; and 3.8 times more likely to experience high resilience with high overall social support ($p < 0.01$)" (p. 361). The ICPWD's perceptions of information dissemination and service provision may also influence their acceptance of support, and consequently the amount of support they actually receive.

Members of the primary care team, including PCPs, are frequently the principal formal care providers and are often the first connection for access to support services for both care recipients and their informal caregivers (McIntosh, Swanson, Power, & Rae, 1998). PCPs must therefore move beyond simply providing care to the patient with dementia and instead also commit to supporting the ICPWD (Aggerwal et al., 2003) and assisting them to better understand and navigate the health care system (Herklots, 2015).

Although the care coordination between PCPs and supportive services "is a defining characteristic of primary care" (Rothman & Wagner, 2003, p. 256), many such services are offered in a way that is fragmented and poorly coordinated, often leading to dissatisfaction amongst informal caregivers (Gill, Kuluski, Jaakkimainen, Upshur, & Wodchis, 2013). Reinhard, Given, Petlick, and Bemis (2008) state that, in addition to fragmented health care services, informal caregivers have historically received inadequate support from health professionals with regards to managing their concurrent caregiving demands and other responsibilities. Informal caregivers are often left unaware of available community services and supports when the information sharing by PCPs, and the direction from them, are insufficient to meet the requirements of the caregiver's situation (Aggerwal et al., 2003; Robinson, Buckwalter, & Reed, 2013); this can be a major barrier to service utilization (Strain & Blandford, 2002) and may precipitate unmet needs for both the care recipient as well as the informal caregiver (Diwan et al., 2004). Further, Hinton et al. (2007) posit that supports are often not put forward until issues such as BPSD become unmanageable, a phenomenon known as "reactive care" (p. 1489). A proactive, rather than reactive, approach that is a hallmark of primary care practice can be applied to the provision of support to

ICPWD, utilizing the stages of dementia as a guide along with the stated needs of individual caregivers.

Service utilization. Results of a study by Robinson et al. (2013) found that higher levels of burden and depression, as well as limited social support, were reported by ICPWD caregivers who did not use available services, such as respite or support groups. Although ICPWD who remain in the workforce and possess multiple roles can feel compelled to utilize these types of services in order to maintain their responsibilities (Robinson et al., 2013), ICPWD generally tend not to use them; such a tendency is well-documented throughout the caregiver literature (Chodosh et al., 2006; Joling et al., 2008; Ploeg et al., 2009; Robinson, 2005). When ICPWD do access services, they will often have commonly waited until late in the disease process to ask for assistance (Robinson et al., 2013) or when care recipients have often become too fragile to benefit from them (Zarit, Stephens, Townsend, Greene, & Leitsch, 1999). Waiting to access formal services such as home support, respite, or adult day programs can also impact ICPWD as, by the time they access these services, they may also be experiencing those negative effects of the caregiving role that can lead to distress and burnout. Further, if ICPWD wait until a crisis occurs to access services, the services may not be readily available, potentially leading to the caregiver turning to support from an acute care facility when they can no longer cope.

A cross-sectional descriptive study performed by Ploeg et al. (2009) found that caregivers who did pursue additional help sought this assistance from family, friends, home health services, community support services, and/or their physicians. Interestingly, the highest number of study participants (37.2%) named their physician as their first source of support (Ploeg et al., 2009). In fact, PCPs are most often the first resource that informal caregivers contact as a source of needed support (Alzheimer's Association, 2001; Fillit et al., 1999). Although informal caregivers reported accessing health care support by way of their physician, Ploeg et al. (2009) also noted that many caregivers indicate an apprehension about using community services due to inconsistent care provision, the substantial cost associated with services, inflexible time frames for service provision, and a lack of cohesion between home and community services. Rothman and Wagner (2003) also acknowledged that care coordination tends to be inadequate between community services and primary care systems.

In a study by Robinson et al. (2013), most of the ICWPD participants provided the majority of the needed care alone, using an average of only nine hours per week of additional informal help, such as the assistance of another family member, and four hours of professional help per week from formal supportive service providers, such as home support. Robinson et al. (2013) found that the use of these services was related to the relationship between the caregiver and care recipient ($p=0.001$); caregivers who chose not to access the services were more often spouses of the care recipient rather than adult children. This relationship was reflected in the study as it was found that caregivers who sought supportive service provision and respite services were much younger than those caregivers who used neither ($p=0.010$) (Robinson et al., 2013).

Older ICPWD are often spouses and they will predominantly have had longer relationships with the care recipient. As a result, these caregivers may feel that the caregiver role is both a customary and expected part of the relationship trajectory (Robinson et al., 2013). Once informal caregivers have established themselves in a caregiver role, they often begin to feel that they are the only ones competent enough to provide the care; they then often become unwilling and frightened to share care provision with others (Boland and Sims, 1996; Robinson et al., 2005; Zarit et al., 1999). Additionally, service utilization can have emotional implications for the caregiver, such as feelings of guilt if the care recipient is resistive to services, or feelings of weakness if the caregiver does not feel capable of fulfilling the caregiving role (Robinson et al., 2005). Due to their emotional ties to the situation, the spousal caregiver may not even recognize the potential benefits offered by service utilization (Robinson et al., 2005). This can then lead to an isolated care recipient/ caregiver dyad as the caregiver becomes less likely to accept assistance, regardless of the potential detriment to their own health (Boland & Sims, 1996).

The Travel Guide: Role of the PCP in Supporting ICPWD

Informal caregivers experience changing needs over time and this becomes evident throughout the caregiving process and journey (Salfi et al., 2005; Wald et al., 2003). Although the needs of ICPWD vary between individuals and the situations they face, many needs can also be anticipated as the care recipient progresses through the disease process. Such caregiver needs may include emotional support, education, advice, facilitation of support service provision, referrals to community supports and programs, and assistance with health care system navigation (Downs et al., 2006; Salfi et al., 2005). PCPs have a critical role in meeting the needs of ICPWD and their care recipients. This is particularly important for PCPs for three reasons: 1) primary care practice is one of the access points for community services; 2) PCPs are often the preferred source of health and resource information for ICPWD (Downs et al., 2006); and 3) PCPs can advocate for change in the policy arena. Therefore, PCPs and other member of the primary care team are in a pivotal position to effectively support ICPWD and to make a difference in their outcomes

(Donaldson & Burns, 1999; Katbamna, Bhakta, Ahmad, Baker, & Parker, 2002; Simon, 2001).

The role of the PCP may be likened to a ‘travel guide’, as PCPs can help these caregivers to more effectively navigate their caregiving journey. Further, PCPs can provide an essential ‘road map’ to help direct ICPWD in directions they need to travel during their journey, as well as a plan to deal with detours when caregivers come up against obstacles along the way, such as an acute decline in the care recipient’s function due to illness. For example, PCPs can guide ICPWD towards specific resources that can help to alleviate the stress and burden they may be experiencing (Joling et al., 2008; Schoenmakers, Buntinx, & DeLepeleire, 2010). PCPs can also use assessment and certain interventions to help ICPWD prepare for issues that may arise during the caregiving journey. These interventions may be simple, such as lending an empathetic ear to the caregiver during an office visit, or they may be more complex, such as recommending a collaborative care program. Curran and Wattis (2004) state that informal caregiver support often requires collaborative efforts between health care organizations and service providers. There is a need to establish and analyze strategies, such as didactic interventions and synergistic multidisciplinary collaborations, to help PCPs strengthen the connections between informal caregivers and available support services (Ploeg et al., 2009).

Effectively Guiding ICPWD Through their Journeys: A Person-Centred Approach to Care

A person-centred philosophy is recommended in dementia care as it ensures individuals with dementia are treated with respect and dignity, while promoting understanding of their prior life experiences and the development of meaningful relationships between care providers and care recipients (Alzheimer Society of Canada, 2013). Person-centred care focuses on tailoring care to each individual's needs, wishes, values, and beliefs (Alzheimer Society of Canada, 2013). The use of a person-centred approach with ICPWD may prove beneficial for both ICPWD and PCPs as it encourages PCPs to gain greater understanding of the needs and experiences of ICPWD; this knowledge and understanding can be used as the foundation on which to build relationships and guide the choice of supportive interventions.

Rogers' (1979) person-centred approach affords care based on the caregiver's subjective understanding of their experiences rather than just the opinion of the PCP. Rogers (1979) maintains that individuals react to their experiences based on their own perceptions of the situation, an assertion which is extensively reflected and supported in caregiving literature. For instance, Schoenmakers et al. (2010) stated that, "the way caregivers perceive their caring role and deal with problematic situations more closely predicts the care burden" (p. 44).

Self-concept is a central idea of the person-centred approach and is interconnected with caregivers' perceptions of their experiences (McLeod, 2015). A caregiver may not view themselves as a particularly proficient caregiver, yet they may be viewed as such by the PCP if the care recipient demonstrates good health and well-being. Conversely, the caregiver may perceive themselves to be a competent caregiver, yet evidence of neglect in both the care recipient and caregiver may suggest otherwise to the PCP. In such a situation, the involvement of social work and home health services, provided in collaboration with the PCP, becomes of paramount importance.

Rogers' (1979) theory is based on three principles: congruence (genuineness); unconditional positive regard (maintaining a positive attitude towards the caregiver); and empathy. If a PCP views the informal caregiver as a "potentially competent individual", this can help to increase the caregiver's feelings of self-worth and feelings of mastery in the caregiving role (McLeod, 2015). Further, if the PCP treats the caregiver as a partner in care, then the caregiver may feel that their knowledge and skill is being more explicitly recognized. Applying these principles during office visits will help ensure that the ICPWD feels supported, thus meeting the needs expressed by many of the caregivers in the literature (Karlsson et al., 2015; Prorok, Horgan, and Seitz, 2013; Shanley, Russell, Middleton, & Simpson-Young, 2011).

An example of a person-centred intervention that has been developed to improve communication between formal care providers and informal caregivers, and improve inpatient care of care recipients with dementia is the strategy called "Top 5" (Clinical Excellence Commission, 2016). Top 5 is an acronym used to guide the care of persons with dementia. Up to five strategies can be documented on a Top 5 form that can be shared between health care providers in both acute care settings and the community. Top 5 involves a discussion between a clinician and the ICPWD in which the strategies are determined to personalize and guide the patient's care (Luxford et al., 2015). Use of the strategies can help to decrease agitation and challenging behaviours that may be demonstrated by the person with dementia. Top 5 stands for:

Talk to the carer;

Obtain the information;

Personalize the care; and

"5" strategies developed (Clinical Excellence Commission, 2016).

The Top 5 strategy was developed by the Carer Support Unit and Central Coast Local Health District (CCLHD) in New South Wales, Australia. Top 5 was first implemented in 21 hospitals within CCLHD, followed by implementation in residential care facilities. The strategy draws upon the informal caregiver's knowledge and expertise about the care recipient and is aimed at decreasing anxiety and discomfort for both the care recipient and the ICPWD when the care recipient transitions between home, acute care, or long term care facilities (Clinical Excellence Commission, 2016).

One example of a Top 5 strategy is: The PCP talks to Mary (who has been providing care for her husband Jack for three years) about Jack's usual routine at home in order to collect information about what may cause Jack to become agitated or exhibit challenging behaviours if he must be admitted to the hospital. Mary states that they always let their dog Mitzy out into the yard at 4:00 p.m. If Jack is admitted to the hospital he may become agitated at this time of day, thinking that this routine is not being followed when he is not at home. Staff should reassure Jack that Mary has let Mitzy out and he will settle. This strategy can be documented and sent to the hospital with Jack for staff to follow. This example demonstrates the 'why' (Jack may become agitated), the strategy, and the intended outcome, all as recommended for Top 5 (Clinical Excellence Commission, 2016).

Evaluation of this low-cost strategy demonstrated not only potential health system cost savings, but significant improvements in ICPWD's experiences, patient outcomes, and satisfaction by staff caring for patients with dementia (Clinical Excellence Commission, 2016). For example, 89% of clinicians found that utilization of the Top 5 strategy improved relationships with ICPWD (Luxford et al., 2015). Further, ICPWD found that usage of the

Top 5 strategy made them feel respected by clinicians while 88.5% reported feeling more engaged in the patient's care (Luxford et al., 2015). Regrettably, no literature has been found suggesting that Top 5 or a similar strategy has been developed or implemented in Canada; however, its use has the potential to greatly improve outcomes for both ICPWD and patients with dementia in Canada.

If ICPWD feel at ease with the care that the care recipient is receiving in a healthcare facility, then they are likely to experience less stress and burden. My Grandpa's biography was developed in line with Top 5 strategy and was successfully used during his last acute care stay. Once the biography was integrated into Grandpa's chart, the quality of care provided to him improved dramatically, thus positively impacting not only Grandpa but my Grandma and Aunt who provided all of his informal care. This biography is presented in Appendix C.

Assessment of ICPWD: Determining Needs Through the Journey

A significant amount of literature encourages PCPs to treat patients with dementia and their ICPWD as dyads, which includes performing comprehensive assessments with the caregivers to address their needs and implementing interventions in order to meet these needs (Family Caregiver Alliance, 2006; Karlsson et al., 2015; Sadavoy & Wesson, 2012). The Family Caregiver Alliance (2006) suggested that a global assessment, guided by a conceptual framework, should be performed at the beginning of a caregiving journey and whenever transitions occur through the caregiving journey. It has been proposed that caregiver assessments that are conducted using well-designed, well-tested, comprehensive, and structured assessment tools by PCPs may contribute to the provision of consistent, quality health care for patients and their informal caregivers (Family Caregiver Alliance, 2012). The Family Caregiver Alliance (2012) has compiled an extensive list of tools that may be used to assess caregivers; however, Deeken et al. (2009) state that although numerous tools have been developed, few are actually used in the practice setting to assess the needs of caregivers. This may, in part, be due to the limited number of suitable, comprehensive tools developed specifically for use in the primary care setting. Moreover, two tools that have been designed and researched to address the specific and unique needs of ICPWD actually have no evidence supporting their use in clinical practice settings (Czaja et al., 2009; Keefe et al., 2009).

In addition to the lack of suitable assessment tools for use in primary care settings, performing an in-depth assessment is not a realistic exercise in many primary care practices, as completing a comprehensive needs assessment is more than most PCPs presently have the time to perform (Rich, Lipson, Libersky, & Parcheman, 2012). Moreover, if the informal caregiver is not a patient of the PCP (which is often the case), then the PCP will be unable to treat the caregiver as such. To address the challenges that PCPs may face in this regard, applicable clinical practice guidelines and a report by the Family Caregiver Alliance (2006) will be analyzed in Chapter Three and strategies for assessment will be discussed in Chapter Four.

Providing “Roadside Assistance”: Interventions and Ethical Issues

Barnard and Yaffe (2014) state that ethical issues are likely to be present in many informal caregiver/care recipient cases. Although supporting the informal caregiver is of critical importance, the patient’s needs and wishes must be taken into account by the PCP. This can lead to difficult and complex situations for the PCP. If the patient does not wish to commence services such as home supports, yet the informal caregiver feels that these services are needed, how should the PCP best structure and implement a response and supportive interventions? This question raises the thorny issue of paternalism if the PCP feels that the patient's wishes to refuse home supports should be overridden for his or her best interest (Barnard & Yaffe, 2014). The PCP's obligations related to confidentiality must also be taken into account if the PCP feels that it is important to have a discussion with the caregiver regarding support, yet the patient does not wish the PCP to engage in such a discussion.

Barnard and Yaffe (2014) suggest that viewing this type of question through the lens of caregiver burden can be essential in developing an understanding of both the positive aspects of caregiving and its associated challenges. Although the patient's autonomy should always be respected by the PCP, it has been suggested in the literature that it is appropriate for the PCP to support ICPWD if it serves to benefit both the caregiver and care recipient (Barnard & Yaffe, 2014). Moreover, Barnard and Yaffe (2014) posit that it is ethically responsible for PCPs to support informal caregivers in providing care for these patients and to advocate for those social policies that may improve the lives of informal caregivers.

The negative impact that caregiving can have on ICPWD has propagated significant interest in the health care arena. This has lead to an increasingly focused effort on conducting research that has examined supportive interventions for ICPWD (Belle et al., 2006). Etters, Goodall and Harrison (2007), as well as Tremont (2011), stated that, with the implementation of judiciously designed interventions, the well-being and health of both patient and caregiver can very often improve. However, it must be emphasized that such interventions must be selected and implemented according to caregivers' specific needs (Dahlberg, Demack, & Bambra, 2007; Etters et al., 2008).

While a systematic review of the impact of psychosocial interventions found evidence supporting the improvement of ICPWD's well-being through the use of both group and individual sessions, individual sessions demonstrated greater efficacy for more of the caregivers (Rosa et al., 2010). Interestingly, an examination of fifteen systematic reviews by Salfi et al. (2005) found that support groups, respite, counseling, and education sessions, all of which are interventions that may simply be assumed to be helpful to informal caregivers, did not actually lead to an improvement in reports of informal caregiver burden. This is important because, as noted previously, a higher degree of perceived burden on the part of the caregiver can negatively impact caregiver well-being.

Many studied interventions have proven to be beneficial for informal caregivers. For example, studies that examined yoga and mindfulness training for ICPWD revealed that daily meditative sessions improved stress levels (Black et al., 2013; Hurley, Patterson & Cooley, 2014; Jain, Nazarian, & Lavretsky, 2014; Oken et al., 2010; Waelde, Thompson, & Gallagher-Thompson, 2004), cognitive function (Waelde et al., 2004), mental health, and decreased depression levels (Hurley et al., 2014; Lavetrsky et al., 2013; Waelde et al., 2004). Salfi et al. (2005) found that a telephone intervention, in which a health care professional provided support to ICPWD over the telephone, provided beneficial emotional support and education. Telephone interventions may be particularly useful for those caregivers who reside in rural or remote areas with limited available services (Glueckauf et al., 2007). Online interventions may also prove similarly useful for individuals residing in rural or remote areas. A study by Gleuckauf and Loomis (2003) found that an online support program improved both caregiver subjective burden and their level of self-efficacy. Psychosocial support programs that offer services such as support groups, education, and counseling, have proven useful in delaying institutionalization of care recipients with dementia (Dröes, Meiland, Schmitz, & van Tilburg, 2006) and decreasing depression in ICPWD (Chu et al., 2011).

Despite the benefits reported in some studies, it is important to recognize that barriers to successful implementation of interventions do, unfortunately, exist. Such potential barriers include transportation issues, lack of familial support, insufficient knowledge of available interventions by PCPs, as well as cultural and socioeconomic factors that may limit accessibility to such services and thereby decrease participation by some caregivers (Czaja et al., 2013). Furthermore, the necessary types of interventions are not always considered for implementation by PCPs and may not even be available in many communities. For those patients with dementia and their informal caregivers who do have access to a PCP, primary care-based interventions may help to eliminate some of these identified barriers and improve support service access and uptake; however, research on interventions implemented within primary care settings is surprisingly scarce (Burns et al., 2003). This lack of research may, in part, be related to time constraints of clinic visits, lack of PCP knowledge of resources or quality dementia care, lack of financial reimbursement (Brotman & Yaffe, 1994), or perceived unrealistic expectations of informal caregivers.

The purpose of this literature review is to examine the specific ways in which PCPs can best support ICPWD. In keeping with a person-centred approach to caregiver care for ICPWD, Chapter Three will explore experiences and reported needs of ICPWD, as well as primary care-based assessment and interventions, with the aim of developing further knowledge and recommendations in which to guide the practice of PCPs in the primary care setting.

Chapter 2: Search Method

The intent of this literature review is to determine the ways in which PCPs can facilitate adaptation and well-being in ICPWD. Methodological strategies developed by Whittemore and Knafl (2005) were implemented in order to strengthen the rigour of the review process and to effectively answer the research question. The use of Whittemore and Knafl's modified review framework was specifically chosen as it affords greater rigour with the use of disparate research methods, as well as with both empirical and theoretical literature (Whittemore & Knafl, 2005). The first part of the search strategy for this project included the development of a search plan. A written table was created in which to track each search and the subsequent number of results for each of the searches. Endnote Basic was utilized as the reference management program to track and organize those references that were applicable to the research topic.

Databases were accessed through the UNBC library webpage and Fraser Health library webpage in order to obtain journal article citations. These resources allowed the search for articles using Cumulative Index of Nursing and Allied Health Literature (CINAHL) Complete, Ovid Medline, Psych Info, Academic Search Complete, Social Sciences Abstracts, and Biomedical Reference Collection: Comprehensive. Various types of literature were considered for this review: qualitative, quantitative or mixed-method studies, systematic reviews, narrative reviews, integrative reviews, clinical practice guidelines, editorials, and grey literature such as reports and conference proceedings.

To begin, the following Medical Subject Headings (MeSH) headings related to my question were used: *dementia, caregiving, caregiver, carer, informal caregiver, adaptation, transitions, primary care, primary care provider, nurse practitioner, caregiver needs,* *assessment,* and *interventions* in order to explore what types of articles would result. The use of these broad headings resulted in thousands of articles. By using the Boolean operator 'and' in order to marry terms such as *adaptation* 'and' *caregivers* 'and' *dementia* or *dementia* 'and' *caregiver* 'and' *primary health care* 'and' *interventions,* the focus of the searches was narrowed and this resulted in more relevant citations.

The search for articles also incorporated the use of Google Scholar, Trip Database (a clinical search engine containing high quality evidence-based literature), and the Agency for Health Care Research and Quality website, as it contributes both research syntheses and original research articles. Once these database searches were exhausted, and in order to complete a comprehensive search, grey literature was examined as well using the New York Academy of Medicine Grey Literature Report. The Institute of Health Economics website and the World Wide Web search engines were also explored. Database and grey literature searches were all conducted via online mechanisms.

Inclusion and Exclusion Criteria for Literature Consideration

Since the research question is quite broad with respect to the ways in which PCPs may facilitate adaptation and well-being in caregivers, many types of articles arose out of the initial search and were initially included in the results. For example, any empirical studies that examined interventions related to ICPWD were included, as were non-experimental articles pertaining to burden, risk factors for burden, service utilization, relationships between caregivers and primary care providers, and caregiver's experiences in the context of dementia. Qualitative studies were also included that examined the needs or experiences of caregivers providing care for individuals with dementia, in the interest of gaining an understanding of the caregiving journey in the context of dementia. The hope was that the inclusion of qualitative data would add depth to the overall review that examining quantitative data only would not afford. Further, the addition of qualitative studies provided insight into those needs that PCPs need to address in order to effectively facilitate adaptation and well-being in ICPWD. However, due to a myriad of literature found during the search, the inclusion criteria were subsequently narrowed to include only caregiver needs, experiences, assessment, and primary care-based interventions that could be performed by PCPs or other members of an interdisciplinary primary care team in collaboration with PCPs. Any studies that examined primary care-based supportive, psychosocial, educational, or multi-component interventions aimed at improving ICPWD's well-being or adaptation to the caregiving role were included. Other inclusion criteria for the selected articles for this literature review included a focus on unpaid or ICPWD, such as a spouse, child, other family member, friend, or neighbour, irrespective of age, ethnicity, level of education, occupation, or gender.

Studies included in this literature review were required to have been peer reviewed. Included studies also needed to have been written or translated into English in order to ensure comprehension of the work. Studies were considered for inclusion if the intended variable outcomes were related to ICPWD, including: depressive symptoms, anxiety, stress, burden, strain, caregiver adaptation, coping, knowledge, social support, or well-being. Studies focusing on outcomes, such as delayed nursing home admission or avoidance of hospital admissions of the care recipient, were also included in the review.

A summary list of inclusion and exclusion criteria is provided in Table 1.

Table 1. Inclusion and Exclusion Criteria

Inclusion Criteria:
Qualitative, quantitative, or mixed method studies
Systematic reviews, meta-analyses, integrative reviews, narrative reviews
Editorials, reports
Clinical practice guidelines
ICPWD of any age, gender, ethnicity, socio-demographic profile
Primary care-based interventions or assessment involving ICPWD
Needs or experiences of ICPWD
Studies written or translated into English
Studies from any country
Any date of publication
Peer reviewed articles

Exclusion Criteria:
Abstracts, study protocols, dissertations
Acute care-based studies
Study written only in a language other than English
Studies involving only paid or formal caregivers
Informal caregiver interventions or assessments that were not primary care-based
Informal caregiver interventions or assessments that could not be performed directly by, or in collaboration with, a PCP
Caregivers of patients with disease processes other than dementia

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Results and Selection of Articles for Review

The complete literature search resulted in a total of 5,369 articles or guidelines. After 812 duplicates were deleted, 4,557 titles and/or abstracts remained for review. Upon completion of a brief review of these articles and after the application of inclusion and exclusion criteria, 4,245 were excluded leaving 312 articles for full review. After these articles were reviewed, 282 were discarded for reasons such as focusing on the needs or experiences of the care recipient rather than the caregiver, not being related to primary care, or interventions not being administered by a PCP. Overall, 30 individual studies, systematic reviews, reports, and clinical practice guidelines were found to be suitable for inclusion in this review. See Appendix E for a diagram of the literature search strategy.

Chapter 3: Findings

In this chapter, qualitative literature will be explored first in order to gain an understanding of the experiences and needs of ICPWD. Next, the evidence pertaining to primary care-based caregiver interventions will be examined in order to help to determine how effective these interventions are at improving the caregiving journey for ICPWD. Finally, clinical practice guidelines will be explored to investigate current practice recommendations in which to provide support to informal caregivers. The search method outlined in Chapter Two produced 30 articles that met all of the search criteria and thus were included in the literature review.

The Caregiver Journey: From the Beginning to the End

Literature was explored that pertained to caregiver experiences and needs in order to provide insight into both the challenges and the positive aspects associated with caregiving. Having awareness of these experiences in different stages of dementia may help to promote ways to best support ICPWD. Galvin, Todres, and Richardson (2005) state that "this 'insider' view is able to facilitate empathic understanding in others and thus empower a deeper level of patient-centred care" (p. 9).

Pulling out of the driveway: The beginning of the journey. Two studies in this review described the experiences of ICPWD in the early stages of dementia. In the first study, Teel and Carson (2003) used a qualitative approach to explore the experiences of ICPWD who sought diagnosis, care, and treatment by PCPs. Fourteen informal caregivers between 45 and 83 years of age were recruited from 11 small urban or rural communities across Kansas, USA. Participants underwent semi-structured interviews lasting approximately one hour each.

With respect to obtaining a diagnosis, most of the caregivers in the Teel and Carson (2003) study reported having been to several specialists and PCPs before a diagnosis was actually made, due to a reluctance of their PCP to make a definitive diagnosis. Following the initial challenges of obtaining a diagnosis, many caregivers felt that their PCPs lacked expertise in supporting both informal caregivers and the care recipients. The hesitation by PCPs to diagnose dementia demonstrates how difficult it is from the PCPs' perspective to inform the patient and ICPWD about such a life-changing diagnosis. PCPs may not diagnose dementia for several other reasons, including: a lack of training in dementia care; a lack of knowledge about resources in which to provide once a diagnosis is made; symptoms may not be noticed during office visits; and they may not wish to disclose a diagnosis that will cause distress to their patient and/or informal caregiver (Alzheimer Society of British Columbia, 2012).

Not only is the diagnosis of dementia a difficult one to absorb but study participants also described causes of stress arising from associated financial, physical, and emotional factors. The cost of medications, formal supportive services, and residential care are now things that the caregiver needs to think about when, perhaps, this had not previously even been part of their thought processes. The study participants described uncertainty and fear about what the future held for themselves and the care recipient.

A sense of loneliness and lack of support from other family members and PCPs were prominent themes in the study. A lack of education provided to the caregivers by PCPs with respect to aspects of caregiving, such as providing personal care, was a noted frustration. One caregiver stated that "they say nobody can prepare you for it. Well, I think they can" (Teel & Carson, 2003, p. 49). Although caregivers felt a lack of support from PCPs in this regard, most study participants reported that attending support groups helped to meet those particular learning needs. Not surprisingly, when asked what they wanted PCPs to know overall about their experiences as family caregivers, the study participants consistently reported their desire to feel supported by PCPs. Overall, the experiences of the ICPWD in Teel and Carson's (2003) study suggest that PCPs need to be aware of the potential stressors that ICPWD may face during their caregiving journey and be open to hearing about ICPWD's experiences.

Although the finding that ICPWD felt that their learning needs were met through support groups, rather than through their PCP, was consistent across study participants, the authors stated that the participants were recruited through support groups and that this particular finding should therefore be interpreted with caution. Therefore, a notable limitation of the study was the underrepresentation of caregivers who did not attend support groups (Teel & Carson, 2003). Another limitation of the study was the homogenous study sample as all of the study participants were Caucasian and the majority (64%) were female. Although this may be a representative sample of the caregiving population in Kansas, the findings may not be generalizable to more multicultural communities.

In the second study, Adams (2006) utilized a phenomenological approach and grounded theory methodology to explore the experiences of ICPWD during the early stages of dementia and how they adjusted to the new caregiving role. Twenty spouse or adult child ICPWD were recruited through the University Memory and Aging Centre in Cleveland, Ohio, USA and underwent in-depth interviews lasting one hour each. Several themes and sub-themes were evident in the study findings. The first theme, 'family member tasks', involved the caregiver taking on new roles and tasks that the care recipient could no longer perform and struggling with the decision of how much to allow the newly-diagnosed person to do, such as paying bills, managing their own medication, or driving a car.

The second theme in the Adams (2006) study involved ‘changes in the relationship’ (protectiveness and concern, loss of confidant). Several of the study participants described how they tried to maintain intimacy and aspects of their relationship that they had always valued, such as humour; however, the caregivers reported experiencing feelings of loss as the care recipient’s cognition deteriorated.

The third prominent theme in this same study addressed negative emotions. Adams (2006) stated that 19 out of 20 study participants reported having experienced negative impact from caregiving. The caregivers expressed feelings of anger, frustration, and impatience towards the care recipient and some reported feelings of resentment.

Support from others (informal and formal) was the fourth theme. Caregivers voiced feeling socially isolated due to the fear of stigma or burdening others. Many caregivers reported feeling hesitant to access formal support due to feelings of guilt or feeling that they were taking away the care recipient’s independence.

The last theme found in the study was that of ‘thoughts of the future’; it involved feelings of uncertainty mixed with hope that the care recipient would not deteriorate quickly (Adams, 2006).

A strength of this study was the involvement of male caregivers in order to gain their perspective as participants in most caregiving studies are predominantly female; however, the small, primarily Caucasian sample all pulled from a single geographical area may prevent broader generalizability of the findings.

On the road: The journey continues through the middle stages. O' Shaughnessy, Lee, and Lintern (2010) conducted a phenomenological qualitative study to investigate the caregiving experiences and perceived meanings that spouse caregivers gave to these experiences. This study consisted of seven informal spouse caregivers (five wives and two husbands, all over the age of 59) who were providing care for a person in the mid-stages of dementia. These study participants were recruited from Alzheimer's Societies in the United Kingdom. Each participant was interviewed independently with each interview lasting 45 to 75 minutes.

The findings of the O'Shaughnessy et al. (2010) study resulted in four overarching themes. The first theme was connectedness and separateness; spouses stated that they still felt connected to the care recipient in some ways, yet felt a concurrent separation from the person as the dementia progressed. The second theme included tension between meeting the needs of the care recipient while still meeting their own needs. The caregivers in the study reported feeling guilty and overwhelmed with the caregiving situation. One caregiver reported feeling as if her needs were never met, including the requirements of her own health conditions. The third theme involved caregiver's uncertainty about the future as caregivers reported oscillating between acceptance about what was to come and uncertainty about the future. The fourth theme involved a need to maintain control in their lives and implement effective coping strategies.

Lilly et al. (2012) conducted a qualitative descriptive study that took place in three communities in the Southern Interior of British Columbia. Twenty-three individuals were recruited for the study, including ICPWD, peer support volunteers, and PCPs who supported ICPWD as a part of their role (social workers, for example). The study participants took part in three focus groups. The participants were primarily women (n = 20) and elderly, living in either small urban areas (21) or rural areas (n = 2).

Analysis of the findings resulted in two themes: 1) ICPWD feeling forgotten, alone and abandoned; and 2) health care providers having unrealistic expectations for caregiver self-care (Lilly et al., 2012). The ICPWD in the Lilly et al. (2012) study reported that, although they were aware of the benefits of self-care, many found this challenging to accomplish. Further, the ICPWD reported a perception that PCPs expected them to be able to perform self-care and this placed additional burden and responsibility on the ICPWD to meet those expectations. With respect to feeling forgotten, ICPWD reported feeling as if they were being taken for granted by the care recipient, family members, PCPs, and representatives of the health care system. Several ICPWD felt as though they had to fight for recognition of their work and to have their own support needs met. ICPWD expressed a need for referrals and information around dementia and available services, increased opportunities for respite, and assistance during the transition of care recipients to residential care. Many study participants reported that the ICPWD waited too long before requesting assistance from formal service providers. Lilly et al. (2012) stated that this was not a surprising finding considering the perceived expectations of PCPs related to caregivers' responsibility and ability for self-care, as well as the limited amount of formal support services actually available.

The authors noted that several methodological limitations existed. First, the sample size was small and homogenous. The experiences of men were not well-represented in the sample. The ethnicity of the participants was not documented. Strengths of the study noted by the authors included having PCPs and volunteers involved in the focus groups, which added different perspectives about the experiences of ICPWD. However, this may have also acted as a limitation as the caregiver responses may have been influenced by the presence of PCPs.

Galvin, Todres, and Richardson (2005) performed a single-case narrative study about one caregiver's experiences of providing care to his wife with dementia. The authors chose this narrative inquiry in order to provide a depth and meaning to the complex journey ICPWD face. Principles that stemmed from hermeneutic phenomenology were used to organize and analyze the information obtained through the single two-hour interview with the study participant (Galvin et al., 2005).

Three themes emerged from this interview regarding the caregiving journey. The first theme that was discovered was the concept that 'something is wrong'. Mr. M. described the crisis involved with memory loss in his wife during the early stage leading up to diagnosis, the social isolation, trying to establish a new relationship within their existing one, and creatively adjusting "shared life that is possible" as the dementia progressed (Galvin et al., 2005, p. 6).

Other shared experiences fell under the second theme of 'the challenging shared journey: being the carer', which included challenges related to physical care, medication management, responding to side effects from medications, and being vigilant to noticing and acting upon changes in his wife's condition. An important difficulty associated with caregiving that was reported by Mr. M., and was similar to the findings of Lilly et al.'s (2012) study, was the challenge associated with a caregiver's self-care. For example, Mr. M. found that self-neglect occurred at times, and he turned to respite when he recognized this occurring. However, although Mr. M. felt relief associated with utilizing respite, he also described experiencing feelings of guilt when he did seek out this service.

The final theme involved 'coping through meaning-making: advocacy'. Mr. M. discussed the importance of continuity of care, and having to learn about different levels of formal support and when to access them, since "such an integrated 'map' was not provided for him" (Galvin et al., 2005, p. 7). Further, Mr. M. described how taking on the role of advocate was a paramount way for him to make meaning out of their difficult circumstances.

A notable weakness of the Galvin et al. (2005) study was that it only included the learned experiences of one participant. However, the themes that emerged from the narrative were similar to many other caregiver's experiences and provided valuable insight into the ways that these experiences can help to drive clinical practice development and improvement (Galvin et al., 2005). The themes that have emerged in this study are consistent with the other qualitative studies that have been reviewed thus far.

Karlsson et al. (2015) performed a qualitative study using focus group methodology. In this study, 137 ICPWD and their care recipients participated in focus group interviews in eight European countries. The purpose of the study was to investigate the views of these participants regarding inter-professional information, collaboration, and communication through the dementia trajectory. Purposive sampling was used in order to capture a representative sample of types of care across the disease trajectory and stages of dementia.

Findings from the focus groups resulted in the development of three themes including the need for a primary coordinator, availability of individualized care and services, and adequate coordination of care between formal supports. The need for a centralized information point or person was also emphasized. One caregiver stated that "there is no coordination! Because that is not the role of those associations. There should be one central point where everyone should be able to go and get information…" (Karlsson et al., 2015, p. 1412).

The ICPWD participants also noted an appreciation for those occasions on which PCPs acknowledged their knowledge and skill, yet continued to provide counseling and education to them. The caregivers expected PCPs to be very knowledgeable with regards to dementia. Early diagnosis, continuity of care, and adequate inter-sectoral information sharing were also considered important by the study participants so that they would not be required to repeat the same information to numerous health care providers. Stage-related dementia care was considered good practice by some of the study participants.

Based on the study findings, Karlsson et al. (2015) suggested the use of collaborative care or case management interventions. However, studies by Connor et al. (2008) and Jansen et al. (2011) that examined case management interventions demonstrated that there is insufficient evidence to support the use of case management to improve informal caregiver well-being. Study strengths included an adequate sample size and the inclusion of numerous quotations that emphasized the meaning of the caregivers' experiences.

Jennings et al. (2015) conducted a cross-sectional observational cohort study to investigate the experiences of ICPWD of patients referred to a dementia care program (DCP). The authors sought to determine the relationship between caregiver strain, depressive symptoms, and self-efficacy for managing caregiving issues, and the type of referring PCP. Study participants were enrolled in the University of California and Los Angeles DCP along with the care recipient. A total of 307 ICPWD were surveyed over a period of one year. The caregivers were mostly female (67%) and either an adult child (49%) or spouse (41%) of the care recipient.

Validated tools were used to measure caregiver outcomes. Depressive symptoms were measured using the nine-item Patient Health Questionnaire (PHQ-9) (Kroenke, Spitzer, & Williams, 2001). The 13-item Modified Caregiver Strain Index (MCSI) (Thornton & Travis (2003) was used to measure caregiver strain, and the Neuropsychiatric Inventory Questionnaire (NPI-Q) (Kaufer, Cummings, & Ketchel, 2000) was used to measure the caregiver's level of distress related to their perception of BPSD severity in the care recipient. A nine-item survey was also used to determine the caregiver's perception of self-efficacy of caregiving, their PCP's recognition of the effect of the care recipient's cognitive impairment on the caregiver's health, and whether or not the caregiver had received education regarding dementia and caregiving.

Study findings demonstrated that, on average, caregivers experienced mild depressive symptoms, and 15% reported moderate to severe symptoms. The mean MCSI score was 11.5 which reflected moderate levels of strain, and 38% of caregivers reported high levels of strain. On the NPI-Q, caregivers reported agitation or aggression by the care recipient and nighttime behaviours as most distressing, leading to coping difficulties. The mean self-efficacy score was low at 2.8. There were no statistically significant differences between caregivers who were referred to the DCP by their geriatrician, internist, psychiatrist, neurologist, or family physician. With respect to information from the care recipient's PCP, only 25% of caregivers recounted being made aware of supportive services by their PCP while 39% received advice on managing dementia related issues, and 35% received advice about potential dementia-related issues they may face. The last three results are particularly interesting, as more than half of the referring physicians were geriatricians with extensive knowledge regarding dementia care (Jennings et al., 2015).

Based on the study findings, Jennings et al. (2015) concluded that more support is needed for ICPWD as many have unmet caregiving needs which may be, in part, due to the current primary care model insufficiently addressing complex dementia care as a result of time constraints, for example. Jennings et al. (2015) suggest that the development and implementation of comprehensive dementia care models may help to address such unmet needs of ICPWD.

A notable strength of the study was the adequate sample size. However, several study limitations were also identified by the authors. First, as the study participants and care recipients were referred to the DCP, the caregiver's level of strain and dementia severity of the care recipient may have been higher than the average ICPWD. Second, the study may not be generalizable due to the participant demographics (mostly female, Caucasian, and medically insured).

Only one study examined the experiences of ethnically diverse ICPWD. In this qualitative study, Boughtwood et al. (2011) used a modified grounded theory approach to examine the perceptions and experiences of CALD ICPWD. One hundred and twenty-one family ICPWD were recruited from Arabic-speaking, Chinese-speaking, Italian-speaking, and Spanish-speaking communities in Australia. The study participants were primarily female (n = 88) and adult children of the care recipient (n = 93). Study data was obtained from 16 focus groups, consisting of approximately eight people from each group.

Four themes emerged from the data, including caregiving duties; family related issues; emotional and personal concerns; and dementia-related concerns. ICPWD from all

CALD backgrounds were involved with physical and emotional care, and assistance when visiting PCPs. With respect to caregiving duties, only the Italian-speaking and Spanish-speaking caregivers reported acting as advocates while the care recipient was in the hospital. Many of the caregivers perceived the hospital staff to be unable to meet the needs of the care recipient, often leading to the caregiver spending long periods of time in the hospital to support the care recipient. The importance and implications of encouraging ICPWD to provide background patient information to those health care workers who are unfamiliar with the care recipient will be discussed further in the following chapter.

Expected gender roles and family conflicts were discussed by Spanish-speaking and Italian-speaking caregivers. For example, the women were expected to perform specific tasks, such as personal care for the care recipient, which may have been perceived in the culture as inappropriate for males to do. With regards to family conflicts, two potential reasons for conflict were brought to light in the study. The first conflict related to refusal of family members to participate in care, and the second was related to conflict between adult children caregivers and their spouses due to the demands involved in care provision which took time away from the caregiver's family. With respect to emotional and personal concerns, all of the study participants reported concerns related to grief and loss, lack of time for self, anxiety about the future, and deterioration of their health. Under the theme of dementia-related concerns, Chinese, Italian, and Spanish-speaking participants noted BPSD as a concern, whereas Arabic, Italian, and Spanish-speaking participants reported safety issues and care recipients confusing family members with other members of the family as concerns.

Boughtwood et al. (2011) found that familism and cultural piety impacted the decisions that CALD ICPWD made. These traits should be considered by PCPs when including ICPWD in dementia care planning. Additional cultural considerations for PCPs include the possibility of numerous informal caregivers being involved in decision making, the stress that CALD ICPWD may experience related to the potential need to translate medical information to the care recipient, and the ethics and challenges associated with using caregivers as translators (Boughtwood et al., 2011). Boughtwood et al. (2011) also stated that PCPs who interact with ICPWD from CALD communities must reflect upon these circumstances and consider possible ways in which to support such caregivers during primary care visits.

The comparison of four different cultural groups, rather than just one or two, is a notable strength of the study. This broader picture provides PCPs with a better understanding of the potential needs of members of different CALD communities.

Two limitations of the study were identified by the researchers. The first limitation was the exclusion of Anglophone participants in which to compare experiences. The second limitation was the inclusion of only the direct caregivers in the study rather than other family members as well. It would have been valuable to compare the perceptions of other family members with those of the direct caregivers regarding family conflict and decisions about the care recipient's care (Boughtwood et al., 2011). Boughtwood et al. (2011) concluded that caregiving experiences were deeply influenced by culture, and that PCPs must be aware of cultural context when providing care to patients with dementia and their informal caregivers.

Two research studies included in this review sought to identify the positive experiences of ICPWD throughout the caregiving journey. In the first study, Cohen, Conantonia, and Vernich (2002) describe the experiences of 289 ICPWD who were part of a sample of caregivers derived from the Canadian Study of Health and Ageing (Lindsay, 1994). Information was collected through personal interviews with the caregivers. The results demonstrated that the majority of the caregivers in the study experienced at least one positive aspect of caring during their caregiving journey. Two hundred and eleven (73%) could find one positive aspect, while 6.9% expressed more than one. Specific positive findings associated with the caregiving role included companionship (22.5%), fulfillment (21.8%), enjoyment (12.8%), fulfillment of a sense of duty (10.4%), improved QOL (7.3%), and finding a sense of meaning (5.9%). Using Noonan and Tennstedt's (1997) conceptual model, Cohen et al. (2002) used a staged stepwise multiple regression approach which incorporated contextual variables (demographics), stressor variables (care recipient's ADL limitations), mediator variables (services used, and positive aspects of caring), and outcome variables (burden, self-assessed health measures, and depression). Based on the study findings, the authors suggest that clinicians ask about positive caregiving experiences in order to better understand the informal caregiver experience and provide assistance to those who need it.

Peacock et al. (2010) performed a secondary analysis of a Canadian mixed method study (Forbes et al., 2008) in order to gain greater insight into the overall experiences of ICPWD. The authors used a strength-based perspective, which acknowledges both negative and positive experiences, in order to analyze the data (Peacock et al., 2010). ICPWD from both rural and urban communities in Ontario, Manitoba, and Saskatchewan were recruited from community support programs, such as the Alzheimer Society support groups for caregivers. Thirty-six ICPWD participated in focus groups and three underwent individual interviews. The use of open-ended interview questions was a notable strength of the study as it allowed for an outpouring of reflection and feelings of the ICPWD (Peacock et al., 2010).

The study findings produced five themes: reciprocity; personal growth; discovery of inner strengths by connecting with others; developing a sense of competence as a caregiver; and an opportunity to build stronger relationship with and a commitment to the care recipient (Peacock et al., 2010). For example, in the study many adult children and husbands voiced feelings of reciprocity; however, wives did not. This may be explained by the fact that many women may consider caregiving for a spouse to be just a continuance of the role they always held within the family context whereas, for adult children or husbands, adult caregiving may be an entirely new experience.

Based on the findings of the study, Peacock et al. (2010) posit that PCPs and researchers alike should not assume that ICPWD are engrossed in only negative caregiving experiences. Identifying the positive aspects of the caregiving experience can help to build positive relationships between both PCPs and ICPWD, and between ICPWD and recipients. Furthermore, focusing on positive experiences may encourage ICPWD to view challenges as opportunities rather than obstacles. An important consideration noted by the authors is the need to avoid placing too much emphasis on positive aspects of caregiving, which risks pushing the ICPWD beyond their capabilities.

A notable limitation of the study identified by the authors is that most of the study participants were users of community supportive services. Well-supported caregivers may report more positive aspects of caregiving compared to those who do not use these services, thereby potentially influencing the study results.

Reaching the end of the road: Near the end of the journey. Only one article in the review pertained to ICPWD experiences during the end stages of dementia. A small qualitative study by Shanley et al. (2011) explored the experiences of 15 spouse or adult child ICPWD through in-depth, semi-structured interviews. Five themes emerged from the data: obtaining formal and informal support including respite; having to trust others with care; managing the loneliness of being a caregiver; witnessing a loved one fade away; anticipating and experiencing death; and re-establishing life after the funeral. Caregivers in the study expressed feelings of extreme loneliness and the need for empathy, yet many did not experience this from formal care providers or family. The lack of empathy and support from PCPs could be related to the fact that dementia is most often not viewed as a palliative diagnosis. PCPs may not recognize the need for palliative support due to the lengthy disease trajectory seen in patients with dementia. Viewing dementia as a palliative diagnosis from the initial diagnosis may help PCPs to better prepare ICPWD for the end of the journey with the care recipient and beyond.

Based on the experiences of ICPWD in the study, Shanley et al. (2011) stressed the importance of providing understanding, empathy, and sensitivity to ICPWD, particularly during the end stages of dementia. Additionally, despite the fact that PCPs most often encourage individuals to make their own health care decisions, Shanley et al. (2011) suggested encouraging certain caregivers to access supportive services if needed.

A notable limitation of this study is the small sample size, which limits generalizability.

Informal Caregiver Needs Throughout the Caregiving Journey

Despite ongoing improvements with respect to informal caregiver recognition and supportive groups, a lack of understanding of informal caregiver needs and the ways in which PCPs can adequately meet those needs is evidenced by recurrent hospital admissions related to caregiver burnout and repeated caregiver reports of role strain and poor coping. Robinson et al. (2013) concur, stating that "efforts to meet caregivers' needs remain piece-meal in a patchwork care delivery system that has improved little over the past several decades" (p. 502). It is imperative that PCPs endeavour to identify these needs of informal caregivers in order to provide comprehensive, effective, holistic, person-centred care.

In a mixed method exploratory study, Stirling et al. (2010) compared measures of caregiver burden with unmet needs and support services received. Twenty-four ICPWD were recruited from the Hobart chapter of the Alzheimer's Australia Organization; 20 of these caregivers consented to study participation. The caregivers in the sample were primarily female (90%), a spouse of the care recipient (70%), and all were over 66 years of age. The study took place over 12 weeks and study participants completed self-reported measures during week one, four, eight, and 12 that assessed burden and stress (normative need measures) and service wants (felt need measures). The study participants also logged their service usage over the 12-week period (expressed need measures) and participated in three semi-structured interviews lasting between 30 and 90 minutes each.

Objective caregiver burden was assessed by measuring functional dependency and dementia severity of the care recipient using the Dementia Rating Scale-2 (DSR-2) (Monsch et al., 1995) and Bayer ADL Scale (BALDS) (Hindmarch, Lehfield, de Johgh, & Erzigkeit, 1998). Subjective caregiver burden was measured using the Carers' Checklist (Hodgson, Higginson, & Jefferys, 1998) and General Health Questionnaire (GHQ-30) (Goldberg & Williams, 1988). Study results demonstrated a relationship between stress in the ICPWD and unmet service needs (p = 0.05) and information needs (p = 0.01). Overall, the study findings suggest that when considering service needs of ICPWD, having an understanding of felt need may be more useful that normative need as felt need has a significant relationship with caregiver's mental health status.

A significant limitation of the study was the small sample size. Studies with larger sample sizes are needed to support the findings of this study. The authors concluded that gaining an understanding of what services the ICPWD want is more important than measuring perceived levels of burden and stress. Felt need may also be a relevant 'red flag' of caregiver burnout, even without the conspicuous 'red flags' caused by decline in the care recipient (Stirling et al., 2010). Therefore, the authors recommend moving away from normative needs assessment in clinical practice and focusing more on voiced needs of ICPWD.

In a qualitative study by Leong, Madjar, and Fiveash (2001), the researchers identified areas of unmet perceived need of ICPWD in an Australian community. Study participants (n = 94) were recruited from community nursing services and local dementia support group meetings. Over two thirds of caregivers were elderly and female. Purposive sampling was used to obtain a varied sample that included caregivers with different backgrounds providing care to persons in different stages of dementia. Qualitative interviews and a survey were used for data collection. The survey consisted of two, five-item Likert-type scales for each of the 42 need items on the list. Ten caregivers in the study also participated in semi-structured qualitative interviews.

Six unmet needs were identified by study participants including: knowing that someone will provide care when the ICPWD is unable to do so; a 24-hour telephone information line; respite; information about ways to deal with stress; time for physical rest; and education about ways to deal with feelings of feeling trapped (role captivity). In response to these study findings, Leong et al. (2001) recommended that PCPs hold family conferences with ICPWD and other family members or persons involved with care of patient with dementia in order to organize respite and develop an alternate plan of care if the primary ICPWD is temporarily or permanently unable to provide care. Leong et al. (2001) also suggested taking measures to raise public awareness about dementia in order to decrease social isolation of ICPWD and care recipients.

Rosa et al. (2010) conducted a mixed methods study in order to determine the unmet needs of ICPWD who were providing care for individuals with moderate to severe dementia. One hundred and twelve ICPWD were recruited from a memory clinic in Italy. Questionnaires were used to identify patient needs. Caregiver's burden was assessed using the Caregiver Burden Inventory (CBI) (Novak & Guest, 1989). Depression and anxiety were evaluated using the Centre for Epidemiological Studies Depression Scale (Radloff, 1977) and State-Trait Anxiety Inventory (Spielberger et al., 1980), respectively. Interestingly, Rosa et al. (2010) found that the caregivers did not express a great need for emotional and psychological support; however, despite the fact many of the caregivers had been providing care for a significant amount of time, they still demonstrated a significant need for obtaining diagnosis (65%), education about dementia (78%), knowledge about pharmacological treatment (75%), caregiver/care recipient communication (83%), and non-pharmacological management of cognitive (77%) and behavioural problems (81%). Based on these findings, Rosa et al. (2010) suggested utilizing a multi-disciplinary primary care team who can provide their expertise in addressing the different areas of need.

In order to explore experiences of patients with dementia and their informal caregivers in primary care settings, Prorok et al. (2013) performed a systematic review and ethnographic meta-synthesis of 46 qualitative and mixed method studies. Five themes related to these experiences were identified. The first identified theme was 'seeking a diagnosis'. The second theme was 'accessing supports and services'. The third was 'addressing information needs'. The fourth was 'disease management' and the fifth theme was 'communication and attitudes'. Prorok et al. (2013) developed a conceptual framework that describes the progression of ICPWD's experiences in health care through phases seeking understanding and information, identifying the problem, role transitions following diagnosis, and living with change.

Based on the results of the review, Prorok et al. (2013) concluded that, overall, the health care experience for ICPWD is substandard and parts of caregivers' experiences could be improved upon. The authors state that implementing certain interventions, such as the use of care managers and psycho-education, may benefit ICPWD. The use of meta-ethnology to analyze the literature is a strength recognized by the authors, as it allows for supplementary analysis and the development of frameworks such as the "conceptual framework for the health care experience of people with dementia and their caregivers" (Prorok et al., 2013, p. E675).

The experiences of my Grandma and Aunt are reflected in many of the study findings discussed thus far in this chapter. Similar to ICPWD in the Boughtwood et al. (2011) study, my Grandma and Aunt both spent significant amounts of time in the hospital when my Grandpa was admitted, as they often felt that his needs were not being met. In many cases, his needs were not met, because staff were not familiar with his history or how to interpret his behaviours. The reported feeling of loneliness was certainly shared by my Grandma and Aunt with other ICPWD in the studies. The common and shared experiences of my family's lived experience and ICPWD in the reviewed studies demonstrates that the challenges and needs reported in the literature are, in fact, a reality for Canadian ICPWD. This reality emphasizes the need for a greater understanding of these lived experiences by PCPs in order to best support ICPWD in primary care using a person-centred approach.

Informal Caregiver Assessment

Of the 30 articles and guidelines reviewed, one consensus report pertained to caregiver assessment. The Family Caregiver Alliance (2006) ascertained that "establishing caregiver assessment as a basic component of practice across care settings-with formal recognition of caregiving families and the goal of strengthening them-calls for a fundamental change of thinking in policy and practice" (p. 1). In order to encourage care providers to incorporate assessment of informal caregivers into practice and narrow the research-practice gap, the Family Caregiver Alliance (2006) developed a consensus report on caregiver assessment based on expert opinions of numerous health care leaders. The report provides both principles and guidelines that health care providers can assimilate into their practice. In the guidelines, the Family Caregiver Alliance (2006) recommends assessing all identified caregivers, considering patients and caregivers as dyads, tailoring assessment and interventions to the caregiving context, and clearly communicating the reasons for assessment to the caregiver. Further, it is suggested that a global assessment, guided by a conceptual framework, should be performed at the beginning of each caregiving journey and whenever transitions occur as part of the caregiving journey.

The guidelines in the report were not graded for quality. Although supporting literature was used throughout the report, recommendations in the guidelines are informed by consensus of opinion and therefore the strength of the recommendations is diminished. Despite the stated limitations, the report proposes salient principles and clear recommendations that PCPs can use to address informal caregiver needs and guide the selection of supportive interventions.

Providing 'Roadside Assistance': How Effective Are Primary Care-Based Interventions?

Intervention-based research studies contribute to the foundation of evidence-based practice by substantiating the efficacy of specific interventions (Grove, Burns, & Grey, 2013). Sidani and Braden (1998) considered interventions to be "treatments, therapies, procedures, or actions implemented by health professionals to and with clients, in a particular situation, to move the clients' condition toward desired health outcomes that are beneficial to the clients" (p. 8). Primary care-based interventions found in the literature aimed at improving the health of informal caregivers are varied. Such interventions range from ensuring knowledge-sharing between the PCP and the client regarding available community resources to the involvement of a much more complex collaborative model that includes a multidisciplinary health professional team and community service partners. Despite the relative abundance of caregiver and dementia care literature available, there are a limited number of studies pertaining specifically to primary care-based interventions. Since PCPs often have frequent contact with ICPWD, a critical step in answering the research question of this literature review involves reviewing and critically analyzing studies that have investigated primary care-based interventions. For the purpose of this review, these articles will be organized and discussed according to the type intervention studied: psychosocial, educational, and collaborative care.

Psychosocial interventions. Out of the 10 intervention articles reviewed, two individual randomized controlled trials (RCTs) and one systematic review examined the effects of psychosocial interventions on spousal ICPWD. In the first study, a multi-centre RCT, Rodriguez-Sanchez et al. (2012) attempted to determine whether a psychological intervention in the context of primary care improved the mental health of ICPWD. The study took place between July 2008 and November 2009 at two primary care sites in Salamanca, Spain. Using consecutive sampling, 125 caregivers were randomized after screening to either the intervention group (who participated in eight cognitive behavioural group sessions) or control groups (who received usual care) at a 2:1 ratio. Usual care consisted of medical care, education about basic care (i.e. falls prevention, nutrition), and coordination of specialist care and social services which was provided by general practitioner and nurses in primary care centres. It was noted that ICPWD did not commonly receive adequate support within the primary care clinic, particularly if the ICPWD was not a patient of the PCP. The interventions were delivered by a psychologist as well as a general practitioner or nurse from the primary care clinic.

A notable strength of the study included the use of validated self-reported questionnaires to obtain outcome data, which enhanced the convergent validity of the study. The validated and replicated 12-item version of the General Health Questionnaire (GHQ-12) (Montazeri et al., 2003) was used to measure the caregiver's perceptions of their mental health as a primary outcome. Secondary outcomes (dysfunctional thoughts, QOL, and burden) were measured using the Dysfunctional Thoughts about Caregiving Questionnaire (Monotorio, Losada, Izal, & Márquez, 2009), Ruiz and Baca's (1993) Questionnaire, and the Short Zarit Burden Interview (Bédard et al., 2001), respectively. Statistically significant improvements were found in relation to dysfunctional thoughts about caregiving (p = .01), as well as within two domains of the GHQ-12: cognition and physiological (p = .04) and general welfare (p = .01). However, no significant improvements were demonstrated in relation to QOL or burden. As a result of these findings, this intervention cannot be recommended in isolation to improve the general well-being of informal caregivers (Rodriguez-Sanchez et al., 2012). Another limitation of this study is the absence of follow-up after the study's completion to determine any long-term effectiveness of the intervention.

A German RCT by Menn et al. (2012) compared three counselling and support interventions of different intensities to the provision of usual care in order to determine whether the interventions impacted timing of nursing home placement of patients with dementia. This three-arm cluster-RCT involved a large sample size of 390 individuals with dementia aged 65 years or older as well as their informal caregivers. The intervention included the training of family physicians in dementia care and their subsequent in-office counseling and referrals to support groups for caregivers. The long-term effects of the intervention were assessed over a four-year period, a marked strength of the study. After two years, 12% of the participant patients had been transferred to residential care while 66% still lived at home. Four years later, 24% of the participant patients had been institutionalized and only 39% remained at home (Menn et al., 2012). These findings support earlier contentions that the inability of the ICPWD to continue caring for the care recipient is congruent with the burden associated with the progressive nature of dementia symptoms.

Overall, Menn et al. (2012) found no significant differences between the intervention and control groups regarding the timing of residential care placement at two and four years ($p = 0.25$ and $p = 0.71$, respectively). Similarly, despite adjusting for confounding demographic variables, secondary outcomes such as cognitive functioning and ADLs of the patients, caregiver burden, and QOL, no significant differences were demonstrated between the intervention and control groups at the two and four year marks. However, it is important to note that the results of this study may have been influenced by several confounding variables. For example, there were a high number of patients in the early stages of dementia at the beginning of the study, likely affecting primary and secondary outcomes such as caregiver burden and IADL functioning as the care recipient's need for assistance is less. Further, in contrast to other studies reviewed, informal caregiver participants in this study voluntarily chose whether or not to use the supportive components of the intervention, such as counseling and support groups. Allowing the study participants to choose what interventions they required more accurately mirrored realistic primary care and transferability to practice, thus providing elevated external validity of the study findings (Menn et al., 2012).

During the comprehensive literature search, only one systematic review was found that examined primary care-based psychosocial interventions specifically. Due to the dearth of literature with regard to primary care-based caregiver interventions, the systematic review conducted by Greenwood, Pelone, and Hassenkamp (2016) included only four research studies that synthesized evidence for the use of psychosocial interventions for informal caregivers of individuals with either dementia or stroke in general practice. Although caregivers of individuals who had experienced a stroke were included in the search, the four studies that fit the criteria of the review investigated ICPWD only. Two of these studies were RCTs. The third study was a non-equivalent control group trial and the fourth was defined as an "uncontrolled before and after study" (Greenwood et al., 2016). The authors used Kmet, Lee, and Cook's (2004) quality assessment criteria to assess the methodological quality and found that only two of the studies were rated as "good", with a score of 85% or more (Greenwood et al., 2016). Studies included in the review measured caregiver outcomes of depressive symptoms, emotional and physical health, caregiving challenges, dementia knowledge, burden, social support, QOL, and well-being. Available evidence suggests that the implementation of psychosocial interventions in primary care settings may improve caregiver well-being and mental health. However, caution was suggested by the authors considering that the results of the studies as the effects on several outcomes were either not statistically significant (burden, QOL, and health status) or were contradictory (depression, knowledge of dementia, and caregiving competence), and the only study that did demonstrate significant results was of poor methodological quality. The instruments used to measure outcomes also varied, making it difficult for the review authors to compare across studies. Another important caution to consider is that the studies did not specify the ideal timing of the interventions with respect to the stage of dementia. Despite the limitations of the reviewed studies, the authors concluded that, overall, psychosocial interventions in general practice settings may prove to be beneficial in improving the well-being, perceptions of burden, and levels of depression in ICPWD.

Educational interventions. Three studies included in this review investigated the effects of psycho-educational interventions on informal caregiver outcomes. In the first study, Burns et al. (2003) compared two 24-month primary care educational interventions focusing on either behaviour management or on behaviour management together with caregiver stress-coping management. In response to the limited number of primary care-based interventions in use, and issues that PCPs have regarding dementia care that have been discussed in the literature, the researchers developed brief interventions that took into account the time constraints inherent in PCP practice and that can guide PCPs care of patients with AD and their informal caregivers. In this study, 167 patient/informal caregiver dyads were recruited from their physicians' offices and randomized from primary care sites in Memphis, Tennessee, USA. Both groups received educational materials, face-to-face education during primary care office visits lasting 30-60 minutes, twice monthly telephone calls for the first six months and then monthly calls for a total duration of 24 months. The phone calls were made to monitor the effectiveness of caregiving strategies that were discussed during office visits for improving behaviour management of the care recipient's problem behaviours and stress reduction in the ICPWD. An educator-interventionalist with a master's degree carried out the interventions. Outcome variables were measured at baseline and then again at six monthly intervals until a total duration of 24 months had elapsed. Over time, statistically significant positive changes were found in relation to both caregiver well-being and caregiver depression. However, a small sample size and a high attrition rate (28% lost to follow up) were limitations of this study recognized by the authors.

In order to evaluate the effect of a 12-month NP-guided dementia care intervention in a primary care setting, Fortinsky et al. (2014) conducted a small RCT that included 31 patients with dementia and their family caregivers at three primary care sites in Connecticut, USA. Twenty-one participating dyads were randomly assigned to the intervention group while 10 dyads were randomly assigned to the control group. All caregivers in the study underwent face-to-face interviews at baseline, at six months, and at 12 months to collect outcome measurements. The intervention used differs from other collaborative care models as the NP was required to assess study participants in monthly home visits rather than in a clinic setting. The NP provided medication management in collaboration with the PCP, monthly home visits for the intervention group, and education pertaining to stress management, exercise plans, communication techniques, financial and legal information, prevention and management of depression and anxiety, behaviour management, mobility management, providing personal care, and managing paranoia, delusions, hallucinations. Updates were sent by the NP to the PCP after each visit with the study participants. The control group received usual care in the clinic from their PCPs The components of 'usual care' in the context of this study were not identified by the authors.

Measured caregiver outcomes in the study included depressive symptoms, which were measured using the 20-item Center for Epidemiologic Studies-Depression (CES-D) inventory (Radloff, 1977), self-efficacy, measured with the use of two questionnaires, and caregiver burden, measured with the Zarit Burden Interview (Bédard et al., 2001).

Several limitations of the study were recognized by Fortinsky et al. (2014). First the sample size was small. Second, the fact only one NP was involved in the intervention may have influenced the results of the study due to positive relationships that developed between the NP and the study participants. Third, the length of the study was not long enough to detect measurable decline in the care recipients and therefore the effectiveness of the intervention through several stages of dementia could not be evaluated.

Although the findings of this study did not support improvement in patient or caregiver outcomes compared to those in the control group, both the study participants and the PCPs involved reported a high level of satisfaction with the intervention, based on results of satisfaction surveys. The researchers stated that NPs with geriatric knowledge are ideal health care providers to implement interventions aimed at improving dementia patients and their informal caregivers. Further research with large scale trials are needed to more comprehensively evaluate the impact of NP-led psychosocial interventions (Fortinsky et al., 2014).

In response to a lack of available formal care for dementia patients and their informal caregivers in Russian communities, Gavrilova et al. (2009) implemented a single blind parallel RCT in Moscow, Russia that examined whether a particular caregiver intervention would improve caregiver outcomes such as QOL, burden, and psychological distress. Sixty care recipient/caregiver dyads were randomized to either the intervention arm of the study (n = 30) or to the control arm (n = 30). Newly-trained physicians implemented the intervention, which consisted of five weekly education sessions, each lasting 30 minutes. The researchers recognized the inexperience of the physicians as a potential limitation of the study given that physicians had limited training in dementia care.

During the first session, the physician focused on caregiver assessment. The following four sessions then consisted of education about dementia, future implications of the disease, treatment options, and training on challenging behaviours. Burden was measured using the Zarit Carer Burden Interview (Bédard et al., 2001), distress using the SRQ 20 carer psychological distress tool (Mari & Williams, 1985), QOL using the WHOQOL-BREF tool (The WHOQOL Group, 1998). BPSD and QOL were measured in the person with dementia using the NPI-Q (Kaufer et al., 2000) and the dementia-specific health-related QOL (DEMQOL, Smith et al., 2005) scales. The researchers reported a statistically significant reduction in caregiver burden and an increase in caregiver QOL in the intervention group; however, it should be noted that the positive finding with respect to burden may be a result of a type I error (false positive result) (Gavrilova et al., 2009). As all other outcomes did not have positive results since the study was "not statistically powered to detect differences in this size" (p. 352) (leading to type II errors), yet the burden outcome was positive despite several statistical comparisons, the researchers felt that the type I error may have occurred (Gavrilova et al., 2009).

Collaborative care interventions. Four studies in this review investigated the impact of collaborative care interventions on caregiver outcomes. In the first study, Bass et al. (2013) implemented a RCT that evaluated the effectiveness of a care-coordination program on improving informal caregiver outcomes over a 12-month period. The intervention consisted of an initial assessment, action plan, and ongoing monitoring and reassessment undertaken by a health care coordinator who was partnered with a community service care coordinator from the Alzheimer's Association. The health care coordinator's professional training was not specified in the study. The care coordinators assisted both care recipients and caregivers with medical and non-medical issues, such as strain, information services, accessing support, medication management, and disease management. A standardized protocol was followed with coordinators contacting participants at least monthly via telephone, mail, or email. The study sample was recruited over 36 months from Department of Veteran Affairs (VA) facilities across the USA. The sample included veterans aged 50 years or older with a dementia diagnosis who received primary care from the VA, who lived near a chapter of the Alzheimer's Association, and who had an informal caregiver. Seven informal caregiver outcomes were measured, including: unmet needs; three types of caregiver strain (relationship strain, physical strain, and role captivity); depression; and the use of support resources (number of other informal caregivers that assisted the primary informal caregiver and use of respite or caregiver support services) (Bass et al., 2013). Depression was measured using the Epidemiologic Studies Depression Scale (Kohout et al., 1993) while all other outcomes were measured using questionnaires. Statistically significant differences were found between the intervention group and control group for all seven outcomes at both six months and at 12 months. Based on the positive findings of this study, the researchers have proposed the use of a care coordination program in order to improve health outcomes for both informal caregivers and individuals with dementia.

Since many studies have found that caregivers are dissatisfied with information received in physician office visits, and since most previously-studied caregiver interventions failed to include primary care providers as collaborators, Fortinsky, Kulldorff, Kleppinger, and Kenyon-Pesce (2009) conducted a study to test the efficacy of a dementia care consultation intervention for ICPWD. The researchers had hypothesized that fewer care recipients in the intervention group would be transferred to a residential care facility than from the control group. Fortinsky et al. (2009) also hypothesized that caregivers would experience positive outcomes, including increased self-efficacy in behaviour management and service utilization, reduced burden and depressive symptoms, and decreased adverse physical health symptoms. The intervention involved an assessment that incorporated a standardized assessment tool as well as monthly contact of the caregiver by the care consultant. Care plans were to be developed by the care consultant from these times of contact. The physician would review the proposed care plans with both the informal caregiver and the patient with dementia during follow-up visits. The intervention was compared to the usual care control group. Overall, although the residential care admission rate was 33% in the control group compared to 16% in the intervention group, over a 12-month period the results did not reach statistical significance ($p = 0.10$). Similarly, the study findings demonstrated no statistically significant results on any of the five secondary outcome variables.

Callahan et al. (2006) implemented a RCT to test the effectiveness of a collaborative care model directed by comprehensive dementia care guidelines to improve the quality of care for patients with AD and their informal caregivers. Patients and their caregivers were randomized to either the intervention group ($n = 84$) consisting of one year of collaborative care management, or to the control group ($n = 69$) who received augmented usual care in primary care practices in 10 primary care centres in Indianapolis, Indiana, USA. The interdisciplinary care management team was led by a family physician and an NP with expertise in geriatrics. The NP acted as the care manager and implemented the educational, behavioural, and group exercise components of the intervention, as well as pharmacological treatment to treat problem behaviours in collaboration with the physician. A psychologist provided caregiver support group sessions in conjunction with other intervention components.

Variable outcomes were measured via telephone interviews at baseline, at six, at 12, and at 18-month follow-up. The researchers demonstrated that the comprehensive collaborative care intervention resulted in significant betterments in BPSD, which successively decreased caregiver stress. No differences were found between the groups in the timing of nursing home placement, improvement of patient cognition, or ADLs. However, it must be noted that both groups were treated with cholinesterase inhibitors, cognitive assessments were performed over the telephone (which may be less sensitive that face to face assessments), and the heterogeneous sample had multiple comorbidities which may have affected efficacy of the pharmacological treatment chosen (Callahan et al., 2006). A significant finding of the study was that, at 12 months, 82.8% of the caregivers in the intervention group rated the patient's primary care as good or excellent compared to only 55.9% of the usual care group (p = 0.002). However, at 18 months (six months after intervention completion), only 70% of the caregivers rated the quality of primary care as "good" or "excellent" compared to 62% in the usual care group (p = 0.27). This finding illustrates that collaborative care interventions can improve the quality of care and relationships between caregivers and PCPs, since the satisfaction with care deteriorated once the intervention was complete. This is a crucial consideration as poor relationships between caregivers and PCPs can be a significant barrier to provision of effective support. Another possible explanation for this finding is that, as time goes on and the disease progresses, the caregiver's perception of satisfaction with their relationship with the PCP may change as the caregiver's level of burden increases.

Lastly, Vickrey et al. (2006) examined the effect of a dementia care management program on care quality, as well as patient and caregiver outcomes, in a cluster RCT over 12 months. Eighteen primary care clinics in San Diego, California were randomized to either an intervention or control group. In total, 408 patients with dementia and their informal caregivers were included in the study, with 238 dyads participating as part of the intervention group. The intervention consisted of a care manager providing structured assessments, developing care plans, referrals, care coordination between health care services, regular telephone or in-home follow-up visits, and educational seminars.

Caregivers from the intervention group reported increased confidence in caregiving at their 12 and 18-month follow-up, while social support and mastery in this group were significantly improved compared to the control group at 18 months. Furthermore, despite reduced reports of health-related QOL in the intervention and control groups, less decline was evident in the intervention group.

Clinical Practice Guidelines

Clinical Practice Guidelines are evidence-based statements and recommendations developed through systematic reviews of relevant literature; they are intended to support practitioners in their decision-making and to enhance patient care (The National Academy of Sciences, 2011). Unfortunately, the literature search for this review failed to produce any guidelines specific to informal caregivers; however, four guidelines related to dementia care were identified that each contain a section on caregiver support and interventions. The guidelines are summarized and analyzed collectively since many of the recommendations were similar and included both assessment and intervention recommendations. All four guidelines based their recommendations on a systematic review of caregiver literature, followed by expert consensus. The grade and strength of supporting evidence was clearly stated in all four guidelines. Unfortunately, due to the limited amount of high quality evidence available through well-executed RCTs and systematic reviews, the strength of the recommendations in the guidelines is not as strong as they might be otherwise.

The first guideline reviewed is an older Canadian guideline, published in 1999 by the Canadian Medical Association (CMA). This guideline was developed with particular consideration of the primary care context. Recommendations include the provision of continuity of care for both the patient and caregiver from diagnosis to death. Additionally, PCPs are encouraged to ensure that regular clinic appointments are scheduled with both the patient and caregiver together, in addition to appointments for the caregiver alone. The recommended frequency of such appointments is not identified however, leaving the PCP with a rather non-specific recommendation. The CMA suggests assessing caregivers for social support needs and availability, coping strategies, financial and legal issues, and offering health promotion, treatment, and referrals as necessary. Utilization of appropriate community services for the patient with dementia is recommended.

The Spanish National Health Service (SNS) published the second guideline on the Comprehensive Care of People with Alzheimer's Disease and Other Dementias in 2011. The SNS (2011) identifies an affiliated Alzheimer's disease support organization as a valuable resource to which PCPs can connect caregivers for appropriate counseling, education, and supportive services. A recommendation is made to establish a "welcome program" for patients with dementia and their caregivers, to be offered by an interdisciplinary primary care team in association with an affiliated supportive dementia organization. During the end stage of dementia, the SNS (2011) suggests collaborating with palliative care services in order to provide caregivers with grief and end-of-life supportive interventions. These recommendations explicitly support the facilitation of adaptation during transitions faced throughout the caregiving journey, a key strength of these particular guidelines.

The third guideline was written in 2006 by the Scottish Intercollegiate Guidelines Network (SIGN). In addition to the one recommendation that education should be both patient- and caregiver-centred, SIGN (2006) offers practice points that were based on the clinical experience of the guideline steering committee. Three practice points were provided, including maintaining effective communication with caregivers, offering information to caregivers in advance of the next stage of the disease, and offering support and interventions throughout the caregiving journey. Although these suggestions are opinion-based, they do reflect what has been suggested in other literature (Rose & Lopez, 2012). The utilization of anticipatory guidance in a fairly predictable disease process may demonstrate significant benefit to caregivers of dementia patients in a similar fashion to the benefit it provides to parents through their children's development.

The fourth and final guideline reviewed was a collaborative effort between the National Collaborative Centre for Mental Health and the National Institute for Health and Clinical Excellence (NICE). This guideline is entitled: Dementia: A NICE–SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care (NICE, 2011). One section in this guideline pertains to the implementation of caregiver interventions specifically. Recommendations include assessing caregivers throughout the disease process and then throughout caregiving transitions, including residential care placement of the person with dementia. Again, the particular frequency of recommended assessment is not identified. The inclusion of various tailored interventions in caregiver care plans is also recommended in the guideline, including a recommendation that direct involvement of the person with dementia should be considered when identifying appropriate supportive interventions. This recommendation is supported by the SNS (2011) guideline, which states that multicomponent interventions tend to be most effective in supporting and meeting the needs of caregivers. As a result, they recommend implementing skills training, education, and psychosocial support within the caregiver care plan.

The assessment of the level of perceived burden, and the implementation of appropriate interventions, is recommended in two guidelines (CMA, 1999, SNS, 2011) with the SNS suggesting the use of validated screening tools such as the Zarit Burden scale (Bédard et al., 2001) to quantify burden. These CMA (1999) and SNS (2011) guidelines also recommend educating the caregiver about manifestations of dementia in order to better prepare caregivers for the future. All four of the guidelines recommend tailoring information and interventions to the perceived needs of caregivers. In addition, three guidelines state that the identification of mental health issues and subsequent treatment with psychotherapy, pharmacological therapy or specialist referrals should be considered (CMA, 1999; NICE, 2011; SNS, 2011).

In summary, all four of the guidelines acknowledge the importance of recognizing caregiver needs along with those the patient with dementia. The inherent need for adequate communication between PCPs and caregivers is similarly highlighted. The implementation of caregiver support through assessment, education, and personalized interventions is recommended in all of the guidelines; however, the timing in which assessments and interventions should be implemented through the caregiving journey is lacking in all four guidelines. In order to develop comprehensive, useful, and effective clinical practice guidelines specific to ICPWD, there is a compelling need for the implementation and publication of further empirical caregiving research with excellent methodological quality.

The qualitative and quantitative research has been reviewed and analyzed in order to answer the research question. Since PCPs are in a prime position to provide support to informal caregivers, evidence was examined that pertained to mechanisms of support that can be provided within a primary care setting. The following chapter will discuss the findings in detail.

Chapter 4: Discussion

The negative physical, psychological, financial, and social effects associated with informal caregiving can become overwhelming for ICPWD. Lilly et al. (2012) stated that, as the health care system greatly depends on the critical contributions of ICPWD, an increased focus on these caregivers, and on caregiver support by PCPs and health systems, needs to occur. A focus on ICPWD may sanction supports which promote caregiver well-being "rather than resorting to costly patient care for caregivers who have reached the point of burnout and care recipients who have been institutionalized" (Lilly et al., 2012, p. 103). In order to be able to provide the most appropriate support and interventions to ICPWD, PCPs need to more clearly understand these caregivers' needs. In particular, they need to be aware of what draws caregivers to provide care, what challenges they may face, and what services are considered necessary while caring for a person with dementia. By identifying caregivers' needs and experiences, relevant and effective interventions can be established to better support them (Karlsson et al., 2015; Leong et al., 2001).

Discussion of the findings from Chapter Four will serve to inform strategies that PCPs can implement within primary care settings in order to provide support to ICPWD. The role of NPs specifically will be discussed with a view to highlight the unique role of NPs and the contributions they can make to ICPWD, their care recipients, and health care systems alike (Sangster-Gormley, 2014). Recommendations for PCP practice, education, and research, with a particular focus on the NP role, will be discussed in greater detail in Chapter Six.

Needs and Experiences of ICPWD: Mapping the Caregiving Journey

Although the studies took place in different settings and focused on the caregiver's experiences during different stages of dementia, several recurring themes and sub-themes were identified in the literature. Two of the reviewed studies focused on positive aspects of caregiving; however, the majority of the literature discussed negative experiences and unmet needs, thus highlighting gaps in caregiver care and the need to develop innovative and effective interventions in primary care settings (Hinton, Chambers, Velásquez, Gonzalez, & Haan (2006). Four major themes and several sub-themes emerged from synthesis of the literature in this review. The four major overarching themes were: the health system; family and community; relationship with the care recipient; and personal journey. These themes were adapted from themes that emerged from a study by Wiersma, Sameshima, and Dupuis (2014).

The health system. The first theme addresses issues that ICPWD raised in the reviewed studies regarding diagnosis, education, communication between PCPs and ICPWD, transitional care, and support services.

Diagnosis. An ICPWD in Karlsson et al.'s (2015) study stated that early diagnosis is the most important aspect of the caregiving journey. When diagnosis is well-timed, treatment can be commenced and supports put into place early in the trajectory, preparing both the ICPWD and care recipient for the upcoming journey. An ICPWD in Karlsson et al.'s (2015) study similarly noted the importance of an early diagnosis and described his satisfaction when his mother received a diagnosis promptly: "She got diagnosed [dementia] very quickly . . . and then everything happened like this (snaps with his fingers). Very soon they contacted homecare. Home care came in. We had a meeting, went through her needs. Everything worked perfect. . ." (p. 1413).

Unfortunately, due to denial of the symptoms of dementia, or an inability to recognize those symptoms, many informal caregivers do not seek diagnosis until a crisis situation occurs, i.e. when the degree of cognitive or functional impairment of the care recipient can no longer remain ignored or attributed to innocuous causes (Adams, 2006; Galvin et al., 2005). Many ICPWD who had reached this point then voiced feelings of frustration (Prorok et al., 2013) and mistrust (Teel & Carson, 2003) towards their PCP due to the process of obtaining a diagnosis for the care recipient. These feelings were associated with the perception that PCPs were reluctant to diagnose dementia, causing the ICPWD and care recipient to see, and relay their story to, numerous PCPs before a diagnosis was made (Teel & Carson, 2003). For patients in rural communities who have access to limited PCPs and specialists, this can have multiple additional implications for both the patient and ICPWD. For instance, the cost and emotional and physical challenges associated with traveling out of town to see specialists may be taxing on both the care recipient and ICPWD. Consequently, the importance of well-timed diagnosis was stressed by ICPWD as critical since early diagnosis can lead to more successful transitions for both the ICPWD and the care recipient (Prorok et al., 2013).

Providing a diagnosis of a progressive and terminal disease may prove challenging for any PCP, especially as it impacts not only the patient but those who will inevitably provide care for that person. The considerable impact of a dementia diagnosis is evident with Kelso's (2016) statement: "When diagnosing an Alzheimer's/dementia patient you are not just diagnosing the individual with the disease; you are in one stroke, assigning a remarkably challenging new lifestyle to at least one member of a family" (para. 6). Leach and Hicks (2013) state that challenges associated with delayed diagnosis have arisen from several factors, including influences from PCPs (dementia care training, attitudes, and confidence in diagnosing), the informal caregivers themselves (differing cultural beliefs and poor recognition of the manifestations of dementia), and the structure of primary care. The difficulty associated with providing such a devastating diagnosis may never get easier for PCPs. However, education for PCPs regarding dementia care and diagnosis, as well as public education around symptoms of dementia, may improve timely diagnosis (Teel & Carson, 2003).

Education. Pinquart and Sörensen (2006) state that improving the education provided to ICPWD about dementia and managing symptoms of dementia was found to be effective in improving well-being and decreasing depressive symptoms and burden. ICPWD listed education as the most significant unmet need they had throughout the entire caregiving journey (Hinton et al., 2006; Jennings et al., 2015; Karlsson et al., 2015; Leong et al., 2001; Lilly et al., 2012; Prorok et al., 2013; Teel & Carson, 2003). Many ICPWD stated that a lack of information from PCPs regarding dementia, behaviour management, pharmacological management, personal care, and available supportive services was a common experience; some caregivers even reported being the ones who had to initiate discussions with PCPs about their concerns and about dementia management (Prorok et al., 2013).

Many ICPWD expect the PCP to have expertise about dementia care and current resources (Jennings et al., 2015; Karlsson et al., 2015; Prorok et al., 2013), yet often perceived the PCP to be lacking knowledge or felt that information provision was not clear (Prorok et al., 2013). There is a distinct potential to close this gap by ensuring that current and future PCPs are educated on these issues and become more proficient at educating and counseling ICPWD about dementia, caregiving, and the resources available to ICPWD (Hinton et al., 2006).

Communication between PCP and ICPWD. Karlsson et al. (2015) found that "information, communication and collaboration were considered to be dependent on establishing a trusting relationship [with PCPs]" (p. 1413). Adequate communication between ICPWD and the care recipient's PCP is important at all stages of the caregiving journey. Poor communication can lead to ineffective relationships between PCPs and ICPWD and a perception of inadequate patient care. Perhaps the most important finding in the literature is the fact that most ICPWD simply want to feel supported by PCPs, feel that their hard work and sacrifice is being recognized, and perceive that their feelings and needs are being validated (Lilly et al., 2012, O'Shaughnessy et al., 2010; Prorok et al., 2013; Shanley et al., 2010). O'Shaughnessy et al. (2010) stated that, in this respect, support groups can serve as a key source of validation for ICPWD and can supplement the efforts of the PCPs in this regard. What is more, ICPWD in the Shanley (2011) study felt that support groups were paramount to meeting their needs. Support groups allowed ICPWD to compare their own experiences with others and to gather beneficial information from other ICPWD (O'Shaughnessy et al., 2010). Most of the participants in this study received a great deal of assistance from a well-facilitated support group and felt that the group was one of the most important ways in which their needs were met.

Transitional care. A care recipient's stay in an acute or long-term care facility can cause increased stress for both the care recipient and ICPWD. The need for advocacy for the care recipient is common. The ICPWD in Karlsson et al.'s (2015) study reported that many hospital staff struggled with dementia care, leaving ICPWD frustrated. Similarly, Boughtwood et al. (2011) found that many CALD ICPWD spent long hours in the hospital to translate and to ensure their family member received adequate care. Utilization of the Top 5 Strategy (Clinical Excellence Commission, 2014) before a care recipient is transferred to a facility may prevent the frustration reported by ICPWD and create a better experience during transitions in care. The Top 5 Strategy promotes recognition and acknowledgement of ICPWD's knowledge and skills by facility staff with respect to the care recipient and care provision for the care recipient (Clinical Excellence Commission, 2014; Strudwick, 2009). See Appendix C for an example of an adaptation of the Top 5 strategy.

Support Services. Many caregivers have reported a significant need for service referrals, yet they often traveled down a long path before obtaining the support they required. Jennings et al. (2015) stated that busy PCPs often are not aware of available support services in their communities nor do they always have the time to provide in-office supportive interventions, such as counselling or education provision. Further, the literature suggests that care overall in this population remains fragmented and poorly coordinated (Bass et al., 2013). One ICPWD reported, "many times you need a team effort, but there is not the connection between the social worker, the Home Care, the doctor, the whatever. There's not somebody that can put it all together for the individual" (Shanley et al., 2011, p. 330).

Lilly et al. (2012) posited that caregivers often only receive services once they are on the verge of becoming patients themselves because of the stress associated with an unsupported caregiving role. The importance of tailoring interventions and services to the articulated needs of ICPWD and the care recipient's needs was stressed (Karlsson et al., 2015; Lilly et al., 2012; Stirling et al., 2010). Moreover, Stirling et al. (2010) emphasized that focusing on ICPWD's felt need and perceived need is much more predictive of their true need for services than normative need. Normative need can be viewed as paternalistic, whereby the PCP refers the ICPWD for services based on their opinion of the caregivers need.

Respite was heralded as the most valuable formal service for many ICPWD (Karlsson et al., 2015; Leong et al., Lilly et al., 2012; Shanley et al., 2011); often, the support needed by ICPWD is not for assistance with the care recipient's ADLs or housework, but rather time away for a needed break or to attend to responsibilities outside the home (Shanley et al., 2011). Despite the need for respite care, this resource is scarce, with ICPWD often unable to access it from either formal or informal sources (Shanley et al., 2011).

In order to provide more effective person-centred collaborative care, Jennings et al. (2015) recommend the implementation of a care delivery model that includes a comprehensive care plan for the care recipient, counseling, education, anticipatory guidance, collaboration with community services, connection to respite, 24-hour support emergency support, and help with advanced care planning. An interdisciplinary team or NP/physician team may successfully implement this care model that is aimed at more comprehensively meeting the needs of both ICPWD and care recipients.

Family and community. This theme involved the relationships between ICPWD and other family members as well as members of the community. Concerns about disclosure of diagnosis due to stigma from family, friends, and other members of the community also fell under this theme. ICPWD in the literature reported a need for ongoing support from family and friends (Teel & Carson, 2003). For many ICPWD, family and friends are positive sources of support. Regrettably, conflict often occurs between ICPWD and other family members as the result of the stress of progressing dementia, leading to an ever-increasing lack of outside support (Boughtwood, 2011). Caregivers in the Boughtwood et al. (2011) study found that conflict may arise between siblings for example, if one refused to assist with care, or between spouses if caregiving for an elderly parent was taking time away from an adult child's immediate family. Conversely, if many people are involved in providing care to the same individual with dementia, conflict may arise out of attempts to make shared or consensus decision-making a reality (Boughtwood et al., 2011).

Due to the fear of stigma or embarrassment, ICPWD may avoid social situations, thereby giving rise to further social isolation (Prorok, 2013). For instance, two ICPWD in Teel and Carson's (2003) study noted a need for better public awareness about dementia. One ICPWD stated, "so many times when I took my husband out in public, people would come over and acknowledge me and talk to me and totally ignore him … You can't just totally ignore them off the face of the earth!". Another participant noted, "maybe it's my imagination, but when I've taken her out, around groups of people, they kind of act like it's a contagious disease" (Teel & Carson, 2003, p. 51).

Findings in the literature demonstrated that culture significantly impacts the caregiving experience. For example, the notion of stigma can significantly affect CALD ICPWD. Miyawaki (2015) found that the diagnosis of dementia is often not disclosed due to stigma. Stigma was associated with shame in some Chinese Canadian and Chinese American ICPWD, isolating them from others in their community and preventing them from seeking supportive services (Miyawaki, 2015). With respect to implications for PCPs, Increased public awareness would serve to address not only stigma, but the delayed diagnosis issue identified and discussed previously.

In order for PCPs to provide supportive care to ICPWD from CALD communities, the cultural context and potential difficulties they may face must be considered in the practice setting (Boughtwood et al., 2011; Miyawaki, 2015). PCPs can provide culturally sensitive care by observing the behaviours of ICPWD in the home or clinic setting, and exploring what aspects of caregiving is important to them (Lehman, n.d.). More specifically, having an understanding of cultural sensitivity is critical when teaching minority informal caregivers about skills to improve their well-being (Cohen & Lee, 2007). While it is essential to recognize that not all CALD ICPWD are entrenched in similar cultural values, "knowledge of common patterns and customs provides a foundation for specific assessment of the caregiver and care receiver experience" (Lehman, n.d., p. 6).

Relationship with the care recipient. Many of the ICPWD in the literature described their experiences of how their relationship with the care recipient changed as the dementia progressed. The changing role of the care recipient from spouse or parent to dependent was found to be very difficult for both the care recipients and ICPWD (O'Shaughnessy et al., 2010). ICPWD in Boughtwood et al.'s (2011) study reported perpetual difficulty to accept this changed relationship. Relationships that once consisted of love and intimacy were described as often volatile and distant (Boughtwood et al., 2011). For example, a caregiver in O'Shaughnessy et al.'s (2010) study reported, "she's become very self centered, she never was that sort of person … she was very outgoing as I was talking to someone that I have known for a few years and she was such a bubbly person, she's lost that . . ." (p. 243). Conversely, some ICPWD reported a newly defined relationship that included greater affection. One ICPWD stated, "thank heavens that she's affectionate towards me, that's wonderful really. She still shows me affection and the little sign is that she's come up and she'll rub my arms or rub my back. That's her affection sign…" (O' Shaughnessy, 2011, p. 243). A common and particularly admirable finding in the literature was that many ICPWD endeavoured to maintain the care recipient's feeling of self-worth and happiness (Adams, 2006; Karlsson et al., 2015; O'Shaughnessy et al., 2010). O'Shaughnessy et al. (2010) state that encouraging ICPWD to focus on 'working together' with the care recipient, especially during the early stages of dementia, can decrease stress and improve the dementia journey for both involved. This strategy can be suggested by PCPs to encourage more positive caregiving experiences.

Personal journey. As ICPWD travel the dementia journey with the care recipient, they embark upon their own personal journey as well. ICPWD reported having experienced many emotions. Even in the early stages of the care recipient's disease process, ICPWD may experience loneliness and social isolation (Galvin et al., 2005; Lilly et al., 2012). Friends and family members may begin to avoid the care recipient once memory impairment and unpredictable behaviours become more noticeable. Many ICPWD reported feelings of uncertainty in this stage of their journey in particular (Lilly et al., 2012; O'Shaughnessy et al., 2010; Prorok et al., 2013; Teel & Carson, 2003). Other negative emotions such as fear, resentment, frustration, guilt, grief, anger, and impatience were frequently mentioned in the literature and several ICPWD stated that they commonly experienced oscillating negative feelings with acceptance (O'Shaughnessy et al., 2010).

Every journey will be different for each ICPWD; however, as noted in the literature many emotions and experiences are shared. The invaluable role of support groups is emphasized again as they give ICPWD the opportunity to relay these feelings to others that can relate to their experiences and iterate to the caregiver that, although they are experiencing many difficulties, they are not alone in their situation.

Another critical implication for PCP practice is being cognizant that ICPWD may reach a point in their journey when they are no longer able or willing to provide care to the care recipient. This is important as "…supporting caregivers also means respecting caregivers' decisions. Support is a large term and means also supporting caregivers who don't want to [be caregivers] anymore" (Ducharme, 2012, para. 62). Providing emotional support and having an awareness of resources available to help ICPWD and sharing them as they relinquish the role of caregiver is an important implication for PCPs.

Positive aspects of caregiving. Much of the literature focuses on negative aspects of the caregiving role; however, two studies examined the positive aspects of caregiving. The positive aspects of caring can be conceptualized using Nolan et al.'s (1996) 'satisfactions of caring' that address the dynamic relationship between the ICPWD and the care recipient, satisfaction from interpersonal views of caregiving, and satisfaction from promoting well-being and protecting the care recipient from harm. The latter was demonstrated by ICPWD who strive to maintain the care recipient's happiness and sense of belonging, as discussed previously. Cohen et al. (2002) found that positive feelings associated with caregiving were inversely significantly related to negative feelings of depression, self-rated health and burden, whereas ICPWD who felt positive about caregiving reported less negative feelings.

Cohen et al. (2002) suggest that, by PCPs asking ICPWD about whether they feel positive about certain aspects of caregiving, those who do not report any positive aspects related to caregiving may be identified as at risk for depression. Conversely, caregivers who feel very positive about their role may refuse an offer of supportive services; they may not feel that others can provide the same level of care to the care recipient that they themselves are able to do. Although not all ICPWD need supportive services at the time they are offered, refusing such services may place them at risk later on in the journey if they subsequently become burdened and have not made those supportive contacts (Cohen et al., 2002). In addition to determining risk through consideration of positive aspects of caregiving, focusing on positive caring experiences may help ICPWD to set their own resources in motion and foster both personal growth and a greater sense of meaning (Peacock et al., 2010). Further, encouraging ICPWD to focus on their strengths may motivate the caregiver to continue on their journey, thus most certainly creating a better dementia journey for the care recipient.

"Roadside Assistance": The Effectiveness of Supportive Interventions

Numerous studies that have examined the effects of various psychosocial and educational interventions on outcomes of ICPWD have demonstrated inconsistent improvements in caregiver QOL or well-being and only moderate effect in meeting other caregiver outcomes (Brodaty, Green, & Koschera, 2003; Czaja et al., 2013; Sörensen, Pinquart, & Duberstein, 2002; Wilz et al., 2011). Greenwood et al. (2016) found that psychosocial interventions may improve ICPWD's well-being and decrease levels of depression. However, due to poor methodological quality or insignificant results, most interventions are not actually being recommended for practice. ICPWD in Karlsson et al.'s (2015) study associated in-office counselling throughout the dementia trajectory with good PCP practice. However, the psychosocial interventions in the studies in this review, including cognitive behavioural sessions, in-office counseling, and referrals to supportive services, demonstrated no improvement in ICPWD QOL or in decreasing burden (Menn et al., 2012; Rodriguez-Sanchez et al., 2012). Although caregivers who received cognitive behavioural therapy reported improvements in their mental health and general well-being in Rodriguez-Sanchez et al.'s study (2012), the methodological quality was lacking.

The findings of the educational intervention studies were contradictory with respect to the effect on caregiver burden (Fortinsky et al., 2014; Gavrilova et al., 2009) and caregiver depression (Burns et al., 2003; Fortinsky et al., 2014). Although the Burns et al. (2003) study did not demonstrate any statistical significance between outcomes due to insufficient power from a small sample size, the authors argued that the stable rates of depression were clinically significant. Burns et al. (2013) stated that "it may be naïve to think that interventions will eliminate or markedly decrease caregiver stress or depression over the course of the illness" (p. 553). Thus, in the context of a neurodegenerative disease, an intervention that maintains a stable level of depression or stress in ICPWD may in fact be considered an effective intervention (Burns et al., 2003).

The transferability of the interventions between research and practice was specifically questioned in two of the studies (Burns et al., 2003; Rodriguez-Sanchez et al., 2012). In some salaried NP-led primary care clinics, a cognitive behavioral therapy intervention may be feasible and improve the mental health of ICPWD. Regrettably, the implementation of most of these interim supportive interventions into 20-90 minute sessions in busy, fee-for-service primary care clinics must largely be viewed as unrealistic. Based on the findings of the literature, it has become clear that the best supportive strategies for ICPWD are provided by a multidisciplinary team that continues throughout all stages of the dementia journey. Jennings et al. (2016) agree, stating that "interventions that … provide ongoing assistance as the disease progresses have been most effective … but busy physicians have neither the time nor, in some cases, the skills to adequately implement interventions …" (p. 283). However, certain aspects of the reviewed interventions could be applied to practice in order to meet the needs of ICPWD. For example, education about disease management, stress management, and behavioural management could be provided by NPs just as education is provided to patients with other chronic diseases during primary care visits (Burns et al., 2003). This view is supported by Gavrilova et al. (2009) who stated that even uncomplicated, short educational interventions may prove valuable for ICPWD. In larger interdisciplinary clinics, other members of the team, such as Registered Nurses, may also be able to provide patients with more detailed education if the NP is working within shorter appointment times.

The implementation of collaborative care interventions in primary care yielded the most promise compared to psychosocial and educational interventions alone (Bass et al, 2013; Vickrey, 2006). Due to the complex nature of caregivers needs, this is not particularly surprising. The effectiveness of the Partners in Dementia Care intervention in the Bass et al. (2013) study in meeting unmet informal caregiver need, strain, and depression may be related to the fact that the program was developed with a view to address specific issues with care that ICPWD had expressed prior to development of the program. These issues mirror the reported needs of ICPWD in the studies in this review, including lack of recognition of caregiver's feelings of isolation, lack of education and resource sharing, fragmented, poorly coordinated service provision, and the lack of consideration of caregivers' needs (Bass et al., 2013). The invaluable benefit of the collaboration between health services and a dementia-focused community agency was evident in the study by Bass et al. (2013).

Both of the NP-led interventions evaluated in the literature resulted in a satisfactory evaluation of the intervention by study participants related to the development of positive relationships with the NPs who implemented the interventions (Callahan et al., 2006; Fortinsky et al., 2009). This may be a significant finding in itself, as the caregiver's perception of the relationship with the PCP influences the perception of support. This demonstrates the importance of providing support through the development and fostering of therapeutic relationships. If the ICPWD continues to feel supported by their PCP or care recipient's PCP, this may be much more powerful than the intervention itself at improving the caregiving journey. Again the transferability of this research to practice in British Columbia (BC) may be limited as the role of the NPs in these studies is very different to the role of most NPs in BC, many of whom have similar roles to Family Physicians.

Clinical Practice Guidelines

Turner, Misso, Harris, and Green (2008) stated that, historically, clinical practice guidelines "were often developed by consensus of a group of expert clinicians without explicit reference to research evidence" (p. 2). Today, it is an expectation of most PCPs that clinical practice guidelines will be developed based on high quality evidence. However, the recommendations in the caregiver support sections in dementia care clinical practice guidelines in this review are not supported by this kind of evidence. Similarly, in an editorial by Collins & Swartz (2011), all of the clinical recommendations for caregiver care found in the literature search are based on consensus, expert opinion, or case studies, or usual practice rather than good quality evidence. This was a surprising finding as most practitioners would use clinical practice guidelines under the assumption that the recommendations are appropriately supported by good quality evidence.

The absence of a BC-based or Canadian guideline on caregiver support was also an unanticipated finding. A lack of available financing in which to support the development and publication of a guideline, a lack recognition of need by a governing body, agency, or organization, or the dearth of quality literature in which to develop quality evidence-based recommendations may all be contributing factors in terms of why no BC or Canadian guidelines have been published to date. Further, adequately supporting caregivers requires the involvement of numerous health care providers, and health care and community agencies. It may prove challenging to connect these numerous stakeholders within BC or Canada in order to develop a guideline for use in primary care practice. The absence of guidelines that are specific to ICPWD provincially, nationally, and internationally is likely contributing to the inconsistent support ICPWD are receiving in primary care practice settings. The availability of a comprehensive BC-based or national guideline outlining the best ways to support ICPWD could benefit NP practice as it would allow NPs to ensure that they were providing consistent evidence-based supportive strategies for ICPWD.

The Role of the NP and Implications for NP Practice

In conducting this integrative literature review, notable gaps in practice, research, and policy have emerged that could affect the perceived and actual support that ICPWD receive. Furthermore, it has become clear through synthesis of the literature that the role of the NP is beneficial in meeting the expressed needs of ICPWD and providing effective support for these caregivers. In a “strongly physician-centric” (Thorne, 2011, para. 1) primary care system that is currently struggling to meet the needs of ICPWD, NPs can provide innovative approaches to care that not only provide much needed support to

ICPWD, but that would also work on organizational and systems levels to create changes for these caregivers, thereby narrowing the existing gaps in health care.

The role of NPs provides a unique perspective from which to successfully guide ICPWD through their journeys. In an interview with Schwartz (2009), Stringari-Murray stated that the NP model of care is patient, family, and community focused rather than the disease focus that comprises the medical model of care. As advanced practice nurses, NPs bring a holistic perspective; this augments their diagnostic knowledge, clinical skills, and ability to aid in developing highly therapeutic interpersonal relationships with ICPWD and their care recipients. NPs can use their clinical knowledge and skills to obtain a thorough history of these clients while also inquiring about social determinants of health and the family context, completing a physical exam, performing cognitive assessments, and interpreting lab work and other investigations to rule out reversible causes of dementia. Once such a comprehensive assessment and workup has been completed, the NP would be able to provide a diagnosis of dementia, where appropriate.

The Canadian Foundation for Healthcare Improvement (2010) stated that patients appreciate the communication style of NPs and the additional time they spend with their patients. Further, studies have demonstrated that NPs tend to ask more questions of patients and offer more information and options for care than physicians (Canadian Foundation for Healthcare Improvement, 2010). An ICPWD speaking with Kelso (2015) stated that, in addition to meeting their medical needs, the NP can "address the psychosocial needs that may or may not be medically serious but still a concern" (para. 5). For instance, NPs can use the themes that emerged in the qualitative literature in this review to initiate conversation with ICPWD regarding issues that they may be facing and emotions that they may be feeling. Many ICPWD may not themselves initiate this conversation with their PCP; therefore, mentioning other ICPWD experiences can allow NPs to assess what issues that ICPWD may be experiencing and address them through in-office counseling and support, as well as offering resources that may benefit the caregiver. The NP can also work with the patient and family in providing anticipatory guidance as they work through the new diagnosis and the changes that will come over time.

The skill set of NPs is of particular significance at the time of diagnosis. Diagnosing a patient with dementia can be very difficult for PCPs. For the patient and their family members, the impact of receiving a diagnosis of a terminal, progressive, neurodegenerative disease that has no hope of a cure can be devastating. NPs can offer the time to provide education and health promotion strategies, address concerns raised by ICPWD or the care recipient, provide emotional support, and connect families to resources that they may need at this critical time in the dementia journey; other PCPs may not be similarly able to offer such comprehensive benefits due to the current fee-for-service model that currently exists in Canada. Many NPs working as members of a multidisciplinary team which will strengthen the care model for the patient and family as they journey through the disease progression of dementia.

Engagement in collaborative practice is a key component of NP practice (Teel & Carson, 2003). NPs can use their effective communication skills to collaborate with members of a multidisciplinary team, specialists, community organizations, as well as the ICPWD and care recipient to develop care plans for the patient with dementia and their ICPWD. The NP may participate in collaborative team visits and family meetings to share their knowledge with the team and aid in providing quality patient care.

The compassionate and professional nature of NPs can lend itself to a successful palliative care approach starting at diagnosis with advanced care planning. Closer to the end of the dementia journey NPs can also collaborate with members of a palliative care team to provide ICPWD and their care recipients with needed support at that time.

Another invaluable aspect of NP practice is the ability to offer home visits where the NP has the opportunity to observe the home environment of ICPWD and care recipients and develop a greater understanding of their situation (Unwin & Tatum, 2011). Home visits are an important component of dementia care, as they may decrease the number of hospital admissions and transfers to residential care facilities (Unwin & Tatum, 2011).

NPs also often work with vulnerable populations who are at high risk of falling into the "diagnostic gap" (Leach & Hicks, 2013, p. 439). Naylor et al. (2013) state that such vulnerable populations can include: individuals without a PCP, marginalized populations, those who live alone, the "oldest old" individuals, and those in rural areas. NPs may be in a particularly good position to identify and assess these high-risk patients, consequently promoting timely diagnosis and the early implementation of supports for patients and their ICPWD. Further, NPs consider all determinants of health that may impact the health and well-being of ICPWD as well as caregiver burden. Overall, NPs can play a key role in supporting both ICPWD and the care recipient with dementia.

The inclusion of NP roles in primary care offers opportunity for improved patient and health care system outcomes, as NPs not only enhance primary care practice with their unique skills and experience, but they also contribute to health care through leadership and consultation. These abilities allow NPs to improve available support through clinical practice as well as through the development of policies and community and organizational capacity-building (CNA, 2011).

With the growing number of aging adults with dementia, and the subsequent number of ICPWD in Canada, the adverse outcomes that can occur related to caregiving will continue to be a compelling problem that must be addressed in primary care. It is imperative that ICPWD are well-supported in order to maintain the health and well-being of both ICPWD and their care recipients through the entire dementia journey. For NPs, this means using a family-centred, collaborative, proactive primary care approach to develop and implement innovative and effective supportive strategies.

Robinson Vollman and Martin-Misener (2005) ascertained that it is essential that NPs engage at multiple systems levels in order to address issues that affect patients and their families. The development of a model or framework that outlines supportive strategies at all levels of influence, and during all stages of dementia, would help NPs and other PCPs to provide consistent, comprehensive, collaborative care to both ICPWD and their care recipients. The development of a new model of care is a quality example of advancement and need for NP roles that extend beyond clinical practice (Bryant-Lukosius, DiCenso, Browne, & Pinelli, 2004). Developing and implementing new interventions and a model of care would provide opportunities for professional development, collaborative efforts between other PCPs and researchers, and allow NPs to demonstrate their work in a scholarly capacity (Corner et al., 1995, Plant et al., 2000).

An adaptation of the Centers for Disease Control and Prevention's (CDC, 2015) social ecological model (see Figure 3) provides an example of a multi-level, multi-disciplinary primary care approach to ICPWD support. NPs can use such a model to develop supportive strategies at all levels of influence. Using a socio-ecological model such as the CDC's (2015) "offers clear implementation guidelines for maximizing the health, economic, and societal benefits" of interventions aimed at health promotion and prevention (Stokols, 1996, p. 295).

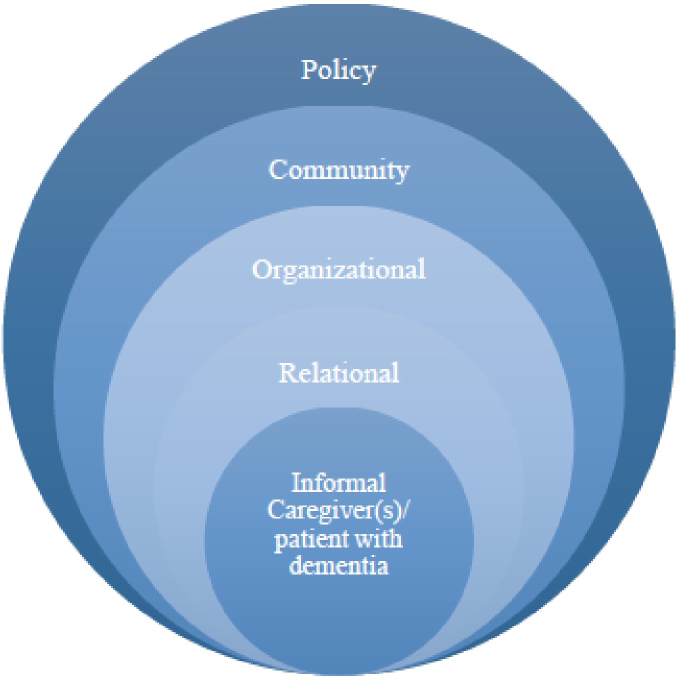

Figure 3. Social ecological model for primary care-based supportive strategies for ICPWD. Adapted from "Social Ecological Model", by *The Centers for Disease Control and Prevention*, 2015. Copyright 2015 by the Province of British Columbia.

Examples of relevant interventions at all levels include:

- *Informal caregiver/patient with dementia*: Increasing knowledge of dementia, caregiver competence, skill building, stress management, and coping skills through education and referrals community programs, and providing timely diagnosis and emotional support at diagnosis and immediately after to prepare ICPWD for the journey ahead;

- *Relational*: assessing support networks, holding family meetings to determine a family respite plan, referral to support groups and supportive community services, and building strong therapeutic relationships with the ICPWD and the care recipient;
- *Organizational*: promoting a family-centred approach in the workplace, ensuring coordinated service provision, piloting ICPWD assessment forms or collaborative programs aimed at improving outcomes for ICPWD; collaborating with other members of the health care team, and providing other PCPs with an updated resource list for supportive services;
- *Community*: raising public awareness of dementia and caregiving through media campaigns or becoming involved in charitable events aimed at raising awareness and funding for dementia care and research, or working with community-based organizations to develop supportive strategies;
- *Policy*: developing clinical practice guidelines aimed at ICPWD support, developing a short ICPWD assessment form that NPs can use in the practice settings for all ICPWD; participating in health care policy changes that encourage a family-centred approach to care; or developing of a new model of care aimed at supporting ICPWD and the care recipient.

Analyzing the literature has provided invaluable insights for NPs into the needs and experiences of ICPWD. Gaining knowledge about their experiences can inform the development of person-centred and family-centred strategies, such as when and how to implement supportive services as a necessary step to meeting the ICPWD's needs and to providing adequate support (Dupuis, Epp, & Smale, 2004). However, direction on what type of information and interventions should be provided at each stage of the dementia journey is lacking. The SIGN guideline (2011) agrees stating that "the research literature does not provide a clear consensus regarding the type of information people with dementia and their carers need at different stages of their journey of care" (p. 21). In addition, while NPs are required to use evidence-based guidelines to promote competent, quality care (CNA, 2006), no guidelines have yet been developed to guide decision making with regards to providing support to ICPWD. At the policy level, NPs can participate in the development of best practice guidelines and the development of a 'road map' that outlines what interventions should be implemented at specific times during the dementia journey. An example of the type of 'road map' that NPs could use in practice based on the findings of this review is provided in Appendix D.

Another implication for practice at the policy level is to advocate for ICPWD by lobbying for change. Dupuis, Epp, & Smale (2004) encourage PCPs to lobby to change existing policies with respect to government funding for supportive services, and "develop innovative approaches to the provision of community support services that are truly sustainable, flexible, portable, and responsive to individual caregivers' needs" (p. 74). This is an important consideration for PCPs as the Family Caregivers' Network Society (2010) reported that 77% of the supportive services for informal caregivers were provided by non-profit organizations who rely on money from health authorities, grants, or fundraising to run their programs. Many programs, such as the Caregiver Association of BC, are forced to cease running due to lack of funding. NPs can lobby for change by speaking to their Member of Parliament directly or by connecting with organizations (such as the Canadian Nurses' Association) to encourage others in the field to join together and create a stronger voice in which to champion change for ICPWD in primary care settings.

The work done in this review has illuminated the important role that NPs can and should play in adequately supporting ICPWD and their care recipients in primary care and the numerous implications for NPs. The growing number of persons with dementia and their informal caregivers, the devastating impact of diagnosis and disease manifestations, and the lack of clinical practice guidelines and available caregiver assessment tools, all significantly impact NP practice. Many opportunities exist for NPs to offer collaborative, coordinated service provision that supports and meets the needs of ICPWD and their care recipients. Policy level strategies have been discussed. Further strategies that can be implemented at the individual, relational, organizational, and community level will be discussed in the following chapter.

Chapter 5: Recommendations

Peacock et al. (2010) state that progress has been made to improve support to ICPWD; however, more improvements are needed in the area of clinical practice, research, and health and social policies. An innovative and proactive approach by PCPs can assist ICPWD to adapt to the changing roles they will experience throughout the caregiving journey (Nolan, Ingram, & Watson, 2002). Gaining understanding of the experiences of ICPWD provides the foundation in which to "map the dementia journey" for caregivers (Wiersma, 2014). Although collaborative care interventions show promise at improving the lived experiences of ICPWD, overall, the literature in this review has demonstrated that complex, time-consuming primary care-based programs are not necessarily the most effective at improving caregiver well-being. Additionally, with respect to caregiver assessment, no evidence has been found that supports the use of assessment tools specific to the unique needs of ICPWD. Elementary, office-based interventions performed by PCPs may, in fact, prove to be more effective at effectively supporting ICPWD. In an attempt to bring about the improvements Peacock et al. (2010) has suggested, this chapter will outline implications for clinical practice for PCPs, recommendations for education, and recommendations for future research.

Recommendations for Clinical Practice

Timely diagnosis. Early diagnosis can help both ICPWD and care recipients by initiating pharmacotherapy to treat dementia, ensuring supports are put into place before a crisis situation occurs, and adequately preparing the ICPWD and the care recipient for the journey they are embarking upon. Although screening for cognitive impairment in asymptomatic patients is not recommended (Guidelines and Protocols Committee, 2014), elderly patients and caregivers should be encouraged to approach the PCP if changes in cognition or functioning are noticed in order to both commence testing and obtain a diagnosis in a timely manner. If a PCP suspects dementia, cognitive testing using validated tools such as the Mini Mental State Exam (Kurlowicz & Wallace, 1999) or the Montreal Cognitive Assessment (Nasreddine, 2016) can be performed, along with a history, physical exam, and diagnostic testing to rule out other causes of cognitive impairment (Guidelines and Protocols Committee, 2014).

The NP utilizes his or her clinical skills to diagnose and manage dementia. Just as importantly, NPs must use his or her expert communication skills to sensitively share the diagnosis with the patient and ICPWD. It is recommended that the NP encourage the patient to bring trusted family members with them during the diagnosis stage in order to share information and act as supports. The time of diagnosis is often incredibly difficult and the NP must provide adequate time for the family to process the diagnosis and to ask their questions. Many ICPWD in the literature described negative experiences during the diagnostic process due to poor communication and a lack of expertise in support provision. NPs can utilize their expert knowledge and skill to provide ICPWD with the support they require during this difficult transition.

End-of-life planning. ICPWD in Shanley et al.'s (2011) study reported a need for palliative care information in order to better prepare for the death of their loved one. As dementia is progressive and incurable, yet may progress over many years, the question of when to provide end-of-life information becomes challenging for PCPs. The SNS (2010) recommended connecting the ICPWD and care recipient with palliative care services but does not actually specify when to start providing end-of-life information. Coombs et al.

(2015) state that many "Canadian leaders from non-governmental organizations, nursing and governmental sectors are recommending a palliative approach be embedded into primary care" (p. 3). In order to best support ICPWD, helping them to prepare for the future is essential. Therefore, it is recommended that palliative care plans and information-sharing begin at diagnosis. Although it might seem too early to commence a palliative approach at that time, Carstairs (2010) states that palliative care ideally starts at diagnosis of a chronic, terminal condition and continues until death. It may seem counter-intuitive to commence palliative care at diagnosis as many individuals with dementia will continue to live for many years; however, advanced care planning with respect to medical, financial, and legal decisions is best started early while the care recipient is still able to participate in decision making. Coombs et al. (2015) state that NPs can promote this interprofessional approach through their leadership abilities.

Support during office visits. In Teel and Carson's (2003) study, ICPWD provided examples of what PCPs could do to better demonstrate evidence of support. These suggestions included allowing sufficient time during office visits to speak with the caregiver alone, listening to the caregivers, and asking questions about the caregiving experience. One caregiver stated "I really wish they [PCPs] would talk to the family separately. You're not getting time to tell what's happening, but you're also not having your experiences validated by the professional" (Teel & Carson, 2003, p. 51).

Adelman, Tmanova, Delgado, Dion, and Lachs (2014) recommend that PCPs should perform more caregiver assessments in practice. However, the authors recognize that the completion of a comprehensive caregiver needs assessment is not necessarily feasible in most primary care settings due to time constraints and a general lack of resources. In addition, if the caregiver is not a patient of the PCP, the lack of financial compensation for the PCP and the possibility that confidentiality issues may arise can also be of concern. However, the PCP should allow enough time during the office visit to explore the caregiver's well-being, need for supports, and address any issues that may be raised by the informal caregiver (Adelman et al., 2014). Social support can be assessed by asking about the ICPWD's support network of resources, functional supports such as home support, and how they perceive those supports available to them. If the caregiver is not a patient of the PCP, a few simple questions can be used to encourage the caregiver to seek help from their own PCP if such assistance is needed:

- "To provide the very best patient care, I find I need to also pay attention to my patients' caregivers. Can you tell me a bit about how you are feeling/doing?"
- "We know that caregivers often neglect their own health. When was the last time you saw your physician?"
- "Do you have your own physician? Is she or he aware of your caregiving situation? What has she or he advised about it?" (Adelman et al., 2014).

If, however, the caregiver is also a patient of the PCP and the care recipient agrees, then an appointment for the caregiver could be scheduled immediately after that of the care recipient to address concerns raised during that first appointment. An adjacent appointment not only prevents valuable time being taken away from the care recipient's visit, but allows for the caregiver's concerns to be addressed immediately, thereby validating the caregiver's experiences. Separate but adjacent appointments also allow for the sharing of information that might not otherwise have been mentioned during the care recipient's appointment, such as feelings of burden or aggression by the care recipient. In addition, providing adjacent appointments means that the caregiver will not have to contend with organizing additional transportation requirements nor with ensuring supervision for the care recipient, thereby decreasing stress and burden.

If the care recipient presents alone to the clinic, especially during the early stages of dementia, the PCP can encourage he or she to include the informal caregiver in clinic visits, in order to develop strong partnerships and make shared decisions while the care recipient is still capable of doing so. NPs have the ability to develop strong therapeutic relationships with the care recipient and their informal caregiver and can facilitate not only the support systems that are required, but also provide the education and anticipatory guidance for individuals who experience this journey.

The use of analogies. Just as this review used the journey analogy to guide the reader through the caregiving experience, the PCP can use lay analogies to assist the caregiver to better understand their experiences (and the commonality of those experiences). For example, to explain the importance of accepting supportive services to ICPWD, the PCP may use an analogy such as the following: when a person is on a long road trip and has been driving for too long, he or she becomes fatigued. When the person reaches the point of exhaustion, he or she needs to rest or they may fall asleep and become involved in a motor vehicle accident. The same applies to caregivers on their long journey. The Australian government agency Transport for New South Wales (2014), adopted the slogan ‘stop, revive, survive’ to combat motor vehicle accidents on state highways related to driver fatigue. The ad campaigns encouraged drivers to stop every two hours at a “driver reviver” site and “stop for a biscuit and a cup of Bushells tea or coffee” (Transport New South Wales, 2014, para. 3). This public safety campaign can be used as a metaphor to teach caregivers about where their ‘driver reviver’ sites might reside and when and how to access them. An example of identifying and accessing such a resource may involve the caregiver asking a relative to stay with the care recipient for two hours every Friday so that the caregiver can meet with a walking group. This short two-hour break each week may be all the caregiver needs to revive in order to survive the journey. PCPs can explain to caregivers that, at some point in the journey even if they are stopping to revive, they may reach a point of exhaustion when it is unsafe for them and the care recipient in the car if they continue on without help. They must let someone else get behind the wheel and take over the driving, even if only for short periods of time. This may be in the form of informal care support from friends or family members, or formal support such as home support or respite.

Using such an analogy may help the caregiver to better understand the necessity of knowing when to get help and accessing the help when it is needed, especially for those that are resistive to relinquishing care of the care recipient. Further, being prepared, knowing where the driver reviver sites are and having the supports arranged in advance of fatigue setting in, will help to safeguard everyone on the journey. ICPWD can then be taught about signs and symptoms of stress, burden, fatigue, and burnout and health promotion strategies to prevent these adverse outcomes.

Improving experiences during transitional care. Most, if not all, persons with dementia will eventually experience time in an acute care or long-term care setting. Many caregivers have mentioned difficulties that they encountered while their loved one was in the hospital (Boughtwood et al., 2011; Teel & Carson, 2003). One caregiver reported that “hospital personnel seem to have very little understanding about Alzheimer’s and how the disease affects people; they would treat her like she was a typical patient with memory and cognition. They need education about how to work with Alzheimer's patients" (Teel & Carson, 2003, p. 52). Shanley et al. (2011) stated that "carers need to feel that staff who look after their loved one are not just providing minimal physical care but are making an effort to know the person and are relating to them on a personal level" (p. 335). ICPWD should be encouraged to utilize the Top 5 strategy (Clinical Excellence Commission, 2016) that was mentioned in Chapter One, and is shown in Appendix C, to alleviate some of stress involved when care recipients are admitted to acute or long-term care facilities. The NP as PCP could formulate a care plan that can be carried by the patient and/or family member to present to another care setting in order to optimize care outcomes.

Collaborative care. Inter-professional collaborative efforts are often required to meet the complex needs of informal caregivers (Schulz & Matire, 2004). Based on the findings from the literature, a collaborative approach to care is recommended. In primary care centres with an interdisciplinary team, NPs, Social Workers and Registered Nurses may all play important roles in providing support and education to ICPWD, as well as completing comprehensive informal caregiver assessments (Adelman, 2014). A notable example of this type of collaborative care is the caregiver support program run by an NP, dietician, social worker, and registered psychiatric nurse at Lakehead NP-Led Clinic in Thunder Bay, Ontario (Lakehead Nurse Practitioner-Led Clinic, 2010). This free, six-week long 1.5 hour per week program provides informal caregivers with education and skills to help them through their journey. This type of program not only provides an excellent source of support for ICPWD but it also fosters positive interprofessional relationships.

Inter-agency collaboration is paramount to effectively support ICPWD. PCPs may refer the care recipient to home support services, refer to an adult day program, or connect the ICPWD to the Alzheimer Society of British Columbia or other local chapter of a dementia support group. Based on the overwhelmingly positive sentiments that ICPWD have shared in the literature regarding the benefit of caregiver support groups, referral to a local support group at diagnosis is recommended. The NP alone is a vital source of support for ICPWD in many ways, yet a collaborative effort is very often necessary to more completely meet the needs of ICPWD.

Family-centred approach to care. Through review of the literature, it became evident that a person and family-centred approach should be implemented in practice as "person- and family-centred care focuses on the whole person as a unique individual and not just on their illness or disease" (Registered Nurses' Association of Ontario [RNAO], 2015, p. 8). The Canadian public health care system is moving towards a family-centred approach to care rather than focusing on the system and PCPs (RNAO, 2015). In viewing the ICPWD through this lens, PCPs may gain better understanding of the caregiver's own story, their health care experiences, and how they may help the person with dementia to maintain their health (RNAO, 2015).

A family-centred approach also ensures that ICPWD are recognized, acknowledged and included in the care planning for the person with dementia. Further, utilization of this approach fosters positive relationships, respect, and culturally competent care that is responsive to the needs of both the ICPWD and care recipient (Accreditation Canada, 2013). Examples of a family-centred approach include: ensuring a family member is with the care recipient during diagnosis and appointments following diagnosis, assessing the psychosocial needs of both the ICPWD and care recipient at all appointments, and organizing family meetings to develop care plans that consider information shared between family members and members of the health care team.

Family meetings. Family meetings are recommended for several reasons. First, these meetings embody a family-centred approach to care as they involve family and friends who are part of the lives of the ICPWD and care recipient. Family meetings allow for sharing of information that may not be shared during an office visit. Interdisciplinary family meetings can contribute to the development of effective care plans that best meet the needs of both ICPWD and care recipients. Such meetings may also help to alleviate some family conflict as they give the ICPWD an opportunity to voice their need for support from those family and friends who attend the meeting. Further, PCPs can reiterate the need for informal and formal support for the ICPWD, the care recipient, and other potential support persons at the meeting. Often, if such a request is made by a PCP rather than the ICPWD, others may be more inclined to help (Adelman et al., 2014; Barnard & Yaffe, 2012). Family meetings can also provide the opportunity for a respite plan to be developed between family and friends, as well as an emergency respite plan if the caregiver is hospitalized, for example. There are no recommendations in the literature related to the timing of family meetings. It is therefore important to assess the situation and offer timely family meetings ongoing as the needs change over time.

Recommendations for Education

Education for ICPWD. Caregiving in the context of dementia is not a predictable journey (Galvin, Todres, & Richardson, 2005). Certain challenges and stressors cannot ever be entirely prevented; however, an important aspect of any journey involves anticipating and appropriately planning for what may lie ahead. The overall caregiving experiences of ICPWD can be conceptualized as moving through several phases as the dementia progresses, each with particular opportunities for effective intervention and support by PCPs (Prorok et al., 2013).

Anticipatory guidance. Preparing caregivers through education for each stage of dementia can provide them with the resources they need to manage those issues that will inevitably occur. The literature demonstrates that ICPWD need ongoing information throughout the caregiving journey, not just at diagnosis. All PCPs can effectively utilize anticipatory guidance to prepare ICPWD for what may lie ahead in their journey and thereby make the inevitable challenges seem less insurmountable.

Anticipatory guidance should be provided to all ICPWD, regardless if they are a patient of the PCP or not. One may compare the office visit of a patient with dementia and their informal caregiver to that of a well-child assessment. For example, the child would be accompanied by a caregiver who may not be a patient of the PCP. The caregiver may be a parent, grandparent, or perhaps a foster parent. Regardless of the caregiver's background, the PCP would ask the caregiver questions about potential safety hazards in the home, family dynamics, family conflict, stress, caregiver fatigue, sleep hygiene, and depression, and whether the caregiver had any concerns about care of the child (Rourke, Leduc, & Rourke, 2014). Similarly, questions could be asked of the ICPWD to ensure safety of the care recipient as well as to ensure the ICPWD is appropriately supported. The challenge associated with dementia is that individuals move through the stages of dementia at different rates. Through regular follow-up appointments and discussions with ICPWD, PCPs may determine when the patient with dementia is transitioning through stages of dementia and be able to provide the ICPWD with appropriate information at the best possible time. Ensuring that resources are provided to ICPWD early in the dementia trajectory, and then at regular intervals throughout the journey, will help ICPWD to adequately prepare for the future and to feel supported along the way.

Education for PCPs. Prince, Livingston, and Katona (2007) remind us that specialists, such as neurologists, geriatricians, and psychiatrists, are a relatively scarce resource (particularly in rural and remote communities) who are most often unable to provide front-line dementia care and caregiver support. Therefore, PCPs hold a critical responsibility to maintain extensive and current knowledge about dementia and community resources. In order to promote knowledge regarding caregiving issues and evidence-based practice with regards to the treatment and management of dementia, PCPs are encouraged to participate in continuing education through reading research and attending conferences, for example. PCPs can then share this knowledge with their peers in various ways, such as grand rounds, journal clubs, conference presentations, publications, or online peer networking groups. For instance, some NPs in British Columbia present online webinars to other NPs within the province in order disseminate information about various medical topics. Sharing knowledge can contribute to improving provider's attitudes and priorities towards dementia care and better supporting ICPWD. Improved knowledge of dementia and caregiving also fosters therapeutic relationships and inspires greater confidence in the caregiver. One caregiver stated that "Anyone who is a [professional] caregiver ought to have current information on what is happening in the drug industry, new pills, new medication, new things that are coming out-because that kind of lifts you up a little" (Teel & Carson, 2003, p. 52).

Education for the public. Increasing public awareness of the potential manifestations of dementia, as well as the challenges with which ICPWD may contend, has several implications, including decreasing the stigma attached to dementia and decreasing feelings of social isolation for ICPWD. Key areas of lack of awareness include risk factors for dementia, pathophysiology of dementia, living with dementia, treatments, early and symptoms of dementia, and, very importantly, when to seek professional help (Alzheimer's Society, 2009). Teel and Carson (2003) suggest that increasing public awareness has been successfully conveyed as a means to improve the quality of care for patients with depression; thus, similar approaches could be used to similarly benefit ICPWD. Several strategies could be implemented in order to raise public awareness. For example, PCPs could hold community education sessions. Ad campaigns could be run through various types of media, including newspapers, television, and social media online sites. Charitable events are another way to raise both awareness and funding to support informal caregivers and persons with dementia.

Recommendations for Research

The lack of high quality research and the absence of guidelines pertaining to ICPWD highlight the existence of significant research and practice gaps. Over the past twenty years, a significant amount of literature has been written about informal caregiver burden and the adverse effects that caregiving can have on the informal caregiver. More recently, qualitative research has explored the caregiving experiences of ICPWD and researchers have investigated the effectiveness of interventions by measuring outcomes such as burden, depression, and QOL. Yet the quantitative literature has failed to evaluate a global measure of the overall caregiving experience. The implementation of mixed method studies may be useful in determining how effective formal interventions actually are at improving the caregiving experience for ICPWD. Additionally, longitudinal studies exploring the experiences of ICPWD over the entire dementia journey would provide valuable information about the changing needs through the disease trajectory to inform the timing of assessment and interventions.

Male ICPWD and CALD ICPWD are noticeably under-represented in caregiving research. Many interventions have targeted primarily female, Caucasian populations from neurology or memory clinics. It is difficult to determine whether or not these same interventions would be effective for minority or male ICPWD (Austrom et al., 2006). Further research focusing on these groups is recommended in order to gain a better understanding of gender and cultural differences within the caregiving experience. Likewise, more intervention research is needed with these groups to determine whether outcomes differ in comparison to the primary Caucasian, elderly female study samples. Gaining the perspectives of male informal caregivers is of particular importance, since almost half of Canadian caregivers are male (Eales et al., 2015). As Canadian studies on the experiences of ICPWD is notably lacking, further research is needed to develop an in-depth understanding of these experiences in a Canadian context in which to inform policy and practice. High quality quantitative research investigating primary care-based interventions is needed to support evidence-based practice as well as to develop clinical practice guidelines that are not based only upon moderate quality studies and expert opinion of guideline committees. Further, more informal caregiver research is desperately needed to inform the development of new clinical practice guidelines that are aimed at recommending evidence-based practice.

Conclusion

The experiences of my own family members as ICPWD, as well as my experiences as a Registered Nurse who has provided care to ICPWD and care recipients in the acute care setting, led to the development of the research question: how can PCPs best support ICPWD through the dementia journey? This question was answered through the review of 30 articles including 23 qualitative, quantitative, or mixed methods studies, two systematic reviews, one report, and four clinical practice guidelines. Review of the literature has generated some important contributions toward understanding the lived experiences and needs of ICPWD and has provided insight into the feasibility and effectiveness of some primary care-based interventions. The literature review uncovered gaps in evidence-based practice with respect to caregiver support.

The research findings have afforded insight into the unique challenges, as well as positive aspects, of caregiving that ICPWD experience. Although caregivers have diverse backgrounds and individual needs, many share similar experiences throughout their caregiving journey. In the literature ICPWD caregivers described feelings of uncertainty, fear, and loneliness. They described difficulties with obtaining timely diagnosis and with obtaining sufficient information from PCPs regarding caregiving or dementia. Many caregivers experienced family conflict as well as interpersonal conflict as they struggle with role changes and balancing their own needs with the needs of the care recipient. Many also expressed difficulty in obtaining both informal and formal supports. Developing an understanding of the needs and experiences of ICPWD affords a foundation on which to construct effective and supportive interventions in primary care settings.

In order to discover effective ways to support ICPWD, primary care-based interventions were investigated. Surprisingly, the findings illustrate that most of the primary care-based interventions reviewed are not necessarily effective or feasible for implementation within Canadian primary care settings. Even more surprisingly, no clinical guidelines were found that pertain to ICPWD specifically and none of the recommendations in the reviewed clinical practice guidelines are based on high quality evidence, highlighting a critical need for further research in which to develop quality Canadian evidence-based guidelines.

Based on the findings in the review, recommendations for practice and education were identified. These recommendations include the use of person-centred and family-centred approaches to care, anticipatory guidance, holding family meetings, caregiver assessment, raising public awareness, and educating PCPs about dementia care. Finally, further research is needed to explore the experiences of both male and CALD ICPWD in particular and to inform clinical practice guidelines and evidence-based primary care practice.

NPs are in an innovative and exciting position to utilize their unique knowledge and skills to effectively provide the much needed support for ICPWD and to champion changes within primary care practice in Canada. Through consideration of the implications for NP practice and the use of recommendations, such as the ones that have developed in this review, NPs can provide more consistent and effective supportive care to ICPWD.

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Appendix A

Types of Degenerative Progressive Dementia

Type of Dementia	Pathophysiologic Changes	Clinical Manifestations
Alzheimer's dementia (AD)	Development of amyloid plaques and neurofibrillary tangles. Oxidative stress occurs within cellular structures Neuronal cell death Cerebral atrophy	Insidious onset Memory loss Impaired physical functioning Impaired executive functioning
Vascular dementia	Most often associated with cerebral vascular accidents, diabetes mellitus, coronary artery disease, hypertension, and peripheral artery disease	May be abrupt or insidious onset Neurological deficits
Lewy Body dementia	Alpha-synuclein protein found in brain cells Development of amyloid plaques and neurofibrillary tangles.	Fluctuating cognitive impairment Memory loss Visual hallucinations Parkinsonism Frequent falls Syncope Transient loss of consciousness
Frontotemporal dementia (Pick's disease)	Damage to cells in the frontal and temporal lobes of the brain Cerebral atrophy Tau positive inclusions or Tau negative inclusions Earlier onset than AD	Disinhibition Memory loss Loss of insight Loss of emotional control Speech/language difficulty

(Agamanolis, 2013; Boss, 2010)

Appendix B

Dementia Staging Scales

	Dementia Staging Scales	
GDS	**FAST**	**CDR**
Stage 1: No cognitive decline (no dementia) *Normal functioning, no memory impairment*	Stage 1: Normal adult *No functional decline*	CDR-0: No dementia
Stage 2: Very mild cognitive decline (no dementia) *No evident symptoms*	Stage 2: Normal older adult *Some functional decline, individual is aware of same*	CDR-0.5: Mild *Consistent yet negligible memory impairment, daily functioning slightly, minor difficulties with problem solving*
Stage 3: Mild cognitive decline (no dementia) *Mild memory impairment, and functional decline. Family members may notice subtle changes* *Average duration: 7 yrs*	Stage 3: Early disease *Noticeable functional impairment of occupational tasks*	CDR-1: Mild *Moderate short term memory impairment affecting daily functioning, moderate difficulties with problem solving, difficulties with complex tasks, unable to independently manage tasks in the community*
Stage 4: Moderate cognitive decline (early stage dementia) *Noticeable short term memory impairment, hindered concentration, need assistance with instrumental tasks such as paying bills, cognitive impairment evident during assessment* *Average duration: 2 yrs*	Stage 4: Mild disease *Requires assistance with instrumental tasks such as paying bills or planning an event*	CDR-2: Moderate *More profound short term memory impairment, disoriented, poor judgment and problem solving, requires assistance with daily activities, has little interests*

Table continues on the next page.

Stage 5: Moderately severe cognitive decline (mid stage dementia) *Severe memory deficits, need assistance with daily activities such as dressing and bathing, profound memory loss, disorientation evident* *Average duration: 1.5 yrs*	Stage 5: Moderate disease *Requires assistance with some daily activities such as choosing appropriate clothing and dressing*	CDR-3: Severe *Severe memory loss and cognitive impairment, disoriented, no judgment or problem solving abilities, unable to partake in activities in a community setting, often incontinent, requires assistance with all daily activities*
Stage 6: Severe cognitive decline (mid stage dementia) *Severe functional impairment, require assistance with most tasks, severely impaired short term and long term memory, incontinence is common, personality changes, agitation, delusions, repetitive behaviours are common* *Average duration: 2.5 yrs*	Stage 6: Moderately severe disease *Requires assistance with all daily activities, experiences incontinence*	
Stage 7: Very severe cognitive decline (late stage dementia) *Require full assistance with all daily activities, may have lost speaking ability and psychomotor activity such as walking* *Average duration: 2.5 yrs*	Stage 7: Severe disease *Progressive loss of psychomotor functioning such as walking or sitting, may lose ability to speak more than approximately six words*	

(DeLeon and Reisberg, 1999; Dementia Care Central, 2013; Morris, 1993; Reisberg, 1982; Sclan & Reisberg, 1992)

Appendix C

Example of Top 5 Strategy: Grandpa's Biography

Don McKnight

Wife for nearly 63 years - Bunny
Daughter – Laurie (Dave), Grandsons – Trevor & Ryan
Son – Rick (Joyce), Granddaughter – Amanda (Lee) Great Granddaughter – Ella
Born in Winnipeg, Manitoba. Worked for Air Canada for many years. Used to be an avid golfer.

Food Likes

Coffee with Splenda and ice cubes, Fresh Fruit (bananas, pear, grapes, blueberries), cream of wheat with milk poured over, vanilla ice cream and puddings, scrambled eggs with ketchup and *Lemon Meringue Pie!*

Food Dislikes

Anything spicy or sour (cranberry Juice), anything with seeds, chewy/stringy meat, Hot (heat) food.

During Care

Please explain what you are doing for Don before you perform any care or treatment. He likes to be approached verbally before being touched or may become agitated due to fear or frustration.

Don is waiting for eye surgery on his left eye. The side effects that he could possibly be experiencing include (but not limited to) blurry vision and floaters. Combined with his cognitive issues, some of his hallucinations might be his brain's inability to recognize this.

A Bit about Don: Favourite Places and Things

- **Warm blankets and big hoodies – Don is always chilled and loves to be kept warm.**
- Home – 2 recliners side by side, so he can hold hands with Bunny while they watch the golfers go by the apartment window.
- Hanging out playing cards with his grandchildren
- Squirrels on the bird feeder outside the living room window
- Barbados
- Music of the 1940's and 50's
- Afternoon naps
- Readers digest and National Geographic

Don has been very fortunate and this is his first extended stay in hospital, ever. The humiliation of a dignified, kind, gentle natured person turning over every aspect of his personal care must be very distressing to him (as it is to his wife and family), causing him frustration that manifests itself in ways that he would be appalled at. Don is a very private, unassuming man who has never raised a hand to another person. You may hear him reminisce and talk about the people and things listed above.

Appendix D

A 'Road Map' for the Dementia Journey: Key Recommendations for NP Practice

STAGES OF DEMENTIA	**Stages 1-3** No to mild cognitive decline	**Stage 4** Early Stage	**Stages 5-6** Middle Stages	**Stage 7** End Stage	**After Placement or Death of the Care Recipient**
STAGES OF CAREGIVING *without support ** with support	**Likely no help required**	**Helping** (A little more help than usual) Home/ work life may be affected	**Involved** (may help with meds/ADLs/ Treatments) **Intensive** (complex/increasing care needs/most often longest stage). May experience family conflict, emotional conflict, significant work/life impacts, isolation *high risk of burnout/health issues **competence and strength	**All Encompassing** (often 24/7 care, provide care with ADLs/IADLs, medical decisions) *high risk of burnout/health issues, social isolation **sense of mastery/stabilization	**Closing** (major transition, may still experience stress if care recipient in a facility, may experience grief and loss *high risk of mental health issues **finds a "new normal" may consider advocacy role
SUPPORTIVE STRATEGIES	*-Raise public awareness and education* *-Media campaigns* *-Disease (dementia) prevention eg. Brain training activities, reg. exercise, healthy diet, smoking cessation*	*-Timely diagnosis* *-Emotional support during diagnosis* *-Referral to specialist/memory clinic if complex case* *-ICPWD assessment to determine needs* *-Referral to support group* *-Provide community resource list*	*-Provide information and encourage home supports/respite* *-ICPWD assessment to determine changing needs/health issues -refer to PCP if ICPWD not a pt.* *-Hold family meeting* *-Provide emotional support* *-Ensure advanced care plan is in place*	*-Ensure ICPWD are connected with services* *-ICPWD assessment to determine changing needs and concerns/health issues -refer to PCP if ICPWD not a pt.* *-Hold family meeting* *-Ensure advanced care plan is in place* *-Ensure emergency plan is in place* *-Education*	*-Emotional support* *-grief counselling* *-Refer to support group* *-Assess for concerns /health issues -refer to PCP if ICPWD not a pt.*

		-Provide link to Alzheimer's organization *-Hold family meeting* *-Create an emergency plan in case ICPWD is hospitalized/away* *-Encourage use of 811 Nurse Line or Alzheimer's support line for after hours emergency advice* *-Commence advanced care planning* *-Link with resources for financial/legal planning eg. NIDUS* *-Encourage the care recipient to continue regular activities such as hobbies for as long as possible* *-Encourage healthy lifestyle choices (diet/exercise/stress management)* *-Medication review* *-Education:* *-dementia* *-stress and coping* *-self-care/health* *-driving* *-Counselling regarding changing relationships*	*-Ensure emergency plan is in place* *-Education (anticipatory guidance)* *-driving* *- behaviour management* *-monitoring for delirium* *-home safety* *-self-care* *-coping strategies* *-safe manual handling* *-Encourage caregiving skills /education program if available* *-Counselling regarding anticipatory grief* *--Encourage healthy lifestyle choices (diet/exercise/stress management)* *-Medication review* *-Ensure ICPWD is linked with a support group*	*- behaviour management* *-monitoring for delirium* *-safe manual handling* *-home safety* *-self-care* *-coping strategies* *-Involve palliative care team for end of life planning*	

(Elizz, 2015)

Appendix E

Literature Search Diagram