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# Comparison of Ontario's Home Care Policies with the Perspectives of Personal Support Workers in the Provision of Quality Dementia Home Care

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences

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## **Abstract**

Personal support workers (PSW) play a primary role caring for persons living with dementia (PLWD). Policies guide PSW to provide quality dementia home care. This study aimed to explore PSW' perspectives on providing quality home care for PLWD in comparison to Ontario's home care policies. Qualitative content analysis was used to analyze fifteen interviews with PSW and six Ontario policy documents. Alignments included: interprofessional care team approach; dementia-specific education and training for PSW; accessible services, information and education for PLWD and family caregivers; and increasing the respect and supports PSW receive from employers. Differences included: PSW emphasizing person-centred care and specific PSW experiences, abilities and characteristics that help deliver quality dementia home care. Importantly, what PSW perceive as quality home care does not match their experiences. Study findings contribute to limited research on quality dementia home care, highlighting the importance of incorporating PSW perspectives when developing and implementing Ontario policies.

Keywords: home care, dementia, quality, PSW, policy, Ontario

## Summary for Lay Audience

There is a global need for sustainable healthcare systems that can effectively and efficiently provide quality dementia care given the expected rise in the prevalence of dementia. This is combined with a large demand for home care because of the amount of people wanting to live at home for as long as possible. Formal caregivers, such as personal support workers (PSW), play a primary role in the direct formal care of persons living with dementia (PLWD). Further, the policies that guide PSW ability to provide quality dementia home care can have great impacts on the care provided. The goals of this research are to explore the perspectives PSW have in providing quality home care for PLWD and to compare them to the current Ontario home care policies. Qualitative content analysis was used to analyze transcripts from fifteen interviews with PSW and six Ontario policy documents to understand how quality dementia home care was compared. Results showed that areas of alignment between PSW and policy documents included: interprofessional care team approach; dementia-specific education and training for PSW; accessible services, information and education for PLWD and family caregivers; and increasing the respect and supports PSW receive from their employers. Differences included: PSW emphasizing person-centred care and specific PSW experiences, abilities and characteristics that help PSW to deliver quality dementia home care. Additionally, it was found that what some PSW perceive as quality home care for PLWD does not always match their experiences in home care. The areas of consistencies between the PSW perspectives and the provincial policy documents suggest that these areas reflect enough alignment to aid in the provision of quality dementia home care. However, the areas of differences also need to be considered as they suggest that policies need to be revised and implemented fully to ensure the provision of quality home care to all PLWD in Ontario. Ultimately, the study findings contribute to the limited amount of research on perspectives of quality dementia home care by highlighting the importance of incorporating the perspectives of PSW in the development and implementation of Ontario home care policies.

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## **Chapter 1: Introduction**

### **1.1 Dementia**

A diagnosis of dementia carries widespread implications for individuals who receive the diagnosis, their families and caregivers, health care systems, and societies at large.

Worldwide, dementia impacts approximately 50 million people (Alzheimer's Disease International, 2019) and does not discriminate against low-, middle-, or high-income countries (Fiest et al., 2016). In the Canadian context, it is estimated that 564,000 people were living with dementia in 2016 (Alzheimer Society of Canada, 2016). It is estimated that this number will increase to approximately 937,000 Canadians by 2031 (Alzheimer Society of Canada, 2016). In Ontario, approximately 228,000 people are living with dementia (Ministry of Health and Long-Term Care, 2016). With Ontario's population aging, it is estimated that the number of persons living with dementia (PLWD) will rise to over 430,000 people by 2038 (Ministry of Health and Long-Term Care, 2016). As the prevalence rises, so too will the associated health and social consequences of dementia for PLWD and their family caregivers.

The Alzheimer Society of Canada (2016) notes that dementia is one of the main causes of disability during the later part of life, coming ahead of cancer, stroke and cardiovascular disease. Dementia ultimately leads to a loss of functioning and independence (Bökberg et al., 2017; Bronskill et al., 2014; Fiest et al., 2016; Home Care Ontario, 2017; Sutherland & Wiersma, 2016). This lack of independence often leads to reliance on informal caregivers, usually within a home care setting (Alzheimer Society of Canada, 2016; Bronskill et al., 2014; Brown, 2016; Feldman & Estabrooks, 2017; Home Care Ontario, 2017). In an assessment of 13,744 Ontarian home care clients, 37.7% had a diagnosis of dementia (Canadian Institute for Health Information, 2018). Further, 96.5% of home care clients had an informal caregiver present and 61.4% of caregivers displayed symptoms of caregiver distress (Canadian Institute for Health Information, 2018).

Caregiver distress occurs when informal caregivers experience anger, depression and other physical and mental health consequences as a result of their caregiver duties (Brodaty & Donkin, 2009; Health Quality Ontario, 2017a; Ministry of Health and Long-Term Care, 2016; Takai et al., 2009; Tremont, 2011). These statistics show how often

individuals with dementia have informal caregivers present and how the caregiving responsibilities can impact the physical and mental health of these caregivers. Reducing distress for informal caregivers of home care clients has been outlined as a goal for Ontario's health care system to achieve (Health Quality Ontario, 2017a). It is essential for care of PLWD to consider these health consequences for both PLWD and their informal caregivers. Moreover, PLWD and their informal caregivers can experience social consequences of dementia. Specifically, both PLWD and their family caregivers may encounter stigmatization related to dementia (Home Care Ontario, 2017; Ministry of Health and Long-Term Care, 2016; Sutherland & Wiersma, 2016; Swaffer, 2014), which may lead to the experience of social isolation (Brodsky & Donkin, 2009; Home Care Ontario, 2017; Ministry of Health and Long-Term Care, 2016).

Monetary costs, including health care system costs and out-of-pocket costs, for care of PLWD are estimated to be five and a half times more than for people living without dementia (Alzheimer Society of Canada, 2016). Between 2008 and 2038, it is estimated that dementia will cost Ontario approximately \$325 billion CDN (Ministry of Health and Long-Term Care, 2016). This figure includes health care costs, lost wages, and out-of-pocket expenses incurred by those living with dementia and their caregivers (Ministry of Health and Long-Term Care, 2016).

Many PLWD require home care services because of a growing dependence due to the progression of dementia, but there is also a general large demand for home care because older adults want to age at home. In Ontario, a reported 87% of adults over the age of 55 have a desire to live at home for as long as possible (Home Care Ontario, 2018). The Government of Ontario is relying increasingly on home care services for PLWD, a significant consideration is likely the lower costs of care delivery, when compared to other settings of care delivery (Home Care Ontario, 2018). To put this in perspective, the average cost of home care per person is \$3,500 per year (Auditor General of Ontario, 2015) and the average cost of long-term care per person is approximately \$54,000 per year (Ontario Long Term Care Association, 2019). However, several staff from organizations, such as Home Care Ontario, and researchers have questioned whether home care funding and resources are keeping up with the demand of the growing number of people wanting to remain at home (Home Care Ontario, 2018; Sharkey &

Lefebvre, 2008; Sinha, 2016; Storch et al., 2014). In June of 2019, the Ministry of Health and Long Term Care was divided into separate ministries (Ministry of Long-Term Care, 2019). The current makeup of the organization of the Ministry of Health consists of one minister who is responsible for Ontario's entire healthcare system, ten assistant deputy ministers, and forty-seven directors, including one director specifically supporting Home and Community Care who reports to the executive lead of Ontario Health Teams (Ministry of Health, 2020). At the same time, the Ministry of Long Term Care includes a minister, five assistant deputy ministers and twenty directors specifically appointed to support Long-Term Care Homes (Ministry of Long-Term Care, 2020). Further, when exploring the Ministries of Health and Long Term Care's websites there are significant levels of resources including resources regarding specific policy guidance for Ontario's long term care sector but few resources to support the community and home care sector. Despite the push to shift care from an institutional setting to a home care setting, the Government of Ontario does not seem to be providing funding and resources on a proportional basis needed to support the community and home care sector. This must be taken into consideration in the context of a province where increasing numbers of people want to age at home.

## **1.2 Quality Dementia Home Care Provision**

### **1.2.1 Goals of Quality Dementia Home Care**

There is growing evidence that supports having PLWD age in a familiar environment, with familiar routines, since these aspects can aid in compensating for progressive losses through reliance on procedural and emotional memory systems (Borbasi, Nurs, et al., 2006; Low et al., 2013; Morton-Chang et al., 2016b). Although this suggests home care as the best option, there is a lack of consensus on what defines quality home care provision for individuals with dementia. The provision of quality home care to PLWD is complicated by the number of stakeholders who are often present within the care process (Gaugler et al., 2005). The stakeholders include PLWD, informal caregivers, an array of health care and service providers, and the Government of Ontario (Gaugler et al., 2005). Quality dementia home care needs to take into consideration all of the stakeholders as well as the other markers of quality dementia care. The markers of quality dementia care are the provision of timely, flexible and individualized services (Borbasi, Nurs, et al.,

2006; Dawson et al., 2015; Edvardsson et al., 2009; Gilster et al., 2018; Janicki, 2011; Low et al., 2013; Manthorpe & Samsi, 2016; Morton-Chang et al., 2016a; Sutherland & Wiersma, 2016; Warshaw & Bragg, 2014); the management of comorbidities (Griffith et al., 2016; Lyketsos, 2012; Mondor et al., 2017); and ultimately the delay of relocation to institutionalized settings (Cepoiu-Martin et al., 2016; Gaugler et al., 2005).

Several researchers have highlighted the importance of the availability of home care services that are timely, flexible and individualized for PLWD (Dawson et al., 2015; Gilster et al., 2018; Janicki, 2011; Morton-Chang et al., 2016a; Sutherland & Wiersma, 2016). Having services that are timely is essential for quality home care because PLWD, as well as their informal caregivers, should be able to access services when they are needed (Borbasi, Nurs, et al., 2006; Dawson et al., 2015; Edick et al., 2017; Janicki, 2011; Tam-Tham et al., 2016). The provision of services that can flexibly meet the needs of PLWD is paramount to the delivery of quality home care. Quality dementia home care should ensure that it has the ability to provide flexible long-term services, and that these services recognize, plan for the progression of the disease and be aligned with best practice guidelines (Dawson et al., 2015; Janicki, 2011; Low et al., 2013; Sutherland & Wiersma, 2016).

The heterogeneous nature of PLWD also highlights the significant emphasis that should be placed on providing person-centred care. Providing individualized or person-centred care is very important to ensure that quality dementia care is being provided (Dawson et al., 2015; Edvardsson et al., 2009; Gilster et al., 2018; Janicki, 2011; Kirkley et al., 2011; Low et al., 2013; Morton-Chang et al., 2016a; Smythe et al., 2015; Sutherland & Wiersma, 2016). Person-centred care is care provision that recognizes each individual as unique with different life histories, preferences, etc., and actively involves them to participate in decisions surrounding their health (Brooker, 2004; Cook, 2017; Dawson et al., 2015; Downs & Collins, 2015; Edvardsson et al., 2009; Gilster et al., 2018; Janicki, 2011; Sutherland & Wiersma, 2016). Generally, services and care that are tailored to individual needs and ensure that PLWD are treated with compassion, dignity and respect, can indicate that quality dementia care is being provided (Borbasi, Nurs, et al., 2006; Dawson et al., 2015; Downs & Collins, 2015; Edick et al., 2017; Gilster et al., 2018; Janicki, 2011; Manthorpe & Samsi, 2016; Morton-Chang et al., 2016a; Smythe et al.,

2015; Sutherland & Wiersma, 2016; Turjamaa et al., 2014; Volicer, 2007; Warshaw & Bragg, 2014). In addition, the idea of empowering PLWD as well as their caregivers in decision-making is closely aligned with the provision of quality dementia care and support (Manthorpe & Samsi, 2016; Morton-Chang et al., 2016a, 2016b; Sinha, 2016; Smythe et al., 2015; Sutherland & Wiersma, 2016).

PLWD have higher rates of hospital admission for dehydration, urinary tract infections, pneumonia, and delirium from adverse effects of medications (Lyketsos, 2012). PLWD also have an increased risk for functional and cognitive decline associated with hospitalization (Borbasi, Nurs, et al., 2006; Mondor et al., 2017; Volicer, 2007). Managing comorbidities to minimize hospital admissions is an important goal for the provision of quality dementia home care. Hospitalizations can be prevented through the proper coordination and integration of care between all of the stakeholders mentioned above (Low & Fletcher, 2015; Lyketsos, 2012). It also has been found that the provision of care-management in home care can demonstrate a decrease in institutionalization for PLWD (Low & Fletcher, 2015; Zabalegui et al., 2014). Care-management is a way of delivering home care and focuses on collaboration between all stakeholders of the care process (Dawson et al., 2015; Gilster et al., 2018; Low & Fletcher, 2015; Morton-Chang et al., 2016b; Zabalegui et al., 2014). The use of case managers within care-management home care can ensure the provision of personalized and continuous dementia care and can enhance the relationship between formal and informal caregivers, thus decreasing the institutionalization of PLWD (Dawson et al., 2015; Gilster et al., 2018; Morton-Chang et al., 2016b; Zabalegui et al., 2014).

Other researchers have noted the importance of having interprofessional teams to encourage open communication and problem solving among different healthcare professionals so that solutions can be created to deal with the myriad of problems faced by community-dwelling PLWD (Brody et al., 2016; Carlisle et al., 2004; Cartwright et al., 2015; D'Astous et al., 2019; Gilster et al., 2018; Low et al., 2013; Sharkey & Lefebvre, 2008; Warshaw & Bragg, 2014). Further, health care professionals providing home care to PLWD should have dementia-specific base education and ongoing dementia-specific training (Brody et al., 2016; Chow et al., 2018; Cook, 2017; D'Astous et al., 2019; Edick et al., 2017; Gilster et al., 2018; Hughes et al., 2009; Low et al., 2013; Robinson et al.,

2014; Smythe et al., 2015; Zabalegui et al., 2014) and be prepared to acknowledge the role of informal caregivers and support them in this caregiving role (Brown, 2016; Dawson et al., 2015; Gilster et al., 2018; Morton-Chang et al., 2016b; Willis et al., 2009; Zabalegui et al., 2014).

The role of home and community-based care on delaying or preventing relocation to long-term care homes has mixed results. The systematic review and meta-analysis carried out by Cepoiu-Martin et al. (2016) found inconsistent results on whether the provision and use of home care and day care services for PLWD increased or decreased the chance of relocation to a long-term care facility. The scope of the analysis did not explore the timing and nature of home care services in-depth, which may have contributed to the inconsistent results (Cepoiu-Martin et al., 2016). However, Gaugler et al. (2005) found that the early utilization of in-home care services for individuals with dementia and their caregivers led to a delay in institutionalization. These findings suggest that a greater emphasis should be put on the timing of home care dementia experience (Gaugler et al., 2005). The emphases on early diagnosis and early care intervention also are highlighted in other research, with several authors citing that timely as possible home care delivery, along with ongoing home and community support, are considered to be best practices in dementia care (Morton-Chang et al., 2016a, 2016b; Sinha, 2016).

### **1.2.2 Home Care Users' Views of Quality**

It is often mentioned throughout the literature that it is important to consider the home care users' perspectives when looking into the quality of the care provided (Bökberg et al., 2017; Francis & Netten, 2004; Hasson & Arnetz, 2011; Jones et al., 2007). A study in England examined which aspects of quality home care were important to home care clients. The authors found six key aspects of quality home care including reliability, flexibility, continuity, communication, staff attitudes, and skills and knowledge (Francis & Netten, 2004). These aspects of quality home care also have been found in various studies taking place in the Canadian context. In terms of reliability, service users wanted to maintain control over their lives, and waiting around for home care providers who potentially show up late or not at all interfered with this sense of control (Francis & Netten, 2004; Jones et al., 2007; Storch et al., 2014). As mentioned previously, having flexible services is a marker of quality and is important for home care users, especially



those who are living with dementia. Home care users consider services to be flexible when the provider helps with tasks outside of the care plan, such as meal preparation (Dempsey et al., 2016; Francis & Netten, 2004; Wojtak & Klopp, 2015), and having home care providers being flexible to make changes in the times that they visit (Francis & Netten, 2004; Gilster et al., 2018; Morton-Chang et al., 2016a; Sutherland & Wiersma, 2016). It also has been found that scheduling inflexibility negatively affects patient-centred care, which is a known aspect of quality dementia care (Abbasi et al., 2017). Home care organizations need to overcome this inflexibility by encouraging home care providers to provide flexible and reliable services (Low et al., 2013). Further, continuity and having consistent care providers are important quality aspects for some home care users, and can have increased significance for those who are living with dementia (Dempsey et al., 2016; Forbes & Neufeld, 2008; Francis & Netten, 2004; Low et al., 2013; Morton-Chang et al., 2016b; Storch et al., 2014; Warshaw & Bragg, 2014). The development of trust within the home care provider-client relationship is important and lack of consistent providers can greatly impact this relationship (Edvardsson et al., 2009; Forbes & Neufeld, 2008; Kieft et al., 2014; Ryan et al., 2004; Storch et al., 2014; Woodward et al., 2004) as well as negatively affect efficiency in terms of time providing care (Storch et al., 2014).

Communication is an important aspect to many home care clients. Communication is related to reliability and continuity because clients wanted to be informed if a care provider was going to be late or if someone new was coming (Dempsey et al., 2016; Francis & Netten, 2004). Communication is a significant factor in terms of quality of care that clients and families experience (Wojtak & Klopp, 2015). Being attentive to language and being accommodating is especially important for PLWD receiving care (Cook, 2017; Downs & Collins, 2015; Ryan et al., 2004; Sutherland & Wiersma, 2016). According to service users, appropriate attitudes among staff are crucial to high-quality service provision and are closely related to the use of effective communication (Francis & Netten, 2004; Jones et al., 2007; Low et al., 2013). Appropriate attitudes among care providers include being respectful, friendly, cheerful, and understanding, and to use flexible communication that is congruent with these attitudes (Francis & Netten, 2004; Sutherland & Wiersma, 2016). Finally, the skills and

knowledge that workers demonstrate are important to home care users (Francis & Netten, 2004). However, home care providers do not receive an adequate amount of training to effectively provide care for those with complex needs, including PLWD (Abbasi et al., 2017; Morton-Chang et al., 2016b; Sinha, 2016; Storch et al., 2014).

Several researchers also have attempted to link self-reported quality of life for PLWD to their perception of quality of care (Beerens et al., 2014; Bökberg et al., 2017; Miguel et al., 2016; Nikmat et al., 2015). Both quality of life and quality of care are multidimensional (McClendon & Smyth, 2015; Nikmat et al., 2015). Several quality of care indicators such as pain, weight loss, depressive symptoms, have different relationships to how people living in the community with dementia rate their overall quality of life. Despite PLWD experiencing daily pain and weight loss, they still perceived their quality of life as high (Bökberg et al., 2017). This demonstrates the importance of ensuring PLWD are satisfied with their care because of the effects it can have on their perceived quality of life. It also has been found that lowering the presence of depressive (Beerens et al., 2014; Miguel et al., 2016) and neuropsychiatric (Miguel et al., 2016) symptoms in PLWD positively affects their perceived quality of life. Quality dementia home care should therefore include the ability to treat and manage these symptoms to maximize the individuals' perceived quality of life.

### **1.2.3 Public Policy**

The Government of Ontario is constantly emphasizing its commitment to strengthening patient-centred care within Ontario, with several government policies and documents focusing on this approach. This is clearly shown in even the title of policies, such as, *Patients First* (Ministry of Health and Long-Term Care, 2015). *Patients First: Ontario's Action Plan for Health Care* is a plan to guide the transformation of Ontario's health care system into one that better serves the people who access it (Ministry of Health and Long-Term Care, 2015). It builds on the *Action Plan for Health Care* (2012), with the goal of putting patients first and improving the overall health care experience (Ministry of Health and Long-Term Care, 2015). To achieve this, the plan focuses on four objectives: access, connect, inform and protect (Ministry of Health and Long-Term Care, 2015). Since Ontario public policy puts emphasis on patient-centred care and person-centred care, it is important to explore both of these concepts.

Effective use of a patient-centred model can lead to improved clinical outcomes and patient safety, therefore, governments and other health care organizations are more frequently committing to this approach (Gluyas, 2015). However, there are several limitations and barriers to achieving truly patient-centred care that need to be considered, including structural-related factors (such as fragmentation of care), health care professional-related factors (such as health care professional beliefs that can reinforce power imbalances), and patient-related factors (such as being overwhelmed by the health care system) (Gluyas, 2015). It is very important to carefully plan out the implementation of a patient-centred model of care delivery, to minimize the effects that these limitations can have. This is especially true when implementing a patient-centred model to serve a vulnerable population, such as those diagnosed with dementia, because barriers (specifically involvement in decision-making and health literacy) may be exacerbated, making this population even more vulnerable. It is also important to note that patient-centred quality dementia care needs to consider the patient/caregiver dyad regardless of whether dementia is the central condition or if multi-morbidities are present (Noel et al., 2017). Therefore, special attention should be paid to not only the person diagnosed with dementia, but also their informal caregivers, to provide high quality patient-centred care. As previously mentioned, policies such as *Patients First: Ontario's Action Plan for Health Care* encompass a patient-centred approach.

There is also a shift occurring in ideologies about high quality care, one that is moving away from the idea of patient-centred care towards person-centred care (Dawson et al., 2015; Gilster et al., 2018; Janicki, 2011; Santana et al., 2018). This shift is occurring not only in dementia literature and research, but also in Ontario public policy. Using a person-centred approach avoids reducing a person to being just a patient that is reduced to their symptoms and disease (Goodwin, 2016; Santana et al., 2018). Implementing policies that are ultimately person-centred can be difficult because everything needs to be redesigned and restructured to be conducive to person-centred care (Santana et al., 2018). However, Santana et al. (2018) have created a framework to address gaps in implementation of person-centred policies. Providing person-centred care is especially important for people living dementia (Downs & Collins, 2015; Fazio et al., 2018; Kirkley et al., 2011; Low et al., 2013; Manthorpe & Samsi, 2016; Smythe et al.,

2015). Health care and service providers need to recognize each person living with dementia (as well as their informal caregivers) as unique individuals that have different life histories, preferences, environments, communication styles, etc. (Brooker, 2004; Cook, 2017; Dawson et al., 2015; Downs & Collins, 2015; Edvardsson et al., 2009; Gilster et al., 2018; Janicki, 2011; Sutherland & Wiersma, 2016).

The benefits of training health care providers to deliver person-centred care for individuals living with dementia have been well researched (Ballard et al., 2018; Brooker et al., 2016; Kim & Park, 2017; Mullan & Sullivan, 2016; Stein-Parbury et al., 2012; Surr et al., 2016). Providing long-term care staff with person-centred dementia care training reduces agitation (Ballard et al., 2018; Kim & Park, 2017; Stein-Parbury et al., 2012), neuropsychiatric symptoms (Ballard et al., 2018; Kim & Park, 2017), depression (Kim & Park, 2017), and use of anti-psychotics (Ballard et al., 2018; Brooker et al., 2016; Fossey et al., 2006) as well as improves the quality of life of PLWD (Ballard et al., 2018; Kim & Park, 2017). Further, health care providers who receive person-centred dementia care training and intend to implement their training find significant improvements in attitudes towards and satisfaction in caring for PLWD (Surr et al., 2016), as well as having a greater sense of competence to provide dementia care (Mullan & Sullivan, 2016). Having person-centred dementia care available for PLWD in every context is clearly important and is an indicator that high quality care is being provided. The importance of person-centred dementia care is clearly highlighted in Health Quality Ontario's (2017b) Quality Standards for the provision of dementia care for people living in the community.

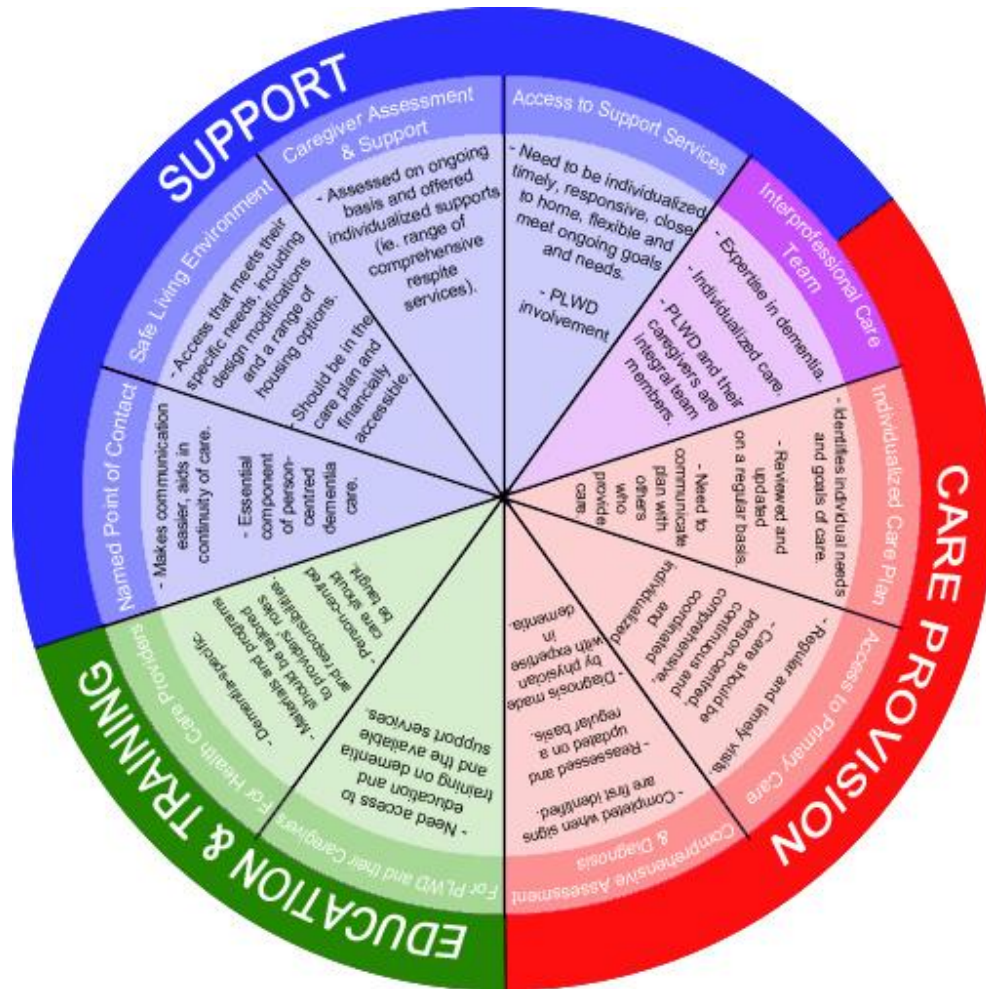
Health Quality Ontario is the province's advisor on health care quality (Health Quality Ontario, 2019). Health Quality Ontario monitors and reports on health system performance, provides guidance on quality issues, and assesses evidence to determine what establishes optimal care (Health Quality Ontario, 2019). Person-centred care is one of the underlying principles throughout the quality standards and is explicitly mentioned in several of the standards (Health Quality Ontario, 2017b). Health Quality Ontario (2017b) describes ten "Quality Statements" that should be present in the delivery of quality dementia care for Ontarians living in the community. Health Quality Ontario (2017b) provides overarching quality standards and indicators that can be used to measure the overall success of dementia home care provincially as well as locally (Health

Quality Ontario, 2017b). Ultimately, the goal of these ten broad quality standards is to provide information that can be utilized by individuals with dementia, their caregivers, healthcare providers, or home care service providers to determine how quality dementia home care can be provided (Health Quality Ontario, 2017b).

The following is a framework developed by the primary researcher (RB), adapted from Health Quality Ontario's (2017b) ten quality standards for the provision of dementia care for people living in the community. The purpose of this framework is to depict clearly how Health Quality Ontario describes quality dementia home care, so Health Quality Ontario's presentation of quality dementia care can be compared to the results of the policy analysis and the interview analysis.

**Figure 1**

*Dementia Quality Standard Framework adapted from Health Quality Ontario's Quality Standards for Dementia: Care for People Living in the Community.*



### 1.2.4 Organizational-Level Policy

There is growing support for the use of quality indicators in areas of health care systems, including for the provision of home care (Hirdes et al., 2004). Current quality indicators mainly emphasize process outcomes, however, outcomes measures should also be considered because of their importance in demonstrating quality as well (Steele Gray et al., 2014). Process outcomes indicate what is done to improve or maintain health while outcome measures reflect the impact of a health care service on the health status of an individual (Steele Gray et al., 2014). Hirdes et al. (2004) examined and refined home care

quality indicators (HCQIs) using data collected from home care clients assessed using the Minimum Data Set – Home Care (MDS-HC). The MDS-HC is a comprehensive assessment tool that was created to inform and guide the provision of home care (Hirdes et al., 2004). The 22 HCQIs that were refined by Hirdes et al. (2004) provided a mixture of process and outcome measures. Some of the indicators for process outcomes included lack of medication review and failure to receive influenza vaccinations, while an indicator of outcome measures included failing to improve and/or having a decline in activities of daily living (Hirdes et al., 2004). Closely related to the MDS-HC, the Resident Assessment Instrument – Home Care (RAI-HC) was developed in 1994 and is utilized to evaluate the needs and strengths of home care clients (Dalby & Hirdes, 2008; Hawes et al., 2007). This comprehensive and standardized instrument is comprised of the MDS-HC and uses this assessment information to care plan decision-making and the creation of individualized care plans (Hawes et al., 2007). A recent evaluation using the Resident Assessment Instrument – Home Care (RAI-HC) in Ontario and British Columbia found that data collected using this assessment are of high quality that are reliable and can be trusted for informing decisions. Both of these assessment tools and the related 22 HCQIs can have an impact on the quality of care provided at an agency policy level (Dalby & Hirdes, 2008; Hirdes et al., 2004).

Certain agency-level policies can also be put into place out of a necessity for increasing accountability, however, they can end up having negative unintended consequences (Steele Gray et al., 2014). Steele Gray et al. (2014) found such an example with policies requiring home care providers to report on details surrounding each care visit, actually causing a shift in the amount of time spent providing care to clients. Thus, policies created at an agency-level have the ability to impact the amount and quality of care provided. A study examining the impact of agency level factors on the quality of home care found that population size and case manager caseload size had important implications on quality, with no effect of quality on for-profit service providers versus not-for-profit service providers (Dalby & Hirdes, 2008). In terms of population size, it was found that the larger the population that an agency served, the greater the decrease in quality (Dalby & Hirdes, 2008). A similar negative correlation was observed for the size of a care manager's caseload (Dalby & Hirdes, 2008). Dalby and Hirdes (2008) noted the

importance of smaller caseload size as it relates to quality of care and that these results match that of anecdotal information provided by home care agencies. This suggests that the ability of case-managers to ensure continuous care and collaboration among everyone involved in the care of PLWD decreases as the number of people they are responsible for increases.

### **1.3 Current Home Care Climate in Ontario**

With the majority of Canadians wishing to stay at home for as long as possible and the prevalence of dementia expected to nearly double in the next few decades, it is important to look into the current climate of Ontario's home care system (Ministry of Health and Long-Term Care, 2016). Home care in Ontario has seen many changes in the past 20 years. This can be seen through the changes of access points to the system, with 43 Community Care Access Centres (CCACs) being amalgamated into 14 CCACs in 2006, and those eventually being transitioned into the current 14 Local Health Integration Networks (LHINs) in 2017 (Home Care Ontario, 2018; Ward-Griffin et al., 2012; Zeytinoglu et al., 2009). Currently, Ontario's healthcare system is undergoing more transformations as the 14 LHINs have been transitioned into 29 local Ontario Health Teams (Government of Ontario, 2020). Ontario's delivery of home care services ultimately changed from a non-competitive system to a market-modelled competitive system where both not-for-profit and for-profit home care organizations have to compete to secure contracts that allow the delivery of services (Zeytinoglu et al., 2009). This market-modelled system has many negative impacts on home care today.

Home and community care services are often cited as being fragmented and available through various access points, which may differ in their eligibility criteria, costs and funding (Expert Group on Home & Community Care, 2015; Maxwell et al., 2013; Sinha, 2016; Steele Gray et al., 2014; Storch et al., 2014). Additionally, many sources emphasize that Ontario's publicly funded home care is meant to complement, but not replace the care that is provided to individuals by informal caregivers (Home Care Ontario, 2017, 2018; A Martin-Matthews et al., 2012; Morton-Chang et al., 2016b; Sinha, 2016; Ward-Griffin et al., 2012). The Ontario healthcare system relies heavily on informal caregivers for PLWD, who provide up to 75% more hours of care than family caregivers of people without dementia (Ministry of Health and Long-Term Care, 2016).



However, the long-term health and care needs of PLWD often become beyond the care their informal caregivers can provide (Home Care Ontario, 2017). This leads to a reliance on formal caregivers, with personal support workers (PSW) playing a significant role in delivering home care in Ontario (Kalenteridis, 2017).

From 2015-2016, approximately 729,000 Ontarians received publicly funded home care services (Home Care Ontario, 2017). This resulted in approximately 28.6 million hours of home care per year purchased by the Ministry of Health and Long-Term Care and another 20 million hours purchased privately (Steele Gray et al., 2014). Publicly funded home care services in Ontario include medical, nursing, social, or therapeutic treatment or assistance with essential activities of daily living, and does not include assistance with instrumental activities, such as meal preparation and housework (Home Care Ontario, 2017; Ward-Griffin et al., 2012). The Ontario government allocates approximately 5% of Ontario's total health care budget towards home care (Home Care Ontario, 2018). Several sources argue that this creates a home care system that is underfunded and does not align with policy attempts to allow people to remain at home (Home Care Ontario, 2018; A Martin-Matthews et al., 2012; Anne Martin-Matthews & Sims-Gould, 2008; Sinha, 2016; Storch et al., 2014). In one of their reports, Home Care Ontario (2018) noted that, "this under investment in a vital pillar of Ontario's health care system has meant a rationing of care and growing wait lists, professional caregivers doing more with fewer resources which leads to burnout, and a lesser patient experience" (pg. 5). Clearly the quantity of resources available to the home care sector has the ability to affect the quality of care being provided to individuals who access it, including PLWD in the community.

The importance of home care appears to be taken for granted in Ontario's current system of individuals wanting and needing home care services. However, government funding for home care is not sufficient to deliver proper and quality care for everyone (Home Care Ontario, 2018; Sinha, 2016). While much is known about how the system has gotten to where it is and the issues that are currently taking place, less is known about how the climate of home care directly affects PLWD specifically, as well as PSW, who provide the most direct care, following family caregivers.

#### **1.4 Problems Facing Home Care PSW Related to Policies**

In Ontario, PSW make up the largest healthcare workforce (Zagrodney & Saks, 2017) and, as was mentioned previously, provide a significant amount of home care for PLWD. Given their significant role, there is extensive research on the problems and issues that PSW within the home care system experience (Berta et al., 2013; Gilster et al., 2018; Kalenteridis, 2017; Sayin et al., 2018; Sims-Gould et al., 2010; Snayde & Moriarty, 2008; Steinmetz et al., 2014; Torres, 2011; Warshaw & Bragg, 2014; Zeytinoglu et al., 2009; Zeytinoglu & Denton, 2005). Challenges have arisen for Canadian home care PSW during home care restructuring and the addition of related policies for PSW (Zeytinoglu et al., 2009). Examples of these challenges include role boundaries, factors that influence what PSW do (Berta et al., 2013), casualized employment (Zeytinoglu et al., 2009; Zeytinoglu & Denton, 2005), decreased job satisfaction, occupational health problems (Zeytinoglu & Denton, 2005), and recruitment and retention issues (Gilster et al., 2018; Joint CCAC/Service Provider Association Committee, 2008; Kalenteridis, 2017; Sims-Gould et al., 2010; Snayde & Moriarty, 2008; Torres, 2011; Warshaw & Bragg, 2014; Zeytinoglu & Denton, 2005).

When examining the evolving roles that PSW have in the context of Canada's home care system, Berta et al. (2013) found that one of the increasingly prevalent challenges PSW faced was role boundaries. Role boundaries are increasingly defined by employers of PSW as a way to ensure PSW spend their time effectively and efficiently (Berta et al., 2013). This includes doing tasks outlined in a care plan and not being relied upon for "extra-role behaviours" or completing additional tasks requested by the client (Berta et al., 2013). This concept was echoed by Martin-Matthews and Sims-Gould, regarding workers needing to provide intimate care at an emotional distance to avoid crossing any role boundary (Anne Martin-Matthews & Sims-Gould, 2008). Additionally, limiting factors that can constrain PSW choice of whether they work in home care or the long-term care sector include market-level differences such as barriers to enter a certain sector and different wages, job mobility, and work structure (Berta et al., 2013; Kalenteridis, 2017; Lilly, 2008).

The elements of casualized employment also appear to be a barrier for PSW working within the home care system as it ultimately results in decreased job satisfaction

(Zagrodney & Saks, 2017; Zeytinoglu et al., 2009; Zeytinoglu & Denton, 2005). Zeytinoglu and colleagues (2009) explored the effects of casualized employment on home care workers' turnover intention within the context of the Ontarian home care system. The findings suggest that casualized employment (especially elements such as casual hours, being on-call, split-shifts, and being paid per visit) leads to decreased job satisfaction and increased turnover intention (Zeytinoglu et al., 2009). This has implications for both employers and home care users as it can affect the continuity of care (Zagrodney & Saks, 2017).

Similar findings resulted from Zeytinoglu and Denton's (2005) attempt to help health system managers and policy makers develop strategies to keep this workforce healthy and satisfied. This document also listed that occupational health was another problem face by PSW (Zeytinoglu & Denton, 2005). Workers reported levels of stress and physical health problems including musculoskeletal disorders at higher rates than the average Canadian. The authors mention that within their study, many of these illnesses were related directly to the work environment (Zeytinoglu & Denton, 2005). Thus, policies affecting the work environment of PSW can impact their mental and physical health, which can ultimately affect the quality of care they provide.

Finally, several sources mention issues surrounding recruitment and retention having great impacts on this workforce (Joint CCAC/Service Provider Association Committee, 2008; Storch et al., 2014; Torres, 2011; Zagrodney & Saks, 2017; Zeytinoglu & Denton, 2005). Several factors contribute to retention problems within this workforce including low wages (Gilster et al., 2018; Kalenteridis, 2017; Torres, 2011; Warshaw & Bragg, 2014; Zagrodney & Saks, 2017; Zeytinoglu & Denton, 2005), lack of resources within the home care sector (Storch et al., 2014; Zeytinoglu & Denton, 2005), government budget cuts (Zeytinoglu & Denton, 2005), lack of support (D'Astous et al., 2019; Gilster et al., 2018; Snayde & Moriarty, 2008; Zagrodney & Saks, 2017), lack of recognition (Kalenteridis, 2017; Zagrodney & Saks, 2017), lack of training (D'Astous et al., 2019; Gilster et al., 2018; Sims-Gould et al., 2010; Snayde & Moriarty, 2008; Storch et al., 2014; Warshaw & Bragg, 2014; Zagrodney & Saks, 2017) and work intensification (Sayin et al., 2018; Torres, 2011; Zeytinoglu & Denton, 2005). The Joint CCAC (2008) discussion paper on *Addressing the Health Human Resource Challenge from a Home and*

*Community Perspective* notes, that despite the government of Ontario launching several initiatives to recruit health practitioners, most efforts have been toward shortages in the acute care sector, with little attention to home care. These staff shortages threaten the capacity to provide effective quality care to an aging population with increasingly complex needs (Storch et al., 2014). With the significant reliance that the home care sector places on PSW providing care, these challenges they face raise questions regarding sustainability.

Clearly policy changes can have significant impacts on the experiences of PSW working within home care. The health system restructuring that occurred in Ontario in the 1990s came with several challenges that PSW within the home care system have needed to face (Zeytinoglu et al., 2009). The precarious work conditions that challenge many PSW need to be addressed to ensure the long-term sustainability of Ontario's healthcare system (D'Astous et al., 2019; Kalenteridis, 2017; Zagrodny & Saks, 2017).

### **1.5 Personal Support Worker Perspectives**

This section describes the perspectives that PSW have in providing home care. These perspectives often note challenges that PSW face when providing quality care. Some of the most cited challenges include the lack of resources and need for more information and training (Cook, 2017; Low et al., 2013; Anne Martin-Matthews & Sims-Gould, 2008; Roelands et al., 2005; Sinha, 2016; Storch et al., 2014; Ward-Griffin et al., 2012).

There have been substantial reductions in the provision of home care services, despite the growing desire to have people age at home and the proven cost-effectiveness of home care (Anne Martin-Matthews & Sims-Gould, 2008; Sinha, 2016; Storch et al., 2014; Ward-Griffin et al., 2012). These reductions have led to the use of efficiencies and trying to do more with fewer resources (Storch et al., 2014). However, PSW have continuously identified that lack of resources and support have created a precarious work environment for PSW in the home care sector. They also feel that the limited resources have created challenges involving timing and scheduling (Jansen et al., 2009; Anne Martin-Matthews & Sims-Gould, 2008; Ward-Griffin et al., 2012) and have led to unintended consequences such as lowered quality of care (Jansen et al., 2009; Steele Gray et al., 2014; Storch et al., 2014).

Another concern of PSW is needing more information and training to increase the

quality of the care they provide (Cook, 2017; Jansen et al., 2009; Low et al., 2013; Roelands et al., 2005; Storch et al., 2014; Wojtak & Klopp, 2015). PSW often felt that they did not receive enough information about new clients which ultimately affected their ability to be prepared for providing care and to be sensitive to the needs of the client and their family (Denton et al., 2002; Roelands et al., 2005; Storch et al., 2014). PSW have also recognized that they have a sense that sharing information regarding client needs between each other is not always sanctioned, further noting that this kind of teamwork might increase quality of care because it would support the sharing of individualized best practices for clients (Ryan et al., 2004; Snayde & Moriarty, 2008; Storch et al., 2014).

PSW have also identified a need for better training opportunities to increase knowledge in areas such as dementia-specific care and interpersonal communication (Cook, 2017; Jansen et al., 2009; Low et al., 2013; Morton-Chang et al., 2016b; Storch et al., 2014; Wojtak & Klopp, 2015). Dementia-specific training can help provide adequate care for the management of dementia and help in creating individualized and tailored care plans (Low et al., 2013; Morton-Chang et al., 2016a; Sinha, 2016). Interpersonal communication is also an important element that PSW feel they need better training in (Storch et al., 2014; Wojtak & Klopp, 2015). Having person-centred conversations that are focused on what matters most to clients is a critical aspect to the overall care experience (Wojtak & Klopp, 2015). Thus, having proper and comprehensive training can help empower PSW to provide quality dementia home care to their clients. The existing literature on PSW perspectives gives a good foundation on some of the challenges home care workers face. However, there are gaps in the literature that explores home care PSW perspectives surrounding providing home care specifically to PLWD in Ontario.

## **1.6 Aims of the Study and Research Questions**

Understanding PSW perceptions of quality dementia home care is important given the rise in prevalence of dementia that is expected in the near future (Ministry of Health and Long-Term Care, 2016). Ontario needs a sustainable healthcare system that can effectively and efficiently provide quality dementia care. It is important to listen to and analyze what formal caregivers, such as PSW, have experienced since it provides the opportunity to show what is working within the home care system and what needs to be

improved upon. Further, the policies that guide the ability of PSW to provide quality home care for PLWD can have great impacts on the care provided. This study provides the opportunity to contribute to the limited amount of research on formal caregiver perspectives of quality dementia home care, especially in relation to how the implementation of Ontario home care policy documents impact the provision of quality home care for PLWD in the community. The aims of this study are (1) to explore how quality home care for PLWD is presented in current Ontario home care policies; (2) to compare them to the perspectives of PSW; and (3) compare the understandings of quality dementia home from the policy documents and PSW to Health Quality Ontario's quality standards for dementia care for people living in the community. The outcomes will highlight the extent to which policies regarding quality dementia home care provision align with the perspectives held by PSW and Health Quality Ontario's quality standards. The following are the primary research questions for this study.

***PSW Perspectives:***

RQ1: What are PSW perceptions of quality home care for individuals diagnosed with dementia?

***Policy Documents:***

RQ2: What is discussed in Ontario policies regarding quality home care provision for PLWD?

***Comparison of PSW Perspectives with Policy Documents:***

RQ3: Do the policies regarding quality home care provision align with PSW perspectives on the provision of quality home care for PLWD?

## **Chapter 2: Method**

### **2.1 Study Design**

This research utilized an interpretivist study framework to capture the multiple realities of PSW involved in the delivery of quality home care for individuals living with dementia. Interpretivism assumes that multiple forms of reality can exist and are socially constructed from experiences (Hsieh & Shannon, 2005; Lincoln & Guba, 1994). A relativist ontology was utilized, meaning that reality is socially constructed through unique life experiences, subjective and may change (Levers, 2013; Wahyuni, 2012). An epistemology of subjectivism proposes that meanings and motivating actions are subjective to individuals because of diverse backgrounds, personal assumptions and experiences (Wahyuni, 2012). A qualitative content analysis method was used to conduct this research and achieve its objectives. According to Hsieh and Shannon (2005), qualitative content analysis is defined as, “a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (pg. 1278).

### **2.2 Qualitative Content Analysis**

Qualitative content analysis is a research method used to analyze text with focus on the contextual meaning of the text (Hsieh & Shannon, 2005). Content analysis is based in interpretivism and found in the naturalistic paradigm (Cho et al., 2014; Lincoln & Guba, 1994). With the flexibility that qualitative content analysis allows, the ontological assumptions of content analysis are open and vary depending on the researchers' standpoint in research (i.e., this research took a more interpretivist point of view) (Ulla H. Graneheim et al., 2017). According to Graneheim, Lindgren and Lundman (2017), “the epistemological basis of qualitative content analysis is that data and interpretation are co-creations of the interviewee and the interviewer, and interpretation during the analysis phase is a co-creation of the researcher and the text” (pg. 29). Qualitative content analysis can be used on all types of written texts and is a useful method when a variety of data is analyzed, ultimately allowing for the reduction of a phenomenon into defined categories, which improves the interpretation of them (Bengtsson, 2016; Cho et al., 2014; Mayring, 2014; White & Marsh, 2006). Hsieh and Shannon (2005) note, “research using qualitative

content analysis focuses on the characteristics of language as communication with attention to the content or contextual meaning of the text” (pg. 1278). These points align with the goals and questions of the research project as a variety of data was collected and analyzed, for example, the text of the policies and the text of the interviews with PSW. Unlike quantitative content analysis, qualitative content analysis takes a hermeneutic approach, is considered to be more holistic and does not need a testable hypothesis (Cho et al., 2014; White & Marsh, 2006). This approach means that an iterative process is utilized for “recontextualizing, reinterpreting, and redefining the research” (White & Marsh, pg. 34) throughout the entire research process. This iterative process was continuous throughout the research project and was useful in the interpretation of meanings from the data as well as the interpretations of the comparison between the two sources of data. For example, the policy documents were revisited when the decision was made to separate the categories for dementia-specific training for health care providers and having an interprofessional care dementia team. Since the interpretive process is essential to content analysis, this method can be very flexible (Cho et al., 2014; Ulla H. Graneheim et al., 2017; Mayring, 2014; White & Marsh, 2006). As mentioned in White and Marsh (2006), the objective of qualitative content analysis is, “to capture the meanings, emphasis, and themes of messages and to understand the organization and process of how they are presented” (pg. 35). The coding process of qualitative content analysis is subjective and the researcher needs to check continuously the interpretation of answers to research questions against all of the data (Cho et al., 2014; Mayring, 2014; White & Marsh, 2006). This process of continuous checking was useful in identifying meanings found in the data sets and was helpful in determining if there are gaps in the available policies as they pertain to the experiences of PSW.

## **2.3 Provincial Policy Documents**

### **2.3.1 Search Strategy:**

After consultation with a research librarian, a basic search was completed of the Canadian Public Policy Collection, Canadian Health Research Collection, Ontario Ministry of Health and Long-Term Care website, Health Quality Ontario website, the Home Care Ontario website and Google. Search terms were used to gather policy



documents that were most relevant to the study. Search terms included (“home care” OR community care AND Ontario), (“home care” OR community care AND dementia AND Ontario), (“home care” OR community care AND dementia OR “dementia care” AND Ontario) (“home care” OR community care AND dementia AND Ontario OR Ministry of Health and Long-Term Care).

### **2.3.2 Scope of the Policy Documents:**

For the purpose of this research, a policy identifies the guidelines created to guide decision-making in the provision of home care to those living with dementia in Ontario. Policy documents provide written direction to policy makers and other stakeholders on the application and implementation of policies as they pertain to Ontario home care and those living with dementia. These include policies, discussion papers, and reports created by Government of Ontario bodies such as the Ministry of Health and Long-Term Care. Documents created by organizations such as Home Care Ontario were also included because they provide commentary on the actual implementation of policies and may provide better insight as to what people working within Ontario’s home care system experience. Policy documents included are from 2015 (the year that marked the most recent major Ontario health care policy, *Patients First*) to any health policies that have been created up until 2019. After reading through several documents, the following policy documents were chosen because of their relevance to the study:

- Patients First: Action Plan for Health Care (2015)
- Patients First: A Roadmap to Strengthen Home & Community Care (2015)
- Developing Ontario’s Dementia Strategy: A Discussion Paper (2016)
- The Expert Group – Bringing Care Home (2015)
- Home Care Ontario - More Home Care for Me and You: Preparing Ontario’s Home Care System for the Challenges of Tomorrow (2018)
- Home Care Ontario – Dementia and Home Care: Advice on Ontario’s Dementia Strategy (2017)

## **2.4 Participants**

Ethics approval for the current study was obtained from Western University’s Ethics Board (HSREB project ID: 114109; see Appendix A). Participants were given a letter of

information and consent (Appendix B) to read and sign prior to the interview. Interview participants consisted of 15 PSW who were employed to provide home care in various locations across Ontario. Eligibility criteria for participating in this study included: age 18 years or older; ability to speak and understand English; employed as a PSW or health care aide within Ontario; employed to provide home care; having a minimum of 6 months experience providing home care to PLWD; and consenting to having the interview audio-recorded.

Participants were recruited through the use of a poster with study information. This poster was posted on social media (the Sam Katz Community Health and Aging Research Unit's Twitter page) and emailed to various home care organizations in the London region. Home care organizations were sent an email with study details that could be distributed to PSW working within the organizations. Potential participants used the contact information on the poster to express interest and a telephone call was completed to outline further the goals of the study and to determine eligibility. Sixteen potential participants expressed interest in the study, with fifteen participants meeting the eligibility criteria.

Interviews were semi-structured and in-depth, with the average length of the interviews being around 68 minutes (range: 28-117 minutes). In-depth interviews meant that the interviewer (RB) was able to generate a rich understanding of participant perceptions of quality dementia home care through probing for additional information and ensuring each participant had nothing else to add by the end of their interview. Interviews were conducted from November 2019 to March 2020 and were completed in-person (n=8), via telephone (n=6) and via video conferencing (n=1). Questions were based on an interview guide (Appendix C) and focused on the PSW perspectives on providing quality home care for individuals living with dementia. Participants were first asked about their experiences providing home care to PLWD and then were asked questions surrounding their perspectives on quality dementia home care. Major topics of interest pertained to how participants defined quality dementia home care as well as enablers and challenges they perceive in the provision of quality care.

## **2.5 Process of Interpretation**

### **2.5.1 Process of Policy Document Interpretation**

The process of interpreting the policy documents began in September 2019, before the interviews took place. Prior (2003) notes that documents, including policy documents, are produced in social settings and need to be considered in terms of their context (as cited in Owen, 2014). Therefore, the context and background of the policy documents was important to understand before beginning to analyze the policy. Once the context of each document was understood, the category definition process began (Mayring, 2014; Owen, 2014) through references and was used to select relevant material from the documents and become familiar with the documents (Mayring, 2014). This process was ultimately informed by the research questions related to exploring how quality of formal dementia care at home is conceptualized in policy documents. Therefore, material that was related to aspects of quality dementia home care, quality home care, or quality dementia care was included in the category definition and analyzed further.

Along with category definition, the primary researcher (RB) became immersed and familiar with the data by reading the material line by line several times (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Mayring, 2014; Vaismoradi et al., 2013; White & Marsh, 2006), as well as using NVivo 12 to identify and explore recurrent words and themes (Hsieh & Shannon, 2005; White & Marsh, 2006). Using NVivo 12, a word query was performed and identified recurrent words or themes such as home, health, dementia, services, community, family, people, and support. Immersing and being familiar with the data, including recurrent words, is very important for the researcher to get a sense of the big picture and the entire body of the documents (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Vaismoradi et al., 2013; White & Marsh, 2006). An inductive method to content analysis was used to allow the categories to be created directly from the documents (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Mayring, 2014). To ensure this, the process of open-coding is recommended (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Mayring, 2014; Vaismoradi et al., 2013). Open-coding was completed by writing down notes and headings in the margins of the documents while reading them (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Owen, 2014). The goal of this step was to write down as many headings as necessary to describe how the policy documents

discussed quality dementia home care (Elo & Kyngäs, 2008). After this step, the headings were grouped together and separated into similar or dissimilar categories (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Mayring, 2014; Vaismoradi et al., 2013; White & Marsh, 2006). This process involved constant comparison and interpretation as to what items belong in the same category (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Vaismoradi et al., 2013; White & Marsh, 2006). It ensured that no data fit into more than one group, resulting in the categories being internally homogeneous and externally heterogeneous (Bengtsson, 2016). This abstraction process of putting items into higher-order categories continued until the researcher has reasonably answered her/his research question (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Mayring, 2014). In the case of this research, codes were organized into sub-categories, categories and main categories. The abstraction process resulted in 5 main categories being created.

### **2.5.2 Process of Interview Interpretation**

The process of interpretation for the interviews began in December 2019 and occurred simultaneously with the data collection process. Overall, the process of interpretation for the interviews was similar to the process for the policy documents, since as soon as the interviews were transcribed, they are considered to be documents (Mayring, 2014; Owen, 2014). The category definition process then was applied to the interview transcripts by the primary researcher (RB) (Mayring, 2014). However, because the interviews were semi-structured and focused on exploring the perspectives of PSW in providing quality home care for individuals with dementia, a higher proportion of the data collected in the interviews was considered related to the category definition.

Similar to the policy analysis, the researcher became familiar and immersed herself in the data. This was facilitated through the primary researcher (RB) performing the transcribing procedure (Bengtsson, 2016), reading the transcripts several times, and using NVivo 12 to explore recurrent words. The NVivo 12 word frequency query identified several recurrent words such as dementia, people, home, family, time, client and quality. For the interview transcripts, the manifest content was taken into consideration during analysis. Manifest content refers to the informants' words and describes the visible text (Bengtsson, 2016; Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Vaismoradi et al., 2013). The open-coding and abstraction steps of the analysis

were completed in a similar way as the process for the policy documents. The abstraction process resulted in 6 main categories being created.

## **2.6 Establishing Trustworthiness**

Establishing trustworthiness in this study included the following elements: credibility, dependability, transferability, and authenticity (Elo & Kyngäs, 2008; Elo, Satu et al., 2014; Ulla Hallgren Graneheim & Lundman, 2004; White & Marsh, 2006).

Credibility is measured by whether the data and process of analysis address the intended focus of the research (Ulla Hallgren Graneheim & Lundman, 2004; White & Marsh, 2006). In qualitative content analysis, this means providing a detailed description of the analysis process and looking at how well the categories reflect and cover the data (Elo & Kyngäs, 2008; Elo, Satu et al., 2014). Findings from analysis of all interviews as well as the analysis of the policy documents were also shared and continuously discussed with the research investigator's supervisor to ensure agreement was established based on the findings (Bengtsson, 2016). Another way to increase credibility is to include any information on the participants' recognition of the research (Bengtsson, 2016; Elo, Satu et al., 2014; Ulla Hallgren Graneheim & Lundman, 2004). This was completed through member checking. Member checking included the interviewer restating participants' responses throughout and at the end of each interview, to achieve an accurate understanding of what was said. It also included sharing a summary of interview data at the end of the analysis process and setting up a member checking meeting to assess if the summary reflected participants' views, feelings, and experiences. All participants were emailed about their interest in participating in the member checking process, with eleven participants replying and expressing their interest. The eleven participants who took part in the member checking process reported that the findings of this study aligned with their perspectives on quality dementia home care and noted that no changes needed to be made.

Dependability can be measured by the degree of stability of data over time and under various conditions (Elo, Satu et al., 2014). To increase the stability, the coding process was completed repeatedly throughout the entire research process (Bengtsson, 2016). Also, to increase dependability of research it is important to consistently make judgments about similarities and differences over the entire research process (Ulla

Hallgren Graneheim & Lundman, 2004). To ensure dependability and stability, notes were kept about decisions that were made throughout the research process, including reflexive notes and notes about the analysis process of the interviews and policy documents. An open-dialogue was kept with the thesis supervisor and insights were shared with members of the CARE Lab (<https://www.uwo.ca/fhs/care/>) to receive feedback as the analysis process was completed (Ulla Hallgren Graneheim & Lundman, 2004).

Transferability is the extent that findings can be transferred to other groups or settings, and ultimately, it is the reader's decision about whether the results are transferable or not (Elo, Satu et al., 2014; Ulla Hallgren Graneheim & Lundman, 2004). To facilitate transferability, it is important to provide clear descriptions of the research process, including context, characteristics of participants, data collection and process of analysis (Elo & Kyngäs, 2008; Elo, Satu et al., 2014; Ulla Hallgren Graneheim & Lundman, 2004). Transferability can also be facilitated by providing findings along with appropriate quotations and a figure that shows an overview of the whole result, which will be shown in the results section (Elo, Satu et al., 2014; Ulla Hallgren Graneheim & Lundman, 2004).

Finally, authenticity refers to the degree that the researchers reasonably show a range of realities (Elo, Satu et al., 2014). Authenticity can be enhanced by continuous and ongoing self-reflection by the researcher (Elo, Satu et al., 2014). With the inductive nature of qualitative content analysis, and through the iterative process mentioned above, self-reflexivity was an important part of this research project. Reflexivity was present throughout the research process, beginning at the pre-research stage where personal preconceptions were examined, during the literature review to see how the existing literature impacted any personal perceptions, and finally self-reflective processes such as memo and note writing (see Appendix D for sample of self-reflection notes) and self-conversations were ongoing (Finlay, 2002) and helped in establishing trustworthiness throughout the study (Cho et al., 2014; Elo, Satu et al., 2014; Ulla Hallgren Graneheim & Lundman, 2004). Another way authenticity was increased was the use of quotations from the interviews and policy documents to facilitate the readers' understanding of where the categories are coming from (Elo & Kyngäs, 2008).

## Chapter 3: Results

This chapter will present the results from the analyses of the interviews with PSW, and the policy documents on their discussions of quality dementia home care. The chapter will conclude with a discussion on the comparisons between the perceptions PSW have on quality dementia home care and how quality dementia home care is described within the policy documents.

### 3.1 Description of the Sample

Interview participants consisted of fifteen PSW employed to provide home care in Ontario (see Table 1). Demographic information about the participants was collected through the Demographic Information Data Collection Tool (Appendix E). All participants were female, except for one male participant. The average age of participants was 52 years. Participants were a mix of PSW who were employed by various home care organizations (n=11) and PSW who were employed to provide private home care to clients (n=4). Seven of the participants provided home care as employees of an organization that is a for-profit corporation. One participant was employed by another organization which is a registered charity and not-for-profit corporation. One participant provided home care as an employee of an organization which is considered a not-for-profit social enterprise. Finally, two participants were employed to provide home care with another organization which is a privately owned corporation. The PSW experience levels varied in terms of the length of time they have provided home care (<1 year [n=2], 1-5 years [n=6], 5-10 years [n=3], >10 years [n=4]), with an average work experience of 7.5 years. The length of time they have been providing home care to PLWD (<1 year [n=2], 1-5 years [n=6], 5-10 years [n=3], >10 years [n=4]), with an average experience of 7.5 years. Overall, this sample reflects the average PSW in Ontario. Most PSW in Ontario are female, have an average age of 49 years, and have an average work experience of 9 years (Denton et al., 2018).

**Table 1***Participant Demographics (N = 15)*

<b>Category</b>	<b>Total (%)</b>
<b>Sex</b>	
Men	1 (6.7)
Women	14 (93.3)
<b>Length of Time Providing Home Care</b>	
<1 year	2 (13.3)
1-5 years	6 (40)
5-10 years	3 (20)
>10 years	4 (26.7)
<b>Length of Time Providing Home Care to PLWD</b>	
<1 year	2 (13.3)
1-5 years	6 (40)
5-10 years	3 (20)
>10 years	4 (26.7)
<b>Home Care Organization</b>	
For-profit corporation	7 (46.6)
Privately owned corporation	2 (13.3)
Not-for-profit social enterprise	1 (6.7)
Registered charity and not-for-profit corporation	1 (6.7)
Private care to client	4 (26.7)

The provincial policy documents that were analyzed included six documents that were created to inform policies regarding the provision of home care for Ontarians living with dementia. Policy documents and discussion papers created by the Ministry of Health and Long-Term Care were included and analyzed. Additionally, documents created by organizations such as Home Care Ontario were also included in the analysis because of the commentary they provide on the implementation of policies. The documents ranged in length from 16-64 pages, with the average length of 32 pages.

### **3.2 PSW Perspectives on Quality Dementia Home Care**

The analysis of the fifteen interviews with PSW resulted in the creation of six main categories that describe what the PSW perceive as necessary for the provision of quality home care for individuals living with dementia. Findings from the study indicated that (1) care for PLWD needs to be person-centred; (2) PSW need dementia-specific training and education that involves hands-on experience; (3) there needs to be an inclusive dementia care team that encourages open communication; (4) specific PSW experiences, abilities



and characteristics can help them provide quality care; (5) home care information, services and education need to be accessible to PLWD and their caregivers; and (6) improvements need to be made in the way employers respect and support home care PSW. Each of these main categories were composed of sub-categories, as described in Table 2.

**Table 2**

*Summary of findings from the interview analysis.*

<b>Main Categories</b>	<b>Subcategories</b>
1) Care for PLWD Needs to be Person-Centred	1) Individualized Care 2) Person-Centred Communication 3) Building Trusting Relationships 4) Consistent Care Provider 5) Time-Limited/Task-Focused Care 6) Safe Living Environment
2) PSW Need Dementia-Specific Education and Training that Involves Hands-On Experience	1) Dementia-Specific Education and Training 2) Training with Hands-On Experience with Dementia
3) An Inclusive Dementia Care Team Encouraging Open Communication	1) Cross-Collaboration Between an Interprofessional Care Team and Family Caregiver 2) Communication Among All Team Members
4) Specific Experiences, Abilities, and Characteristics can Help PSW Provide Quality Care	1) Informal and Formal Caregiving Experiences 2) Ability to be Adaptable and Practice Self-Care 3) Being Compassionate and Passionate
5) Accessible Information, Services, and Education to Support PLWD and their Family Caregivers	1) Access to Information and Care Services 2) Support for Family Caregivers 3) Education and Training for PLWD and their Family Caregivers
6) Improvements Need to be Made in the Way Employers Respect and Support Home Care PSW	1) PSW are Not Respected 2) PSW Need to be Supported

### **3.2.1 Care for PLWD Needs to be Person-Centred**

The first major category describing quality dementia home care was the need for person-centred care. It is comprised of six subcategories from the PSW interviews including: (1) individualized care; (2) person-centred communication; (3) building of trusting relationships; (4) consistent care provider; (5) time-limited and task-focused care provision; and (6) safe living environment.

#### **3.2.1.1 Individualized care**

Participants reported that care needs to be individualized and focused on each client with dementia. Statements such as “the client is the number one focus” (PSW12) and how PSW “need to consider the client” (PSW11) demonstrate that participants understand the need to recognize that every client is different and that they “can’t treat all of them the same” (PSW15). This recognition of differences between clients is essential for PSW to “individualize each person” (PSW14) while providing care.

Related to providing individualized care was the need for PSW to “really get to know” (PSW15) their clients with dementia. For participants, getting to know their clients was an important factor of quality and person-centred care because it let them know the individual in a holistic way. One participant demonstrated this by stating, “so, for myself, quality care starts with the care plan, and digging down to the root. Knowing the individual as a whole, holistically, as a part of the family, everything. It’s knowing everything you can know about each client” (PSW12). Another participant mentioned, “we do understand what he or she likes and what [they] did like and even what they don’t like. We need to know as much as possible about their past and present” (PSW03). Participants stated that getting to know their clients as much as possible meant that they could then deliver individualized care based on the life history and preferences of the client with dementia. Importantly, participants stated that the information about a client’s life history and preferences can be used in engaging PLWD in meaningful activities. Specifically, PLWD need to be engaged in meaningful activities they enjoy:

You know, because if you can find something like they really like. Some like the really old movies. Some like the, uh, the old game shows. Some like, like the Lavern and Shirley, and whatever else was there in the, in the 70s. And it just, you

gotta try different things. And anything that will get their interest is a win.  
(PSW02)

Another important factor of individualized care that considers clients' preferences highlighted by participants was that care needs to "complement their schedule, not just other schedules. Complement their schedule" (PSW05). The connection between scheduling times that work for clients and quality care is especially demonstrated by PSW11: "at six o'clock in the morning and dragging them into the bathtub, is not quality care. Because it's your schedule, not theirs." Importantly, all of the PSW who provided private care to clients with dementia reported that they can easily complement their clients' schedules because they have the ability to create their own schedules throughout the week. Further, this ability meant that participants providing private care could also easily stay consistent with their clients and get to know their clients very well. Participants reported that getting to know their clients with dementia as much as possible was essential for quality care provision.

### **3.2.1.2 Person-centred Communication**

The next element of person-centred care that participants described was the use of effective communication with their clients with dementia. For participants, communication needed to involve being person-centred because "the way you talk to them, makes a difference" (PSW04). Person-centred communication for participants involved avoiding patronizing communication, as indicated by PSW10: "and people have to understand that, just because they have dementia, they're not a kid. Don't talk to them like a kid. Talk to them like an adult". Another participant emphasized further the importance of sincerity when asking open-ended questions:

So, when you're busy doing things, it's really not a good communication. So, you're busy doing something, "so what happened, how was your day?" And it is just, doesn't make them feel great, that you know. They probably don't feel, don't feel that you're sincere about wanting to know their story. (PSW09)

Participants also highlighted the importance of observing a person with dementia's non-verbal communication. One participant stated, "she couldn't tell me verbally but her body language and her facial expressions, those are very important to read... We have to pick up on those cues" (PSW11). Another participant stated, "what's the language? What is it

that they are trying to say? You know, so, I guess it's still then goes back to listening to them and, you know, understanding that person" (PSW13). This participant clearly demonstrated the link between knowing a client and understanding the way they communicate non-verbally. Participants also reported that care is enhanced when they can speak the native language of their clients with dementia: "I understand and I just talk back in their own language and I know I can give that way better care because, yeah" (PSW01). Speaking a client's native language is not always an option. In these circumstances, PSW used smartphone solutions such as "whip out your phone and you go to a translator" (PSW13).

### **3.2.1.3 Building Trusting Relationships**

The next element of person-centred care was building close and trusting relationships with clients with dementia. PSW02 expressed that it is important to "[make] sure that they're comfortable with me, before I take any actions on them". PSW07 emphasized further a similar sentiment: "you build a trust; you build a rapport. They trust you. They have faith in you. And you want to maintain that for sure". Another participant similarly mentioned "I think that's part of building that rapport and that relationship. You don't, you won't get cooperation from your dementia client. You have to have a rapport and relationship and they have to like you" (PSW11). Participants also reported that building these trusting relationships could be impacted by their communication and their actions towards clients with dementia. Specifically, the participants noted how PLWD need to be respected to facilitate the building of a trusting relationship. This meant respecting a client's dignity and valuing the person because everybody "still has something to offer" (PSW07). This desire to treat people with respect is especially highlighted by one participant mentioning that "everyone deserves to be treated with respect and dignity, autonomy, and um, empathy and all of those things, and you have to put yourself in their foot, no matter who they are" (PSW02). According to participants, respecting PLWD was a fundamental part to the development of a trusting relationship. Being "a good match" (PSW11) with a client with dementia was another facilitator of building a close relationship that was identified by participants. According to one participant, "trying to find a PSW who is a good match with the same kind of a personality. Um, having somethings in common" (PSW07). Taken together, getting to

know the client and having effective communication with them are valuable in building trusting relationships with clients with dementia.

#### **3.2.1.4 Consistent Care Provider**

Participants identified that consistent care providers for clients with dementia are important for individualized care and relationship building and thus important for the provision of quality person-centred care. This is especially emphasized by one participant:

I think consistency, consistency is huge. Um, because, and, and I'm trying to look at it from the quality care for the dementia clients, whether they remember you or not, it's important for you to know them because then you can provide the quality care because you know, to a point, what makes a person tick? Like I said before, what they dislike, you know what to stay away from. (PSW07)

Another participant stated:

But I could establish trust with her or, or a sort of familiarity, because I went in on a, like once a week basis. And that's, that's good when our company can keep that up. So, keeping just two people going in instead of a constant stream of change. (PSW08)

One participant also mentioned how consistent caregivers was especially important for PLWD because it is “really hard” for PLWD “to have different people coming in and out” (PSW04). Further, some participants reported that having consistent formal caregivers was important for family caregivers. Participants also felt that they should not be the only ones that value consistency and that home care organizations “should concentrate on keeping people regular with their clients” (PSW06). Participants highly valued being kept consistent with their clients, especially those with dementia, and related it to providing quality and person-centred care.

#### **3.2.1.5 Time-Limited and Task-Focused Care Provision**

Many participants stated that quality care for PLWD takes time, and that care needs to have “the right time for the right client” (PSW04). Specifically, “dementia clients and their families need more time, time to adjust” (PSW11) because rushing clients was not seen as quality care. It was made clear that care needs to be done at a client's “speed of understanding versus your speed of requirement” (PSW02) to achieve

person-centredness. However, participants describe the reality of home care being time-limited and task-focused. According to participants, this negatively affects the provision of quality person-centred care. One participant highlighted the priority on tasks by saying, “we just do, please do that, do this, because we have certain limited time usually, right? That means rather uh personal care, focus on physical personal care, not the companionship” (PSW03). Further, the time-limited, task-focused reality has negative impacts on the participants’ ability to engage socially clients with dementia. One participant noted:

You would have more time than you have now. Because some people it takes a long time to get them movin’. And some people, especially if they get seen four times a day, you go in, say a supper time visit, they don’t give you enough time to, they give you enough time to get the food ready, but you don’t have enough time to stay there and make sure they eat all that food. (PSW10)

Participants also often highlighted the importance of socially engaging PLWD by talking with them and taking them into the community. One participant noted, “do the social. So, if you find somebody that’s not eating, it may be because you’re not sitting down and having dinner with them. That’s what can happen with dementia” (PSW11). Another participant highlighted the importance of social engagement by stating:

They’re in the home, they’re isolated. If at all possible, when possible, I’d love to see more individuals getting out of the home and going to some kind of day program or having somebody with them to take them to do something. Let’s go on a walk. Let’s have the time to do this or let’s go to a gardening program. (PSW12)

Participants advocated for an increase in the amount of time given for home care visits and a change in the prioritization of task completion. Contrastingly, the PSW who provided private care to their clients reported that they often have the autonomy to take more time to provide care to clients when it is necessary.

### **3.2.1.6 Safe Living Environment**

Finally, participants reported that a safe living environment for PLWD was an important element for person-centred care. Specifically, PSW discussed that “making sure there is a safe environment. I mean, that’s part of maybe my job” (PSW08).

Participants also mentioned how safety is very important for PLWD and that they need to watch out for “little things, you know, that for safety, it’s hard, ‘cause sometimes they don’t realize” (PSW04). Another common thing related to a safe living environment that participants discussed was a need for “modifications in the home to, to try and accommodate, you know, the changes” (PSW13) and for a home to be “renovated as, as much as you could to help that person out” (PSW14). According to participants, modifications were necessary to keep PLWD living at home for as long as possible. Lastly, while participants mentioned wanting to keep clients with dementia at home for as long as possible, some PSW noted that for safety reasons, clients should have access to long-term care if/when it is needed. One participant demonstrated this by stating, “they decided to send her to one of the retirement homes. And she knew, and she was told that we’re moving her there immediately, um, because she wasn’t safe to be there [at home]” (PSW09).

### **3.2.2 PSW Need Dementia-Specific Training and Education that Involves Hands-On Experience**

The next main category was that PSW need to receive dementia-specific education and training to provide quality dementia home care. Further, participants mentioned that including a hands-on component related to dementia within their education and training would aid in their ability to gain experience with PLWD before in-person care provision.

#### **3.2.2.1 Dementia-Specific Education and Training**

Having general dementia-specific content within their base education and any training they did afterwards was seen as a positive contributor to participants’ ability to provide quality home care for individuals with dementia. One participant reported, “I want to help these people and to help them, then you have to be knowledgeable” (PSW05). This was echoed by another participant who mentioned, “but giving quality care, I think is knowing the client and things about Alzheimer’s and dementia” (PSW07). Some of the participants went into specifics about how dementia-specific education and training could also help PSW recognize and monitor for changes in PLWD. One participant highlighted this by stating, “recognizing those changes to continue to support and meet their ongoing needs and, um, goals and needs” (PSW11). Additionally, some

participants discussed how receiving dementia-specific information can aid them in retaining what PLWD are able to do. One participant discussed knowing how to “engage them to the best of what their abilities still are” (PSW07). Another participant stated, “...to maintain cognitive abilities. So, I will engage in activities that will support their cognition so, puzzles, we might do some physical activities” (PSW11). Dementia-specific education and training for PSW clearly needs to include information about dementia as a disease and information on how to provide care specifically for PLWD.

### **3.2.2.2 Hands-on Experience with Dementia**

Participants also discussed that their formal education and training did not prepare them fully for their work with clients with dementia. One participant demonstrated this in stating, “when you take your PSW [education] there’s not a lot of information on dementia. You know, you get your little pamphlet type of thing, but there’s no real experience with your PSW [education]” (PSW04). Another participant also noted:

‘Cause sometimes most of the training, you face, okay, this is, the, the, somebody with dementia they wander, they get lost, and they forget to eat, forget how to use the bathroom. It mainly focuses on the forgetting part of it. Um, but maybe um, more of the training could face on, um, how to deal with aggressive behavior and um, and, and, so forth. (PSW15)

Participants discussed that this lack of dementia-specific information could be overcome by including hands-on experience with dementia in their formal education and training. Participants noted that working with PLWD is not something that can be learnt “through a book” (PSW12) and that adding elements that promote building or sharing experiences would be beneficial within their formal education and training. One participant highlighted this by stating, “training is just sitting and then reading a book, it’s uh good. But I mean it’s beyond that. We need to share the experience and then share the how I uh did, and it worked or not” (PSW03). Another participant similarly reflected the value of a person-centred interactive training program:

Cause it kind of makes it real and brings it into an actual, having the, in that program, having fake dementia patients, where we had to practice our skills, was excessively valuable. And I would say that’s what needs to be in that base education. (PSW02)



Participants value dementia-specific education and training in providing quality care for people living at home with dementia. However, they reported that their education and training needs improvement, specifically by including more hands-on experience with dementia, to better prepare them for providing quality care.

### **3.2.3 An Inclusive Dementia Care Team Encouraging Open Communication**

The third main category that was created from the analysis of the interviews was the need for an inclusive dementia care team that encourages open communication among all members.

#### **3.2.3.1 Cross-Collaboration Between an Interprofessional Care Team and Family Caregivers**

Participants reported frequently that dementia care needed to be provided by a dementia care team. Importantly, these care teams needed to include all interprofessional care providers and include family members, with the goal of having “everybody on the same boat” (PSW14) for the clients. One participant stated:

I think in home care it’s nice to have, yeah it would be really ideal if you have a dementia team that works with the same goals, and not just like will have to do their work for them and get out. (PSW01)

Similarly, another participant stated:

Yes, that we can all work together, whether you’re a PSW, right up to the, you know, the, the doctor, the nurse practitioner, I would like to think no matter who you are, what educational level you have, what degree you have, that we should be able to talk to each other. (PSW07)

This desire for an interprofessional care team was highlighted by many participants, but some participants emphasized the need to include PSW in interprofessional care teams for PLWD: “I want to be part of that interprofessional care team” (PSW11). Participants often explained that they need to be involved actively in the interprofessional care team because they spend the most time with clients. One participant mentioned:

The LHIN come in, they do their assessment, they leave. They don't see the changes. They don't, they're not with person every day or every week. The only

person that's going to see that is the family members and the PSW. So, ideally the care plan should involve everybody. (PSW11)

However, according to many of the participants, PSW involvement in the care team is not a common occurrence in the home care environment. One participant noted, "myself, I'm not really aware of, myself being on a team" (PSW08). Another participant stated, "there's no team there that I see. There might be in the background, but I don't personally see them. So, I don't see where they're working with me if I don't even have communication with them" (PSW04).

### **3.2.3.2 Communication Among All Care Team**

Similar to there being an interprofessional care team for PLWD, participants reported that quality care involves open communication among everyone caring for a person with dementia. For participants, open communication encompasses communication that was clear, ongoing and allowed everyone to express their thoughts and ideas. PSW specifically talked about the importance of having communication with a client's family members, other health care providers and other PSW providing care. Participants stated that two-way communication with family members is essential to quality dementia home care provision. One participant stated, "that's something that, like for us to provide better care, there's going to have to be a lot more communication with the family, if that's possible, to do as good a job as possible" (PSW08). Another participant mentioned:

And the best thing to do when you walk in, is to talk to family. If there's family there, you want to ask them as much as you can. It doesn't mean that you don't know your job, it means that you want to be prepared and knowledgeable to do your job. (PSW05)

Participants reported that quality care involves sharing notes with family members about the care visit, so that the family members could remain fully informed as well. One participant noted this importance by stating, "having a communication book is also good for the family because they're away at work or, you know, they don't know what goes on during the day. So, if you notice something weird, write it down. Let everybody know that they can read what you said" (PSW07).

Participants stated that quality care included communication with other healthcare providers including assessors from the LHIN, home care managers, and all members of the interprofessional team. This is demonstrated by PSW07: “communication has to be there between the front-line, the managers, the caregivers, and I would say pretty much the rest of the interdisciplinary team, like case managers and stuff.” Another participant stated:

Well, I think it would help because like I could say to the LHIN person, when you plan your visits, these, these are the times I’m there. Can you plan on being there just before or just after our shower? So that I have an extra fifteen minutes that I can be part of the conversation too. (PSW04)

While participants knew that communication among everyone in the care teams is important, they described the reality of home care as not being conducive to this level of open communication. Participants noted that communication needs to be improved and team meetings can help make these improvements. Specifically one participant mentioned, “those lines of communication being kept open or people that interact with each other, to let each other know what’s going on. Like I still feel it needs to be more interdisciplinary” (PSW07). Another participant said:

You think this works better or that? So, I know in the home care, that doesn’t happen really, maybe once a month you have, you have a meeting and, and there’s always rushed, you rush over the clients because they, they want to go home. (PSW01)

Finally, participants discussed the importance for PSW to maintain communication with each other as a way to problem solve when caring for clients with dementia. According to participants, being able to talk with each other helps them to provide quality care to PLWD. One of the participants mentioned, “we’ve tried to feed off each other to see if we can’t come up with a better solution to some of the problems that may have arisen” (PSW07). Another participant noted similarly:

So sometimes they also just have like a lunchtime, um, chat. So, sharing experiences even amongst ourselves as caregivers, you know, also helps because, you never know what you’ll come across. So, you know, sharing those experiences in a session helps. (PSW13)

Having access to other PSW to problem solve collaboratively with each other was not a reality for all of the participants. As one participant mentioned, “I don’t have a lot of access to other personal support workers’ knowledge or opinions in the way that I live and work... I wish that was a little easier to, so that we could actually talk about people” (PSW08). Overall, having an inclusive interprofessional team that collaborates and has open communication with everyone involved in the care of a person living with dementia was viewed by PSW as being immensely valuable in the provision of quality dementia home care.

### **3.2.4 Specific Experiences, Abilities and Characteristics can Help PSW Provide Quality Care**

The next main category that was discussed by participants was that certain experiences, abilities, and characteristics that PSW have can help them provide quality care to PLWD.

#### **3.2.4.1 Informal and Formal Caregiving Experience**

Many participants mentioned that having personal experiences as an informal and formal caregiver can help PSW provide quality dementia care. Many participants discussed having experience caring for a family member or friend with dementia. These experiences helped them gain familiarity with dementia as well as gain an appreciation for working with this group of individuals. This is highlighted by PSW09: “I’ve have had experience at a young age of providing care for a neighbor’s mother, who had Alzheimer’s. I would have been in grade 9 or 10 back then. And then I enjoyed it.” Participants reported that past experience working with PLWD allowed them to provide quality care by making them feel comfortable and enabling them to know how to do tasks efficiently. One participant emphasized this by saying, “now, I’ve been there fifteen, eighteen, I can’t remember, lost track, um, so, I know the quickest way to do things” (PSW04). Another participant noted:

And not to knock anybody that’s just graduated, um, but I find, you know, working with dementia and Alzheimer’s for the many, like the amount of years I have, I do have to say, if you’re not comfortable, and if you’re not experienced, and you don’t know what you’re doing, you should not be in there. (PSW12)

### **3.2.4.2 Ability to be Adaptable and Practice Self-care**

Next, participants cited that quality care involves the ability to be adaptable. This is especially demonstrated by a participant stating, “so, it’s very dynamic and it’s very much about that person in that moment to kind of adjusting their care to what they need in that moment” (PSW02). Another participant stated:

So, it’s very difficult to have one prescription of, you know, this is how you should do. You know, I think it just boils down to having that ability to adapt to what the situation or what that one client demands. (PSW13)

Participants shared that being adaptable could help them problem solve and “think outside the box” (PSW02, PSW12) while providing care. According to participants, having this ability allowed them to overcome any challenges encountered while caring for PLWD. One participant mentioned, “and you just problem solve and go, “okay, well, this is what I can do and this is how I can provide it” (PSW12). Another participant stated, “I think the caregivers have to be creative, you know. You just have to think on your feet, you know” (PSW13). Additionally, participants discussed how the ability to be observant can help them in noticing problems and using the resources around them to create solutions. This was demonstrated by PSW10: “I just walk in and go, okay, I know what to do, because I got taught when you walk in a room, you look at your environment. You assess it first, you figure out what’s safe, what’s not safe.” Participants also noted that observing the environment helps PSW figure out what might trigger a client with dementia. One participant demonstrated this by stating, “but I think you have to have like, um, an extra sense to be able to pick up on certain things that aren’t totally obvious to other people, like, like I said, the body language, the environment. Like just even look around the room and see what, what the environment is like” (PSW07).

Practicing self-care was also described by participants as an ability that helped them continue to provide quality care to PLWD. Participants spoke of the importance of practicing self-care while providing care for PLWD as well as after their shifts. This is highlighted by this participant:

You know, but I just have to step back sometimes and take a deep breath and, you know, I get home, maybe do some self-care after work. Do something just for me,

take care of myself too. If I don't take care of myself, I can't take care of them.  
(PSW07)

The most cited way that participants spoke of practicing self-care was making sure they understood that they are doing the best they can for their clients with dementia. Many participants described the challenges of caring for PLWD, but many also noted that recognizing that they are “doing the very best [they] can” (PSW12) for clients really helped them continue working. One participant noted, “understanding that you are human and you're doing the best you can and taking care of yourself, is really what makes it okay to continue working in the field” (PSW02).

### **3.2.4.3 Being Compassionate and Passionate**

Finally, participants spoke about having characteristics that helped in the provision of quality care, such as being compassionate when providing care and being passionate about providing quality care to PLWD. According to participants, being compassionate was closely linked to providing person-centred care through respecting clients and being truly caring. One participant highlighted the need to be compassionate by stating, “when you approach somebody with dementia they don't know what's going on necessarily. You have to be very gentle and again compassionate” (PSW11). An important part of providing compassionate care was PSW being sympathetic towards their clients with dementia so that they knew when and how to act with compassion. One participant noted, “I try to be um, sympathetic with them, you know. If they're angry, upset, I don't look at the person that is doing it. I tell myself, “oh, that's just the dementia doing that” (PSW15).

Next, participants described that being passionate about providing quality care for their clients and going in with the goal to “make a difference” (PSW09), ultimately aids in the provision of quality dementia home care. One participant mentioned, “yes, alone, we are told, to give you, give the quality care. But it shouldn't be forced, it should be something you want to do” (PSW09). Another participant also said, “we just try our best to, you know, accommodate them. Help them out. You know, yeah. But me, honestly I'm passionate what I'm doing with these people” (PSW14).

### **3.2.5 Accessible Information, Services and Education to Support PLWD and their Family Caregivers**

The fifth major category that emerged was the need for accessible information, services and education to support PLWD and their family caregivers.

#### **3.2.5.1 Access to Information and Home and Community Care Supports**

Participants discussed that the information that needs to be available is about home care services and dementia. First, participants noted that PLWD and their families who do not know information about home care services “were overwhelmed” (PSW14). One of the participants explained, “some people they do not know how to contact to get the support, help. So, sometimes we need to know how you can get good services that resources would be much beneficial for anyone” (PSW03). Another participant mentioned, “having those resources available from, you know the Alzheimer’s Society and being able to know what’s out there in the community that might be useful to the client that, that they can access” (PSW07).

Additionally, participants emphasized that PLWD and their families need access to necessary support services. According to PSW, these supports need to be in place to support people to live at home for as long as possible. This is highlighted by one of the participants:

A lot of them, they live on their own. Which is fine because we have such a great support. And here from home care providers, to many resources. So many home care companies come in. Not just my company you know there’s other agencies come in and take care of all the needs. And it’s just wonderful that, um, how we provide good care in their own home. (PSW09)

While participants discussed the importance of accessible support for PLWD, some also spoke of challenges they have seen clients have in accessing these supports. According to one participant, there needs to be “more open kind of supports” (PSW02) with greater variety of times being available for PLWD and their caregivers to be able to access supports. A participant also spoke of waitlists being a problem, saying that day programs are “very good, but there’s a waiting list for them. So that makes it difficult for families to access right away” (PSW02).

### **3.2.5.2 Family Caregivers Need Support**

Next, many of the participants noted the importance of families in the provision of quality home care for PLWD. This is shown through one of the participants mentioning, “and in the community component, family is big. We’re an extra help for the family. They’re the main. We’re going in the homes, they are the main caregiver. We’re the support” (PSW09). Another participant stated:

And then they’ll have family and friends come in as well sometimes to look after that family member. Which is good, they need to have that somebody else to rely on besides the facility or besides company that they wanted to come in. (PSW05)

However, participants also frequently discussed that family caregivers of PLWD are often “burnt out” (PSW07) and face challenges associated with caregiving. Participants would mention that family caregivers are “frustrated because it’s not a short-term disease” (PSW03) and quite simply “just exhausted” (PSW02). Many participants emphasized that family caregivers need support to help prevent or reduce this burn out. One participant stated that her “goal is to support that caregiver in supporting that person” (PSW02). This notion of supporting the family caregivers is echoed by another participant, who noted, “I think the caregiver needs care as well. Definitely, not just the client, especially in community” (PSW07). Another participant highlighted that PSW could support family caregivers by “[giving] them a word of encouragement” (PSW15). Further, participants discussed that family caregivers need access to services to support them and especially “need a respite” (PSW11).

### **3.2.5.3 Education and Training for PLWD and Family Caregivers**

Finally, participants discussed that PLWD and their caregivers need education and training about dementia, both before and after diagnosis of dementia. Participants felt that the public needs to have a better understanding of dementia for people and family to notice the onset of dementia and to receive an early diagnosis and the appropriate supports, which they noted was important for quality care. This is demonstrated by one participant stating “it is the family, the mild cognitive impairment would be noticed by the caregiver. That’s going to take education” (PSW11). Another participant similarly stated:



They can have like, you know, um, more educational session where people want to know more about dementia. What to look for if you're having early onset of dementia and so forth. So, when you reach a certain stage, you know, you know exactly what to expect. 'Cause the earlier you're educated, the more you'll remember it. (PSW15)

Similarly, many participants emphasized that once there was a diagnosis of dementia, both the person and their family need to receive education to understand dementia. PSW10 described how PLWD should be taught any new information: "they're so used to doing the one thing it's hard to teach them to use the new stuff... But you have to do it gradually." Moreover, many of the participants highlighted that the family needs education and training to provide quality dementia care in the home environment and "understand their role in taking care of that person" (PSW02). One of the participants stated, "if [family] don't receive the training to the same level that a PSW will receive the training, you know. Because they are a PSW, you know? And, they can't run away from that fact" (PSW13). This participant emphasized that family caregivers need to receive a lot of dementia-specific education and training because they need to know how to provide quality care when a PSW cannot be present at the home. Another participant further demonstrated this by saying:

It's not easy understanding to the family members because a lot of the time people go into long-term care, they can't stay at home because the family can't handle it or doesn't understand what they need to do. So, educate the family. (PSW11)

Participants shared that education and training for family caregivers of PLWD needs to be made more easily accessible. They noted that family caregivers face many challenges and accessing necessary education about dementia should not be one of them. This is demonstrated by one participant:

They don't, it might be there, but it's how do they leave their person for two hours to go listen to a seminar on how to be a better caregiver? I've, I've seen families try to get to them and then it's like "'m too tired." And they won't. So, I, that should be better than it is. But I think that, I think that that needs to come to them. (PSW02)

Another participant stated:

So, the Alzheimer's Society has great training, people are reluctant to engage. So, there needs to be a plan on how to engage them and how to engage them early. But there also needs to be flexibility in provision of that education and training to meet the family's needs... We need to be able to go to them to provide the support. We have to serve them and reach out to them and accommodate their schedule. (PSW11)

### **3.2.6 Improvements Need to be Made in the Way Employers Respect and Support Home Care PSW**

The final main category describing quality dementia home care was the need for employers to respect and support home care PSW.

#### **3.2.6.1 Not Respected as a PSW**

Participants reported a lack of respect: "the company is not treating their employees properly. Like they should" (PSW05). Another participant described how not feeling respected can affect the care they provide to clients: "support workers like getting, just not feeling respected, in your work from management, kinda can bleed down to your work. Like, yeah, that's been a common theme being a support worker, is just not feeling any respect" (PSW06). While participants often did not feel they were respected, it is noted that "being valued is very, very important" (PSW09).

#### **3.2.6.2 PSW Need to be Supported**

These feelings of lack of respect were closely related to the lack of support that the participants felt they had. Therefore, improving the ways that PSW are supported can have a positive impact on the respect and value they feel they have as care providers. Participants often felt that there "need[s] to have supports in place, not just for clients, but also for PSW themselves" (PSW07). Participants discussed how caring for PLWD can be especially challenging and they need more support to ensure the provision of quality care for these individuals. One participant emphasized, "it does affect you mentally, also and physically as a home support worker or a PSW, to deal with people with dementia. So, we need a little more support just the same" (PSW15). Another participant described the unsupportive home care system:

I know a lot of agencies and a lot of PSW who may not feel like they have that support. And when you don't feel like you have that support, yeah, I think the quality of care is going to suffer. (PSW07)

According to participants, the support they receive from their employers can be improved through a variety of ways. First, the participants described the home care system as providing PSW with low wages that do not align with the work they have to do, which may lead to negative feelings and higher turnover. One participant emphasized this by saying, "the other big thing, which is just the PSW I think are not recognized, they're not paid for the work that they do" (PSW13). This is highlighted by another participant stating:

I think one of the ways can be resolved is the wages for PSW in health, in home care, and I know the nursing homes pay better, so that's why there's a shortage in where, you know, the home care. That's what I see anyway, around me. So, I think that if the wages go up, it will be more attractive to work in home care, it will keep more PSW. (PSW01)

Providing more financial support for home care PSW can help them feel more supported and respected. One participant noted, "there has to be a wage increase but again, without it affecting the client" (PSW12). Similarly, another participant mentioned, "I really think that those who take care of dementia clients, they should at least get more pay for it" (PSW15).

The next way participants discussed that home care PSW need to be supported is through ongoing education and training. Continuous education and training for PSW allows them to "keep building the skills [they] have" (PSW02) and is considered to be an "investment for better services, for the better care" (PSW03). Participants noted that home care organizations should be responsible for providing it to home care PSW to fully support ongoing education and training. However, participants noted that this is frequently not a reality in home care: "the problem with going to the community and thinking you're going to get more training, is actually they don't actually train you" (PSW05). Another participant stated:

I'm not sure that the company totally supports us or gives us the time [or] sort of accommodates the time that it would take to take a course. That it seems not easily encouraged that you take time out from your job to take a course. (PSW08)

There was variability with respect to ongoing training among participants. One participant noted, "those educational resources, through the company, are a huge help" (PSW07). Another participant also spoke about how supported they feel when their employer provides "educational classes free. Go in and some other classes they pay you to go and so you are sitting there and getting paid" (PSW09).

Participants also described that being supported with information about clients helped them feel prepared to provide quality care to clients, especially PLWD. However, this is often not the reality of home care, with one participant citing that they often "don't know what we're walking into" (PSW07). Another participant echoed this occurrence of not receiving enough information about clients to support them in providing quality care:

I would have no information for that client. I didn't know if they had dementia. I didn't know if they had a stroke. I didn't know if they had Parkinson's. I didn't know if they had, who knows, COPD. It could be a million things. (PSW02)

Additionally, another participant reported:

And honestly I didn't know from the information on my phone which of the two people, one had a 15-minute visit on my phone and one had a much longer visit on my phone, but never having been there before I did not know when the door was opened which of my clients had dementia. (PSW08)

Next, participants reported that sufficient staffing was essential for quality home care for PLWD. One participant stated, "we're stressed. We're short staffed. We're getting burnt out" (PSW07). Another participant mentioned, "well again, that would be related to my business or the company I work for. But they can spread me a little thin" (PSW06). According to participants, employers need to ensure there are a sufficient number of available workers and that workers are all qualified to provide quality care to clients. Specifically, participants reported that regulation of PSW could create accountability by ensuring that all PSW are qualified to provide quality dementia home care. This is demonstrated by the following quotation:

You wanna provide a safe environment for people with dementia. Well it's kinda hard to provide a safe environment when you're letting PSW in that are unregulated. (PSW05)

Another participant stated:

There's no accountability. Where I've heard that, you know, regulation, at least, can be tracked and be like, "okay, well, you know, this person has abused somebody." (PSW12)

Finally, participants discuss the need to be supported to ensure their safety while working in the home care environment. This support could come in the form of being able to report or having someone to talk to about incidents. This is demonstrated by one participant noting, "... a lot of organizations don't have somebody they can go to, to talk about these things, 'cause well a lot of the time we're not allowed to talk about our jobs to our husband or wife because it's confidentiality" (PSW07). Other participants discuss that having the opportunity to work directly with another PSW while providing care to clients can help ensure safety. As one participant highlighted, "And then it's like, okay, well, for these outings and stuff, there should probably be more than one person, just because it's important to have that security and safety" (PSW12).

In summary, interviews with fifteen PSW revealed six main categories related to quality dementia home care during the analysis process. First, all of the participants described a holistic view of person-centred care and how important it is for the provision of quality home care for PLWD. Participants also highlighted that PSW need to receive dementia-specific education and training, and that this needs to involve hands-on experience with dementia to better prepare them to provide quality care. Next, participants discussed the need for open communication among an interprofessional dementia care team. Importantly, participants mentioned that PSW that care for PLWD need to be involved in the care team because they often know these clients very well. Additionally, participants spoke about PSW having caregiving experiences, being adaptable, being able to practice self-care, having compassion and passion, can all help them provide quality care to individuals with dementia. Next, participants discussed how PLWD and their family caregivers need to have access to information, services and education that support them in remaining at home for as long as possible. Finally,

participants highlighted the reality of feeling a lack of respect and support from their employers. To ensure the provision of quality dementia home care, employers need to improve the ways they respect and support home care PSW, specifically by increasing wages, providing ongoing training, increasing information sharing about clients, ensuring there are enough qualified staff, and providing a safe work environment.

### **3.3 Provincial Policy Documents**

Six Ontario policy documents were analyzed to understand how quality dementia home care is discussed in the health system. The analysis process resulted in the creation of five main categories: (1) seamless care through effective communication and coordination among an interprofessional care team; (2) education and training for health care providers that is also dementia-specific; (3) client empowerment and active involvement; (4) easily accessible support services, accurate information, and education for PLWD and their family caregivers; and (5) the need for improvements in the ways the home care workforce are empowered and supported. A variety of subcategories were associated with these categories, as shown in Table 3.

**Table 3**

*Summary of findings from the policy document analysis.*

<b>Main Categories</b>	<b>Subcategories</b>
1) Seamless Care Through Care Coordination and Effective Communication Among an Interprofessional Care Team	1) Interprofessional Care Team 2) Meaningful Communication
2) Education and Training for Health Care Providers that is also Dementia-specific	1) Dementia-specific Education and Training
3) Client Empowerment and Active Involvement to Meet Their Needs	1) Client Empowerment and Active Involvement 2) Putting Patients First
4) Increased Awareness of Dementia and Easily Accessible Information, Support Services and Education for PLWD and Their Family Caregivers	1) Public Awareness of Dementia 2) Accessible Information and Support Services 3) Supporting Family Caregivers
5) Need for Improvements in the Ways the Home Care Workforce are Empowered and Supported	1) Empower Home Care Workers 2) Home Care Workers Need Support

### **3.3.1 Seamless Care Through Care Coordination and Effective Communication among an Interprofessional Care Team**

The six policy documents all outlined the need for coordinated care and communication among an interprofessional care team for quality care to be delivered to PLWD.

#### **3.3.1.1 Interprofessional Care Team**

One policy document stated, “all members of the team must be respected and valued for their knowledge, as care in the home clearly builds on the contribution of others” (Dementia and Home Care, 2017). Another document stated, “interdisciplinary teams play an important role in providing high quality care and in supporting people with

dementia and their care partners to live well” (Developing Ontario’s Dementia Strategy, 2017).

Policy documents discussed that the basis of interprofessional care teams was “bringing health care providers together to better coordinate care for patients” (Patients First: Action Plan for Health Care, 2015). One policy document noted “we know that strengthening home and community care requires better integration of the health care services that patients receive. All health care providers must work together” (Patients First: A Roadmap to Strengthen Home and Community Care, 2015). Developing Ontario’s Dementia Strategy (2017) stated, “coordinated care is vital to improving the experience of people with dementia and their care partners. It ensures smooth navigation and connections between health care and other service providers as their needs change.”

### **3.3.1.2 Meaningful Communication**

To ensure quality care through a coordinated interprofessional care team, one policy document stated that “timely and meaningful communication is needed” (Bringing Care Home, 2015) among everyone in the circle of care. Policy documents specifically indicated that all health providers needing to share and access client information. This is demonstrated in one document statement that, “everyone in the circle of care has access to the client record and is aware of changes in the care plan” (Bringing Care Home, 2015). Another policy document stated, “strengthen the mechanisms for information exchange between all Health Service Providers, including frontline home care caregivers” (More Home Care For Me And You, 2018).

### **3.3.2 Education and Training for Health Care Providers that is also Dementia-Specific**

Five of the policy documents discussed the importance of health care providers receiving education and training to ensure the provision of quality care. This is highlighted by one of the policy documents noting, “it is imperative the industry has the skilled and professional workforce required to meet the increasing needs of a growing population” (More Home Care For Me And You, 2018). Further, two of the policy documents specified that “dementia-specific education and training can help them to provide excellent services to people with dementia and their care partners and to support the strengths of people with dementia” (Developing Ontario’s Dementia Strategy, 2017).



This need for dementia-specific education and training for health care providers is echoed in another policy document that stated, “efforts must be made to increase awareness and provide training to all levels of staff in the care of people with dementia throughout all stages of the illness, including palliative and end-of-life care” (Dementia and Home Care, 2017). Dementia and Home Care (2017) further stated:

It is imperative that specially trained caregivers are available to provide home care services to individuals with dementia. Staff need to be aware of the different types of dementia, including the symptoms and impact on the brain to anticipate care needs and respond appropriately.

The policy documents show that for quality dementia home care to be provided, any health care provider working with PLWD needs to be trained and educated well enough to delivery it.

### **3.3.3 Client Empowerment and Active Involvement to Meet Their Needs**

The next main category found in the analysis was that home care clients need to be empowered and actively involved in their care. According to four of the policy documents, clients can be empowered in their care through their involvement in it. Engaging people in their own care is clearly a goal of importance in this policy document that stated, “engage Ontarians on health care, so we fully understand their needs and concerns” (Patients First: Action Plan for Health Care, 2015).

Another way that the policy documents discussed involving people in their own care is through “a patient-centred health care system” (More Home Care For Me And You, 2018) and “putting patients first” (More Home Care For Me And You, 2018; Patients First: A Roadmap to Strengthen Home and Community Care, 2015). This connection between “putting patients at the centre of our health system” (Developing Ontario’s Dementia Strategy, 2017) and clients’ active involvement in their care is identified by one policy document noting, “a health care system that puts patients first requires their participation. We will continue to expand how patients are engaged throughout the health care system” (Patients First: Action Plan for Health Care, 2015).

### **3.3.4 Increased Awareness of Dementia and Easily Accessible Information, Support Services and Education for PLWD and Their Family Caregivers**

The next main category that emerged from all six of the policy documents regarding quality dementia care was increased public awareness of dementia and accurate and accessible information, support services and education for PLWD and their caregivers.

#### **3.3.4.1 Public Awareness of Dementia**

First, the policy documents discussed how the general public of Ontario need a greater understanding and awareness of dementia to encourage early diagnosis and reduce the stigma associated with dementia. According to one policy document, “receiving an accurate diagnosis as soon as possible is important to enable a person to properly plan and live well with dementia” (Developing Ontario’s Dementia Strategy, 2017). To ensure the early diagnosis of dementia, the policy documents noted that the public needs dementia education to identify the initial signs of cognitive impairment. The policy documents stated that education about dementia can reduce its stigma, thus better support the individuals affected by it. This is demonstrated in a statement in a policy document: “greater public awareness is needed not only to support those with dementia and those providing care but to educate and normalize dementia-friendly strategies across society” (Dementia and Home Care, 2017). Another document further stated:

All Ontarians need accessible and credible information to assist them in: 1) understanding dementia, including its signs, symptoms and treatments; 2) reducing their risk of developing dementia; 3) supporting people with dementia in living well; 4) reducing stigma faced by people with dementia and their care partners. (Developing Ontario’s Dementia Strategy, 2017)

#### **3.3.4.2 Accessible Information and Support Services**

Next, the policy documents stated that PLWD and their families need easy access to information on the services available to them. To accomplish this, “they need to know where to get the right kind of help” (Patients First: Action Plan for Health Care, 2015). The policy documents emphasized that information about support services and how to access them needs to be made more available to make care truly accessible to everyone. Specifically, one policy document stated, “people living with dementia and their care

partners may have difficulty finding out what services are available and how to access them” (Developing Ontario’s Dementia Strategy, 2017). Another policy demonstrated this by stating:

... families do not understand what services are available and under what circumstances. There were many calls for a clearly articulated statement of publicly-funded and unfunded services that clients and families can access and more transparency regarding the assessment process to determine eligibility. (Bringing Care Home, 2015)

Further, PLWD need “both clinical and non-clinical supports” (Bringing Care Home, 2015). One document claimed that people need “services to address needs along the full continuum of care” (Bringing Care Home, 2015). While another policy document stated, “as a person with dementia grows older and their needs become more complex, a variety of services are needed that respond to the unique physical, psychological and social needs of a person with dementia” (Developing Ontario’s Dementia Strategy, 2017). Three of the documents indicated that having support services available for PLWD can help enable them to live meaningfully and remain at home longer. These were both seen as increasing quality of care for PLWD and is demonstrated by one of the policy documents stating, “it is also important to ensure that supports are available that empower people with dementia to continue to enjoy meaningful and active lives” (Developing Ontario’s Dementia Strategy, 2017). Another policy document noted, “people with dementia can remain at home longer when dementia-specific day programs are available” (Dementia and Home Care, 2017). It is clear that PLWD need access to support services to receive quality dementia home care, however, some of the policy documents mentioned that this is not always possible and that access to these services needs to be improved upon. One policy document stated that “an important part of this plan is improving access to dementia supports” (Developing Ontario’s Dementia Strategy, 2017). This document also specifically stated that “adult day programs may have limited capacity to accept new participants, eligibility criteria may not allow those with higher care needs to attend, or programs may not be affordable” (Developing Ontario’s Dementia Strategy, 2017).

### 3.3.4.3 Supporting Family Caregivers

Finally, all of the policy documents also discussed the importance of recognizing the client-caregiver dyad and supporting “family-centred care” (Bringing Care Home, 2015; Patients First: A Roadmap to Strengthen Home and Community Care, 2015; Dementia and Home Care, 2017). Family-centred care acknowledges that family need support. One policy document stated, “the residents of Ontario told us that they want the family to be the ‘client’ and the planning and delivery of care to be truly client and family-centred” (Bringing Care Home, 2015). According to policy documents, family-centred home care should focus on the needs of both the client and their families. For example, “the Home Care program must be structured so that the services can be responsive to the specific needs of the person and those of the family and family caregiver” (Dementia and Home Care, 2017).

“Families are integral to maintaining care at home” (Dementia and Home Care, 2017) and thus, supporting them is a component of quality care for PLWD. This is demonstrated by one document stating, “family caregivers must receive the services they need to establish balance in their lives and to cope with care needs of their loved one” (Dementia and Home Care, 2017). Another policy document further stated:

To better recognize caregivers’ important role and to empower both caregivers and clients, we will introduce expanded caregiver supports. These supports will ensure caregivers have better resources to care for their loved ones and also to take care of themselves. (Patients First: A Roadmap to Strengthen Home and Community Care, 2015)

Similarly, the policy documents also discussed that family caregivers of PLWD need accessible “education and training to support them” (Bringing Care Home, 2015). The policy documents clearly describe that providing family caregivers with education and training on dementia is closely related to providing services and supporting caregiving responsibilities. One policy document demonstrated this by stating, “family caregivers urgently need respite along with access to information about available public and private services and how to access them, as well as education and training to support them” (Bringing Care Home, 2015). Another document stated:

Care partners also need to be supported when caring for a person with dementia. This includes having access to respite care services, such as adult day programs or overnight care for people with dementia, and being able to gain practical skills for caregiving. (Developing Ontario’s Dementia Strategy, 2017)

### **3.3.5 Need for Improvements in the Ways the Home Care Workforce is Empowered and Supported**

The final main category that emerged from five of the policy documents was the need for improvements in ways that the home care workforce is empowered and supported, such as through ensuring enough staff, ongoing training, increasing wages, and providing a safe workplace.

#### **3.3.5.1 Empower Home Care Workers**

Policy documents emphasized that home care providers need to be better respected and empowered in their roles. Specifically, policy documents discussed needing “staff with the autonomy to do what is most helpful at the time” (Dementia and Home Care, 2017). Empowering home care providers through increasing their autonomy is echoed in another policy document that stated that home care needs to “provide for greater professional home caregiver autonomy and flexibility so the care needs of patients in the moment of distress can be addressed” (More Home Care For Me And You, 2018). Other ways that the policy documents suggest supporting home care providers through empowering them is by “improving the image and recognition of professional home caregivers” (More Home Care For Me And You, 2018) and inclusion in home care teams, as demonstrated by another policy document stating, “further examine challenges affecting recruitment and retention, including how PSW can become more involved in teams of health care professionals to better care for clients” (Patients First: A Roadmap to Strengthen Home and Community Care, 2015).

#### **3.3.5.2 Home Care Workers Need Support**

Further, policy documents highlight that the home care system needs to “develop measures to create more permanent and less casual employment for PSW” (Patients First: A Roadmap to Strengthen Home and Community Care, 2015) and other home care providers. Having a sufficient amount of care providers is key to enhancing the stability

of the home care workforce. As one policy document noted, there is a need to “address shortages of health human resources” (Bringing Care Home, 2015).

The policy documents also recommended ongoing training to support and retain the home care workforce. According to one policy document, this ongoing training needs to include “more on-the-job orientation for new graduates” (Patients First: A Roadmap to Strengthen Home and Community Care, 2015). The need to support home care workers by providing ongoing training is demonstrated in this statement, “in addition to promotion, providing ongoing training resources and placement opportunities is critical to growing the home care workforce” (More Home Care For Me And You, 2018). Another policy document further stated “clients need to know that they are receiving care from providers who are adequately trained and compensated and part of a stable workforce” (Patients First: A Roadmap to Strengthen Home and Community Care, 2015).

Next, the policy documents supported wage increases for home care workers, which was essential for workforce stability. Indeed, the quotation above mentioned that clients need to know they are receiving care from providers who are adequately compensated. This need for increasing the wages of home care providers is presented further in this policy document by stating, “recruiting and retaining personal support workers who provide publicly funded care in the home and community through pay increases and more on-the-job orientation for new graduates, to help make this a more permanent, less casual job” (Patients First: Action Plan for Health Care, 2015). Another policy document also stated, “we intend to continue moving forward with our plan to enhance the wages of personal support workers and provide other supports to improve the stability of our PSW workforce. (Patients First: A Roadmap to Strengthen Home and Community Care, 2015)

The final way that one of the policy documents discussed supporting home care providers is through providing a safe workplace. This policy document noted that “it is more difficult to ensure a safe environment for both the client and the care provider” (Bringing Care Home, 2015). To ensure there is a stable and supported home care workforce, this policy document clearly stated, “strategies and policies are needed to provide a safe workplace for home and community care providers” (Bringing Care Home, 2015). While this policy document made this statement, there was no further

information included in regards to the specific ways in which a safe workplace can be provided for home care providers.

In summary, the six policy documents identified several elements necessary in the provision of quality home care for PLWD. First, care needs to appear seamless to PLWD and their families. According to the policy documents, this can be achieved through coordinated care and effective communication among an interprofessional care team. Next, it was found that for home care providers to deliver quality home care to PLWD, they need to receive dementia-specific education and training. Engaging PLWD by involving them and putting them in the center of their care was also seen as desirable. Next, the policy documents discussed the need for greater public awareness and support information, services, and education to be easily accessible for anyone in need of them. The policy documents emphasized that increasing the awareness of dementia in the general public could be beneficial towards early diagnosis and reducing the stigma of dementia. Policy documents also noted that both information and a variety of support services for both PLWD and their caregivers need to be in place to keep people living at home. Family-centred care was found to recognize the value and importance of the client-caregiver dyad and the need for caregivers to be supported through services and education. Finally, the policy documents cited the need to improve the empowerment and support given to the home care workforce. Policy documents noted that the current home care workforce needs support to ensure there are enough staff, receive on-going training, receive increased wages, and have a safe workplace.

### **3.4 Alignment of PSW Perspectives and Provincial Policy Documents on Quality Dementia Home Care**

In this section, the main categories from the analyses of the PSW interviews and the policy documents will be explored for areas of consistencies and areas of differences in regard to quality dementia home care (see Figure 2). Several of the emergent main categories did have similarities, but there were also key areas of difference between some of the main categories in the understanding of quality home care for PLWD.

**Figure 2**

*Summary of the key findings.*

<b>PSW Perspectives</b>	<b>Provincial Policy Documents</b>
An Inclusive Dementia Care Team Encouraging Open Communication	Seamless Care Through Care Coordination And Effective Communication Among An Interprofessional Care Team
PSW Need Dementia-Specific Training And Education That Involves Hands-On Experience	Education And Training For Health Care Providers That Is Also Dementia-Specific
Accessible Information, Services And Education To Support PLWD And Their Family Caregivers	Increased Awareness Of Dementia and Easily Accessible Information, Support Services And Education For PLWD And Their Family Caregivers
Improvements Need To Be Made In The Way Employers Respect And Support Home Care PSW	Need For Improvements In The Ways The Home Care Workforce Are Empowered And Supported
Care For PLWD Needs To Be Person-Centred	Client Empowerment And Active Involvement To Meet Their Needs
Specific Experiences, Abilities And Characteristics Can Help PSW Provide Quality Care	

*Note.* Areas of consistency between the analyses are highlighted by matching colours.

### **3.4.1 Areas of Consistency**

The perspectives of PSW and the provincial policy documents align in terms of the following four areas: (1) coordinated interprofessional care team that has open communication; (2) accessible support services, information and education for PLWD and their caregivers; (3) health care providers needing dementia-specific education and training; and (4) needing to encourage home care providers to stay in the field through the provision of support. The overall meanings of these main categories are consistent between the interview analysis and the policy document analysis, however, the PSW shared specific details about each of these main categories.

First, a coordinated interprofessional care team was a common indicator of quality dementia home care across interview data and provincial policy documents.



Interprofessional care teams need to be able to collaborate and have open communication with everyone involved in the care team. PSW specifically mentioned how important it was for them to be involved in these interprofessional care teams and they noted that family members need to be involved in the care team and in the communication about PLWD.

Second, the importance of information, services, and education being accessible to PLWD and their families was identified by both analyses. Both the interview data and policy documents noted the need for information about services to be easily available for PLWD and their families. Further, both sources of data indicated that PLWD need access to a full range of services to support them living at home. Next, both sources of data discussed how integral family caregivers are in the home care system, however they may struggle with burnout.

The PSW and the policy documents *differ in the way they discussed supporting families*. This is shown in the way the PSW separated the support family caregivers need from the support PLWD need. The policy documents often grouped families and clients together as a dyad both in need of care and support.

Lastly, both the PSW and the policy documents made note of the importance of education on dementia being available to PLWD and their families, and to the general public to encourage early diagnosis of dementia. The policy documents went further by discussing how information and education about dementia being available to the general public can help reduce the stigma associated with dementia.

The third area of consistency was that health care providers need to receive dementia-specific education and training. To provide PLWD with quality home care, both sources of data emphasized that providers need to have knowledge of dementia and they need to be trained on how to care for PLWD. While the policy documents tended to discuss the broad notion of dementia-specific education and training, the PSW went into more details about this main category. Specifically, the PSW spoke about how their book-based education often does not prepare them for the realities of caring for PLWD. For their education and training to be improved to better prepare them, it needs to involve hands-on experience with dementia.

Finally, the need to support the home care workforce was identified by both sources of data. The home care workforce is faced with precarious working conditions resulting in PSW feeling undervalued and unsupported by employers. Ongoing training, increased wages, sufficient amount of staff and the provision of a safe work environment were identified as ways to support the home care workforce. PSW also reported that support includes providing sufficient client information and having more qualified peers.

### **3.4.2 Areas of Difference**

While there are clearly areas of consistency between the PSW and the provincial policy documents, there are also distinct areas of difference. As was mentioned in the previous section, even the areas of consistency for some of the main categories had a few differences between what the PSW and the policy documents discussed. There were also more significant areas of differences found in both of the analyses, which is explored in the following section.

First, the policy documents discussed the need for patients to be put first by empowering them and actively involving them in their care to meet their needs. While this notion aligned with areas of person-centred care, this main category was not highlighted as consistent with the PSW perspectives of care for PLWD needing to be person-centred. This is because the policy documents highlighted the need to empower and involve patients in their care and used language that supported the idea of patient-centred care. The PSW spoke of a more holistic notion of person-centred care which is demonstrated by the many different elements of person-centred care they discussed throughout their interviews.

Secondly, the PSW often discussed that having certain experience, abilities, and characteristics can help them to provide quality home care to PLWD. PSW specifically stated that personal facilitators for providing quality dementia home care included having caregiving experiences, being adaptable, being able to practice self-care, being compassionate when providing care and being passionate about providing quality care to PLWD. The policy documents did not include information on specific experiences, abilities or characteristics home care providers can or should have to provide quality care to PLWD at home.

In summary, four areas of alignment existed for the main categories of both sources of data. While these areas of consistency were found between the main categories, there were areas of differences found in the categories and sub-categories within these main categories. These differences were often created by PSW going into more specific details about each of the main categories. The analyses also revealed areas of differences in other main categories that emerged. Differences were found in the language used, with the policy documents using patient-centred language and ideology. Contrastingly, the PSW described a more holistic idea of person-centred care, encapsulated by many elements. Finally, the PSW frequently described various experiences, abilities and characteristics that they viewed as being essential in the provision of quality dementia home care.

## Chapter 4: Discussion

This study explored the perspectives of fifteen PSW on the provision of quality dementia home care. Their perspectives were compared to statements made in six provincial policy documents about quality home care for PLWD. This study also aimed to explore the extent to which policies regarding quality home care provision aid in the delivery of quality home care by PSW. The results of the qualitative content analysis found both similarities and differences in how quality dementia home care was discussed among PSW and presented in provincial policy documents. The perspectives of PSW and the policy documents align on the following four categories: a coordinated interprofessional care team that has open communication; health care providers needing dementia-specific education and training; accessible support services, information and education for PLWD and their caregivers; and improving the respect and support home care providers are receiving. Areas of differences include a variation in ideology and language use with patient-centred care in policy documents versus person-centred care discussed by PSW; and PSW noting that specific experiences, abilities and characteristics can help them in providing quality dementia home care.

The need for a coordinated interprofessional care team to support successfully all the needs of PLWD at home was discussed by PSW and the policy documents as an important element of quality dementia home care. Previous literature strongly supports having a collaborative and integrated interprofessional care team approach in place for PLWD living in the community (Berta et al., 2013; Brody et al., 2016; Carlisle et al., 2004; Cartwright et al., 2015; Dawson et al., 2015; Gilster et al., 2018; Low et al., 2013; Snayde & Moriarty, 2008; Turjamaa et al., 2014). PSW also emphasized that they needed to be included in the interprofessional care team because they spend the most time to get to know their clients with dementia. This call for the inclusion of front-line home care staff in interprofessional care teams is echoed in the literature (Canadian Academy of Health Sciences, 2019; D'Astous et al., 2019; Ryan et al., 2004; Storch et al., 2014; Torres, 2011). Unfortunately, PSW reported a lack of teamwork when providing home care. Exclusion from teams, despite having a significant role in the care of PLWD, has implications on the respect and support that PSW feel they are receiving. This reality of

front-line home care workers having to work alone is documented in other literature (Craftman et al., 2018; Storch et al., 2014; Turjamaa et al., 2014). For there to be better alignment between PSW perspectives and policy documents, Ontario policy documents need to include and recognize PSW and other front-line home care workers as contributing and valuable members of the interprofessional care team. Additionally, the home care sector needs to do its part in recognizing the value of PSW being apart of the interprofessional care team for PLWD by ensuring and facilitating effective communication among everyone caring for PLWD. An integral part of interprofessional care teams is effective communication among all healthcare professionals, including supervisors, nurses, and other PSW. These findings are aligned with other research findings on the importance of team meetings (Carlisle et al., 2004; Craftman et al., 2018; Gilster et al., 2018; Kieft et al., 2014; Ryan et al., 2004; Snayde & Moriarty, 2008) to support open and meaningful communication among all interprofessional care team members (Abbasi et al., 2017; D’Astous et al., 2019; Downs & Collins, 2015; Edick et al., 2017; Goodwin, 2016; Storch et al., 2014). PSW reported that effective communication needs to include the family of PLWD to exchange relevant person-centred information regarding the PLWD. This importance placed on open communication with the family members of PLWD can also be found in existing literature (Ayalon & Rozinre, 2016; Dawson et al., 2015; Francis & Netten, 2004; Roelands et al., 2005; Smythe et al., 2015; Wojtak & Klopp, 2015). The alignment between both the PSW perspectives and the policy documents shows that having an inclusive care team that is available for PLWD and encourages meaningful communication among all members is a critical part of quality dementia home care.

The second area of consistency between PSW and policy documents is on providing dementia-specific education and training to health care providers. Evidence from the interviews with PSW, the policy documents and existing literature made it clear that any health care provider who interacts with PLWD needs knowledge and training about dementia (Borbasi, Jones, et al., 2006; Brody et al., 2016; Chow et al., 2018; Cook, 2017; D’Astous et al., 2019; Edick et al., 2017; Hughes et al., 2009; Janicki, 2011; Low et al., 2013; Nies, 2016; Robinson et al., 2014; Warshaw & Bragg, 2014). The provincial policy documents did not present detailed areas of dementia-specific education and

training that health care providers should receive. However, one document (Dementia and Home Care, 2017) briefly stated that care provider education needs to include awareness of the types of dementia, symptoms and its impacts. In contrast, PSW discussed specific topics for training including, information about dementia, recognizing that PLWD will change, and the need to be able to monitor these changes. Additionally, PSW need to know how to engage PLWD to assist them with retaining what they are able to do. Existing literature also discusses that PLWD need to be monitored for changes and receive ongoing assessments for fluctuating needs (Francis & Netten, 2004; Goodwin, 2016; Janicki, 2011; Low et al., 2013; Warshaw & Bragg, 2014; Wojtak & Klopp, 2015). Additionally, literature supports home care providers attempting to retain the abilities of PLWD by engaging them in stimulating activities (Dempsey et al., 2016; Downs & Collins, 2015; Low et al., 2013). Given the emphasis PSW put on the importance of person-centred care being provided to achieve quality dementia home care, this is clearly a vital topic that needs to be taught to health care providers through education and training (Goodwin, 2016; Kim & Park, 2017; Kirkley et al., 2011; Savundranayagam et al., 2020; Smythe et al., 2015; Surr et al., 2016). Another specific area of education and training found in the literature and reported by PSW is receiving more information on how to interact with family members (Dawson et al., 2015; Gilster et al., 2018; Storch et al., 2014). The PSW discussed further the need for their education and training to involve hands-on experience working with PLWD for them to be prepared fully. This demonstrates that PSW find the information they learn about dementia important and also believe the way in which they learn this information is important. This adds to the existing literature which has found experiential learning for care providers to be very valuable (Savundranayagam et al., 2020; Smythe et al., 2015). While both sources of data align in viewing dementia-specific education and training as important, they differed in the discussions on the information that should be included in the education and training and how the information should be taught to PSW. The education and training of home care providers needs to ensure the inclusion of specific dementia care strategies that PSW perceive to be vital in the delivery of quality care.

The next area of consistency between both the PSW and the policy documents emphasized the importance of accessible information, support services and education

being available to PLWD and their families. First, PLWD and their caregivers lack awareness of and therefore, do not always access necessary home and community care services (Jansen et al., 2009; Joint CCAC/Service Provider Association Committee, 2008; Low et al., 2013; Low & Fletcher, 2015; Sinha, 2016; Willis et al., 2009). Therefore, the home care sector needs to address this gap by ensuring it is providing easily accessible information about available home care services and supports.

Additionally, both sources of data highlighted that PLWD require a range of services that are flexible to meet their needs (Cartwright et al., 2015; Dawson et al., 2015; Edick et al., 2017; Gaugler et al., 2005; Janicki, 2011; Manthorpe & Samsi, 2016; Steele Gray et al., 2014; Tam-Tham et al., 2016; Turjamaa et al., 2014; Ward-Griffin et al., 2012; Willis et al., 2009). Moreover, family caregivers need to be supported to continue providing care (Borbasi, Jones, et al., 2006; Brown, 2016; Cepoiu-Martin et al., 2016; Feldman & Estabrooks, 2017; Jansen et al., 2009; A Martin-Matthews et al., 2012; Morton-Chang et al., 2016b; Sinha, 2016; Sutherland & Wiersma, 2016; Zabalegui et al., 2014) with the help of home and community support services (Brown, 2016; Dawson et al., 2015; Gaugler et al., 2005; Jansen et al., 2009; Low et al., 2013; Morton-Chang et al., 2016b; Sinha, 2016; Sutherland & Wiersma, 2016; Takai et al., 2009; Tam-Tham et al., 2016; Willis et al., 2009; Zabalegui et al., 2014). Dementia-specific education is also critical for PLWD and their families (Borbasi, Jones, et al., 2006; Chow et al., 2018; Edick et al., 2017; Fazio et al., 2018; Jansen et al., 2009; Low et al., 2013; Robinson et al., 2014; Sinha, 2016; Tam-Tham et al., 2016; Willis et al., 2009; Zabalegui et al., 2014). Finally, providing education to the general public to encourage the early diagnosis is highlighted by both analyses and existing literature (Edick et al., 2017; Morton-Chang et al., 2016a; Sinha, 2016). Increasing awareness of dementia among the general public can reduce the stigma associated with dementia (Chow et al., 2018; Edick et al., 2017; Morton-Chang et al., 2016a). Both sources of data aligned so well because, unquestionably, both PLWD and their family caregivers need to have accessible information, services and education to ensure they can maintain their wellbeing while living at home and in the community.

The final area of consistency between the PSW and the policy documents is that improvements need to be made in the ways employers respect and support home care providers. PSW reported lack of respect and value, which has implications on the quality

of care they provide. Existing literature has emphasized the importance of giving front-line home care providers the respect and value they deserve (D'Astous et al., 2019; Joint CCAC/Service Provider Association Committee, 2008; Kalenteridis, 2017; Ryan et al., 2004; Sims-Gould et al., 2010; Smythe et al., 2015; Storch et al., 2014; Torres, 2011) and empowering them to make autonomous decisions (Denton et al., 2002; Fazio et al., 2018; Gilster et al., 2018; Ryan et al., 2004; Smythe et al., 2015). The respect that home care providers feel was also related to the support they are receiving from their employers. Further, organizational support can impact the care that home care providers deliver (Cook, 2017; D'Astous et al., 2019; Dawson et al., 2015; Kirkley et al., 2011; Savundranayagam et al., 2020; Zagrodney & Saks, 2017; Zeytinoglu & Denton, 2005). Specifically, supporting home care workers through increased wages (D'Astous et al., 2019; Joint CCAC/Service Provider Association Committee, 2008; Kalenteridis, 2017; Low et al., 2013; A Martin-Matthews et al., 2012; Sayin et al., 2018; Sims-Gould et al., 2010; Smythe et al., 2015; Steinmetz et al., 2014; Torres, 2011; Warshaw & Bragg, 2014; Zagrodney & Saks, 2017; Zeytinoglu et al., 2009; Zeytinoglu & Denton, 2005) and providing ongoing training (Cook, 2017; D'Astous et al., 2019; Denton et al., 2002; Hughes et al., 2009; Kalenteridis, 2017; Kirkley et al., 2011; Low et al., 2013; Ryan et al., 2004; Smythe et al., 2015; Snayde & Moriarty, 2008; Storch et al., 2014; Warshaw & Bragg, 2014; Zagrodney & Saks, 2017) are two important ways to better incentivise being in home care and encouraging continuous knowledge and skill building.

Next, home care staff shortages and high staff turnover rates have direct effects on provision of person-centred care, leading to higher chances of inconsistent caregivers and less collaboration among a care team (Abbasi et al., 2017; Berta et al., 2013; Carlisle et al., 2004; D'Astous et al., 2019; Edvardsson et al., 2009; Francis & Netten, 2004b; Joint CCAC/Service Provider Association Committee, 2008; Kalenteridis, 2017; Sims-Gould et al., 2010; Steele Gray et al., 2014; Storch et al., 2014; Torres, 2011; Turjamaa et al., 2014; Ward-Griffin et al., 2012; Zagrodney & Saks, 2017). Therefore, current home care providers need to be supported through a sufficient amount of staff being available to also deliver care. Additionally, ensuring home care workers have a safe workplace is important for both their own safety and their clients' safety (Denton et al., 2002; Joint CCAC/Service Provider Association Committee, 2008; Storch et al., 2014; Torres, 2011).



A safe workplace can also improve worker satisfaction (Zeytinoglu & Denton, 2005). Finally, the PSW discussed that home care workers need to be supported with information about the clients they see. Not knowing what they are walking into when visiting clients can make it extremely difficult for home care workers to provide quality dementia care that effectively meets their clients' needs (D'Astous et al., 2019; Denton et al., 2002; Downs & Collins, 2015; Francis & Netten, 2004; Gilster et al., 2018; Roelands et al., 2005; Storch et al., 2014). Receiving client information can also improve PSW feelings of being part of the care team, as it encourages reciprocal communication and information sharing between the front-line workers and supervisors. For better alignment between PSW perspectives and policy documents, policy documents need to outline the importance of providing home care client information to care providers. Having a respected and fully supported home care workforce has a direct impact on the quality of the care provided. The strategies outlined in this study, which are supported by previous research findings, need to be in place at the organizational and provincial levels to respect, support and encourage retention of quality workers.

The first area of difference between the PSW' perspectives and the provincial policy documents was that the PSW supported a more holistic notion of person-centred care for PLWD, while the policy documents were a lot more patient-centred in their focus and language used. This area of difference is caused by the policy documents not shifting fully to support and encompass the notion of person-centred care. The ideological shift from patient-centred care to person-centred care is well supported as it tends to focus more on people instead of focusing on or reducing them to their illness (Brooker, 2004; Cook, 2017; Downs & Collins, 2015; Edvardsson et al., 2009; Fazio et al., 2018; Gilster et al., 2018; Goodwin, 2016; Kim & Park, 2017; Kirkley et al., 2011; Low et al., 2013; Manthorpe & Samsi, 2016; Mullan & Sullivan, 2016; Santana et al., 2018; Smythe et al., 2015; Wojtak & Klopp, 2015). The policy documents highlighted the need of some person-centred elements such as empowering clients and actively involving them in their own care. Empowering PLWD (Brown, 2016; Downs & Collins, 2015; Manthorpe & Samsi, 2016; Smythe et al., 2015; Ward-Griffin et al., 2012) and actively involving them in their care (Dempsey et al., 2016; Edvardsson et al., 2009; Gilster et al., 2018; Low et al., 2013; Manthorpe & Samsi, 2016; Morton-Chang et al., 2016b; Sutherland &

Wiersma, 2016; Wojtak & Klopp, 2015) are indicators of quality care given that PLWD get overlooked in the decision-making process surrounding their health care. However, the language used throughout most of the policy documents was patient-centred, often referring to people as *patients* and *clients*. To create better alignment between what is found in policy documents and what PSW perceive as quality care, policy makers need to revise the language they use to support and encourage person-centred care instead of focusing on patient-centred care.

The PSW consistently discussed a more in-depth understanding of the relationship between person-centred care and the provision of quality dementia home care, describing many elements of person-centred care. Notably, care for PLWD needs to be individualized (Brooker, 2004; Dawson et al., 2015; Fazio et al., 2018; Goodwin, 2016; Janicki, 2011; Low et al., 2013; Sutherland & Wiersma, 2016) and flexible enough to adapt to the progression of the disease in each person (Dawson et al., 2015; Edvardsson et al., 2009; Goodwin, 2016; Low et al., 2013; Manthorpe & Samsi, 2016; Wojtak & Klopp, 2015). Recognizing that care needs to be individualized, for PSW also meant that home care providers need to get to know PLWD's life history and preferences. Getting to know the person with dementia as much as possible (Downs & Collins, 2015; Edvardsson et al., 2009; Fazio et al., 2018; Francis & Netten, 2004; Gilster et al., 2018; Janicki, 2011; Manthorpe & Samsi, 2016; Willis et al., 2009), which also allows PSW to engage them in activities that they find to be meaningful (Edvardsson et al., 2009; Fazio et al., 2018; Low et al., 2013; Nies, 2016; Sutherland & Wiersma, 2016; Turjamaa et al., 2014). Another important part of individualized care that PSW reported was that care needs to compliment the person with dementia and their family's schedules. Similarly, literature demonstrates that if care does not take place during times that are convenient for the person with dementia and their family, it should not be considered person-centred care (Francis & Netten, 2004; Gilster et al., 2018; Low et al., 2013; Storch et al., 2014). Next, person-centred communication was reported as important for getting to know PLWD and also for building trusting relationships (Cook, 2017; Downs & Collins, 2015; Ryan et al., 2004; Sutherland & Wiersma, 2016; Turjamaa et al., 2014; Wojtak & Klopp, 2015). Importantly, PSW also noted that person-centred communication with PLWD needs to include observing their non-verbal communication since PLWD can have difficulty with

communicating (Bökberg et al., 2017; Cook, 2017; Downs & Collins, 2015; Ryan et al., 2004). Additionally, PSW reported that quality person-centred dementia care needs to include building a trusting relationship with the PLWD (Cook, 2017; Edvardsson et al., 2009; Fazio et al., 2018; Manthorpe & Samsi, 2016; Ryan et al., 2004). Moreover, these relationships need to be built on respect for the person with dementia (Borbasi, Jones, et al., 2006; Downs & Collins, 2015; Edvardsson et al., 2009; Fazio et al., 2018; Gilster et al., 2018; Goodwin, 2016; Janicki, 2011; Low et al., 2013; Manthorpe & Samsi, 2016; Smythe et al., 2015; Turjamaa et al., 2014) and having home care providers be a good match with the person with dementia can help to facilitate the building of this relationship (Kirkley et al., 2011; Low et al., 2013; Storch et al., 2014).

Further, PSW demonstrated that care, especially for PLWD, needs the right amount of time because rushing is not conducive to person-centred or quality care (Dempsey et al., 2016; Storch et al., 2014; Sutherland & Wiersma, 2016; Turjamaa et al., 2014). Additionally, PSW reported that having enough time encourages them to engage socially PLWD, which provides stimulation and builds close relationships (Brooker, 2004; Low et al., 2013; Nies, 2016; Sutherland & Wiersma, 2016; Tam-Tham et al., 2016; Wojtak & Klopp, 2015). However, the PSW reported that the reality of providing home care is time-limited and task-focused. This research demonstrates that home care needs to shift from prioritizing task completion to encouraging providers to care about caring for the provision of quality person-centred care to occur. Next, PSW reported that continuity of formal caregivers facilitated the provision of quality person-centred care for PLWD. According to PSW, keeping home care providers consistent with PLWD allowed them to get to know that individual and build a close and trusting relationship. Continuity of formal caregivers is often linked as being valuable in the provision of quality care to PLWD (Dempsey et al., 2016; Edvardsson et al., 2009; Gilster et al., 2018; Kalenteridis, 2017; Low et al., 2013; Ryan et al., 2004; Storch et al., 2014). Therefore, home care organizations need to prioritize keeping home care providers consistent with PLWD. Finally, PSW reported that providing PLWD with a safe living environment is of importance in person-centred care (Feldman & Estabrooks, 2017; Janicki, 2011; Low et al., 2013; Morton-Chang et al., 2016b; Nies, 2016; Storch et al., 2014; Turjamaa et al., 2014). Implicit in a safe living environment, PSW noted that PLWD need access to

necessary equipment and home modifications to ensure their safety while living at home (Edick et al., 2017; Janicki, 2011; Nies, 2016; Turjamaa et al., 2014). Ultimately, both the PSW in this study and existing literature support a holistic view of person-centred care as being essential to quality dementia home care. Ontario policy documents need to better align with the PSW' perspectives to encourage the provision of quality person-centred dementia home care across the province.

The final area of difference was that PSW discussed specific experiences, abilities and characteristics that can help them provide quality care to PLWD. The PSW noted that having either informal (Sims-Gould et al., 2010) or formal caregiving experiences (D'Astous et al., 2019; Sims-Gould et al., 2010) can help home care providers deliver quality dementia home care by preparing them through these experiences. Next, PSW discussed that having the ability to be adaptable while providing care to PLWD can help them meet that person's needs (Borbasi, Jones, et al., 2006; Edvardsson et al., 2009; Low et al., 2013; A Martin-Matthews et al., 2012). Specifically, PSW reported that they need to be able to problem-solve (Craftman et al., 2018; Kirkley et al., 2011; Sims-Gould & Martin-Matthews, 2010; Smythe et al., 2015) to know how to be adaptable. Further, they also need to be observant (Smythe et al., 2015) in noticing situations that require them to be adaptable. PSW also reported that being able to practice self-care aided them in continuing to provide quality home care to PLWD. PSW indicated that practicing self-care should be encouraged and supported for home care providers. However, the impact of practicing self-care on the provision of quality home care was not found in the existing literature retrieved for this research. This could implicate an area of research that needs to be done to understand fully the role of the practice of self-care in the delivery of quality dementia home care. Next, according to both the PSW and existing literature, compassion is associated with being person-centred since it allows care providers to care truly and act towards PLWD with understanding (Brooker, 2004; Craftman et al., 2018; Downs & Collins, 2015; Fazio et al., 2018; Francis & Netten, 2004; Janicki, 2011; Low et al., 2013; Manthorpe & Samsi, 2016; Mullan & Sullivan, 2016; Smythe et al., 2015; Willis et al., 2009; Wojtak & Klopp, 2015). The final characteristic that PSW noted was that care providers need to be passionate about providing quality care to PLWD. Being passionate is necessary in quality care because having passion for working with PLWD validates

care providers in knowing that they provide meaningful care (Denton et al., 2002; Kirkley et al., 2011; Low et al., 2013; Mullan & Sullivan, 2016; Ryan et al., 2004; Sims-Gould et al., 2010; Smythe et al., 2015). These experiences, abilities and characteristics reported by the PSW have implications on what can help them to provide quality dementia home care and on the characteristics employers may want to look for when recruiting home care staff to provide quality dementia home care. The Ontario policy documents do not discuss any specific experiences, abilities or characteristics that may help home care workers provide quality dementia home care. This may be strategic because explicitly listing these items in provincial policies might have the negative consequence of restricting employment opportunities in a field facing recruitment and retention challenges.

The number of consistencies between the analyses of the PSW interviews and the provincial policy documents suggests that the policy documents reflect positive alignment to aid in the provision of quality dementia home care. However, implications exist in the areas of differences between the sources of data. Importantly, policy documents need to revise the language they use to support and encourage holistic person-centred care instead of focusing on patient-centred care. Further, while PSW perspectives of quality home care align with the policy documents, the PSW reported several instances where they are experiencing the realities of home care as the opposite of what they perceive for quality dementia care. Specifically, while the importance of an interprofessional dementia care team is undisputed among the PSW and policy documents, PSW consistently described not feeling like a part of a team when working in home care. Additionally, policy documents and PSW indicated that home care organizations need to provide formal caregivers with adequate information about their clients and ongoing training, but unfortunately in reality, PSW often do not receive either of these supports. This suggests that policies need to be both revised and be implemented fully in the home care sector to ensure the provision of quality home care to all PLWD in Ontario. Incorporating both the perspectives and experiences of PSW in providing quality dementia home care in the creation and implementation of provincial policy is of great importance.

## 4.2 Alignment of PSW Perspectives and Provincial Policy Documents with Health Quality Ontario’s Quality Standards for Dementia Care for People Living in the Community

As mentioned in the literature review, a framework was developed from Health Quality Ontario’s quality standards for dementia care for people living in the community (see Figure 1) to compare the results from the policy and interview analyses and to understand fully how these findings align with Ontario’s current gold standard for community dementia care. This section will demonstrate how each of the 10 quality standards compare to the results from the policy analysis and the interview analysis (see Table 4 below).

**Table 4**

*Comparison of Health Quality Ontario’s Quality Standards to PSW Interview and Provincial Policy Analyses.*

<b>Health Quality Ontario’s Quality Standards for Dementia: Care for People Living in the Community</b>	<b>Found in PSW Interview Analysis</b>	<b>Found in Provincial Policy Analysis</b>
1. Comprehensive Assessment & Diagnosis	X	
2. Interprofessional Care Team	X	X
3. Individualized Care Plan	X	
4. Named Point of Contact		
5. Education & Training for PLWD & their Caregivers	X	X
6. Education & Training for Health Care Providers	X	X
7. Access to Support Services	X	X
8. Caregiver Assessment & Support	X	X
9. Safe Living Environment	X	
10. Access to Primary Care		

The first quality standard is a comprehensive assessment and diagnosis when “signs are first identified” (Health Quality Ontario, 2017b). This standard states that the assessment and diagnosis should be completed by a physician with expertise in diagnosing and treating dementia. The interview analysis revealed that PSW perspectives aligned with this quality standard, noting that PLWD need to receive an early diagnosis to access the supports they need. PSW also reported that PLWD need to be reassessed as

the dementia progresses. While PSW did not comment that the assessment and diagnosis should be performed by a physician with expertise in dementia, a few PSW did imply this, highlighting that family doctors need to be involved in assessing and diagnosing dementia. The policy documents did not include a comprehensive assessment. There is limited discussion throughout the policy documents of people needing an early diagnosis of dementia to access the services they need early.

The second quality standard is having an interprofessional care team available to PLWD. Importantly, care teams need members from multiple disciplines with expertise in dementia care and involve PLWD and their family caregivers. Both analyses stated the importance of collaboration among an interprofessional care team. Some PSW highlighted that they consider family caregivers to be a valuable part of the care team and communication with them is of the utmost importance in the care of a person with dementia. While some of the policy documents stated the value of involving people in their care, only one document expressed that people and their caregivers are to be a part of the “circle of care” (Bringing Care Home, 2015).

The third quality standard is an individualized care plan that identifies the needs of PLWD and their caregivers, and goals of care. This quality standard noted that care plans need to be reviewed and updated on a regular basis for PLWD, which should be every 6 to 12 months. Further, care plans need to be accessible to everyone involved in care including the person with dementia, their caregivers and all members of the interprofessional care team. Similarly, PSW reported the necessity of individualized care plans for PLWD to be updated regularly and accessible to anyone providing care to that individual. The need for an individualized care plan for PLWD only had limited discussion within two of the policy documents. Bringing Care Home (2015) stated that clients and families need to be actively involved in the creation of the care plan and that care plans need to be shared with all members of the care team. The other policy document, Dementia and Home Care (2017), only briefly noted that a “plan of care” should support people and their families.

The fourth quality standard is having a named point of contact that facilitates communication and continuity of care, especially in transitions across settings. Health Quality Ontario highlighted that having a named point of contact is an essential

component of person-centred dementia care. Only one PSW mentioned anything about case managers in the care of PLWD, saying that they only experience what is going on for a client when they are actually in the home to do an initial assessment. The policy documents also have limited discussion of the importance and benefits of having a named point of contact available to help PLWD, their caregivers and other members of the care team. With the limited discussion of a named point of contact found in both analyses, this was not found as a significant part of quality dementia home care in this research study. Contrastingly, existing literature aligns with this standard by demonstrating the importance of case management in the delivery of quality home care for PLWD (Dalby & Hirdes, 2008; Low et al., 2013; Low & Fletcher, 2015; Tam-Tham et al., 2016; Zabalegui et al., 2014).

The fifth quality standard is education and training for PLWD and their caregivers. Specifically, PLWD and caregivers need to receive dementia-specific education including self-care strategies, dementia types, signs and symptoms, techniques for de-escalation and behavioural management, and adaptive communication strategies. Both analyses highlighted the importance of family caregivers receiving education and training. The policy documents did not report on providing education and training to PLWD, however, PSW noted that PLWD should receive education. The PSW also aligned further with this quality standard by specifically noting the kind of education and training PLWD and caregivers should be receiving, mentioning that education needs to provide information of the signs of symptoms of dementia, behavioural management techniques and strategies for effective communication.

The sixth quality standard is education and training for health care providers, specifically, the knowledge and skills to effectively deliver care that meets the needs of PLWD. Accordingly, the standard recommends that dementia-specific education and training should include: person-centred care; dementia signs, symptoms, disease progression and types; early identification of behavioural and psychological symptoms of dementia and techniques for de-escalation and management; appropriate use of nonpharmacological and pharmacological treatments; self-care and safety for health care providers; how to communicate with PLWD; and how to coordinate multidisciplinary care. Both sets of data closely aligned with this quality standard, reporting the necessity



of health care providers to receive dementia-specific education and ongoing training. The PSW specifically noted needing education and training that includes knowledge about dementia, how to handle difficult situations, how to monitor for changes, how to communicate effectively with PLWD and how to interact with family caregivers. Interestingly, the PSW reported needing to be able to practice self-care while providing care to PLWD, but did not state they need education on self-care. The policy documents noted that dementia-specific education and training needs to be available to every care provider and include information about dementia and how to work effectively within an interprofessional care team.

The seventh quality standard is timely access to a variety of support services that are individualized and meet the ongoing needs and goals of PLWD. Further, PLWD and their caregivers need access to information about available services and care providers should be able to advise them on this and how to access the services. The PSW and policy documents reported that PLWD need access to a variety of support services that are flexible and individualized. They both also agreed that PLWD and their caregivers need to receive information regarding the available services and how to access them, which can come from care providers or through written resources.

The eighth quality standard is ongoing caregiver assessment and supports to meet their individual needs. The ongoing assessment of caregivers should evaluate how they are managing in their caregiving responsibilities. Caregivers also need tailored supports and services, especially respite services. Both analyses overlapped with this quality standard and support the need for caregivers to be assessed separately from their loved one with dementia and be provided with individualized supports to meet their needs. Further, both the PSW and the policy documents emphasized the high level of importance they place on providing respite to family caregivers of PLWD, so they can continue being a caregiver.

The ninth quality standard is providing PLWD with a safe living environment. According to Health Quality Ontario, a safe living environment should be able to meet the needs of PLWD with individualized design modifications and accessible housing options offering more supportive living environments. The analysis of the PSW interviews revealed they also emphasized the importance of PLWD having a safe

environment. Further, PSW also noted that this environment may need to change as the person changes, either through modifications to the home or access to long-term care when it is needed. Contrastingly, the policy documents did not explicitly state the need for PLWD to have a safe living environment. Instead, only two of the documents noted that clients need access to safe care and to be able to remain safe in the community.

The tenth and final quality standard is access to primary care, with PLWD having regular visits with a primary care physician every 3 to 6 months. Primary care providers need to provide person-centred, comprehensive, and coordinated care to meet the often complex needs of PLWD. Both the PSW and the policy documents rarely highlighted the need for the involvement of a primary care provider. A few PSW only discussed a client's family doctor in terms of the fact that they can be a good part of the client's care or have no involvement in it. Additionally, PSW noted that doctors need to be patient with PLWD, especially since families can struggle to get them to scheduled appointments. One of the policy documents directly agreed with this statement by mentioning that an involved primary care provider is critical to successful home care.

It is clear that the Health Quality Ontario quality standards for care of PLWD living in the community have greater alignment with perspectives of PSW than current provincial policy documents. Additionally, there is alignment in the emphasis of person-centred care that PSW promoted for quality dementia care and the person-centred language found throughout this quality standard document. PSW did not perceive named point of contacts and primary care providers as directly important to quality dementia home care. Not having regular interactions with other care providers may be contributing to this perception. This suggests that PSW need to be better involved and acknowledged as integral care team members for them to recognize and appreciate the contributions of other interprofessional care team members. The limited discussion of five out of the ten quality standards analyzed in the policy documents shows a lack of alignment between the policy documents and Health Quality Ontario's current gold standard for quality dementia home care. Ultimately, this suggests a gap in the current provincial policies to support fully the provision of quality dementia care in a home care setting. The creation of future provincial policies to guide the delivery of quality dementia home care needs to consider and align better with these quality standards.

### **4.3 Implications for Research, Policy and Practice**

Findings from this research have implications for research, policy and practice. This research study captured the in-depth perceptions of PSW in providing quality dementia home care. To explore fully the notion of quality dementia home care provision, future research needs to analyze the perspectives of more stakeholders, including perspectives of policy makers and other members of the interprofessional care team, such as home care managers, primary care providers, nurses, occupational therapists, physiotherapists, and compare them to the perspectives of PSW. Ensuring that all members involved in the care teams for PLWD have similar perceptions of quality care is vital for a multidisciplinary team approach to quality dementia home care. Additionally, future research should explore perceptions of quality care by PLWD and their family caregivers. The study findings highlight the importance placed on person-centred dementia care, which requires input from PLWD and their family caregivers. Another area for future research is exploring self-care practices of home care PSW. Current study findings showed that providing dementia care can be especially challenging for home care providers and being able to practice self-care techniques is vital for providers in continuing to deliver quality dementia care. Health Quality Ontario's dementia standards is the only document that mentioned briefly the need for health care providers to be educated and trained on self-care. Ultimately, the gap in research regarding the practice of self-care among home care providers needs to be addressed to explore further its impact on the provision of quality dementia home care.

As highlighted previously, one of the major differences between the perceptions of quality dementia home care of PSW and the policy documents was a difference in equating person-centred care to quality care for PLWD. Future policies need to use person-centred care in content and in the language used to support the delivery of quality dementia home care for all Ontarians. Further, the current Ontario home care policy documents do not align enough with the Health Quality Ontario dementia standards to guide fully and support the delivery of quality dementia care. The government of Ontario needs to create future home care policies that take a holistic view of person-centred care for PLWD and encompass and align with the quality standards outlined by Health Quality Ontario. Additionally, the findings from this research demonstrate the valuable

perspectives key stakeholders have. Unfortunately, policymakers do not always consult these stakeholders when creating policies. Therefore, the development of future policies about dementia home care need to be informed by the people who have experiential knowledge of quality dementia home care.

Finally, the findings from this research also have several implications on the practice of home care in Ontario. Improvements need to be made within the home care sector to allow for the policies to be completely implemented in practice. PSW often had similar views to the policy documents as to what is involved in quality home care for PLWD. However, what PSW perceive as quality dementia home care does not match their experience in home care. For policies to have any impact in the provision of quality dementia home care, they need to be implemented fully within the home care sector. For example, it is recommended that quality assurance check-ins are preformed regularly in home care. These quality assurance measures may include home care client and caregiver satisfaction surveys as well as ongoing check-ins with front-line workers. Additionally, home care organizations can utilize the quality indicators created by Health Quality Ontario to measure various areas of quality dementia home care.

Another important finding was that the analyses and literature align in emphasizing the importance of having an interprofessional care team available for PLWD and their family caregivers. In contrast, PSW reveal that there is a lack of teamwork and they do not feel included in an interprofessional care team even though they provide the bulk of direct formal care to PLWD. Having a fully inclusive care team is beneficial for PLWD and recognizes the value of PSW in home care. An additional finding in this study was the need for home care providers to be educated and trained in specific areas of dementia. Education and training programs for health care providers need to be expanded upon to make sure vital topics related to quality dementia home care are taught. Some of these topics include behavioural management and communication strategies, person-centred training, and how to work within an interprofessional care team. Further, the PSW provided insights on how this information can be effectively taught to them, specifically through including experiential components into their education and training. As highlighted by Health Quality Ontario's quality standards, health care providers should also be taught about self-care strategies they can use to continue providing quality

care to PLWD. While the PSW discuss self-care as an ability helpful in the provision of quality care, fostering this ability through education and training is beneficial for ensuring anyone providing care to PLWD is able to use it. Therefore, it is recommended that home care providers' education and training include information about the importance of practicing self-care and how they can utilize it while providing care.

Finally, not all of the participants were employees of home care organizations. Four out of the fifteen PSW provided care to private home care clients. These four PSW often held similar perspectives surrounding quality dementia home care, however, they reported different experiences. All of the PSW who provided private care to PLWD mentioned that they had more time for caring, can better complement their clients' schedules, and have the opportunity to get to know their clients very well. These differences show that there are opportunities to facilitate better the person-centred care PLWD need when care is not provided under the currently under-resourced home care system. Therefore, the final recommendation is that the structure and funding for Ontario's home care system be improved to ensure both publicly and privately funded home care providers have the appropriate resources to deliver quality home care to PLWD. Specifically, the structure of the home care system needs to ensure that high levels of organizational supports are in place for home care providers. These organizational supports need to be in the form of increased wages that recognize the work of home care providers, sufficient and qualified staffing, and increased exchange of client information. Ultimately, the funding provided to the home care system needs to be increased to ensure these organizational supports are consistently available across Ontario.

#### **4.4 Limitations**

A limitation of this study was that the scope of this research was limited to exploring the perspectives of PSW. As discussed in the previous section, the perspectives of all key stakeholders need to be explored to gain a full and complete understanding of quality dementia home care. However, understanding their perspectives on this matter is a suitable starting point considering the important role PSW have in the delivery of home care for PLWD. Another limitation was the recruiting process for this study. An email describing the research study was sent to several home care organization managers asking

them to relay the information to their PSW employees. Therefore, there had to be reliance on the individual managers to disseminate the study information. This resulted in only a few managers replying that they would pass along the information to potential participants. While enough participants were interviewed to reach saturation (n=10), this recruitment process meant that the participants who expressed interest and were interviewed only came from four home care organizations. This meant that potential alternative perspectives regarding quality dementia home care that PSW working for other home care organizations could not be explored. A final limitation was that not all of the participants provided home care as employees of a home care organization, with four PSW providing home care to private clients (see Table 1). This did impact the results by indicating that privately funded PSW are generally better able to provide quality person-centred care because they have more time, are more flexible around their clients' schedules and consistently provide care to individuals. This was often achievable for the privately funded PSW because they saw the same few private clients weekly and received a higher pay per hour. The implications of this are discussed above.

#### **4.5 Conclusions**

As the prevalence of dementia rises, so does the demand for a sustainable healthcare system that can safely and effectively provide care for PLWD at home. The goal of this study was to compare PSW perceptions of quality dementia home care with Ontario home care policy documents. Study findings suggest that the perspectives of PSW and policy documents align in their discussions surrounding the need for a collaborative interprofessional care team approach; dementia-specific education and training for health care providers; accessible services, information and education to support PLWD and their family caregivers; and increasing the respect and supports that home care providers receive from their employers. A major difference that was found between the PSW and the policy documents is PSW encompassing a holistic view of person-centred care in the provision of quality dementia care. Another difference was that specific experiences, abilities and characteristics can help care providers in the delivery of quality dementia home care. Findings also suggest a difference in what PSW perceive as quality dementia home care versus what they are actually experiencing when providing care. Further, this research found that the Health Quality Ontario quality standards for care of PLWD living

in the community have greater alignment with perspectives of PSW than the current provincial policy documents. Ultimately, the findings of this study contribute to the limited amount of research on perspectives of quality dementia home care, especially in relation to how the implementation of Ontario home care policy documents impact the provision of quality home care for PLWD in the community.

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# Appendices

## Appendix A: HSREB Initial Application Approval Letter



**Date:** 15 October 2019

**To:** Dr. Marie Savundranayagam

**Project ID:** 114109

**Study Title:** The Experiences of Personal Support Workers in the Provision of Quality Dementia Home Care

**Application Type:** HSREB Initial Application

**Review Type:** Delegate

**Full Board Reporting Date:** 05November2019

**Date Approval Issued:** 15/Oct/2019 09:13

**REB Approval Expiry Date:** 15/Oct/2020

Dear Dr. Marie Savundranayagam

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

**Documents Approved:**

Document Name	Document Type	Document Date	Document Version
Demographic Information Data Collection Tool - September 30, 2019	Other Data Collection Instruments	30/Sep/2019	1
Home Care Organization Email - September 30, 2019	Email Script	30/Sep/2019	2
Interview Guide - September 30, 2019	Interview Guide	30/Sep/2019	2
Letter of Information and Consent - October 9, 2019	Written Consent/Assent	09/Oct/2019	4
Recruitment Email Script - September 30, 2019	Email Script	30/Sep/2019	2
Recruitment Poster - September 26, 2019	Recruitment Materials	26/Sep/2019	2
Recruitment Telephone Script - September 30, 2019	Telephone Script	30/Sep/2019	2
Research Plan - September 12, 2019	Protocol	12/Sep/2019	

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Nicola Geoghegan-Morphet, Ethics Officer on behalf of Dr. Philip Jones, HSREB Vice-Chair

*Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).*



## Appendix B: Letter of Information and Consent

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Health Studies

### Letter of Information

**Project Title:** The Experiences of Personal Support Workers in the Provision of Quality Dementia Home Care

**Principal Investigator:**

Marie Savundranayagam, PhD, Western University, School of Health Studies.

**Co-Investigator:**

Rachel Breen, MSc candidate, Western University, Health and Rehabilitation Sciences Program.

**Contact Information:**

Marie Savundranayagam, PhD: Phone [REDACTED] email [REDACTED]

Rachel Breen, MSc candidate: email [REDACTED]

#### **1. Invitation to Participate**

You are being invited to participate in a research study that explores what perceptions you, a personal support worker, have in relation to providing quality dementia home care to people living in the community. This is a student project that is part of the requirements for Ms. Rachel Breen to complete her master's degree at Western University. You are being asked to participate in this study because of your experience in providing home care to persons living with dementia.

#### **2. Purpose of the Letter and Purpose of this Study**

The purpose of this letter is to provide you with the information required for you to make an informed decision regarding your participation in this research.

The goal of this research is to explore how the experiences of personal support workers (PSWs) fit within the home care system in Ontario. By examining the experiences that PSWs have, in specifically providing quality home care for people diagnosed with dementia, it will be made clear what steps go into providing quality care and what resources are available to PSWs as caregivers. Understanding these perceptions of quality dementia home care is important, given the rise in prevalence of dementia that is expected to take place in the near future.

#### **3. Inclusion Criteria**

Personal support workers who meet the following criteria are eligible to participate in this study:

- Age 18 years or older
- Speaks and understands English
- Currently employed as a PSW or health care aide within Ontario
- Employed to provide home care
- Has a minimum of 6 months of experience providing home care to individual(s) with dementia
- Consent to having interview audio-recorded

#### **4. Exclusion Criteria**

Individuals who do not meet all of the criteria listed above are not eligible to participate in the study.

## **5. Length of Involvement**

Your participation in this study involves one interview that is approximately 60 minutes in length.

## **6. Study Procedures**

Your participation in this study would involve a face-to-face, telephone or teleconference (via Zoom) interview discussing your perceptions of quality dementia home care. Interviews will be scheduled at a date, time, and public location that is most convenient for you. It is anticipated that the interview will be approximately 60 minutes, however, you are welcome to take as much time as you need. Interviews will be audio recorded for analysis. After your interview, the audio recording will be typed and analyzed using qualitative content analysis. All typed interviews will not include your name and will be kept private. That is, all content that can be linked directly to you will be changed so that the information cannot be traced back to you. Qualitative content analysis will allow for themes to emerge and be compared from what is said in the interviews.

Member checking is a procedure that includes the interviewer restating your responses at the end of your interview, in order to achieve an accurate understanding of what was said. It also includes sharing a summary of your interview data at the end of the analysis process to assess if the summary reflects your views, feelings, and experiences. If you are interested in being a part of member checking, let the research team know, and another time will be scheduled to go over the summary data in person, via telephone or via teleconferencing. If you are interested in receiving a copy of your interview summary data, an in-person interview will be set up in order for the copy of the summary data to be given directly to you. In total, approximately 10 to 15 personal support workers will be interviewed for this study.

## **7. Possible Risks, Harms, and Inconveniences**

When communicating with the research team via email, there is a risk of privacy breach since email is not necessarily a secure form of communication. Also, while safeguards have been put into place to protect your privacy and confidentiality, there is still a risk of privacy breach throughout the research process

For some individuals, there may be a risk for stress or anxiety while recounting work experiences with clients with dementia. Providing rest breaks will help to minimize potential stress, anxiety, and/or discomfort.

There may also be a risk of stress and anxiety related to questions about quality of care and participants feeling the care they provide is not considered to be quality. In this circumstance, please know that the definition of "quality" is subjective, which is why it is being studied. Your opinions and experiences are valuable.

## **8. Possible Benefits**

There are no direct benefits to participating in this study. You may gain a greater understanding of what providing quality dementia home care means to you, which may lead to benefits in your professional life.

### **9. Voluntary Participation**

This study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. If you withdraw from the study, your data collected up until the point of your withdrawal will be kept in the study. Your decision will not impact your current or future employment.

### **10. Confidentiality**

All data collected will remain private and accessible only to the investigators of this study. Anything that could identify you personally will be removed from the audio recording and the transcribed version of the audio recording.

Signed letters of information and consent will be stored in a locked cabinet in the Sam Katz Community Health and Aging Research Unit (Room 316, Arthur & Sonia Labatt Health Sciences Building). Electronic data will be stored on Western's secure network drive (R drive in the CaRE Laboratory located at the Arthur & Sonia Labatt Health Sciences Building) and on cloud-storage using OneDrive. Audio-recordings and transcriptions of the interviews will be stored on Western's secure network drive and on cloud-storage using OneDrive. The electronic data will be destroyed/deleted after 7 years in accordance to University of Western Ontario policy.

Representatives of Western University Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

### **11. Compensation**

You will not be paid or rewarded for your participation in this study. There is minimal cost to participating in this study as interviews will be scheduled for a time and public location that are convenient to you.

### **12. Rights of Participants**

You have the right to not answer any questions that you do not want to or do not feel comfortable answering.

### **13. Contacts for Further Information/Questions about Study**

If you require any further information regarding this research project or your participation in the study, you may contact any of the following individuals:

- Marie Savundranayagam, PhD: [REDACTED] email [REDACTED]
- Rachel Breen, MSc candidate: email [REDACTED]

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics. Telephone (519) 661-3036; email: [ethics@uwo.ca](mailto:ethics@uwo.ca)

**14. Publication**

If the results of this study are published, your name and audio recordings will not be used. Direct quotes may be used in publication. If direct quotes are used, they will adhere to what was said in the *Confidentiality* section and will not include anything that could identify you personally. The results of this study may be presented at research conferences or community meetings. The results of this study may be published in the form of research articles and the thesis of Ms. Breen.

*This letter is yours to keep for future reference*

**Consent Form**

**Project Title:** The Experiences of Personal Support Workers in the Provision of Quality Dementia Home Care

**Principal Investigator:**

Marie Savundranayagam, PhD, Western University, School of Health Studies.

**Co-Investigator:**

Rachel Breen, MSc candidate, Western University, Health and Rehabilitation Sciences Program.

I have read the Letter of Information, have had the nature of the study explained to me, and I agree to participate. All questions have been answered to my satisfaction. I do not waive my legal rights by signing the Consent Form.

Participant's Name (please print): \_\_\_\_\_

Participant's Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Person Obtaining Informed Consent (please print): \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## **Appendix C: Interview Guide – Version date 30/09/2019**

Interviews will be semi-structured around these questions to get an in-depth understanding of how personal support workers perceive quality dementia home care.

“During this interview, you will be asked a few questions about your experiences and opinions related to provided quality dementia home care. You can take as long as you need to answer each question and can skip questions by saying “pass”. If you need to take any breaks, please feel free to let me know. Do have any questions for me, before we begin? The interview and audio recording will begin now.”

- Tell me about providing home care to people living with dementia.
- How would you define high-quality dementia home care?
- What enables you to provide high quality dementia care in a home care setting?
- Are there any challenges you have faced in providing quality dementia home care to clients?
- How do you think these challenges can be resolved?

## **Appendix D: Sample of Self-Reflection Notes**

September 27, 2019

Yesterday, I completed the coding and sorting the codes into sub-categories and categories of the first of the policy documents. I decided to start with Patients First because it is the most recent major policy change. Today, I revisited the literature on qualitative content analysis and noticed that I have made a mistake in how I am coding the data and sorting the categories. It is clear from Bengtsson (2016) that data cannot fall between two categories and should not fit into more than one group. However, I have certain codes that I felt were similar and could go into two different sub-categories while I was separating the codes. When I looked back at each of these codes, I recognized that each time this happened it was because the code was too broad and could go into two sub-categories because I had connected ideas with “and”. I need to look over this document again and make sure I am coding so that only one idea is in each code so that the codes can be abstracted into appropriate sub-categories and categories. I also need to be sure I continue this while coding the rest of the policy documents and the interview transcripts in the future.

November 14, 2019

I just held my first interview with a participant. The interview was done over the phone and I difficult to gauge how the participant was truly feeling because there was no facial expressions or body language to read into. There seemed to be a lot of pauses during the interview and I felt that it was sometimes difficult to tell whether these were caused by the participant thinking about how to answer or if they were done and had already said what they wanted to say. I also feel like because I could not non-verbally, follow along with what this participant was saying, I resorted to saying things like “okay” and “mhmm” often. When interviews are done in-person I think that nodding my head will be more effective because then I am not potentially disrupting their train of thought. However, because I am sure there will be other interviews conducted over the phone, I need to make sure that I am not resorting to saying “okay” and “mhmm” so often so that I can make sure I am letting each participant finish all of their thoughts.

January 22, 2020

The interview I conducted today took place in a very noisy environment. Because the interviews are held in public locations, there really was not anyway for me to adjust this loud environment. I tried my best to think about how to potentially minimize the distractions of this busy and noisy environment by finding a table in the corner of the coffee shop and positioned myself so that my back was against the wall, which meant that the participant was facing me and the wall and not the busy environment. However, at times the noisy environment was compounded with the participant talking quietly. I need to keep this in mind when transcribing and listening to the audio recording because these factors may affect the overall quality and accuracy of the transcript. I also may need to reconnect with this PSW in order to verify that I have correctly transcribed their perspectives if there are gaps in the audio recording.

## **Appendix E: Demographic Information Collection Tool**

All of this demographic information will be collected from the participants just before the interviews, to describe the sample of participants for the interviews. All data will be saved separately from the master list and saved electronically.

What is your age?

What is your sex?

Where did you receive your training as a PSW?

How long have you provided care in the home care sector?

Approximately how long have you been providing care to people living with dementia in the home care sector?

What home care organization do you work for?



## Curriculum Vitae

**Name:** Rachel Breen

### **Post-Secondary Education and Degrees:**

Western University  
London, Ontario, Canada  
2014-2018, Hon. HSc (Health Science)

Western University  
London, Ontario, Canada  
2018-2020, MSc (Rehabilitation and Health Sciences – Health and Aging)

### **Related Work:**

Teaching Assitant  
Western University, 2018-2020

### **Presentations:**

Health & Rehabilitation Science Graduate Research Conference  
Western University, 2020

3-Minute Thesis  
Western University, 2020