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# The Continuous Learning Needs of Personal Support Workers Who Care For People Living with Dementia in Long-Term 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 (PSWs) comprise over half of the long-term care (LTC) workforce who care for people living with dementia yet are considered less skilled compared to other healthcare professionals. Improvements to dementia education from the perspectives of PSWs are under-explored. To address this gap, this study investigated PSW perspectives of their dementia-specific learning needs in LTC. Guided by Interpretive Description (Thorne, 2016) and adult learning theory (Knowles, 1990), four major learning needs were discerned through a secondary qualitative analysis: understanding dementia, addressing responsive behaviours, person-centered communication and attitudes, and delirium. Learning needs are best met in supportive environments with experiential methods that involve peer learning, feedback, and evaluation. Successful learning is mediated through an openness to learning and a good teamwork culture. The findings underscore the importance of ongoing dementia education tailored to the needs of PSWs, with implications for future training programs aimed at improving dementia care.

Keywords: Dementia, personal support workers, formal caregivers, learning need assessment, education, training, long-term care, qualitative secondary analysis.

## Summary for Lay Audience

When it comes to providing care to people living with dementia in long-term care homes, personal support workers (PSWs) provide the most out of any healthcare professional. Despite this, PSWs are considered the least skilled due to the lack of comprehensiveness in their formal education and few opportunities for continuous education throughout their career. As a result, the quality of dementia care is compromised. Improvements to dementia education from the perspectives and needs of PSWs have been under-explored. To address this knowledge gap, this study investigated PSW perspectives of their dementia-specific learning needs while working in long-term care homes. Interpretive Description (Thorne, 2016) and adult learning theory (Knowles, 1990) were used to guide a secondary qualitative analysis of 22 one-hour focus groups with 39 PSWs working in long-term care settings across London, Ontario. Three major findings were discerned from the data: 1) gaps in dementia-specific competencies (i.e., the learning needs), 2) how the gaps should be addressed (i.e., learning methods), and 3) contextual factors that can influence the application of knowledge into practice (i.e., mediators). The gaps in dementia-specific competencies were attributed to limited preparation during formal PSW education and a lack of continuous training opportunities. PSWs wanted additional education concerning dementia, how to address responsive behaviours, how to use person-centered communication and attitudes, and understanding and recognize delirium among persons living with dementia. These topics are best met within a supportive peer environment with opportunities to learn from coworkers through feedback, groups discussions, observations, and experiential learning activities. For education to translate into practice, PSWs needed to be open to learning from both educational programs and their coworkers. The findings underscore the importance of ongoing dementia education tailored to the needs of PSWs, with implications for future training programs aimed at improving dementia care.

## Co-Authorship Statement

This thesis is composed of original work conducted and written by Grace Irene Norris in fulfillment of a Master of Science under the supervision of Dr. Marie Y. Savundranayagam. The thesis includes an introductory chapter (chapter one), an integrated manuscript (chapter two), a secondary qualitative data analysis (chapters three and four), and a concluding chapter (chapter five). Chapter two was published in the *Educational Gerontology*, a peer-reviewed journal, on May 21<sup>st</sup>, 2024 (citation below). A manuscript for the remaining chapters of this thesis is in progress for publication. The data analyzed in chapter four was collected by Dr. Savundranayagam and members of the Sam Katz Community Health and Aging Research Unit at the University of Western Ontario.

Dr. Savundranayagam provided invaluable guidance in the design, analysis, interpretation, and written conceptualization of all chapters within this thesis. Additionally, the advisory committee, Dr. Ashfin Vafaei and Dr. Gail Teachman, provided significant intellectual guidance and input regarding the design, interpretations, and written conceptualizations of all chapters within this thesis. In addition, all mentioned collaborators provided revisions and feedback on all chapters.

Citation (chapter two):

Norris, G., Savundranayagam, M.Y., Vafaei, A., & Teachman, G. (2024). The representation of personal support workers in dementia-specific learning need assessments: a scoping review. *Educational Gerontology*.

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# Chapter 1

## 1 Introduction

### 1.1 Background

#### 1.1.1 Dementia

A dementia diagnosis occurs every three seconds (Alzheimer's Disease International, n.d.; World Health Organization, 2023). In 2020, over 500,000 Canadians were living with dementia (Alzheimer Society of Canada, 2022). Within ten years, this number will reach one million (Alzheimer Society of Canada, 2022). Dementia is classified as a chronic neurodegenerative syndrome causing significant deterioration in cognitive functioning (Alzheimer's Disease International, n.d.; World Health Organization, 2017). The deterioration commonly targets areas of the brain responsible for memory, executive functioning, comprehension, verbal communication, navigational abilities, judgement, and motor skills (World Health Organization, 2023). As a result, the ability to verbally communicate about physical, social, spiritual, occupational, and emotional needs can become increasingly difficult (American Psychiatric Association, 2022; Eggenberger et al., 2013; Kitwood, 1997). A person living with dementia may communicate their unmet needs through physical behaviours (e.g., resisting care, pushing, kicking) and/or vocalizations (e.g., yelling, crying, repeated questioning), referred to as responsive behaviours (Clifford & Doody, 2018; Whall & Kolanowski, 2004). It can be equally distressing to both persons living with dementia and their caregivers when the latter is unable to understand, communicate, and provide care in ways that meet these needs, and can result in physical harm (Holst & Skär, 2017; Whall & Kolanowski, 2004). Due to the severity of symptom progression, dementia is considered a major cause of disability and dependency among older adults (World Health Organization, 2017), requiring specialized and high quality care provision.

Person-centered care constitutes the philosophical foundation for optimal dementia-specific services and support standards (Alzheimer Society of Canada, 2014; Breen et al.,

2022). Person-centered care involves recognizing a person living with dementia as a unique individual with feelings, experiences, values, and preferences, which are incorporated and considered into care practices (Kitwood, 1997; Savundranayagam et al., 2016). It promotes a high quality of care by equipping caregivers with the knowledge, skills, and attitudes (collectively referred to as ‘competencies’) to provide care that focuses on understanding and responding to the unique needs, preferences, and experiences of each person (Kitwood, 1997). Person-centered care principles promote the development of meaningful relationships with persons with dementia, personalized care provision, prioritization of emotional and psychological well-being, creating supportive environments, and empathetically understanding the experiences and feelings of a person living with dementia (Breen et al., 2022; Kary et al., 2020; Kitwood, 1997). For instance, Cohen and colleagues (2022) found that caregivers with person-centered attitudes were able to positively and effectively interact and communicate with persons with dementia, interpret meanings behind responsive behaviours, and address needs more easily than staff without person-centered attitudes. The provision of person-centered care is significantly important to persons living with dementia, as they are often viewed through a perspective of loss (e.g., loss of memory and cognitive abilities) or behavioural symptoms (e.g., aggressive, difficult to care for, unable to socially engage), placing them at risk for depersonalized care and no longer being viewed as a person (Holst & Skär, 2017; Kitwood, 1997). Therefore, ensuring caregivers are equipped adequately with the competencies to provide person-centered care, is essential for high quality dementia care.

### 1.1.2 Long-Term Care

Many individuals living with dementia rely on long-term care services (Sethna, 2013). As of 2023, there are 626 long-term care homes in Ontario with approximately 63% of residents living with dementia (Office of the Auditor General of Ontario, 2023). The purpose of long-term care homes is to provide 24/7 essential care to individuals who are not able to access care in the community or care for themselves (Office of the Auditor General of Ontario, 2023). Long-term care services include nursing (e.g., medication administration) and personal care (e.g., assistance with activities of daily living), therapeutic services (e.g., physiotherapy), dietary services, and recreational programs

(Office of the Auditor General of Ontario, 2023). The fundamental principle of long-term care homes is defined in Section One of the *Fixing Long-Term Care Homes Act, 2021*, as a place where residents “may live with dignity and in security, safety and comfort and have their physical, psychological, social, spiritual and cultural needs adequately met” (Government of Ontario, 2023), underscoring a person-centered model of care.

Yet, long-term care homes have consistently reported inadequate working conditions which fail to meet the needs of persons living with dementia and foster a culture of dignity and respect among both residents and staff (Baines & Armstrong, 2018; Office of the Auditor General of Ontario, 2023; Ostaszkievicz et al., 2020). The prioritization of profits over the quality of care has resulted in under-valuing and under-supporting long-term care staff and perpetuating a “task-oriented” culture of care rather than a “person-centered” one (Lightman, 2022; Savundranayagam et al., 2021). PSWs represent over half of the long-term care workforce and provide 80% of daily direct care to persons living with dementia (Chamberlain et al., 2019; Ministry of Long-Term Care, 2020; Public Health Agency of Canada, 2021). However, PSWs consistently report feeling unprepared, under-supported, under-pressure, and lacking confidence which contributes to work-related stress and burnout, low occupational satisfaction, and high turnover rates (Boamah et al., 2023; Kane et al., 2023; Li et al., 2021; Lightman, 2022; Rivett et al., 2019; Savundranayagam et al., 2021; Scales, 2022). The quality of care provided to residents is also compromised as care provision becomes rushed, depersonalized, and limits autonomy, dignity, and respect (Holst & Skär, 2017; Mialkowski, 2020; Rasmussen et al., 2023; Savundranayagam et al., 2016; Scott et al., 2011; Swinton et al., 2023). Persons living with dementia in long-term care homes rely on and trust PSWs to provide safe, effective, timely, and person-centered care, underscoring the importance of ensuring PSWs feel prepared, supported, and confident in their abilities to quality dementia care.

National strategies have recognized the importance of improving and building the capacity of long-term care organizations and staff to provide optimal dementia care (Public Health Agency of Canada [PHAC], 2021). This includes initiatives to improve

the quality of dementia care provided by PSWs, such as Bill 121 *Improving Dementia Care in Ontario Act, 2023*, which, upon approval, would require the Ontario Ministry of Colleges and Universities to review the PSW Training Standard (2022) to include more in-depth learning about person-centered dementia care (Kusendova-Bashta & Smith, 2023) (see below for further information regarding the PSW Training Standard). Placing a greater emphasis on ensuring PSWs receive adequate education in dementia care can significantly improve the quality of care provided to persons living with dementia (PHAC, 2021; Ministry of Long-Term Care, 2020).

### 1.1.3 PSW In Practice

The goal of PSW practice is to provide quality daily personal care and support to vulnerable individuals (Grant, 2016). PSWs provide a wide range of care activities based on the needs, desires, and well-being of the individuals they support. These include both basic (e.g., eating, toileting, etc.) and instrumental (e.g., shopping, cooking, etc.) activities of daily living, clinical care services (e.g., measuring temperature and blood pressure), and carrying out controlled acts by the Regulated Health Professions Act (e.g., administering medication) under the supervision of a regulated healthcare professional (e.g., nurse) (Government of Canada, 2021; Grant, 2016). In addition, PSWs provide mental and emotional assistance by encouraging independence, dignity, and comfort (Grant, 2016). Unlike other healthcare professionals, PSWs are not regulated or licensed by government bodies or professional associations. This means that PSWs do not have a governing body, a certification process, and standardized code of conduct (Rossiter & Godderis, 2020; Sethna, 2013).

### 1.1.4 Ontario PSW Education

An education standard for Ontario PSWs was first developed and implemented within Ontario colleges in 2014 (Grant, 2016; Kelly & Bourgeault, 2015; Ministry of Training, Colleges and Universities, 2014). Formal PSW education is offered through three distinct types of institutions: district school board continuing education programs, community colleges, and private career colleges (Grant, 2016; Ministry of Training, Colleges and Universities, 2022). While each program in Ontario is required to comply with the

*Personal Support Worker Training Standard* by the Ministry of Training, Colleges and Universities (2022), separate government branches regulate each institution (Grant, 2016). Thus, variability exists between program costs, duration, hours of clinical experience, delivery methods, degree of theoretical competencies included, and evaluation process (Brooks et al., 2008; Grant, 2016; Kelly & Bourgeault, 2015; Sethna, 2013). The training standard includes 14 ‘vocational standards’, ‘essential employability skills’, and general education requirements which students must reliably demonstrate to receive a PSW certificate and begin caring for persons living with dementia (Kelly & Bourgeault, 2015; Ministry of Training, Colleges and Universities, 2014, 2022). Out of the 14 vocational learning outcomes, one requires students to “provide client-centered and client-directed care to individuals experiencing various mental health illnesses and challenges, cognitive and intellectual impairments, and/or responsive behaviours by using supportive approaches and evidence-based practices to promote positive and safe behaviours in clients” (Ministry of Training, Colleges and Universities, 2022, p. 40). However, PSW education programs have been criticized for the content largely focusing on vocational and task-based activities with many lacking thorough dementia-related content and person-centered language (Foster et al., 2019; Grant, 2016). PSWs have reported a need for education to include more dementia-specific and person-centered content to adequately prepare them to provide optimal care within long-term care homes (Rasmussen et al., 2023). The 2014 standard was updated in 2022 to include more person-centered language and as well as three additional competencies related to dementia, namely identifying changes in an individual’s behaviour by understanding signs and symptoms of cognitive impairments (Ministry of Colleges and Universities, 2022). However, it is not well understood how these changes have addressed gaps in dementia-specific competencies. Furthermore, when PSWs enter the workforce, they rely on continuing education programs to address gaps in knowledge, skills, and attitudes left by formal education.

### **1.1.5 Dementia-Specific Continuing Education Programs**

There are several dementia-specific continuing education programs (also referred to as professional development opportunities or training programs) available across Ontario,



including Gentle Persuasive Approaches (GPA), U-FIRST, DementiAbility, and various education modules provided by the Alzheimer's Society of Canada. These programs are delivered predominantly online, with some in-person opportunities, and designed based on adult learning theory (Knowles, 1990), but vary in terms of target audience (e.g., healthcare professionals, informal care partners), cost (\$0 - 450/participant), and learning objectives (e.g., addressing responsive behaviours, self-care, understanding dementia) (Geriatric Certificate Program, n.d.-a, -b, -c). GPA was developed to teach healthcare professionals how to address, prevent, and understand responsive behaviours from a person-centered perspective, and has since become the most widely distributed dementia-specific training program in Ontario. (Advanced Gerontological Education, n.d.; Geriatric Certificate Program, n.d.-b). As of 2022, GPA is recommended in the PSW Training Standard for best practices in addressing responsive behaviours (Ministry of Training, Colleges and Universities, 2022). U-First focuses on building healthcare professionals' self-efficacy in addressing responsive behaviours and encouraging quality interactions with persons living with dementia (Geriatric Certificate Program, n.d.-c; McAiney & Service, 2005). DementiAbility builds the capacity of healthcare professionals to limit excess disability, promote independence, and enhance meaningful engagement in occupational interests among persons living with dementia (DementiAbility, n.d.). Finally, the Alzheimer's Society of Canada offers over thirteen online training modules for healthcare professionals, in addition to webinars and workshops, most of which are offered for free online and on-demand (Alzheimer Society of Ontario, n.d.). These programs cover a large range of topics including foundational information on dementia (i.e., signs and symptoms, treatments, progression, risks, etc.), palliative care, self-care, person-centered care, oral care, and transitions into long-term care (Alzheimer Society of Ontario, n.d.).

Despite these opportunities for dementia-specific continuing education, PSWs consistently report the lowest levels of confidence and competence in providing dementia care compared to other healthcare professionals (Hapsari et al., 2022; Morgan, Kosteniuk, O'Connell, Dal Bello-Haas, et al., 2016; Nguyen et al., 2022; K. Zagrodney & Saks, 2017; Zeytinoglu et al., 2009). Kosteniuk and colleagues (2016) found that

compared to nurses, PSWs are more likely to report that dementia-specific continuing education programs do not address their learning needs, acting as a barrier to participation (Kosteniuk et al., 2016). Furthermore, recent shortages in the number of incoming PSW students have drastically undermined the growing available positions and vacancies within long-term care and is not sustainable to meet the needs of the growing dementia population (Grant, 2016; Ministry of Long-Term Care, 2020). Therefore, it is critical to equip the current PSW workforce with the competencies for optimal dementia care. This can be done by developing and implementing dementia-specific continuing education programs tailored and designed to the specific learning needs of PSWs in practice.

## 1.2 Adult Learning Theory

Educational theories provide conceptual frameworks for understanding how an individual acquires knowledge, skills, and attitudes that influence their behaviour (Mukhalalati & Taylor, 2019). Educational theories for children and adolescents, referred to as pedagogy, is different compared to learning theories in adulthood, termed andragogy (Merriam & Bierema, 2013). The pedagogical model of education arose in the seventh and twelfth centuries and has since been continuously adopted worldwide as the major model of institutional education from preschool to higher education levels (Knowles, 1990). This model outlines a set of beliefs where teachers and external stakeholders are solely responsible for determining when, why, where, and what should be learned (Knowles, 1990). Pedagogy is, therefore, a teacher-oriented model of learning, where learners are passive recipients of education, with little input or control over educational decisions. Andragogy is the opposite of pedagogy. First coined by Alexander Kapp (1799-1869) and refined by Malcolm Knowles throughout the nineteenth century to be known as ‘adult learning theory’, the andragogy model is learner-oriented and places adult learners in an active, self-directed role to control educational decisions (Knowles, 1990; Sorin-Peters, 2003). This means the responsibility of deciding when, why, how, and what is learned is placed on the adult learner, promoting curriculums that are developed around the needs and interests of the students (Ahmed et al., 2021; Knowles, 1990).

Adult learning theory encompasses six principles of adult learning that constitute a foundation for understanding how and why adults make decisions about their learning. The six principles are: 1) learning must be self-directed, 2) individual experiences provide the richest resource for learning, 3) an individual's readiness to learning is intimately linked with their social roles (e.g., parent, community member, child, working citizen, etc.), 4) learning must be problem-centred, 5) internal motivation drives an adult's openness to learning rather than external motivation, and 6) the learner must understand why learning is necessary and apply it to themselves (Knowles, 1990; Merriam & Bierema, 2013). Merriam & Bierema (2013) describe adult learning theory as a "mostly humanist philosophy wherein the individual is central, internally motivated and self-directed, and engages in learning for self-fulfillment, problem solving, and greater competency in life roles" (p. 56).

Self-direction in learning assumes the adult learner to be the most knowledgeable in their own learning capacities and deficiencies, with their experiences providing the strongest foundation for learning (Knowles, 1990). Experiences provide a basis to draw on to enhance relevancy and openness to learning (e.g., relating educational content to personal experiences) and stimulate a need for learning (Knowles, 1990). An individual's motivation and readiness to learn is driven by understanding or recognizing the need to learn something to cope with real-life situations within their social roles (e.g., caring for a person living with dementia as a PSW) (Knowles, 1990). Based on these principles, education programs tailored to the learners ensure that the content is relevant and often directly applicable to the needs and contexts of its intended audience (Knowles, 1990; Laxdal, 1982). The relevancy and applicability of topics covered in education programs to PSWs' caring for people living with dementia are, therefore, best perceived by PSWs themselves, necessitating their involvement in determining what, how, and when something needs to be learned. Adult learning theory therefore provides a theoretical foundation that positions PSWs as unique healthcare professionals with a rich composite of experience and knowledge in determining learning needs in dementia care. Furthermore, the theory promotes the importance of having PSWs play an active role in

designing, disseminating, and ensuring continuing education programs are relevant to their needs.

### 1.3 Significance and Outline of the Research

The objectives of this study are two-fold: 1) identify the dementia-specific learning needs of working PSWs in long-term care homes, and 2) examine how learning needs evolve as PSWs engage in a dementia-specific training program (Be EPIC). The following chapters aimed to describe the dementia-specific learning needs of PSWs in long-term care homes across London, Ontario.

PSWs are uniquely positioned to provide optimal, frequent, and highly personalized dementia care to residents because of their consistent and prominent role in daily personal care. This also positions PSWs as individuals with a large composite of knowledge concerning the daily care needs of persons living with dementia within the long-term care context. Yet, the perspectives of PSWs regarding their needs in dementia-specific education remains under explored due their minimal representation in learning need assessments (Norris et al., 2024). Therefore, there is a significant knowledge gap regarding the learning needs of PSWs in long-term care homes who care for persons living with dementia. PSWs are provided the least comprehensive education and fewest continuing education opportunities compared to all other healthcare workers (Afzal et al., 2018; Hewko et al., 2015; Knopp-Sihota et al., 2023). As a result, PSWs consistently report the lowest levels of confidence and competence in dementia care (Hapsari et al., 2022; Morgan, Kosteniuk, O'Connell, Dal Bello-Haas, et al., 2016; Nguyen et al., 2022; K. Zagrodney & Saks, 2017; Zeytinoglu et al., 2009). Thus, education should be provided to PSWs in ways that are meaningful to their roles and address their unique learning needs.

The introductory chapter outlined relevant background information regarding my research study, including a brief description of dementia, quality of dementia care within long-term care homes, PSW education and roles, current dementia-specific continuing education programs and the study's theoretical background. Chapter two includes a

scoping review examining how PSWs are represented within dementia-specific learning need assessments and how their needs are assessed. The review presents a rationale for the current study, highlighting that PSWs' dementia-specific learning needs are largely under-explored due to their inadequate representation in academic literature. Chapter three details the qualitative methods employed in the current study, including the paradigm, methodology, research methods, rigor, and my positionality as a researcher. Chapter four presents the analytic findings of PSWs' dementia-specific learning needs, including learning methods and mediators for sustainable learning. These findings advocate for the improvement of PSWs' formal and continuing education by tailoring content and delivery to the needs of PSWs, as well as providing more equitable and ongoing opportunities for PSWs to engage in continuing education. Chapter five discusses the findings in relation to the current literature, my interpretations in relation to adult learning theory, the study's strengths and limitations, and implications for future research.

## Chapter 2

### 2 The Representation of Personal Support Workers in Dementia-Specific Learning Need Assessments: A Scoping Review

#### 2.1 Background

There is a growing pressure to equip healthcare workers with adequate competencies to care for the projected global increase in the incidence of people living with dementia (Marx et al., 2014; Public Health Agency of Canada, 2021; Rasmussen et al., 2023). Globally, over 55 million people are living with dementia (Alzheimer's Disease International, n.d.). This number is estimated to exceed 78 million by 2030 and 139 million by 2050 (Alzheimer's Disease International, n.d.; World Health Organization, 2017, 2023). Unregulated healthcare workers, such as PSWs, represent over half (65.5%) of the healthcare workers in formal care settings and provide the most daily direct care to people living with dementia in Canada (Grant, 2016; Ministry of Long-Term Care, 2020; Morgan, Kosteniuk, O'Connell, Dal Bello-Haas, et al., 2016; Rossiter & Godderis, 2020; Statistics Canada, 2021).

Despite their critical and essential role, PSWs in Canada are often overlooked, undervalued, and provided insufficient support compared to other healthcare workers (Hewko et al., 2015; Rossiter & Godderis, 2020). PSWs are the lowest-paid group of healthcare workers and are frequently considered the least skilled in the healthcare workforce (Hapsari et al., 2022; Zagrodney & Saks, 2017; Zeytinoglu et al., 2009). Relatively low wages are a common characteristic of PSW work, with the hourly range in Ontario being \$16.78-\$27.23, almost half of what nurses receive (Ministry of Long-Term Care, 2020). The ability to increase wages remains limited within government funding envelopes and therefore has caused wages to plateau over the past decade (Zagrodney et al., 2023). PSWs experience significant work-related stress and burnout rates, often due to their exposure to physically demanding activities, physical and verbal abuse, and

inadequate support (Hignett et al., 2016). Moreover, they are often not provided with the opportunities to engage in training or continuing education programs to improve or maintain their skills, especially those that are specific to PSW practice and challenges (Afzal et al., 2018; Hewko et al., 2015; Knopp-Sihota et al., 2023). The insufficient support provided to PSWs also highlights the presence of sexism and discrimination faced by these essential workers, given that the role is predominantly occupied by women and historically marginalized communities (Block & Galabuzi, 2011; Sethna, 2013). In Ontario long-term care homes, 90% of PSWs are female and 41% are historically marginalized persons (Ministry of Long-Term Care, 2020). One explanation for the discrepancy in support is that PSW practice is not licensed or regulated by professional associations or government bodies unlike nurses and physicians (Grant, 2016; Kosteniuk et al., 2016). For example, in Canada, PSW education, certification standards, and titles are provided on a province-to-province basis, making it difficult to establish standardized practice regulations and ensure competency standards (Grant, 2016; Sethna, 2013).

Continuing education and professional development opportunities for healthcare workers are essential for maintaining and improving their clinical competencies including knowledge, skills, attitudes, and clinical behaviours (Al-Ismail et al., 2023; Laxdal, 1982). Competency in clinical contexts is most commonly defined as consistently demonstrating professional responsibility through practice and providing exceptional care by combining knowledge, skills, and professional attitudes (Fukada, 2018; Laxdal, 1982). Most healthcare workers are mandated to participate in continuing education programs, illuminating competency as a lifelong endeavour and demonstrating a commitment to excellence and adaptability to local care needs (Al-Ismail et al., 2023; Leach, 2002). The foundation for successful continuing education programs is ensuring they are relevant and directly applicable to the target audience through the identification and assessment of the learning needs and priorities of the learners (Laxdal, 1982; Rasmussen et al., 2023).

A learning need is defined as “the gap between current and optimal competence or performance” (Laxdal, 1982, p. 828). Learning need assessments can be used to establish a baseline of competency gaps to shape the development of continuing education programs and evaluate their effectiveness (Hauer & Quill, 2011). The assessments themselves are personal and specific to an individual or group and utilize a range of methods such as surveys, practice audits, peer reviews, observations, and interviews. Learning need assessments are useful in eliciting thoughtful reflections on gaps in personal abilities and educational topics of interest (Laxdal, 1982; Norman et al., 2004). For example, a 2020 systematic review found that training and education that are responsive to staff needs is a facilitator of effective dementia training (Cunningham et al., 2020). Moreover, evidence has demonstrated that programs developed based on well-designed learning need assessments are the most successful in changing healthcare provider behaviours, practices, and competencies (Davis et al., 1995; Davis et al., 2008; Fox & Bennett, 1998; Grant, 2002; Laxdal, 1982). This has also been demonstrated in dementia-specific contexts (Kang et al., 2017; Karlin et al., 2017; Lawler et al., 2021; Mastel-Smith et al., 2019), however, the applicability of these programs to PSWs is unknown.

Currently, PSWs are not mandated to complete a registration exam to demonstrate their competence to enter the workforce, nor are they required to participate in continuing education to maintain competencies throughout their careers (Sethna, 2013). This may explain why previous evidence has reported that continuing education programs do not address the learning needs of PSWs (Kosteniuk et al., 2016). Yet, the extent to which PSWs’ dementia-specific learning needs are included in learning need assessments remains unclear. Understanding the representation of PSWs’ learning needs in academic literature can play a crucial role in advocating for their perspectives and ensuring their needs are considered and incorporated into future educational programs. Accordingly, the purpose of this scoping review is to examine the ways in which PSWs are included in dementia-specific learning needs assessments and how their needs are assessed.



## 2.2 Methods

The scoping review was conducted according to the Johanna Briggs Institute (JBI) Manual for Evidence Synthesis for Scoping Reviews (Peters et al., 2020) and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist (Tricco et al., 2018). The search was conducted in July 2023. The databases PubMed, Scopus, CINAHL, PsychINFO (Ovid), Embase, and Medline (Ovid) were searched due to their focus on nursing and health sciences literature. The search terms used are stated in Table 1. The initial search strategy was produced in consultation with a faculty librarian at the University of Western Ontario, who assisted the first author (GN) in developing an initial search strategy using CINAHL. This strategy was then applied and modified to each remaining database when necessary. All final search strategies were reviewed and refined in consultation with the faculty librarian.

### 2.2.1 Inclusion and Exclusion Criteria

Articles were eligible for the title and abstract inclusion if they were primary research articles, written or translated into English and focused on identifying dementia-specific learning needs of groups or individuals containing unregulated healthcare workers. Learning needs were understood according to Laxdal's (1982) definition. Therefore, learning needs not resulting from a lack of education, skills, attitudes, personal qualities and/or opportunities to participate in continuing education were excluded. Review reference lists were searched manually to identify relevant articles.

To be eligible for full-text screening, the sample population needed to include unregulated healthcare workers or a broad description of the sample population such as "long-term care staff", "home care staff", "nursing home personnel", or "nursing staff". This eliminated the risk of excluding papers that grouped PSWs with other health and social care workers in the sample populations. See Table 1 for the complete list of occupational titles included in the search strategy.

During the full-text screening, studies were eligible for inclusion if the sample population included PSWs, nursing assistants (NAs), care aides, and healthcare assistants (HCAs), or defined the sample population in accordance with PSW roles and responsibilities. Definitions from PSW competency frameworks or practice guides were used to determine eligibility. These documents commonly described PSWs as unregulated healthcare professionals providing and assisting vulnerable individuals across the lifespan with activities of daily living (Government of Alberta, 2018; Government of British Columbia, 2014; Ministry of Training, Colleges and Universities, 2022; Nova Scotia Department of Health and Wellness, 2019). Studies that did not provide sufficient definitions of the study population, or included a definition that did not align with the PSW definition were excluded. Studies containing heterogeneous sample populations were included in the review to ensure that the examination of PSWs and their learning needs within the learning need assessment literature was comprehensive in scope. Studies were further excluded if they did not focus on identifying dementia-specific learning needs, conducting a learning need assessment related to dementia care, or including diseases other than dementia (e.g., cancer, schizophrenia, etc.).

**Table 1: Search strategy keywords and terms**

<b>Keywords</b>	<b>Search Terms<sup>1</sup></b>
Learning needs	Learning need or learning need assessment or learning need analysis or needs assessment or education need or training need or information need
	AND
Dementia	Dementia <sup>1</sup> or Alzheimer’s disease <sup>1</sup> or Dementia patient <sup>1</sup> or Lewy Body Disease <sup>1</sup> or Frontotemporal dementia <sup>1</sup> or Vascular dementia <sup>1</sup> or Delirium, Dementia, Amnestic, Cognitive Disorders <sup>1</sup> or Multi-Infarct dementia <sup>1</sup> or AIDs dementia complex <sup>1</sup> or Senile dementia <sup>1</sup> or Presenile dementia <sup>1</sup> or Lewy Body dementia or Parkinson’s or frontotemporal or Creutzfeldt-Jakob or Wernicke-Korsakoff or Mixed dementia or Cognitive impairment or mild cognitive impairment
	AND

Personal Support Worker    Personal support worker or PSW or nursing assistant<sup>1</sup> or nurse aide<sup>1</sup> or healthcare assistant or healthcare aide or HCA or long-term care staff or home care staff or unlicensed healthcare worker or unlicensed health personnel or home health aides or nursing home personnel or nursing staff <sup>1</sup>

Note. <sup>1</sup>MeSH headings applied where applicable.

## 2.2.2 Evidence Selection

The first author (GN) and two undergraduate research assistants used the platform Covidence to conduct all screenings and organize articles. Covidence automatically removed all duplicate studies once the research strategy results from each database were imported. Title and abstract screening were conducted based on the inclusion and exclusion criteria. The screening was an iterative and collaborative process, as many studies included various terms for PSWs (e.g., certified and uncertified NAs, HCAs, etc.), used broad terms to describe the sample population (e.g., care team) and conducted learning need assessments in conjunction with other research aims (i.e., assessments of continuous training programs). The inclusion and exclusion criteria were refined based on the literature during the title and abstract screening and collaborative discussions between research team members to ensure relevant studies were not missed. Articles flagged as “maybe” included reviews and those without an abstract. GN completed manual searching of review reference lists independently. All final screening decisions were made collaboratively.

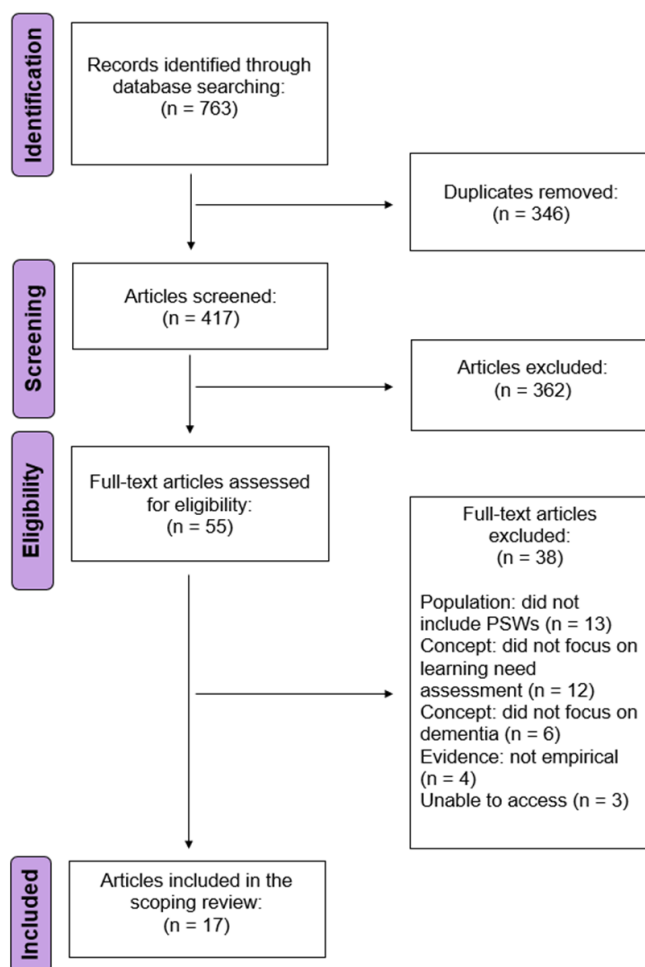
## 2.2.3 Data Extraction and Charting

Data was charted by GN and an undergraduate research assistant. The chart was based on the review’s objectives (i.e., sample population, reporting of learning needs from PSWs, methods and study design, objectives, etc.) and iteratively refined as evidence was extracted. A descriptive summary table was developed in Excel with the following headings: first author and publication year, objective(s), country, study type, sample population, setting, method, learning needs assessment tool(s), and if PSW learning needs were analyzed and/or reported.

## 2.3 Results

### 2.3.1 Sources of Evidence Selection

In April 2023, a total of 729 articles were derived from a search of six electronic databases. Once duplicates were removed ( $n = 341$ ) automatically by Covidence, 338 studies underwent title and abstract screening by two research team members. In July 2023, the search strategy was updated in consultation with MYS to include additional dementia keywords and MeSH terms and reran through all six databases. An additional 39 studies were identified, with five being automatically removed as duplicates. Thus, as seen in Figure 1, a total of 763 articles were identified and 346 were removed as duplicates. In total, 417 studies underwent title and abstract screening. Based on the inclusion and exclusion criteria, 362 articles were excluded, with 55 full-text articles to be assessed for eligibility. A total of 38 articles were deemed ineligible due to the reasons set out in Figure 1. No additional studies were identified through manual reference list searches. The remaining 17 studies were considered eligible for this review.



**Figure 1: PRISMA diagram**

### 2.3.2 Characteristics of Sources of Evidence

The 17 studies included in this review spanned 19 years (2003 – 2022), with 13 (81.2%) published within the last decade. The selected articles were conducted in the United States of America (n = 4), United Kingdom (n = 4), Netherlands (n = 2), Australia (n = 2), Malta (n = 1), Ireland (n = 1), New Zealand (n = 1), Canada (n = 1), and Japan (n = 1). Six (35.3%) studies were conducted in both long-term care and home care settings while the remaining included five (29.4%) in long-term care exclusively (including nursing homes and assisted living homes), three (17.6%) in home care, two (11.7%) in hospital wards and one (5%) unspecified. Table 2 summarizes the research objectives, sample population, inclusion of PSW learning needs, and study design/methods of the 17 studies.

**Table 2: Summary of included articles**

	<b>Author, Year</b>	<b>Aim of Study</b>	<b>Sample Population</b>	<b>Study Design/Methods</b>	<b>PSW Learning Needs Reported</b>
1	Adler <i>et al.</i> , 2015	Investigated the dementia-specific learning needs of staff at community-based outpatient clinics who care for veterans living with dementia.	n = 105 healthcare workers (62 nurses, 23 support staff, and 12 physicians)	Quantitative. A survey explored interests and perspectives on dementia-specific education using the Approaches to Dementia Questionnaire. Participants ranked education topics related to medical and psychosocial management.	No
2	Annear <i>et al.</i> , 2018	Investigated the self-reported learning needs of a randomly selected national sample of geriatric healthcare workers.	n = 117 geriatric healthcare workers (74 care worker and 22 other (e.g., managerial or service staff), 13 other geriatric healthcare staff (e.g., physical therapists), 6 nurses, a clinical educator, and a medical student)	Quantitative. A survey explored the self-identified perceptions of learning needs and confidence in dementia care, preferences concerning education, and demographic questions.	No
3	Attard, Sammut, and Scerri, 2020	Investigated the knowledge, attitudes, and learning needs of healthcare professionals caring for people living with dementia. Explored the	n = 207 healthcare professionals (103 NAs and 104 nurses)	Quantitative. The survey included three measurement tools: (1) the Alzheimer's Disease Knowledge Scale to assess carers' knowledge about the	Yes

	<b>Author, Year</b>	<b>Aim of Study</b>	<b>Sample Population</b>	<b>Study Design/Methods</b>	<b>PSW Learning Needs Reported</b>
		relationships between knowledge, attitudes, and demographic characteristics.		disease; true/false statements; (2) the Dementia Attitude Scale to identify carers' attitudes towards people with dementia, and; (3) the Dementia Learning Needs Assessment tool (rating 20-items to indicate learning needs).	
4	Bolt <i>et al.</i> , 2020	Explored the palliative care learning needs of staff working with people living with dementia, the types of support needed, and compare the educational levels of staff between home care and long-term care settings.	n = 416 staff members (164 RNs, 218 certified NAs, and 34 uncertified NAs)	Quantitative. The survey focused on palliative caregiving and end-of-life communication, and interprofessional collaboration and transitions of care, self-perceived competence in providing palliative care for people living with dementia, learning needs, and preferred forms of support.	Yes
5	Chang <i>et al.</i> , 2009	Investigated the challenges of providing care for people living with advanced dementia in residential aged-care facilities from the perspectives of multiple key healthcare professionals.	<b>Focus groups n = 29</b> (4 general practitioners and 4 palliative care specialty staff, 5 palliative care RNs, 4 volunteers, 3 senior RNs, 2 palliative care volunteer managers, 2 RNs from a community psychogeriatrics team, a social worker, an RN from a community aged care	Qualitative. Focus group discussion centered on the needs and deficits in service delivery. Interviews focused on building from focus group information.	No

	<b>Author, Year</b>	<b>Aim of Study</b>	<b>Sample Population</b>	<b>Study Design/Methods</b>	<b>PSW Learning Needs Reported</b>
			assessment team, an RN from acute care, a recreational therapist, and an NA) <b>Interviews n = 20</b> (4 NAs, 3 RNs, 2 directors of nursing, 2 enrolled nurses, and 2 therapists, 1 specialist medical officer, 1 psycho-geriatric nurse specialist, a geriatric nurse specialist, an OT, and a bereavement counsellor)		
6	Foster <i>et al.</i> , 2019	Uncovered and critically examined healthcare assistants' experiences of providing person-centered care to people living with dementia during end-of-life stages and perspectives on formal education preparedness for palliative and dementia care.	n = 34 HCAs	Qualitative. Semi-structured interviews were conducted to explore experiences of end-of-life care for people living with dementia, communication with staff, residents, and families relating to end-of-life, and education experiences.	Yes



	<b>Author, Year</b>	<b>Aim of Study</b>	<b>Sample Population</b>	<b>Study Design/Methods</b>	<b>PSW Learning Needs Reported</b>
7	Gandesha <i>et al.</i> , 2012	Assessing how hospital staff view the sufficiency of formal training preparation for caring for people living with dementia	n= 1779  (270 physicians, 968 nurses, and 541 HCAs)	Qualitative.  Two audits were performed at the hospital level (open to all) and ward-level (nominated ward staff only). Questionnaires were shared with staff during the ward-level audit, inquiring about the sufficiency of training in 13 areas related to dementia care.	Yes
8	Gurnik and Hollid-Sawyer, 2003	Uncovered the learning needs of frontline care staff to develop a training manual based tailored to their needs. Also evaluated the effectiveness and helpfulness of the training manual.	n = 24 care staff. Did not specify the titles of care staff but defined them as " <i>staff who conduct the day-to-day full range of care needed by residents</i> ".	Mixed Methods. A survey included open-ended items on four topics areas: (1) role needs; (2) social interaction needs; (3) personal growth needs, and (4) knowledge and understanding of dementia and the aging process. A second survey and focus group were conducted to collect post-training feedback.	No

	<b>Author, Year</b>	<b>Aim of Study</b>	<b>Sample Population</b>	<b>Study Design/Methods</b>	<b>PSW Learning Needs Reported</b>
9	Leverton <i>et al.</i> , 2021	To identify the skills, training and support needs of homecare workers providing care for people living with dementia from the perspectives of multiple key stakeholders involved in homecare provision.	n = 82 participants.  (11 people living with dementia, 22 family caregivers, 19 health and social care professionals, and 30 homecare staff including 7 managers, 4 office staff, and 19 homecare workers)	Qualitative.  Observations of homecare workers (n = 16) and people living with dementia and family caregiver care interactions.  Semi-structured interviews with all stakeholders focused on perspectives on preferences for content and delivery method of a training program for homecare workers caring for people living with dementia.	Yes
10	Marx <i>et al.</i> , 2014	Identified dementia knowledge, learning needs, and experiences within the care environment.	n = 37 staff members of a specialized geropsychiatry unit (15 nursing staff (patient care technicians, nurses, and NAs), 8 physiotherapists, 7 occupational therapists (OT), 6 recreation therapists, and a speech-language pathologist)	Quantitative. A survey assessed dementia knowledge (using a modified Alzheimer's Disease Knowledge Scale), attitudes toward dementia-specific education needs, and the care environment.	No

	<b>Author, Year</b>	<b>Aim of Study</b>	<b>Sample Population</b>	<b>Study Design/Methods</b>	<b>PSW Learning Needs Reported</b>
11	Mayrhofer, Goodman and Smeeton, 2016	Understand the perspectives of dementia champions regarding their roles, remit, and training needs.	n = 34 dementia champions. (13 nurses, therapists and emergency staff, 11 senior practitioners, 6 managers, and 2 support staff)	Quantitative. A survey explored perceptions of the dementia champion role, its remit, and perceived learning needs.	No
12	Morgan <i>et al.</i> , 2016	Investigated perceived competency in dementia-related homecare activities, frequency of activities, and interest in dementia-specific continuing education topics.	n = 82 homecare staff (41 NAs, 20 home care nurses, 10 case managers (5 nurses and 5 social workers) and 11 dual nurse/case manager roles (all nurses))	Quantitative. A survey identified dementia-related work activities based on the frequency of their occurrence, perceived competence, and ranking as a preferred continuing education topic.	Yes
13	Nguyen <i>et al.</i> , 2022	Investigated the communication learning needs, challenges, coping strategies, and influencing factors of healthcare workers caring for people living with dementia.	n = 258 carers (141 formal caregivers, 57 informal or family caregivers, 11 volunteer caregivers, and 49 other (e.g. registered nurses (RNs)))	Quantitative. A survey identified communication challenges in dementia care and related coping strategies, perceived factors that influence communication, and communication learning needs.	No
14	Szymcynska & Innes, 2011	Evaluated a training workshop developed for rural health and social-care staff providing services to	n = 18 health and social care staff, 10 of whom provided dementia care. Staff demographics were not provided but the sample	Qualitative. Participants attended a workshop developed to address dementia-specific learning needs, raise awareness of dementia, identify	No

	<b>Author, Year</b>	<b>Aim of Study</b>	<b>Sample Population</b>	<b>Study Design/Methods</b>	<b>PSW Learning Needs Reported</b>
		people living with dementia, regarding its success in achieving learning outcomes and addressing learning needs.	population was defined as: " <i>...all staff who may offer services to persons with dementia were encouraged to participate.</i> "	service and learning needs, and understand staff's roles in providing care to people living with dementia. Informal discussions were conducted to collect information about staff experiences with the workshop. A post-workshop questionnaire was sent to participants to identify satisfaction with the information and content, how they thought the course would influence their practice, and identify future learning needs.	
15	Timmons <i>et al.</i> , 2021	Investigated staff training in dementia and palliative care, learning needs, readiness for change, and the care environment.	n = 60 staff members (2 nurses, 27 HCAs, and 10 health care practitioners (only used demographic data))	Quantitative. A survey explored barriers and facilitators to implementing changes in long-term care facilities, experiences of powerlessness, confidence, and de-motivation, and asked participants to rank their top three learning needs relating to medication, pain, hydration and nutrition. It also allowed for free text responses as well for learning needs that were not included under the three guidance topics.	Yes

	<b>Author, Year</b>	<b>Aim of Study</b>	<b>Sample Population</b>	<b>Study Design/Methods</b>	<b>PSW Learning Needs Reported</b>
16	Toteh Osakwe et al., 2022	Investigated the dementia-specific learning needs of home HCAs regarding dementia care plans	n = 25 HCAs	Qualitative. Interview questions were specific to processes of care in the homecare setting and related outcomes such as interactions with homecare nurses and desired information from nurses regarding care plans.	Yes
17	Verkaik <i>et al.</i> , 2017	Investigated the learning needs and preparedness of nursing staff to provide self-management support to people living with dementia.	n = 206 (questionnaire) (46 RNs and 160 NAs) n = 12 (interviews) (8 RNs and 4 NAs)	Mixed Methods. Quantitative data were derived from a secondary analysis of a questionnaire on nursing staff's experiences, opinions and perceived knowledge on self-management support (SMS). Semi-structured interviews were conducted to further inquire and deepen the data from the questionnaires. The interviews also covered topics on essential SMS, practice and experiences with SMS, interest in self-management support, practices and experiences of SMS with people living with dementia and learning needs for SMS in dementia care.	Yes

### 2.3.3 PSW Representation in Sample Population

Of the 17 included studies, two (11.7%) reported the dementia-specific learning needs of PSWs exclusively (Foster et al., 2019; Toteh Osakwe et al., 2022). Twelve (70.5%) studies involved multi-professional sample populations of at least two healthcare professions. Of these, eight (47%) studies included at least three distinct professions, such as physicians, nurses, and PSWs (Adler et al., 2015; Chang et al., 2009; Gandesha et al., 2012; Leverton et al., 2021; Marx et al., 2014; Mayrhofer et al., 2016; Morgan, Kosteniuk, O’Connell, Dal Bello-Haas, et al., 2016; Nguyen et al., 2022). The remaining four (23.5%) studies grouped PSWs with nurses (Attard et al., 2020; Bolt et al., 2020; Timmons et al., 2021; Verkaik et al., 2017). Three (17.6%) studies did not specify the official occupational titles of participants but rather described them broadly such as “care staff” or “support staff”, and a respective definition (Annear et al., 2017; Gurnik & Hollis-Sawyer, 2003; Szymczynska & Innes, 2011).

PSWs represented an equal proportion of the sample population with other healthcare workers in two (11.7%) studies (Attard et al., 2020; Morgan et al., 2016) and below half of the sample population in seven (41.1%) (Adler et al., 2015; Chang et al., 2009; Gandesha et al., 2012; Leverton et al., 2021; Marx et al., 2014; Mayrhofer et al., 2016; Timmons et al., 2021). PSWs represented greater than half of the sample population in five (29.4%) studies (Bolt et al., 2020; Foster et al., 2019; Nguyen et al., 2022; Toteh Osakwe et al., 2022; Verkaik et al., 2017). Two of these studies contained sample populations of nursing assistants exclusively while the remaining three used a multi-professional sample population. Notably, the ratio of PSWs to other healthcare workers fluctuated depending on the type of data collection method being used. In Verkaik et al., (2017), data was initially collected through a survey and followed by interviews. Nursing assistants represented three times the number of nurses (160 nursing assistants to 46 nurses) in the survey responses, which inquired about staff experiences caring for people living with dementia and opinions and perceived expertise regarding self-management support (Verkaik et al., 2017). In contrast, the number of nurses was twice that of nursing assistants (4 nursing assistants to 8 nurses) in follow-up interviews to obtain a deeper

insight and context into the survey results (Verkaik et al., 2017). Furthermore, in Leverton and colleagues (2021) a larger proportion of PSWs (referred to as homecare workers) consented to be observed (n=16) compared to being interviewed (n = 4). The proportion of PSWs was unidentifiable in three (17.6%) studies due to the use of broad occupation terms such as “care staff” and “support staff” (Annear et al., 2017; Gurnik & Hollis-Sawyer, 2003; Szymczyńska & Innes, 2011).

Eight (47%) of the studies did not analyze and/or report learning need data based on occupational titles of the sample population (Adler et al., 2015; Annear et al., 2017; Chang et al., 2009; Gurnik & Hollis-Sawyer, 2003; Marx et al., 2014; Mayrhofer et al., 2016; Nguyen et al., 2022; Szymczyńska & Innes, 2011), while nine (52.9%) did (Attard et al., 2020; Bolt et al., 2020; Foster et al., 2019; Gandesha et al., 2012; Leverton et al., 2021; Morgan et al., 2016; Timmons et al., 2021; Toteh Osakwe et al., 2022; Verkaik et al., 2017). Of those that reported PSW-specific learning needs, four were quantitative studies, four were qualitative, and one was mixed methods. Of the four studies that included nurses and PSWs in the sample population, all studies disaggregated the data based on occupational title, however, only three reported the findings based on disaggregation while the remaining article did not report differences in learning needs since there was an abundance of similarities in the results (Bolt et al., 2020).

### 2.3.4 Data Collection Methods

The studies included ten (58.8%) quantitative, five (29.4%) qualitative and two (11.7%) mixed methods. Surveys were used in 13 (76.4%) of the studies, with nine (52.9%) using them as the sole method of data collection (Adler et al., 2015; Annear et al., 2017; Attard et al., 2020; Bolt et al., 2020; Gurnik & Hollis-Sawyer, 2003; Marx et al., 2014; Mayrhofer et al., 2016; Morgan et al., 2016, 2016; Szymczyńska & Innes, 2011; Timmons et al., 2021; Verkaik et al., 2017). Three (17.6%) studies used surveys in conjunction with qualitative methods such as interviews (Verkaik et al., 2017), focus groups (Gurnik & Hollis-Sawyer, 2003), or opportunistic discussions (Szymczyńska & Innes, 2011). Interviews and/or focus groups alone were less frequent, as only three (17.6%) studies adopted these as the sole method for data collection (Chang et al., 2009;

Foster et al., 2019; Toteh Osakwe et al., 2022). Leverton and colleagues (2021) combined the use of interviews with direct participant observation. The mixed method studies used interviews and informal discussions to support and deepen the understanding of quantitative insights from surveys (Gurnik & Hollis-Sawyer, 2003; Verkaik et al., 2017). See Table 3 for a summary of the reported methods adopted in the included studies.

All 17 studies collected data based on the participants' self-assessment of their own knowledge, skills, training sufficiency, and/or learning needs. Among the 13 studies that used surveys, four used standardized survey tools, such as the Dementia Attitude Scale (Attard et al., 2020), the Dementia Learning Needs Assessment tool (Attard et al., 2020), Approaches to Dementia Questionnaire (Adler et al., 2015), and the Alzheimer's Disease Knowledge Scale (Attard et al., 2020) (with some modification in Marx et al., (2014)). The remaining studies used surveys developed by either the primary researchers or secondary data analysis of previous survey responses.

**Table 3: Methods of data collection**

<b>Data Collection Method</b>	<b><i>n</i> / 17 (%)</b>
Survey/Questionnaire	10 (58.8)
Interview	2 (11.7)
Survey and Focus Groups	1 (5)
Survey and Informal Discussions	1 (5)
Survey and Interview	1 (5)
Interview and Focus Group	1 (5)
Survey and Audit	1 (5)

### 2.3.5 Dementia-Specific Learning Needs Assessed in Included Studies

Although all 17 reviewed studies conducted a dementia-specific learning needs assessment, 11 (64.7%) had a specific focus on an aspect of dementia care, while six (35.3%) investigated dementia-specific learning needs as a broad, all-inclusive topic (Adler et al., 2015; Annear et al., 2017; Attard et al., 2020; Gandesha et al., 2012;



Leverton et al., 2021; Marx et al., 2014). See Table 4 for the specific dementia-care topics. All six studies focusing on dementia care as a broad topic for learning need assessments were quantitative and used surveys and questionnaires as the main data collection method.

**Table 4: Study objectives**

<b>Learning Need Assessment Focus</b>	<b><i>n</i> / 17 (%)</b>
<b>Broad</b>	
Dementia Care	6 (35.3)
<b>Specific</b>	
Palliative Care	3 (17.6)
Evaluation of an education program developed from a learning needs assessment	2 (11.7)
Advanced Dementia	1 (5)
Dementia Care Plans	1 (5)
Self-Management	1 (5)
Dementia Champion Roles	1 (5)

Six of the nine articles that aggregated and reported PSW-specific learning needs had a narrow focus on an aspect of dementia care. These included learning needs related to palliative and end-of-life care for people living with dementia (Bolt et al., 2020; Foster et al., 2019; Timmons et al., 2021), self-management support (Verkaik et al., 2017), dementia home care activities (Morgan et al., 2016) and information for care plans (Totah Oskawe et al., 2022). Attard et al., (2020), Leverton et al., (2021), and Gandesha et al., (2012) disaggregated and reported PSW’s specific learning needs related to dementia as a broad topic of investigation relative to other healthcare professionals within the sample populations. The two (11.7%) articles that used PSWs exclusively in the sample population also had a specific focus on dementia care learning needs. Foster et al., (2019) investigated the learning needs of home care NAs related to palliative care for persons living with dementia and Totah Oskawe et al., (2022) explored the information needs of NAs regarding dementia care plans.

## 2.4 Discussion

This review demonstrated a critical gap in the validity of data which involves but does not report on PSWs' needs. PSWs' distinct perspectives, skills, and knowledge are overlooked and oversaturated with those of other healthcare workers. This gap makes it difficult for key stakeholders to understand PSW challenges, experiences, and areas of knowledge and skill needed to provide optimal dementia care. Compared to other healthcare workers, PSWs are underrepresented in academic literature, lending them few opportunities to be involved in evidence-based research, practices, or contribute their perspectives in meaningful and impactful ways.

Learning needs will vary based on educational qualifications and experience levels, highlighting the importance of conducting assessments with PSWs exclusively in mind (Bing-Jonsson et al., 2013). Only two studies (Foster et al., 2019; Toteh Osakwe et al., 2022) in this review included PSWs exclusively, while the remaining 15 used a multi-professional sample. Furthermore, nearly half reported PSW-specific learning needs amongst other healthcare workers within the sample populations. These results are consistent with other learning need assessments, which have included PSWs in sample populations with other healthcare professionals, but report needs in a summative nature rather than based on occupational titles (Gillham et al., 2018). The grouping of PSWs with other, similar occupations during data collection and analysis is a common and recognized issue among researchers and organizations (Grant, 2016). Historically, the voices of PSWs have been ignored and devalued by organizations, as many have reported feeling their needs and concerns frequently being dismissed, minimized, or slow to resolve (Hapsari et al., 2022; Rossiter & Godderis, 2020). This was also recently demonstrated during the COVID-19 pandemic, where Ontario PSWs did not receive the same concern, treatment, or resources for their risk of contracting the disease, nor were they included in social configurations of infection risk assessments (Rossiter & Godderis, 2020). The invisibility and minimization of the importance of PSW knowledge, perspectives, and voices perpetuate the narrative of PSWs being unskilled, poorly compensated, and invisible/illegitimate as a professional healthcare occupation

(Zagrodney & Saks, 2017; Zeytinoglu et al., 2009). Consequently, PSWs being overlooked and undervalued is reflected in the inaccuracy of learning needs unique to their profession being represented in dementia-specific learning need assessments. This therefore creates difficulties in understanding where challenges in delivering optimal dementia care exist and identifying opportunities to address specific gaps in PSW competencies.

In terms of data collection methods, this review demonstrates that researchers most commonly use quantitative approaches, namely surveys, as the predominant method for assessing dementia-specific learning needs of PSWs. This finding aligns with a recent scoping review on learning need assessments, which identified the widespread use of quantitative approaches (Al-Ismail et al., 2023). Quantitative approaches to learning need assessments are often attractive due to their cost-effectiveness, ability to objectively measure outcomes (i.e., dementia knowledge), and use of collecting data from large groups (Grant, 2002; Hauer & Quill, 2011). Surveys and questionnaires typically involve testing participants' knowledge, attitudes, and/or skills, as well as ranking their pre-established learning need topics (Adler et al., 2015; Attard et al., 2020; Carnahan et al., 2019; Chung & Lai, 2003; Lawler et al., 2021). This approach can help researchers understand the prioritization of specific learning needs by conducting frequency analyses and encouraging participants to select and rank predetermined needs (Grant, 2002). Some potential drawbacks of using quantitative methods include a large dependency on the quality of survey questions to elicit truthful responses and the lack of choice provided to participants to discuss learning needs candidly (Grant, 2002; Hauer & Quill, 2011). Quantitative approaches have also been criticized for their scope of needs identification, which focus on immediate needs rather than long-term, foundational needs, and are dependent on the quality of the questions (Al-Ismail et al., 2023; Ferreira & Abbad, 2013).

Qualitative methods are effective mechanisms for identifying learning needs and exploring the contextual factors that shape those needs at individual or group levels. Interviews and focus groups encourage candid responses and provide deep insight into an

individual's or group's perspectives on perceived learning needs, attitudes and beliefs that influence behaviours, potentially offering a more proactive approach in comparison to quantitative methods (Daley & Wilson, 1999; Ferreira & Abbad, 2013; Hauer & Quill, 2011). Previous dementia specific learning need assessments have used focus groups (Allen et al., 2005; Daley & Wilson, 1999; Gillham et al., 2018; Hsiao et al., 2016; Xu et al., 2018) and reported that they allow participants to create meaning collaboratively, engage in discussions and challenge each other's perspectives to uncover knowledge (Daley & Wilson, 1999). However, qualitative methods that identify and report subjective data have been criticized for being "less accurate" when compared to objective, quantitative methods (Grant, 2002). Other methods for collecting learning need data include gap analyses, standardized patients, video assessments, peer reviews, risk assessments, observations, and chart audits (Grant, 2002; Lockyer, 1998). Evidence suggests that for learning need assessments to be comprehensive and limit the potential to miss needs, the methods should be based on the local environment and culture, professional reflection and judgement, discussions, and incorporate various levels of data (Al-Ismail et al., 2023; Grant, 2002).

All studies included in the scoping review used self-assessment methods, which relied on the participant's ability to recognize their own deficiencies in dementia care. For instance, some studies asked participants to rank or select from a list of education topics based on their interest or needs (Morgan et al., 2016; Timmons et al., 2021). Self-assessment of learning needs is an essential component of professional development, especially within medical and health-related disciplines, such as medicine (Al-Ismail et al., 2023; Davis et al., 2008). However, previous evidence has demonstrated that self-reporting and assessment of needs may not be accurate or align with objective measures (Davis et al., 2008). The use of self-assessments has therefore been cautioned as the sole method to data collection in learning need assessments, as the responses may not be reflective of actual learning needs (those that are difficult to admit, perceive in oneself, or are not of interest to learners) and may be subject to biases such as reporting bias and self-enhancement bias (Al-Ismail et al., 2023; Raley, 2020). These biases can be mitigated by pairing self-assessments with more objective methods such as interacting

with standardized patients, standardized survey tools, or peer reviews involving individuals who are knowledgeable about each other and/or participate in similar activities (Campbell, 1990; Raley, 2020). Despite these potential challenges, self-perceived learning needs are vital when assessments are being used to design continuing education programs, as motivation is key for the successful uptake of knowledge (Kosyluk & Rigg, 2021). Changes to behaviours, attitudes, knowledge, and skills are more likely to arise when learners identify the education contents as being personally meaningful and relevant (Kosyluk & Rigg, 2021).

In this review, dementia-specific learning need assessments focused mostly on specific aspects of dementia care, rather than gathering learning need information on dementia care as a broad topic. PSWs are reported to have the least amount of education and the fewest opportunities to participate in continuous education programs compared to other healthcare workers (Chen et al., 2018; Kosteniuk et al., 2016; Timmons et al., 2021) and consider themselves “beginners” in terms of knowledge and skills in dementia care (Adler et al., 2015). Due to the lack of continuing education and training support provided to PSWs in dementia care, their learning needs should be explored in a broad manner to understand the depths and range of their potential for professional growth. Studies have suggested that PSWs are eager to participate in dementia specific continuing education, in part to improve their competency and confidence in completing dementia care activities (Morgan et al., 2016). In a 2016 cross-sectional Canadian study, discrepancies in competency among home care nurses and nursing aides were reported in almost all dementia-related care tasks, such as communication skills with family about dementia and managing responsive behaviours (Morgan et al., 2016). Although all aspects of care are equally as important, the lack of skill and knowledge provided to PSWs through formal education and continuing education opportunities suggests that a more comprehensive inquiry should be made regarding dementia care as a broad topic.

#### **2.4.1 Strengths and Limitations**

The strengths of this review include the use of six online databases to comprehensively search for all articles eligible for inclusion. Moreover, the results of the review add to the

literature on PSWs and explicitly present gaps in research surrounding their learning needs related to dementia care. This provides a unique overview of how PSWs are presented within dementia-specific learning need assessments and contributes to the literature on the lack of representation of PSWs within research. The content in this review provides readers with an overview on the current state of PSW involvement in dementia-specific research and how their perspectives and voices are included in data collection and analysis.

A limitation of this scoping review is that it only included studies written or translated in English. Articles written in French or other languages were not included and therefore potential studies could have been missed. Further, this review did not include grey literature, which could have resulted in the exclusion of learning need assessments done by care organizations or governing bodies.

#### **2.4.2 Implications for Future Research**

More research needs to be conducted on PSW-specific learning needs in dementia care. Future research in this area should include qualitative or mixed methods to identify learning needs and empower PSWs in the process. Compared to quantitative methods, qualitative and mixed method approaches can provide opportunities to conceptualize the holistic environments which can aid in the understanding of interpersonal and environmental influences on learning needs, such as educational preparedness and workplace support. Further research should also explore learning needs within dementia care as a broad topic, to illuminate the depth, variation, and complexity of needs that exist for PSWs.

### **2.5 Conclusion**

PSWs spend the most time on average caring for people living with dementia in organized care settings and therefore play a critical professional role in ensuring the delivery of optimal dementia care. However, optimal care can only be delivered if the value of PSW's is formally acknowledged, and they are provided the necessary support to thrive in their dementia care roles in meaningful ways. Their perspectives, opinions,

and learning needs should therefore be investigated in a manner that acknowledges the value of PSWs alongside their skills, knowledge, and experience caring for people living with dementia.

This review has demonstrated a gap in knowledge concerning the dementia specific learning needs of PSWs. Ensuring PSWs have ample opportunities to improve their knowledge, skills, and attitudes towards dementia care is a priority to improve PSW satisfaction, reduce work-related stressors and optimize the quality of care provided to people living with dementia. Hughes and colleagues (2008) suggest that simply the presence of training opportunities for healthcare workers has a significant influence on their self-perceived confidence in caring for people living with dementia. Empirical evidence has also suggested that effective training programs targeted to healthcare workers' needs can have positive effects on both healthcare workers and their clients (Li et al., 2021). Providing these opportunities can improve worker satisfaction with workplace roles, potentially reducing turnover rates and improving client care satisfaction by ensuring consistent and highly skilled staff (Li et al., 2021). Uncovering and understanding PSWs' views of dementia-specific learning needs is a crucially necessary step to identifying underlying problems in delivering essential care within formal care organizations. Improved understanding of the gaps in PSWs' knowledge, attitudes, and/or skills related to dementia care are urgently needed to better inform and focus discipline specific and concentrated PSW training in the future.

## Chapter 3

### 3 Method

This study used interpretive description (Thorne, 2016) to identify and examine the dementia-specific learning needs of PSWs participating in a dementia-focused education program. A secondary analysis of focus group data collected between September 2019 to March 2020 was performed.

#### 3.1 Paradigm

This study used a constructivist paradigm based on the notion that learning needs are unique to individuals based on personal experiences. Constructivism views reality as mentally constructed with multiple forms that are local and specific in nature and dependent on the context of the individual or groups of individuals (Guba & Lincoln, 1994). Knowledge is therefore based on subjective experiences and interpretations, as well as socially constructed through dialogue and social interactions (Carpenter & Suto, 2008; Guba & Lincoln, 1994). Thus, rather than certain learning needs being more or less “true” than others, all can be viewed as valid and understood by being derived by personal experiences working in long-term care and/or caring for people living with dementia.

#### 3.2 Methodology: Interpretive Description

This study uses an equity lens to identify the dementia-specific learning needs of PSWs in long-term care homes and critically examine the context in which they exist. In educational contexts, equity can be understood and addressed by identifying barriers and discriminatory practices to ensure students of diverse backgrounds have the opportunity to advance and reach their full potential (Government of Ontario, 2020; Green, 2020). The primary aim of the study is to inform future continuing dementia education programs on the unique needs of PSWs in long-term care and advocate for the inclusion of PSW voices in future research and continuing education programs.



Interpretive description seeks to pragmatically answer broad questions iteratively and inductively concerning subjective clinical experiences from a holistic, interpretive, and relational perspective (Burdine et al., 2021). Interpretation is used to understand subjective experiences within larger social contexts (Thorne, 2016). Pragmatism focuses on developing knowledge and producing findings with practical outcomes that are highly applicable to real-world contexts (DeForge & Shaw, 2012). Thus, inquiry is driven by the desire to address practical problems or understand experiences to generate knowledge that possess clear implications for the local context (e.g., clinical practice, community wellness, etc.), as opposed to metaphysical (i.e., ontology, epistemology, axiology, and methodology) considerations (DeForge & Shaw, 2012; Thorne, 2016).

The philosophical foundation of interpretive description is within interpretive naturalistic orientations (Thorne et al., 2004), which focuses on studying phenomena in their natural context to understand the complexities and nuances of real-world experiences. Key philosophical principles of naturalistic inquiry include: (1) reality is multiple, complex, contextually constructed, and subjective and must be studied holistically, (2) the researcher and participants interact to influence each other, and (3) a single theory is unable to encompass the multiple realities likely to be encountered during interpretive description (Thorne, 2016). Ontologically, interpretive description acknowledges the constructed and contextual nature of human experiences when interpreting and understanding subjective data (Burdine et al., 2021; Thorne, 2016). Experiences and environmental context are fundamental in shaping what is understood as real or true in the world, and contribute to the composition of individual identity and consciousness (DeForge & Shaw, 2012). Epistemologically, environmental contexts and experiences provide meaning for the development of knowledge, and individuals learn from and adapt with their local contexts (DeForge & Shaw, 2012). Knowledge is constructed through dialectic interactivity, typically between the investigator and participants, and is based on subjective experiences and interpretations which is impossible to partition from objectivism (Thorne et al., 2004). Yet, interpretative description supports the integration of theoretical insights in interpreting data, namely, the incorporation of various perspectives to inform the analysis with the intention to enhance relevance and

applicability of the findings (Thorne, 2016). Therefore, the methodology encourages and promotes the generation of knowledge that possesses clear implications for the local context rather than simply theorizing (Jensen et al., 2018; Thestrup Hansen et al., 2021; Thome, 1998; Thorne, 2016). The explicit intention to inform and support practice through contextualized findings is a unique feature of interpretive description (Thorne, 2016) and well suited to support the research aims of this study.

This methodology is particularly well-suited to analyze focus group data since subjective perspectives are interpreted within themes and common characteristics across participants, while concurrently accounting for individual variation to promote the inclusion and equality of all individual realities (Burdine et al., 2021). The guidance towards contextualization and practical implications rather than abstraction or theorization is additionally beneficial for reducing the risk of interpretation bias, which is particularly relevant during secondary analyses (Thorne, 1997). Furthermore, interpretive description supports PSWs as “situated knowers” who can meaningfully contribute to identifying career- and context-specific learning needs. Thus, interpretive description is well suited to understand the dementia-specific continuous learning needs of PSWs in long-term care homes, by centralizing their subjective experiences working with persons living with dementia and presenting results with clear implications for their continuing education.

### 3.3 Research Methods

#### 3.3.1 Ethics

Ethical approval was granted by the University of Western Ontario Research Ethics Board for the primary study. Ethical approval was re-approved for the secondary qualitative analysis by the University of Western Ontario Research Ethics Board on August 16<sup>th</sup>, 2023 (see Appendix A). Furthermore, ethical concerns regarding the use of secondary qualitative analysis were addressed. These concerns are primarily focused on issues of informed consent, confidentiality, and anonymity (Ruggiano & Perry, 2019; Thome, 1998). In the original study, all participants consented to the use of their data in

additional studies. The data was not anonymized for analysis, as observing focus groups through video recordings was crucial for the analysis of group conversations to consider the tone and behaviours of participants towards each other and the social environments (Krueger, 1998). However, confidentiality was maintained through limiting data access to the first author (GN).

### 3.3.2 Sampling and Recruitment

This study uses and reexamines qualitative data collected from a Be EPIC research project conducted in 2019 and 2020. The principal investigator of the primary study recruited participants through email and phone calls to care organizations describing the intention of the study, eligibility, and contact information. Care organization managers then shared this information with their PSW staff. A list of interested participants were communicated back to the principal investigator (MYS). Participants were screened to determine eligibility. Details regarding the Be EPIC intervention and how data was generated are described in the following sections.

### 3.3.3 Be EPIC

Be EPIC is an innovative, evidence-informed and theoretically grounded person-centered communication intervention designed specifically for PSWs who care for persons living with dementia. The program uses simulated persons living with dementia via professional actors to allow participants an opportunity to practice the knowledge and skills introduced in the program. Participants observed each other interacting with simulated persons living with dementia which promoted learning through observation (Savundranayagam et al., 2021). After each simulation, peer feedback and debriefing sessions were held to promote learning through self-reflection, peer problem-solving, and further opportunities to provide feedback (Savundranayagam, et al., 2021).

### 3.3.4 Data Collection

In the primary study, qualitative data collection was conducted through one-hour focus groups with PSWs (N = 39) from four long-term care homes across London, Ontario between September 2019 to March 2020. Data collection was terminated in March 2020

due to the state of emergency ordered by the Ontario Premier on March 17<sup>th</sup> (Long et al., 2023). This was the first quarantine and lockdown in Ontario, Canada (Long et al., 2023). As a result, it was not feasible to complete data collection for some groups. The data were originally collected for a study investigating the impact of Be EPIC and exploring the working conditions in long-term care homes that influence person-centered dementia care from ‘mid-career’ PSW perspectives (Savundranayagam, et al., 2021).

Focus groups were held before, during, and after the PSWs completed a dementia-specific person-centered communication training intervention called Be EPIC; which focuses on assessing the [E]nvironment, using [P]erson-centered communication, developing client-centered relationships ([I] matter too), and integrating the [C]lient’s experiences, abilities, and personality into care practices (Savundranayagam, et al., 2021). See Table 5 for a summary of focus group sessions according to group and training session. During the focus groups, semi-structured interview questions prompted participants to share and discuss their learning goals and reflect on what they learned from the program and the applicability of learned material to their clinical experiences. Discussions between PSWs also provided in-depth information about their perspectives regarding contextual work experiences, challenges in dementia care, and discrepancies between current competencies in dementia care and desired knowledge and skills and dementia care outcomes, identifying dementia-specific learning needs. Focus groups were audio and video recorded. Recordings were transcribed verbatim and stored in a secure file with the principal investigator (MYS).

**Table 5: Focus group sessions**

Focus Group	Pre-Training		During Training			Post-Training		Total
	Baseline 1	Baseline 2	Module 1	Module 2	Module 3	Module 4	Three Month Follow-up	
B1	1	1	1	1	1	1		6
B2	1	1						2

B3	+	1	1	1	1	1	5
A4			1	1	1	1	5
A5			1	1	1	1	4
Total	2	3	4	4	4	4	22

+Audio recording of group B3’s baseline 1 focus group was not captured in the video recording. Therefore, transcripts could not be produced.

### 3.3.5 Data Analysis and Interpretation

I conducted a secondary qualitative data analysis of focus group data collected between September 2019 - March 2020. Secondary analysis provides an opportunity for the investigator to use previously collected data to explore new questions and expand on previous findings (Thorne, 1998; Ruggiano & Perry, 2019). Focus groups capitalize on group processes to generate social knowledge such as shared beliefs and attitudes motivating certain behaviours or thought processes (Thorne, 2016). The analysis of focus group data is distinctly different from individual interview data analysis, as participants tend to influence each other, changing opinions, attitudes, and building conversation based on previous comments or perspectives (Krueger, 1998). Analysis of focus group data also relies on being attentive to the tone of participants towards each other, the social atmosphere created, and group and individual behaviours (Krueger, 1998).

The secondary data analysis was conducted through an iterative, inductive approach, following the guidelines for Interpretive Description (Thorne, 2016) (explained below). The iterative process in Interpretive Description (Thorne, 2016) encourages the researcher to engage in data collection and analysis concurrently, with the analytic processes informing subsequent data collection and construction (Thorne, 2016). Due to the secondary analysis nature of this study, iterative practices were involved in the analysis and reasoning processes to organize and conceptualize the data (Slaughter et al., 2007). Data was analyzed chronologically and organized in meaningful ways to address the research question and have clear implications for PSW continuing education.

Thorne (2016) describes three broad stages of data analysis: familiarization and initial reflexivity, initial broad coding, and interrogation and refinement of codes. During the familiarization and reflexivity stages, each focus group transcript and video was reviewed in its entirety and reflexive writing was practiced throughout to discern initial thoughts, opinions, and pre-conceptions. I reviewed the data in the same order it was collected in (i.e., baseline data first, followed by module one, then module two, and so on) and recorded patterns and data that stood out to me for potential codes in a written document (audit trail). Reflexivity during this stage included asking myself why particular pieces of data or themes captured my attention over others. The initial patterns, codes and reflexive notes were then shared with MYS for further review and to discuss future considerations of the analytic approach, such as observing if certain learning needs changed over time.

Once all transcripts and videos had been reviewed, open coding was then performed in NVivo to synthesize meanings within the data by identifying and developing concepts related to dementia-specific learning needs. The same order of transcript and video review was maintained during open coding. The goal was to use coding as a mechanism for grouping together sections of data that could be thematically related to allow for a more detailed interrogation of evolving themes, potential relationships with other codes, and how each code contribute to understanding the dataset (Thorne, 2016). Codes were created when I encountered data that was important to identify for further interrogation. With this approach, codes and themes evolved as I moved through the dataset and my understanding of data became stronger and when patterns began to form. Further, once a new code was identified and created, I would iteratively review previous transcripts to ensure that data was not missed or revise codes to reflect new understandings of the data as it evolved.

Interrogation and refinement of codes involved axial and selective coding techniques (Thorne, 2016). Axial coding develops primary codes into broader, more conceptual categories (Charmaz & Thornberg, 2021). This involves using constant comparison methods to examine relationships between codes and understand their contribution to the

conceptualization of the dataset and address the research question (Thorne, 2016). This involved several interrogations with the initial coding to synthesize meanings, investigate relationships, and refine themes or codes (Charmaz & Thornberg, 2021). For instance, I interrogated a code titled ‘lack of confidence’, which was originally created to categorize all data encompassing when PSWs reported a lack of confidence in a particular dementia-specific activity. Through interrogation, I reviewed each excerpt assigned to this code and found that data related largely to insecurities in addressing responsive behaviours, and therefore made this a subcode to the ‘addressing responsive behaviours’ code. Selective coding was the final stage of data analysis, which encompassed interpretive reasoning with the research team to refine conceptualizations of the themes in relation to the broader social contexts and implications for PSW education. For example, excerpts coded within the ‘learning methods’ theme were investigated to determine if they were specific to Be EPIC or applicable to other training contexts.

### 3.4 Rigor

In keeping with methodological coherence, credibility, and rigour, the main investigator (GN) practiced reflexivity throughout the analysis process, performed audit trails, and validated findings with the principal investigator of the primary research study (MYS) (Ruggiano & Perry, 2019; Thorne et al., 1997). Reflexivity is essential in interpretive description as the researcher is assumed to influence the interpretation of the data, which must be acknowledged (Thorne, 2016; Thorne, 1997). Audit trailing is of equal importance as the quality of the interpretation resides in the ability to present how and why certain interpretive directions were taken and how they arrived at certain findings (Thorne, 2016; Thorne, 1997). Furthermore, ethical and representational challenges of qualitative secondary analysis were addressed through transparency regarding the primary study’s data collection methods, decisions, and context, and collaborating with the principal investigator of the primary study (MYS) (Ruggiano & Perr, 2019; Thorne, 1997).

### 3.5 Positionality of the Researcher

This research may help contribute valuable knowledge about where PSWs need support in terms of continuing education and training opportunities in dementia care. As the main investigator, I show up to this work as both an ‘insider’ and an ‘outsider’, as I worked as a frontline support worker at the outset of this study but am now taking the role of a student and researcher. I worked for a year and three months as a support worker in a community home for older adults living with developmental and physical disabilities. My work was located in a small, rural area in Ontario during the COVID-19 pandemic (May 2021 – August 2022). My role consisted of all PSW responsibilities including aiding with basic and instrumental activities of daily living, mental and emotional support, palliative and hospice care, and household maintenance (e.g., laundry, cleaning, etc.). In addition, I was also responsible for managing and assisting people with personal and government finances, administering daily and ‘pro re nata’ (or ‘taken as needed’) medications, scheduling personal appointments, and advocating on behalf of individuals during medical appointments, community engagements, organizational policy changes, and legal consultations.

In my view, the inadequate educational and training support provided to employees during my time as a frontline caregiver was significant. Most of the employee training was rushed or signed off on before I could complete it, due to the staffing crisis at the home, my status as a part-time employee (despite often working overtime), and COVID-19 training priorities. My co-workers shared with me that they accumulated and attributed all of their knowledge to work experience in the homes rather than formal or continuing education opportunities, as they felt their frequency and relevancy to their roles were insufficient. As a result, we often felt lost when navigating individual behaviours derived from medical conditions, such as responsive behaviours or mood swings from individuals living with dementia. I experienced this firsthand when I inquired to my manager about American Sign Language (ASL) classes. In a house of four older adults requiring support, two were hard of hearing or deafness and relied exclusively on ASL to communicate. I continued to request and advocate for ASL classes



by the organization to better care for these individuals, but my request was always dismissed.

This research project has been inspired by working frontline during the pandemic, hearing my co-workers' perspectives on educational preparedness, and my own difficulties advocating for continuing education in this role. Thus, this thesis is situated within these contextual factors, that have shaped who I am as a researcher and the perspectives I bring to this analysis.

## Chapter 4

### 4 Results

This study aimed to identify the dementia-specific learning needs of working PSWs in long-term care homes and examine how learning needs evolve throughout a dementia-specific training program (Be EPIC). The following section presents the demographic data of the participants, followed by a detailed description of three major themes that were discerned from the data: (1) demand for dementia-specific education, (2) learning methods, and (3) mediators. The evolution of learning needs and methods is described within both themes respectively.

#### 4.1 Participants and Demographic Data

Thirty-nine 'mid-career' PSWs participated in the training program and focus group sessions. The average age was 48 years old and participants possessed an average of 16 years of work experience as a PSW. Of these participants, thirty-five identified as female (90%) and four as male (10%). Twenty-four participants self-identified as White (63%), Canadian citizens (61.5%), who spoke English as their first language (82%). The remaining participants self-identified as Black (13%) or Hispanic (13%), Asian (5%), and the remaining as Middle Eastern (6%) or Indigenous (6%).

The length of time participants worked in long-term care ranged from 2-41 years, with the average being 15 years. Thirty-six participants (92%) held permanent positions as PSWs in long-term care homes at the time of data collection. Participants worked an average of 38 hours, most commonly during a morning/day shift (i.e.,  $n = 25$ , 64%). However, the number of hours worked/week varied from 8 to 75 hours. During these shifts, thirty-four participants (87%) provided care to more than ten residents. Twenty-eight participants (72%) reported spending an average of 15 minutes or less with each residents per shift.

Twenty-four participants attained a college degree (61.5%), eight attained a high school diploma or an equivalency (20%), five attained a university bachelor’s degree (13%), and one attained less than a high school diploma (3%). Most participants (i.e., n = 30, 77%) received formal PSW training and thirty-five (90%) received dementia-specific continuing education including GPA, U-First, DementiAbility, in-service training, and others. See Table 6 for further details on the demographic data.

**Table 6: Participant demographics**

Variables	N	%
Sex		
Female	35	90
Male	4	10
Gender*		
Female	34	87
Male	4	10
Age		
Mean (Range)	48 (29-65)	-
Ethnicity*		
White	24	61.5
Black	5	13
Asian	2	5
Hispanic	5	13
Middle Eastern	1	3
Aboriginal	1	3
Immigration Status*		
Canadian citizen by birth	24	61.5
Canadian citizen by naturalization	8	20.5
Landed immigrant	5	13
Years as PSW		
Mean (Range)	16 (2-41)	-

Years in Long-Term Care		
Mean (Range)	16 (2-41)	-
Position*		
Permanent	36	92
Temporary	2	5
Shifts Worked*		
Morning/Day	25	64
Afternoon	4	10
Evening	6	15
Overnight	1	3
Hours/Week working in Long-Term Care		
Mean (Range)	38 (8-75)	-
Number of Residents Cared for/Shift*		
1-5	1	3
6-10	2	5
>10	34	87
Daily Length of Interaction with Residents*		
≤15 minutes	28	72
30-60 minutes	7	18
>60 minutes	3	8
Education*		
Less than High School	1	3
High School or Equivalent	8	20.5
College, CEGEP, other non-university certificates	24	61.5
University Bachelor's Degree	5	12.8
Formal PSW Training*		
Yes	30	77
No	7	18
Dementia Specific Training Experiences		

GPA	35	87
U-First	15	38
DementiAbility	3	8
In-service Training	19	49
Other	3	8

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\*Numbers reflect participants who completed the demographic survey questions. Therefore, discrepancies in numbers exist due to participants leaving certain questions blank.

## 4.2 Demand for Dementia-Specific Education

The learning needs identified by PSWs were informed by their experiences in formal and continuing education. Learning needs were most commonly attributed to limited preparation during formal PSW education and a lack of continuous training opportunities provided to PSWs. As a result of these experiences, the following four learning needs were identified: (1) understanding dementia, (2) addressing responsive behaviours, (3) person-centered communication and attitudes, and (4) delirium. In this section, the educational context in which learning needs emerged is described first, followed by the learning needs themselves.

### 4.2.1 Formal and Continuing Education

Dementia-specific education was lacking throughout the PSWs' careers. Participants commented that their formal PSW education did not equip them with enough knowledge or skill to provide dementia care within the context of long-term care. In terms of formal education, two PSWs insinuated content on dementia was completely absent from their curriculum during program attendance by advocating for these courses to be added in:

“You should put [dementia care] in the actual PSW classes” (PSW5). “In the actual program itself like you know, you’ve got health and wellness, and this, and this, and this. There should be like a dementia class” (PSW2). “Like a course like you know

how they have other courses spread out. Maybe in like the PSW part, they can add that in there somewhere” (PSW5).

These judgements were further extended to current education curricula and practices based on their experiences working with placement students and recent graduates. Consequently, PSWs recognized a sense of inadequacy in confidence to provide optimal dementia care among both themselves and new PSWs entering the long-term care sector: “Really the newer people definitely...they’re lacking confidence, as well with dealing with a lot of these situations, and I don’t know what they’re getting taught in school anymore, but I don’t think it’s dementia-specific...” (PSW5).

PSWs emphasized that in addition to adding more dementia-specific content, the delivery methods also need to be improved. Multiple focus groups identified the need for more experiential learning methods to be included in formal PSW education to improve confidence in dementia care: “It’s only the new people that don’t have that much experience...And they’re just like...they are afraid to step in...They are not having hands-on [training]” (PSW32).

Certified PSWs working in long-term care relied on continuing education opportunities to address gaps in dementia-specific competencies. However, PSWs expressed dissatisfaction with the limited frequency of these opportunities. The lack of opportunities for PSWs was particularly troubling as they voiced concerns regarding equitable educational support compared to other industries as well as remaining current with care research:

“I took the PSW course 18 years ago. So, what changed from 18 years to present? There’s been a lot of research, and obviously, a lot of stuff changed. So, like I was saying, in any industry, there’s always educational training and upgrading, and I don’t know if the focus for PSWs really has that strength on it.” (PSW30).

PSWs emphasized that the opportunities they did receive fell short of addressing their learning needs, both in terms of delivery methods and content. These opportunities were most commonly online, asynchronous modules mandated to either address problems

and/or meet regulation standards. While topics such as oxygen administration, infection control, and Workplace Hazardous Materials Information System (WHMIS) were covered, PSWs felt they did not receive enough continuing education opportunities tailored specifically to dementia care. As a result, they advocated strongly for more opportunities to be offered on a regular and ongoing basis:

“My problem with the training though, with the oxygen and stuff, it's all done in reaction. So, there is either a ministry order, there is a problem and then they'd go around and [mandate] everybody in the training and then it's done. That stuff should be done on a regular basis.” (PSW26).

Another PSW commented:

“In two months down the road, we might completely forget this training, not forget, but we're not going to be implementing it. But if we have continued education, it will always be there. As PSWs in the workforce, we don't have any room for advancement. We are PSWs, we will never advance in this home, right? That is our job: PSW, but we need continuous training. There is no training at all in dementia training, teamwork training, or morale training. All-around training needs to be done continuously here.” (PSW29).

A discrepancy in knowledge based on experience levels existed in some homes as a consequence of inadequate continuing education opportunities for certified PSWs in long-term care. One PSW emphasized the importance of equal education opportunities, regardless of experience level, to ensure consistency in dementia care practices. One suggestion was to offer continuing education courses aligned with updated learning outcomes in PSW programs:

“And for the PSWs, like for example, you've been doing it for a long time, versus a person who's been doing it for two years who just finished school two years ago and learned about the responsive behaviours and stuff so then when a PSW like that comes in and then works maybe with somebody who has been doing it for a longer time who seems a little bit shorter in that kind of thing, maybe refresher courses...or maybe they

should be rolled out to everybody everywhere you know...so that everybody is educated and people aren't just feeling like 'oh my God she's coming in and she's going to tell me what to do, she's only been doing it for a year or whatever it is.' (PSW24)

## 4.2.2 Learning Needs

### 4.2.2.1 Understanding Dementia

PSWs identified a general need for more education to understand dementia more precisely. Most PSWs identified this as a broad learning need without specifying exactly what they wanted to understand about dementia. For instance, one PSW stated their desired learning outcome from the training program was to: "Understand the disease more, to be able to be more hands-on with the clients I'm working with" (PSW29). Others elaborated on this by distinguishing a need to understand the different types of dementia: "And also, I would like to learn if there are certain things that differentiate or are common between different types of dementias" (PSW26).

### 4.2.2.2 Addressing Responsive Behaviours

Addressing responsive behaviours was the most frequently discussed learning need across all focus groups. Responsive behaviours can be understood as how an individual living with dementia might communicate unmet needs and feelings in response to their personal, social or physical environments and contexts (Clifford & Doody, 2018). Participants described these behaviours as 'violent' and 'aggressive' and emphasized a need for additional education on how to appropriately address them:

"I would like to see more tools that we can implement working with people with heavy dementia. And when they are a little bit on the side of aggression, a gentle approach yes, but we would like to get more training with it." (PSW32)

The number of staff who are trained to appropriately address responsive behaviours was not sufficient for the frequency of responsive behaviours in their long-term care homes:



“As a staff member, I would like to feel more confident to approach this situation right. Like I know we have [gestures to PSWs in the group] as [staff with additional behaviour-specific training], but sometimes when we are waiting for them to come, even just to prevent anything bad from happening right, so some tools maybe. Like that’s why I signed up for education.” (PSW33)

PSWs did not feel confident in appropriately addressing responsive behaviours when caring for people living with dementia. This included preventing behaviours before they happen and while someone is experiencing responsive behaviours. When engaging in the experiential-based learning with simulated persons living with dementia in Be EPIC, PSWs noted that despite having previous experiences in similar situations, they still felt uncertain, uncomfortable, and afraid in their approach. One participant described feeling their ‘fight or flight’ response activate when they engaged with a simulated person living with dementia displaying responsive behaviours:

“I was ready to be thrown [by the simulated person living with dementia] ...and I’m not saying that I had to jump out of my comfort zone...but like you said, [it was a] fight or flight [response for me]...I want more of a confidence to deal with aggressive residents, like I mean the ones with high-end dementia but [they’re] more aggressive...getting the confidence up there...if it does happen again or to stop it before it happens again.” (PSW23)

The lack of confidence was also extended to newly graduated PSWs, noting that many appeared unprepared when addressing responsive behaviours. Many of the ‘mid-career’ PSWs within the focus groups expressed concern regarding the adequacy of current training programs to address responsive behaviours appropriately and confidently. As a consequence, new PSWs were described as feeling overwhelmed and potentially abandoning a person living with dementia. One PSW emphasized the necessity of a comprehensive training program to equip PSWs with the skills, knowledge, and confidence required to address responsive behaviours:

“In order for the industry to somehow survive without any great tragedies taking place they need a two-day annual training and several hours... Because I don’t even know if they’re being taught that and they don’t seem to have...new PSWs don’t seem to have any idea of what is in front of them...they just don’t know how to handle [responsive behaviours] and many of them would have just walked away from [the simulation] and left [the simulated person living with dementia] to his own demise.” (PSW7)

Responsive behaviours can be expressed through verbal/vocal and physical behaviours (Cohen-Mansfield, 2000). Verbal/vocal behaviours can include complaining, yelling or screaming, cursing, repetitive sentences, questions or unwarranted requests for attention or help, and verbal sexual advances, while physical behaviours can include pacing, restlessness, hoarding or hiding objects, scratching, grabbing, kicking, biting, hitting, and physical sexual advances, to name a few (Cohen-Mansfield, 2000). The approach used to address these behaviours will vary due to the differences in behaviour presentation and the potential for harm. However, distinguishing between verbal and physical responsive behaviours was difficult for some PSWs, as they often automatically labelled all responsive behaviours and, most importantly, the person expressing these behaviours, as ‘aggressive’, or ‘violent’. This was particularly evident during a focus group immediately following the education module on addressing responsive behaviours with the simulated persons living with dementia. During the focus group, one PSW asked if the others had received “violence” from the actor, prompting a discussion about how to accurately classify behaviours. The facilitator as well as the PSWs involved in the simulation explained the importance of describing the behaviours accurately as it can influence the care approach used with that individual in the future:

“Because my impression of violence is that someone’s got their hands and they’re ready to smoke you, so if you come to me and say ‘[person living with dementia] is being violent.’ I am going into that room expecting that he’s going to have to be restrained or something. (Facilitator) Well, I said [they] were violent in the sense that I thought he was going to be banging his head, for example. He was agitated, he was frantic, he was scared, he was crying, he was panicked. He seemed panicked and I

think that if I got in his way, I would've gotten hit, but I don't think it was intentional to hurt me, it was just in the state of panic that he was in." (PSW28)

In another example, one of the PSWs involved in a simulation expressed uncertainty concerning how to address the behaviours appropriately. This sparked several PSWs to jump in and answer their question, however, each with different approaches, including calling a "code white" (violent/aggressive behaviour) and leaving the person exhibiting the behaviours. However, the facilitator reminded the group that the simulated person living with dementia was not displaying physically responsive behaviours, and therefore did not constitute a "code white" for violent/aggressive behaviour or being abandoned:

"But for the safety part, what do we do? They are trying to jump out, they are falling, knocking themselves so what do we do? (PSW19) You call a code white (PSW21). I would say take yourself out and bring someone else in." (PSW22). "[The simulated person living with dementia] wasn't being aggressive, like [they weren't] being physically responsive to you, she wasn't a code white, she was just escalating, she just wanted to get out." (Facilitator).

Involving mental health support within care practices for people living with dementia was becoming more common for PSWs, however, adequate education and training in this area was severely lacking:

"There are a lot of mental health problems coming into long-term care, so trying to deal with those behaviours as well...some more tools would be helpful." (PSW12).

"We're struggling... definitely mental health is huge right now." (PSW16).

PSWs recognized trauma as having a pervasive impact on the prevalence and patterns of responsive behaviours amongst persons living with dementia in long-term care. Several PSWs shared instances where they uncovered a direct link between specific responsive behaviours and past traumatic events in their client's lives. Discovering and acknowledging the association was an important skill set for PSWs to have to prevent and address behaviours in person-centered ways. However, PSWs were rarely provided information regarding potential traumatic experiences or education on how to address

such situations effectively and efficiently. This left many in vulnerable positions where they needed to develop their own strategies and approaches to uncover such information to better meet the needs of individuals in their care. PSWs noted that this process often required a trial-and-error approach due to a lack of education on trauma-informed care:

“We had a gentleman. This gentleman, he was afraid. Every time we put him in the shower, he was very aggressive. Then we found out that his brother drowned, that’s why he was like that. He was scared of drowning. So, if we know that, we try a different way... we just try, like you know, go maybe with a little wet towel. Just go around his body and like you know in the shower chair without putting the hose on him...put [him] in the tub is better, or sometime not because it depends on history, yeah.” (PSW18).

#### 4.2.2.3 Person-centered Communication and Attitudes

PSWs identified a need for further educational support in effectively approaching and communicating with persons living with dementia in person-centered ways. Person-centered communication is a key aspect of person-centered care, which seeks to foster meaningful relationships between persons living with dementia and their peers (Kitwood, 1997; Savundranayagam & Moore-Nielsen, 2015). This approach involves the recognition and inclusion of the life history, preferences, and values of the person living with dementia during social and care interactions (Kitwood, 1997; Savundranayagam & Moore-Nielsen, 2015). Learning needs within this domain include person-centered communication strategies and stigmatizing language, as well as attitudes that influence dementia care approaches. Attitudes included those held by PSWs toward their approach to providing person-centered care and their roles in providing care for people living with dementia.

A general need for further education on person-centered communication was identified by PSWs to optimize the quality of care provided to persons living with dementia in long-term care. Acknowledging and understanding clients as unique individuals through

person-centered communication strategies was important. One PSW identified this as a personal learning need during a pre-training focus group session:

“More time and more background knowledge of who they are as a person before the dementia. Like I find that we don’t really know their wife’s name, their kids’ names, their grandkids’ names, what they did, where they lived, where they’re from. Just to like, have more interaction with them [...] so just would like to know more about them.” (PSW30).

Communicating with persons living with dementia in person-centered ways was difficult for most PSWs among all five focus groups. PSWs shared their gap in knowledge and skills in effectively communicating with persons living with dementia often provoked distress during care interactions for both them and their clients. PSWs experienced frustrations and moral distress when navigating repetitive conversations with persons living with dementia. This was particularly distressing when a person would repeatedly ask about topics that had the potential to prompt feelings of grief, such as inquiring about relatives who have passed away; especially if the PSW did not feel knowledgeable on how to respond appropriately.

“One of the questions that [persons living with dementia] ask is, for example, ‘where is my husband? Why isn’t he coming?’ And the husband is gone for a long time, and they forget about that, [...] is there any way that we can do something or we tell them something so that they don’t have to go through the grief every day or every hour or every two hours of losing their loved ones? That bothers me as a worker that is working day in and out.” (PSW6).

Another PSW shared that not knowing how to navigate repetitive conversations was a particularly frustrating experience when it prevented them from providing care on time:

“So, you feel guilty, and you have less patience for the residents because they are holding you up. This person makes you repeat everything five times, and they don’t understand what you’re saying, you have to walk away because it is so frustrating.” (PSW11).

Improving the efficiency of care interactions through person-centered communication was another motivator for further education in this area:

“You know, maybe if we’re learning how to communicate with people better, then we’ll be able to get it done quicker. Sometimes arguing with somebody and forcing them ends up taking a lot longer and if we get better skills to communicate, then we’ll be able to be more efficient at our other jobs.” (PSW36).

Complicating this knowledge gap is the addition of communication impairments among persons living with dementia. Without adequate knowledge or skills, PSWs found it difficult to comprehend or use alternative communication strategies in person-centered ways. This led some PSWs to perceive that communication was not possible once an impairment was present:

“We often make the choices for [people living with dementia] which does take away from them but are they able to always answer...like on our floor, not very often.” (PSW2).

Another PSW described how they may speak at or over persons living with dementia instead of with them, causing frustrations and potentially responsive behaviours:

“Many people go and talking, talking, talking, doing, doing, doing, and that may upset, may irritate. Many residents get aggressive because of us not... (PSW18) Yeah, they can’t follow that conversation, like over their head. (PSW21) They don’t cooperate with you when you [do that]...because they can sense sometimes, you know, your voice, [that] it’s not about them.” (PSW18).

Certain communication impairments resulted in the loss of the ability of people living with dementia to speak English. This was identified as a common problem amongst PSWs in one focus group in particular. This difficulty caused frustration for both persons living with dementia and PSWs.

“But then again, you get to know the residents who like to hear you talk, even though they aren’t answering you. Some, it angers them because maybe it’s frustrating, they can’t answer you, no idea. ‘You don’t even speak my language, right?’ That’s a big difficulty, not speaking the language.” (PSW2).

The use of stigmatizing language toward persons living with dementia was used amongst nearly all PSWs from each long-term care home. The language used to describe persons living with dementia included labels such as ‘aggressive’, ‘dementia or Alzheimer’s resident’, ‘feeders’, and ‘demented people’. PSWs from one long-term care home referred to people who did not live with dementia as ‘cognitive people’ in addition to ‘dementia residents’. Behaviours amongst persons living with dementia were described as ‘unpredictable’, ‘demanding’, ‘resistive to care’, and ‘dangerous’. Furthermore, PSWs described themselves as ‘dealing with’ persons living with dementia rather than ‘caring for’ or ‘working with’ them. For instance, one PSW expressed their learning goal while using stigmatizing language:

“I want more of a confidence to deal with aggressive residents, like I mean the ones that have high-end dementia but more aggressive. I have dealt with a lot of aggressive residents while I have been here, I have been a victim to a lot of aggressive residents here.” (PSW23).

The use of this language indicated a knowledge gap related to identifying and using stigmatizing language in all focus groups. However, PSWs only recognized this knowledge gap after being exposed to the topic during the training program:

“I went to school 12 years ago and when I went to school we were taught well they are an aggressive resident, we weren’t taught so much about different behaviours and responsive behaviours whereas now, things are ‘responsive behaviours’ but I wasn’t taught that way in school so my whole career leading up to this point is that is an aggressive behaviour, so [the training program]’s changing the whole mindset on how do you deal and implement supports for these residents.” (PSW29).

PSWs became aware of the consequences of using stigmatizing language. For example, labelling someone as “aggressive” can impact the mindset and approach used to provide care for a person living with dementia:

“Maybe a few weeks ago, I would think, oh I know this is an aggressive resident when they are not aggressive, right? So, if you can change your mindset on the aggression part, like, you said, and realize that it’s the dementia or the delirium and how we’re interacting with that resident differently from now on compared to how we were say a week ago or two weeks ago.” (PSW29).

Person-centered attitudes and approaches for providing care to people living with dementia were identified as a learning need as well. Particularly, approaches and attitudes promoting patience amongst PSWs and independence amongst persons living with dementia were the two most commonly identified learning needs in this topic.

Approaching people living with dementia with attitudes centered around promoting independence was identified as a learning need immediately before PSWs were introduced to the training program: “I think I’d like to get more tools to continue to grow to support independence for my residents” (PSW30). This was also extended to approaching people living with dementia with attitudes similar to restorative care and how people living with dementia are perceived by some PSWs as only ‘getting worse’:

“I kind of think that maybe some of the mindset is that when residents come in here, they’re not going to get any better, they are only going to get worse. But that’s not how it is [...] I would like to change that mindset.” (PSW24). “Yeah, the mindset for sure. Hopefully, we get those tools to carry it forward with the rest of the team.” (PSW30).

The need for further education on approaches to promote independence and the attitudes’ influencing behaviour was also exemplified through descriptions provided by PSWs on their approaches at the time of the training. For example, one PSW sought advice on how to approach a person living with dementia who does not want them to brush their teeth for them: “I have the blanket on top of him, he is in the bed and I am pushing his arms, so



he doesn't get his arm off because he is going to throw the toothbrush away" (PSW20). This comment indicates that the PSW lacks the communication skills and attitudes to provide care in a manner that aligns with person-centeredness through the promotion of dignity, independence, and respect for the person living with dementia, rather than using physically restrictive strategies. Furthermore, PSWs described often making decisions on behalf of persons living with dementia due to inadequate communication skills and time limits imposed by the conditions of long-term care homes:

"We often make the choices for them [...] It's kind of hard even to give them a choice on what to wear. That decision seems a little difficult for them or we don't give them enough time to make it." (PSW4).

Several PSWs referred to providing care for persons living with dementia as a "task". One PSW described how this mindset influences their verbal and non-verbal communication with persons living with dementia and their approach to providing person-centered care:

"That's one of the things [persons living with dementia] will say is that we probably don't talk enough, and we don't smile enough, but it's because we're on task, right...I don't want to refer to them as a job, but they are a job, a task at that moment, it just so happens that the task involved a human being." (PSW7).

#### 4.2.2.4 Delirium

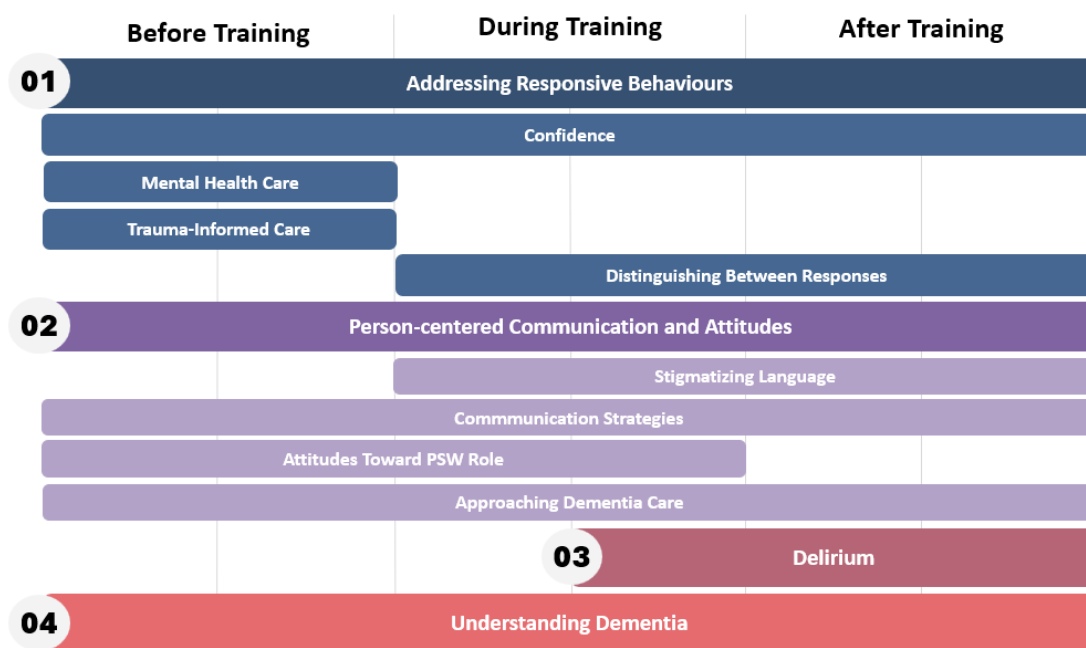
Delirium was identified as a learning need after PSWs were introduced to the topic in the training program. Familiarity with the topic was varied as some recognized the term while others did not. However, upon reflection, PSWs recognized that delirium education was needed before it was recognized as a learning need, as a handful of PSWs admitted they previously believed delirium and dementia were the same: "A lot of the time we label [delirium] automatically as 'oh they have dementia' but there's a big difference between having dementia and having delirium" (PSW29).

After learning about delirium, PSWs identified the topic as urgently needed in the PSW curriculum and continuing education programs. This included learning about the different types of delirium, causes, symptoms, and approaches to address them in PSW practice:

“How come this isn’t in the [PSW] curriculum [...] this isn’t in any of the curriculum for any of the courses like college or universities really. I took a little bit of it but the hypo and hyperactive [delirium], they weren’t [included]...honestly, I didn’t even know the hypo and hyper existed, all I heard was ‘there is delirium, there is dementia, here’s an umbrella [term], these are the symptoms of what can cause this, this, and this. Your exam is next week.’ Where with [Be EPIC], you branched right out, you said it can be caused by this, this, this, also could be caused by this, these are the signs...then you did it in a scenario with the signs showing it, I didn’t learn any of that [in PSW curriculum].” (PSW23).

#### 4.2.3 Evolution of Learning Needs

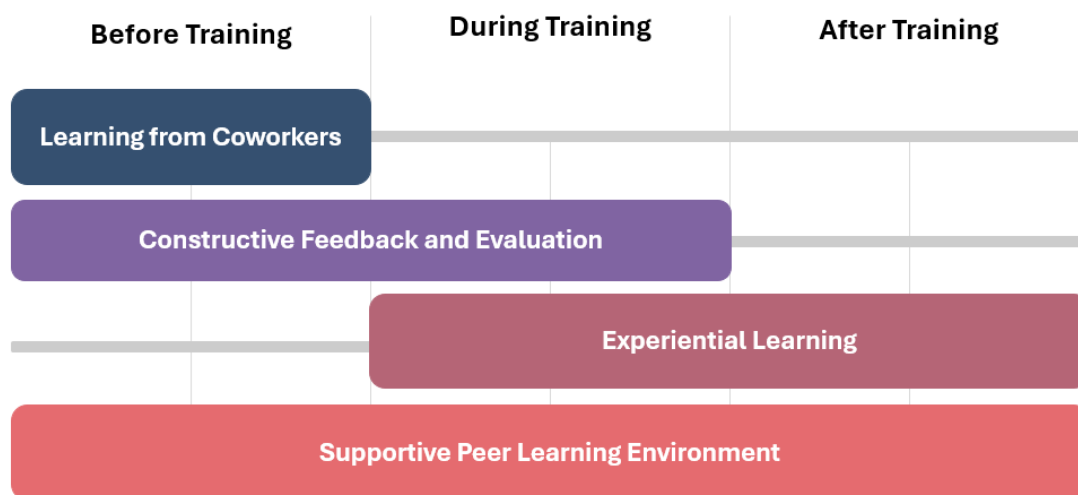
Figure 2 outlines the evolution of learning needs as PSWs were introduced to concepts and educational content during the training program. Before PSWs were introduced to the program, self-perceived learning needs included understanding dementia, addressing responsive behaviours, and person-centered communication strategies and approaches in dementia care. The content introduced to PSWs during Be EPIC expanded their previous learning needs to include a wider range of topics and subtopics. For instance, identifying and using stigmatizing language, distinguishing between verbal/vocal and physical responsive behaviours, and delirium were identified as learning needs after PSWs learned about them.



**Figure 2: Identification of learning needs before, during, and after participating in Be EPIC**

### 4.3 Learning Methods

How PSWs wanted to learn was also an important factor in the identification of learning needs. Before being exposed to the training program, PSWs emphasized a need for training and education methods to include opportunities to learn from their co-workers and receive constructive feedback and evaluation within a supportive learning environment. Once engaged in the training program, PSWs also highlighted a need for training/education to be conducted through experiential methods. PSWs commented on the lack of experiential methods in formal and continuing education opportunities, as discussed under heading 4.3.1. See Figure 3 for a timeline on the identification of learning methods before, during, and after participating in Be EPIC.



**Figure 3: Identification of learning methods before, during, and after participating in Be EPIC**

PSWs expressed a need for continuing education to reflect the collaborative nature of PSW work within long-term care homes by incorporating opportunities to learn from their peers through conversational and observational methods. The preference for peer learning was present before participants engaged in the training program, however, the importance of this element in future education programs was reinforced by the effectiveness of the debriefing opportunities in the training program. During the training program, participants were provided with opportunities to observe each other participate with a simulated person living with dementia. Afterwards, the participants would reflect on their experiences and provide feedback to each other. Particularly, the uniqueness of individual experiences, and therefore diversity across a team/group of PSWs, was highlighted as an important resource for learning:

“When people come in from other units as well, like someone who’s part-time or there for one time, they can bring knowledge with them as well. Sometimes they’ll say, ‘Oh, we have a person on our unit, and we try this.’ And so sometimes that’s a really good tool for us to use is the knowledge that everybody brings to the table.” (PSW36).

Learning while observing offered PSWs the opportunity to learn by watching their co-workers. This method added to the learning being done through conversations by

modelling various care approaches with the simulated persons living with dementia: “Yeah, I think it was a great exercise because you can see how another person is acting and how I act too.” (PSW20). Other PSWs commented:

“I like that there was three of us [in the simulation] and two could observe so then I could know what is going on after. (PSW21) So, you could see how someone else does a thing too not just thinking [...]” (PSW22).

Further, PSWs identified that having their peers share their observations about each other following the simulations generated a greater sense of self-awareness. This was particularly helpful for identifying unconscious behaviours and relating the educational material to their self-concepts and experiences. The significance of receiving feedback emerged during a baseline focus group and was subsequently amplified as PSWs actively participated in providing and receiving feedback from their peers, simulated persons living with dementia, and training facilitators throughout Be EPIC. Peer feedback was valued by participants because it provided an opportunity to share knowledge, experiences, and skills, offer reassurance, and build confidence and self-awareness during care interactions:

“I think it would be nice to see if there was training like this in the workforce [...] for example, giving us feedback as PSWs and what [we] are doing wrong [something that could be improved] and right. Because I think there are a lot of staff who might do something they are not aware of, whereas doing this will make them aware that ‘Hey I have done that every day in my whole ten-year career.’ Right where [I am] now, someone has made me aware of it, where I can stop and [tell myself] ‘don’t do that’.” (PSW29).

The feedback provided by the simulated persons living with dementia was viewed as crucial for PSWs’ learning process and professional growth because it was from the unique perspective of an individual receiving dementia care: “And you can change things too after and they’ll tell you like ‘Hey you tugged on my shoulder a little too heavy,’ or

something. You can work on that. It will always stick in the back of your head” (PSW25). Another PSW shared:

“[Receiving feedback from the actors] was huge. That was invaluable because they can give us a different perspective than co-workers [...] They can tell us how they felt. They can tell us whether or not they felt safe, whether they felt mistreated, or you know, respected. They can tell us those things better because they are the ones who feel it.” (PSW26).

This feedback was especially important for PSWs, as their clients living with dementia often conveyed difficulties communicating feedback verbally.

“On the job, we are not ever going to get that feedback from someone who actually has dementia. So, that’s the thing, they have got into their acting roles so well, so to get that feedback was good. Because on the job, we’ll never [know].” (PSW29).

PSWs also recognized that for feedback to truly foster professional growth and learning, it needed to be delivered constructively and positively: “And [the facilitators] are always encouraging to learn and like make mistakes and learn from your mistakes and like what could’ve been done better and ‘you did this great’” (PSW27).

Across PSW accounts, the positive and constructive nature of feedback was seen to contribute to building a supportive peer learning environment. Participants described feeling safe within the learning environment when it fostered collaboration, trust, and mutual respect. Two key areas stuck out to the participants in this area: (1) providing and receiving peer feedback as a group and (2) supportive teamwork dynamics.

The ability to provide and receive constructive feedback as a group was described as creating a psychologically safe learning environment for all PSWs. As a result, trust could be built and maintained for future training sessions or opportunities for peer feedback:

“I think the debriefs, even in the smaller groups, allow us to rethink things, and give tips. I think one of the things I’ve noticed though is that it has built a lot of trust amongst us, being able to trust that I can say something and I’m not going to offend anybody and trust that it’s coming from... (PSW26). “An honest place.” (PSW24). “A safe place.” (PSW25).

One PSW mentioned the presence of the supportive learning environment facilitated a greater ability to engage and focus on learning within the simulations:

“And when I’m doing the scenarios, it doesn’t bother me because if I screw up, I’m going to learn and if I do it right, I’m going to learn and not be offended...the feedback I’ve gotten has been constructive feedback [...] everybody has been okay with the feedback from each other which is not what I was expecting.” (PSW24).

The assurance of support from co-workers during interactions with simulated persons living with dementia was another element of the learning environment that fostered a feeling of safety and trust. This was particularly important as some PSWs perceived this level of teamwork was missing in real-world care interactions: “It was nice to know that when you needed the tap out, the tap out was like welcoming not just like ‘oh you can’t handle it?’” (PSW27) “There was a positive energy in this room rather than on the floor” (PSW28).

#### 4.3.1 Experiential Learning

Learning through experience and practice was a highly effective learning method for PSWs, a consensus observed across all focus groups. Simulations during the training program involved practicing and applying new concepts with the simulated persons living with dementia. PSWs recognized both the practicality of these simulations and the hands-on approach as crucial for successfully applying knowledge, skills, and attitudes to real-world care interactions. The practicality of the simulations facilitated learning retention by accurately modelling the PSW role within long-term care. The hands-on approach involved both physically and verbally interacting with the simulated persons living with dementia, allowing PSWs to apply knowledge obtained from the training program and

gain further knowledge through experience within the simulation itself: “I like the hands-on because that’s what we do. It puts us in our comfort zone, it puts us in our world and then our instincts and our training kind of kicks in and you go through it” (PSW26).

Another PSW expressed:

“There was a practical component added in as opposed to just like theory, so we were able to apply what you were showing to us. So, it gave us an opportunity to see if we were able to or if we had to expand and grow.” (PSW30).

The hands-on approach to simulation-based training with simulated persons living with dementia was also beneficial for learning as it reduced the possibility of distractions outside of the learning environment:

“And I find with [online training], I will sit and watch a video for two hours and I am trying to do it and all of a sudden, I am like I don’t remember. I’ve got kids screaming in the background, I have my husband watching TV, yelling at the TV, and at the end of it I am like ‘I have no idea what I just watched’. Then I have to watch that whole two-hour video again. My eight-hour training took me four days.” (PSW29).

Furthermore, when compared to previous learning methods, such as simulation-based learning with mannequins in formal education and asynchronous online methods in continuing education, the utilization of simulated persons living with dementia was perceived as the most effective method for learning. PSWs described this method to be particularly realistic to their daily interactions with persons living with dementia:

“I went to [name of school], we actually had like the simulation with the...mannequins...but that is nothing compared to [simulated persons living with dementia]. Like I feel like the simulation [in school] should involve something like this, you know what I mean? Because we actually have the simulation rooms, and it is set up as like an actual hospital room. Like there is actual oxygen, you check their blood pressure, you do everything to these mannequins. But when you have the actual person that can get up and actually do, they should implement that.” (PSW25).



Another PSW commented:

“Every home has their mandatory education stuff and a program like this being built into it where it’s not just online, but where you’re actually able to get in and do more in-service stuff...But I think the benefit to your residents, the benefit to your workers and the value you’ve put in your work when you do [this type of training], as opposed to going home, watching a bunch of videos, taking a couple of tests, have your computer crash all the time, get frustrated.” (PSW20).

#### 4.4 Mediators

Openness to dementia education and the presence of a good teamwork culture were identified as key mediators of learning being successfully transferred into long-term care practices. PSWs commented on the fact that for education to have any real meaningful impact on a PSW and the people they care for, they must be open to dementia education. This openness was described by PSWs as being associated with the individual’s passion for providing optimal dementia care:

“You can give them free education all you want, but it’s not even that if you’re just giving education away and somebody just goes and does it, but if your heart isn’t [in] it like this job is not for everybody.” (PSW7).

Furthermore, throughout the focus groups, a good teamwork culture was identified as an essential mediator to successfully transferring learning into clinical contexts and behaviours. PSWs described their roles as working largely in pairs or teams to provide care to people living with dementia. A good teamwork culture in long-term care homes was described as involving the presence of mutual respect, trust, and openness to learn from each other, and to facilitate an exchange of knowledge. For instance, PSWs who received training needed to inform and support their peers who did not have the same opportunity to facilitate the exchange of new knowledge and promote changes in clinical behaviours. This was described as an essential component of applying new knowledge, skills, and attitudes to real-world care interactions:

“If we don’t have something that bridges us using the skills and sharing them with other [staff]...to use it on a daily basis, it is going to be like anything else we have ever been taught: it’s going to slide under the table. Not because it’s not a good program, not because we don’t want to [apply new knowledge], but because there aren’t opportunities for us to share it. The more we end up having to teach this, as opposed to just modelling it...Like, talk about certain things and different approaches and whatnot where [staff] are willing to listen. And I think as long as we are able to do that over the period of time, it’ll stick. But that has to be a buy-in by co-workers.” (PSW26).

However, this was described as an issue within some teamwork dynamics when an openness to learn from peers was not present. PSWs mentioned this problem with more experienced PSWs discrediting the knowledge of those who are relatively new to the role:

“We do have some newer, younger PSWs here that some of the more senior PSWs are going to discredit just because they’re young, you’re new, you don’t know, I’ve been doing this for a lifetime. And we need to switch that mentality and have something collaborative from management and staff to be able to bring this [...] if we are expected to just learn this information, go on the floor, and model it, it’s going to die and then we’ve wasted our time.” (PSW26).

Others shared concerns that their co-workers might be close-minded and dogmatic about learning something new if their current knowledge and experiences have worked for them in the past:

“It depends on the person again that you’re speaking with. Again, with [name of PSW], I 100% feel like I can say, ‘Hey, da da da da, this is what I find is working with this resident,’ and they’ll take that information. But some other PSWs: ‘Oh no no no we just do this. Oh no we just do this’. It just depends.” (PSW24).

In addition to being open to learning from peers, team members needed to be open to giving and receiving constructive feedback on work performance. This was a learning strategy used in the Be EPIC and was recognized by PSWs as an essential skill for

transferring knowledge from training into practice within the long-term care setting. However, many noted that this openness was missing in many long-term care homes, along with the knowledge and skills to provide feedback constructively:

“I feel like some staff members take [feedback] really personally. If you say, ‘Hey why don’t you try doing this?’ they’re like ‘Okay well you’re going to tell me how to do my job’ kind of thing. There’s a lot of that. Or ‘Don’t worry I worked here for thirty years, I know what I’m doing’ there’s a lot of that so...” (PSW38).

## Chapter 5

### 5 Discussion

The findings from this study provide insight into the dementia-specific learning needs of PSWs working in long-term care homes, the desired methods for delivering such education, and the significance of ongoing education opportunities. This is the first study to identify and examine dementia-specific learning needs from the exclusive perspectives and experiences of PSWs working in long-term care homes. Furthermore, this is one of few dementia-specific learning need assessments to acknowledge PSWs as healthcare professionals with a rich composite of experience to guide interests and needs in dementia care education.

#### 5.1 Demand for Dementia-Specific Education

The findings of this study contribute to and expand upon the existing literature on dementia-specific learning needs of unregulated healthcare workers. PSWs identified several gaps in competencies concerning dementia care including understanding dementia, addressing responsive behaviours, person-centered communication and attitudes, and delirium. Similar topics have been previously identified in other dementia-specific learning need assessments (Attard et al., 2020; Bolt et al., 2020; Chang et al., 2009; Foster et al., 2019; Hughes et al., 2008; Kolanowski et al., 2015; Marx et al., 2014; Morgan, Kosteniuk, O'Connell, Bello-Haas, et al., 2016; Sabbe et al., 2023; Timmons et al., 2021), despite only a handful reporting those specific to unregulated healthcare workers. In the Canadian literature, rural home care PSWs also identified understanding dementia, assessing cognitive and functional abilities, communicating with persons living with dementia and family members, and addressing responsive behaviours as significant areas needing effective educational support (Morgan, Kosteniuk, O'Connell, Bello-Haas, et al., 2016). Outside of the Canadian context, addressing responsive behaviours, person-centered communication and attitudes, delirium, and understanding dementia have been consistently identified areas of knowledge and skill requiring additional support by unregulated healthcare workers (Attard et al., 2020; Bolt et al., 2020; Chang et al., 2009;

Foster et al., 2019; Hughes et al., 2008; Kolanowski et al., 2015; Marx et al., 2014; Sabbe et al., 2023; Timmons et al., 2021; Toteh Osakwe et al., 2022).

However, the present study is the first to identify trauma-informed care and dementia-specific stigmatizing language. The novelty of these findings can be due to differences in data collection and analysis, and dementia-specific objectives. Quantitative data collection approaches, such as surveys and questionnaires, are the most commonly used methods for identifying learning needs, especially within the dementia-specific literature (Al-Ismaïl et al., 2023; Ferreira & Abbad, 2013; Grant, 2002; Hauer & Quill, 2011; Norris et al., 2024). However, these methods involve providing a predetermined list of competencies and/or topics for participants to choose from, potentially limiting their ability to express needs. Studies that employed a qualitative approach have narrowly focused on an aspect of dementia care rather than broadly exploring the topic, such as end-of-life care (Foster et al., 2019), self-management (Verkaik et al., 2017), and care plans (Toteh Osakwe et al., 2022). This narrow focus may limit the identification of dementia-specific learning needs that are beyond the objective's scope, yet within the realm of dementia care (Norris et al., 2024). Moreover, this study is the first to examine the identification of learning needs throughout a dementia-specific program, which led to the identification of the following learning needs: dementia-specific stigmatizing language and delirium (See Figure 2).

The wide range of learning needs identified by PSWs within this study align with existing research associating competency and confidence in dementia care with formal qualifications, dementia-specific training, and knowledge levels (Chen et al., 2013; Chung & Lai, 2003; Hughes et al., 2008; Morgan et al., 2016; Nguyen et al., 2022; Wang et al., 2020; Zimmerman et al., 2005). PSWs receive the least comprehensive formal education and fewest continuing education opportunities, compared to regulated healthcare professionals, which contributes to the perception of their profession being of 'low-skill' with minimal competencies and confidence in dementia care provision (Grant, 2016; Savundranayagam et al., 2021). Limitations in education exist despite PSWs representing the largest workforce in Canadian long-term care homes and providing over

80% of daily direct care to persons living with dementia (Chamberlain et al., 2019; Chen et al., 2018; Kane et al., 2023; Morgan, Kosteniuk, O'Connell, Bello-Haas, et al., 2016; Statistics Canada, 2004; Timmons et al., 2021). The range and quantity of learning needs identified in this study reflect a discrepancy in the competencies outlined in formal education standards and the reality of dementia care within the context of long-term care homes (Kary et al., 2020; Kelly, 2017; Kelly & Bourgeault, 2015; Scales, 2022). PSWs in this study identified the lack of dementia-specific education was evident within themselves as well as newly graduated PSWs, suggesting minimal improvements in dementia-specific curriculum within formal PSW education (Kane et al., 2023; Kelly, 2017; Ontario Centres for Learning, Research & Innovation in Long-Term Care, 2021; Scales, 2022).

Inadequate formal and continuing education significantly contribute to adverse outcomes on the well-being of PSWs and persons living with dementia, such as increasing the risk of burnout and dissatisfaction in the PSW role, challenges in retention, and issues providing person-centered care (Rivett et al., 2019). In the current study, PSWs working in long-term care homes did not feel adequately prepared with the competencies and confidence to provide dementia care through their formal and continuing education programs. As a result, PSWs reported feeling scared, uncertain, and uncomfortable during care interactions and during the training program's simulations, despite possessing an average of 16 years of working experience in long-term care. The findings of this study are consistent with previous literature reporting that PSWs experience feelings of fear, unpreparedness, and distress during care interactions with persons living with dementia due to insufficient education (Holst & Skär, 2017; Rivett et al., 2019). As a consequence, the risk of burnout and feeling dissatisfied in the PSW role increases, contributing to high turnover rates and issues in recruitment to long-term care sectors (Ministry of Long-Term Care, 2020; Savundranayagam & Lee, 2017). Staff who are stressed, dissatisfied, burnt out, and underprepared may experience a reduction in the capacity to empathize with persons living with dementia and are at an increased risk of providing depersonalized and task-oriented care (Rivett et al., 2019; Savundranayagam et al., 2021; Scott et al., 2011). This can lead to viewing persons living with dementia as tasks or objects rather than

unique individuals deserving of respectful, dignifying, and person-centered care (Holst & Skär, 2017; T. Kitwood, 1997; Scott et al., 2011), and is often reflected in depersonalized and technical care approaches (Baines & Armstrong, 2018; Leiter & Maslach, 1988; Scott et al., 2011). In the current study, PSWs' described challenges in providing person-centered care due to inadequate dementia-specific teachings in formal education and opportunities to engage in ongoing continuing education. This was discerned from PSWs' acknowledgement of dementia-specific learning needs as well as their descriptions of task-oriented attitudes and approaches towards care, situations where they limited autonomous choices for persons living with dementia and the use of stigmatizing language. In light of these challenges, it is evident that PSWs' well-being and the quality of care provided to persons living with dementia is intricately intertwined with the quality and effectiveness of PSW education to adequately prepare them for their roles within the long-term care sector.

Formal and continuing education for healthcare professionals has been internationally recognized as crucial for delivering high-quality care by competent, satisfied, and healthy healthcare workers (Public Health Agency of Canada, 2021; Kary et al., 2020; Savundranayagam et al., 2021). Studies consistently demonstrate that higher confidence and competency levels are linked to reductions in work-related stress, higher role satisfaction and retention rates (Li et al., 2021; Scales, 2022; Zimmerman et al., 2005). As a result, frontline staff are more confident in providing optimal care, increasing positive care outcomes and person-centered care (Kane et al., 2023; Li et al., 2021; Morgan, Kosteniuk, O'Connell, Bello-Haas, et al., 2016; Zimmerman et al., 2005). The most effective strategy in fostering feelings of preparedness and improving competency and confidence is through education that is tailored to the needs and contexts of its intended audience (Institute of Medicine, 2010; Laxdal, 1982; Rasmussen et al., 2023).

Adult learning theory specifies that the content of education programs must be immediately applicable to the learners' contexts or necessary to effectively cope with real-life situations, for learners to be motivated and ready to learn (Knowles, 1990). To do this, the learning needs to be directed by the learners themselves. Adults are self-

directing individuals responsible for their own decisions and have a deep psychological need to be recognized, acknowledged, and treated accordingly by others (Knowles, 1990). The most critical element of understanding competencies and developing an effective education model is the individual learners' perception of the discrepancies between their current abilities and the level at which they want (or need) to achieve (Knowles, 1990). This self-concept of being self-directed and independent in adults is intimately connected with unique and personal experiences accumulated over an individual's lifetime. Experiences, according to Knowles (1990), are the greatest resource for learning as they encourage a need to learn and can be drawn upon to help foster applicability and relevancy (Knowles, 1990). The assumption implies that if experiences are ignored or devalued, adult learners will associate this with a threat to their self-concept and ability to be self-directing, increasing the risk of becoming closed-off, apathetic, and uncommitted to learning (Knowles, 1990; Merriam & Bierema, 2013). This emphasizes the importance of recognizing PSWs as experienced and knowledgeable professionals and providing opportunities to contribute to the development and improvement of their education. However, PSWs have historically been overlooked in their capacity to contribute in these ways (Norris et al., 2024). To enhance the effectiveness of dementia-specific education, PSWs must be acknowledged as individuals capable of identifying learning needs based on their perceived competencies and experiences caring for people living with dementia, and programs must be tailored accordingly (Kary et al., 2020; Rasmussen et al., 2023).

### 5.1.1 Understanding Dementia

Understanding dementia was identified by PSWs in the current study as a broad learning need encompassing an overall need for foundational dementia education. Understanding dementia has been reported as a learning need by unregulated healthcare workers across care settings and countries (Attard et al., 2020; Morgan et al., 2016; Timmons et al., 2021). Often encompassed within this need are understanding and recognizing signs and symptoms of dementia, progression, and the different types of dementias (Attard et al., 2020; Morgan et al., 2016; Timmons et al., 2021). This learning need is reflective of a gap in the quality and quantity of dementia-specific education afforded to PSWs.



Participants in the current study reported between two to forty-one years of experience as a PSW, indicating that their formal education adhered to the 2014 or earlier Ontario PSW Training Standards, which placed minimal focus on competencies related to dementia care and predominantly focused on task-based skills (Grant, 2016; Sethna, 2013). The standard outlines 14 vocational outcomes in which formal education institutions must incorporate into their curriculum, and students must reliably demonstrate to graduate with PSW certification (Ministry of Training, Colleges and Universities, 2022). One outcome pertains to competencies related to caring for individuals living with cognitive and/or intellectual impairments, mental health challenges, and responsive behaviours. Therefore, the findings underscore the importance of ensuring formal PSW standards accurately reflect the necessary competencies for delivering optimal dementia care in long-term care homes (Baines & Armstrong, 2018; Kosteniuk et al., 2016; Lightman, 2022).

PSWs must rely on continuing education programs when formal education is insufficient in establishing a strong foundation for dementia-specific competencies. PSWs in this research study advocated for equitable and ongoing opportunities for dementia-specific continuing education programs. Their accounts revealed that these opportunities are infrequent and often inadequate to maintain competencies and integrate new ones into practice throughout their professional career. Unregulated healthcare professionals have the fewest opportunities for dementia-specific continuing education compared to other healthcare professionals (Morgan, Kosteniuk, O'Connell, Bello-Haas, et al., 2016; Timmons et al., 2021), with some reporting no opportunities for dementia-specific education at all (Chen et al., 2018). PSWs in this study reported previous experiences in several dementia-specific continuing education programs, including Gentle Persuasive Approaches (GPA) (87%), U-First (38%), and DementiAbility (8%). As of 2022, GPA is endorsed in the 2022 Ontario PSW Training Standard for addressing responsive behaviours through best practices and person-centered approaches (Ministry of Training, Colleges and Universities, 2022). GPA's curriculum focuses on providing healthcare workers with the knowledge and skills to understand and address responsive behaviours including self-protection, gentle redirecting, communication strategies, and supportive approaches for persons at risk of delirium (Advanced Gerontological Education, n.d.).

Similarly, U-First and DementiAbility aim to provide education to healthcare professionals and care partners on person-centered perspectives and approaches to understanding dementia, the importance of physical environments, and addressing responsive behaviours (Alzheimer Society, n.d.; DementiAbility, n.d.). However, despite experiences in these programs, the current findings recognized that PSWs' learning needs overlapped with program objectives such as addressing responsive behaviours, person-centered communication, and delirium. One explanation for this could be that these programs target a large range of healthcare professionals and care partners, rather than being tailored specifically to PSWs. Currently, there's a lack of dementia-specific continuing education programs tailored to the needs of PSWs. Education programs based on the learning needs of the intended audience are the most successful in changing behaviours, practices, and competencies among healthcare professionals (Davis et al., 1995; Davis et al., 2008; Fox & Bennett, 1998; Grant, 2002; Institute of Medicine, 2010). The importance of education being oriented to the needs of the learner is further emphasized in adult learning theory, as Knowles (1990) claims that adults will "learn new knowledge, understandings, skills, and attitudes most effectively when they are presented in the context of application to real-life situations" (p.59).

The absence of continuing education opportunities became evident with the participants' progress in Be EPIC, which promoted new learning needs and methods. These included topics on dementia-specific stigmatizing language, differentiating between responsive behaviours, and delirium. Further, PSWs identified experiential learning methods as significantly effective once they were exposed to approaches such as simulated persons with dementia (See Figure 3). The addition of learning needs and methods with the training program indicates that PSWs became more aware of their deficiencies in the knowledge and skills that were introduced and the methods which yielded the most successful learning results. PSWs may not have had opportunities to learn about these topics or learn from experiential methods in ways that are meaningful to their roles and contexts. For instance, dementia-specific person-centered language is a relatively new area of education (Scott et al., 2011). PSWs in the current study described their lack of awareness and opportunities to learn about stigmatizing language before their

participation in Be EPIC. This has been cited in other studies (Clifford & Doody, 2018; Scott et al., 2011) which suggest that the use of stigmatizing language is a result of inadequate knowledge about person-centered care approaches.

Adult learning theory acknowledges that learners will not always be immediately aware of their learning needs (Knowles, 1990). However, an individual's awareness can be raised through exposure to new information and understanding the value learning something will bring to their lives (Knowles, 1990; Merriam & Bierema, 2013). Learners need to understand the value of learning something in the context of their own lives (Knowles, 1990; Merriam & Bierema, 2013), such as increased self-confidence in a specific skill, job satisfaction, or care outcomes. Raising an individual's awareness of the need to know something can be done through exposure to simulated experiences (e.g., role-playing with simulated persons with dementia) or relating new information to personal experiences (Knowles, 1990). This raised awareness can help individuals understand where their capabilities and deficiencies lie within a particular topic or ability, to more realistically gauge their learning needs (Knowles, 1990). Therefore, ongoing continuing education is essential to increase an individual's awareness of the need to learn something relevant to their lives (Knowles, 1990), highlighting the importance of increasing dementia-specific continuing education opportunities for PSWs (Rasmussen et al., 2023; Savundranayagam et al., 2021). Given that half (50%) of the PSW workforce in Ontario is between the ages of 35-54, continuing education is essential for addressing gaps left by formal education, re-skilling and maintaining competencies, changing attitudes and/or behaviours, and remaining knowledgeable in best practices (Kary et al., 2020; Ministry of Long-Term Care, 2020; Mlambo et al., 2021; Rasmussen et al., 2023).

### **5.1.2 Person-Centered Communication and Addressing Responsive Behaviours**

In this study, PSWs revealed a need for further education on person-centered communication and attitudes. Without adequate knowledge or skills, PSWs in this study expressed difficulties communicating with persons living with dementia using alternative communication strategies, namely with persons who reverted to their mother tongue and

experienced challenges in formulating speech. Communication is an essential component of effective caregiving, especially in long-term care settings where PSWs interact with residents living with dementia and communication impairments (Savundranayagam & Lee, 2017). However, dementia can impact the ability of individuals to communicate effectively through expression and comprehension of language (American Psychiatric Association, 2022; Mundadan et al., 2023; Savundranayagam & Moore-Nielsen, 2015; Scott et al., 2011). Despite communication challenges, persons living with dementia remain relational beings, capable of engaging with their environments and the people within them and are not only willing to connect with others in meaningful ways but are deserving of dignified and respectful relationships (Clifford & Doody, 2018; Swinton et al., 2023). Maintaining these relationships is not only beneficial for the well-being of people living with dementia but is also key for maintaining and improving satisfaction among PSWs (Cohen et al., 2022; Savundranayagam & Lee, 2017). Furthermore, research suggests these relationships help to sustain a sense of identity and agency among persons living with dementia and facilitate successful care outcomes (Cohen et al., 2022; Gaviola et al., 2024; Medvene & Lann-Wolcott, 2010). This is particularly true for persons living with dementia who revert to their mother tongue, as providing care in an individual's own language is essential to prevent disengagement in meaningful activities and isolation (Gaviola et al., 2024). Thus, strong verbal and nonverbal communication skills are crucial for PSWs to possess to help deliver person-centered care and meet the needs of persons living with dementia (Foster et al., 2019).

Moreover, PSWs in the current study often assumed that persons with communication impairments were incapable of connecting and engaging with care staff, which has been a previously reported perception among PSWs (Savundranayagam et al., 2016). PSWs described instances where they limited personal autonomy and used inappropriate restraints during care interactions (e.g., holding a person with dementia down with their own body to brush their teeth) due to attitudes regarding the person with dementia's ability to communicate. A caregiver's perception of a person living with dementia shapes their behaviour during care (Cohen et al., 2022). Thus, perceptions of persons living with dementia being unable to engage with staff due to communication impairments increases

the risk of an individual receiving care that is task-oriented and focused on primarily meeting physical needs rather than considering the individuals' preferences, abilities, personality, or autonomy (Kitwood, 1997; Savundranayagam & Lee, 2017). Cohen and colleagues (2022) reported person-centered attitudes towards residents living with dementia were associated with more positive interactions, as nursing assistants were able to empathetically understand and interpret the meaning behind their behaviours and consider the uniqueness of each resident. Therefore, person-centered communication and attitudes in long-term care homes are essential skills that must be nurtured among PSWs to help develop and sustain relationships and promote person-centered care.

In the current study, PSWs described a significant lack of confidence in addressing responsive behaviours, both during care interactions with people living with dementia and the training programs' simulations. Through a person-centered lens, responsive behaviours are understood as alternative approaches to communication among persons living with dementia to convey emotional, physical, spiritual, or occupational needs, such as verbal expressions or physical behaviours (Cohen-Mansfield, 2000; Rivett et al., 2019). Responsive behaviours can be precipitated by feelings of confusion, fear, or frustration due an inability to recognize their caregivers, themselves, or their environment, being misunderstood, dependency on others, and waiting for care (Holst & Skär, 2021). Addressing responsive behaviours has been consistently identified as an area of dementia care requiring significant support, especially among unregulated healthcare workers such as PSWs (Hughes et al., 2008; Marx et al., 2014; Morgan et al., 2016; Timmons et al., 2021). Responsive behaviours have been associated with moral distress and burnout from fear, hopelessness, and negative impacts on professional self-esteem, as well as physical injuries, contributing to issues in retention and concerns regarding the quality of care provided to persons living with dementia (Holst & Skär, 2021; Rivett et al., 2019; Scott et al., 2010). PSWs in long-term care homes encounter responsive behaviours more frequently compared to other healthcare workers due to their prominent roles in providing daily personal care (Holst & Skär, 2021; Scott et al., 2010). Despite this, PSWs have the lowest levels of confidence and self-perceived competence in addressing responsive behaviours (Morgan et al., 2016). Without the knowledge, skills,

or attitudes to understand responsive behaviours as a form of communication and to identify precipitating factors, staff are unable to consider alternative or creative approaches to meeting their needs, most often resulting in non-person-centered strategies (Scott et al., 2011). This was observed among some of the PSWs in the current study, who described using improper physical restraints, abandoning the person displaying responsive behaviours, and using stigmatizing language.

The lack of sufficient education for addressing responsive behaviours through person-centered methods was also evident in the attitudes and approaches PSWs described towards persons living with dementia. How staff understand and view responsive behaviours can dictate how they will respond (Clifford & Doody, 2018). In this study, PSWs often automatically labelled persons living with dementia displaying responsive behaviour as ‘violent’, ‘aggressive’, ‘dangerous’, ‘difficult’, ‘demanding’, and ‘unpredictable’. In previous studies, the use of these terms has been found to reflect beliefs that behaviours are deliberate and premeditated acts to cause intentional harm, rather than a form of communication regarding unmet needs (Holst & Skär, 2017; Scott et al., 2011). The use of stigmatizing labels can damage relationships between PSWs and persons living with dementia and increase the potential for caregivers to adopt a task-oriented care approach, reduce the capacity for empathy and increase the prevalence of dehumanizing behaviour (Rivett et al., 2019; Scott et al., 2010). When responsive behaviours are understood according to person-centered care, staff can respond by using strategies to uncover the meaning in the behaviour (i.e., the unmet need) or search for precipitating factors (Kitwood, 1997). Fortunately, some of the PSWs in the current study viewed responsive behaviours from a person-centered paradigm by describing instances when they found meaning within behaviours, rather than attributing them to dementia symptoms, such as previous traumatic events in an individual’s life as well as communication impairments. Nonpharmacological interventions for addressing responsive behaviours are encouraged to maintain the individual’s dignity and personhood and are the most effective methods to prevent/reduce responsive behaviours (Azermi et al., 2014; Clifford & Doody, 2018; Duxbury et al., 2013). Therefore, PSWs

must be provided with education regarding person-centered communication, attitudes, and responsive behaviour, to promote person-centered care.

### 5.1.3 Delirium

This research showed that delirium was recognized as a learning need once PSWs were exposed to the topic and its relevancy to their roles in caring for persons living with dementia in long-term care (see Figure 2). Sabbe and colleagues (2023) reported similar results among certified nursing assistants in Belgium, who provided delirium care based on intuition and previous working experiences, highlighting an urgent need for formal delirium education. The current study is the first to identify delirium as a dementia-specific learning need from the perspectives of PSWs working in Canada. Persons living with dementia are at an increased risk of experiencing delirium compared to persons without dementia (Holt et al., 2013). Delirium is an acute-onset syndrome triggered by acute illness, injury, or intoxication, emphasizing the necessity of its recognition as it can predict poor functionality and mortality, as well as cause significant distress (Kristensen et al., 2018; Oh et al., 2017). Behavioural symptoms of dementia and delirium have some overlap such as rapid onset and fluctuations of symptoms, impairments in attention, memory, disorientation, and disturbances to perception, thinking/speech, emotional regulation, and sleep (Denning, 2020). This overlap can create difficulties for care providers in identifying delirium among persons living with dementia, especially if they are provided limited education and training on both delirium and dementia. This was found in the current study, as participants were not aware of the need for delirium education until they were exposed to the topic in the training program. Failure to recognize delirium among persons living with dementia is an established issue within the nursing literature (FitzGerald et al., 2019; Lee & Roh, 2023). For instance, hypoactive delirium (characterized by low concentration, apathy, inactivity, and drowsiness) is reported to be misdiagnosed or unidentified at a rate of 33-66% (Denning, 2020). Moreover, recognizing delirium from dementia can reduce the potential for unnecessary antipsychotic administration (Denning, 2020; FitzGerald et al., 2018). Since PSWs spend the most time providing direct care to people living with dementia on a daily basis, they possess the most significant familiarity with the personalities, behaviours, and baseline

functioning of their clients compared to any other long-term care healthcare worker (Ministry of Long-Term Care, 2020; Sabbe et al., 2023). Therefore, they are optimally positioned to recognize delirium symptoms based on changes to behaviours, personalities, and baseline functioning. Proper education and training therefore must be provided to equip PSWs with the knowledge and confidence to identify and address delirium among persons living with dementia.

## 5.2 Learning Methods

In addition to the content of formal and continuing education not meeting the dementia-specific learning needs of PSWs in long-term care, delivery methods can also be improved to ensure knowledge and skills are retained and, most importantly, applied to care practices. PSWs in this study advocated for education approaches to incorporate experiential methods that are conscientious of the context of application to real-life situations, peer learning and feedback, and a safe peer learning environment. A systematic review performed by Kane and colleagues (2023) found that interactive, experiential, and peer-based learning methods facilitated successful learning outcomes among dementia homecare workers. Similarly, other studies have revealed that combining traditional teaching techniques (e.g., classroom-style teaching and lecturing) with experiential methods (e.g., peer learning during care interactions) was most successful in enhancing confidence, competence, and application to dementia care practices (Rasmussen et al., 2023; Rivett et al., 2019).

According to adult learning theory, the uptake and application of knowledge, skills, and attitudes are the most effective when presented in the context of where they will be applied (Knowles, 1990), underscoring the importance of experiential methods being directly applicable and immediately relevant to the learners. In the current study, participants engaged in experiential methods with simulated persons living with dementia, which were described as a unique and useful opportunity to draw on individual experiences providing care to persons living with dementia while simultaneously applying their learning. Incorporating techniques that align with and tap into the learners' previous experiences and existing knowledge are key suggestions for improving the



efficiency and effectiveness of continuing education based on principles of adult learning theory (Knowles, 1990). Examples of additional experiential techniques include group discussions, role-playing, problem-solving activities, case methods, and peer-learning activities (Knowles, 1990).

Moreover, PSWs expressed a desire to learn from their peers through conversational and observational methods within a safe peer learning environment. These findings align with previous research indicating that peer learning can increase opportunities for knowledge exchange and emotional support, which have been associated with fostering person-centered attitudes, competencies, and knowledge (Kane et al., 2023; Su et al., 2021). Knowles (1990) emphasized the importance of a collaborative learning environment that supports interpersonal relationships and normalizes interactive participation opportunities. Incorporating and promoting peer learning in education programs tailored to PSWs is particularly important given the prevalence of their casual and part-time employment in long-term care homes (Baines & Armstrong, 2018; Boamah et al., 2023; Rossiter & Godderis, 2020). Inconsistent staffing is a barrier to providing person-centered care as it limits the opportunities to form positive relationships and understand the person living with dementia (Baines & Armstrong, 2018). Peer learning can facilitate knowledge exchange to help address knowledge gaps about persons living with dementia and ensure all PSWs, regardless of their employment status, have access to critical information and skills needed for providing person-centered care (Baines & Armstrong, 2018).

While the delivery methods identified in this study have been emphasized previously as essential components of continuing medical education for practicing physicians (Institute of Medicine, 2010), their importance has not had the same recognition for unregulated healthcare workers. For instance, many PSWs in this study identified that experiential methods were largely missing from both formal and continuing education opportunities. This oversight not only undermines the effectiveness of these methods for knowledge retention and application but also reflects a lack of recognition regarding the importance of adequately preparing PSWs to provide dementia care. Current continuing education is offered to PSWs through passive online modules, mainly concerned with meeting

compliance rather than focusing on improving care interactions (Bains & Armstrong, 2018; Savundranayagam et al., 2021). Learning methods that are meaningful and effective for PSW learning retention need to be integrated into formal and continuing education opportunities with the same importance as education opportunities afforded to other healthcare professionals, to maximize their effectiveness in knowledge application and uptake.

### 5.3 Mediators

For dementia-specific competencies to be integrated into care practices sustainably, learners need to be open to learning from educational programs and their peers (Rasmussen et al., 2023; Savundranayagam et al., 2020). In the current study, PSWs emphasized the importance of fostering a culture of teamwork within homes to promote openness to learning and sustain changes in behaviour and attitudes. Several other studies have acknowledged the crucial role of learners' openness in the success of dementia-specific education programs (Auxier et al., 2020; Hung et al., 2022; Kary et al., 2020; Rasmussen et al., 2023). For example, Rasmussen and colleagues (2023) found that the participants' openness to learn and engage in education programs was equally as important as the program's design and delivery methods in facilitating successful learning outcomes. An openness to learning was demonstrated by a willingness to participate in education programs, receive new knowledge, and/or change behaviours (Rasmussen et al., 2023). Learning from coworkers was described by PSWs in this current study as an essential method of sustaining knowledge uptake and integration into dementia care practices within the long-term care setting. However, this was often described as an issue among more experienced PSWs being close-minded and dogmatic about learning due to the virtue of their titles (i.e., tenured vs. new) or the perceived effectiveness of their previous care approach. Experience can contribute to a close-mindedness for learning among PSWs with the development of habits, biases, and presuppositions (Knowles, 1990). If a PSW's prior knowledge and approaches have been effective in the past, or their biases and presuppositions have been reinforced, they can develop a close-mindedness toward new ideas, perspectives, and ways of thinking or doing (Knowles,

1990). Since PSWs largely lack quality dementia-specific education and opportunities, their practices may not reflect best practices or person-centered care, as discerned in the current study's learning needs. Remaining close-minded about learning, whether through formal programs or peer interactions, could result in care practices that are unable to understand and address the needs of individuals living with dementia. Savundranayagam and Lee (2017) observed similar issues among PSWs who endorsed communication strategies that were not person-centered, such as ignoring the resident or completing care on their own. The use of these strategies was attributed to a lack of education regarding the abilities of persons living with dementia to meaningfully engage in care interactions as well as how to engage them as PSWs (Savundranayagam & Lee, 2017). To foster an openness to learning, organizations and continuing education providers must create environments that foster a continuous desire for learning and assist PSWs in understanding the need for additional education (Institute of Medicine, 2010; Merriam & Bierema, 2013).

## 5.4 Strengths and Limitations

The strengths of this study include the exclusive focus on the dementia-specific learning needs of PSWs from the voices of PSWs themselves. The representation of PSWs within the study is reflective of demographics in the Ontario workforce, regarding participants' age, sex and gender, education and employment experiences. The results of this study add to the literature advocating for the inclusion of PSW perspectives in future research and improved dementia-specific education. The use of focus group data capitalized on group processes to generate social knowledge such as shared beliefs and attitudes motivating certain behaviours or thought processes (Thorne, 2016). This allowed for the exploration of both unique perspectives from individuals as well as patterns across and within groups, based on social interactions and common experiences among PSWs relating to dementia-specific learning needs, methods, mediators, and education. Although there is a risk of focus groups obscuring non-dominant perspectives among participants (Thorne, 2016), a skilled facilitator was used to mitigate this risk by encouraging participants to address

each other in conversation and ensured equal opportunities for participants to contribute to focus groups.

The current study conducted a secondary qualitative interpretive approach to identify the dementia-specific learning needs of PSWs and examine how they evolve with education. Therefore, limitations exist regarding the interpretation of the data and inherent limitations to secondary analysis. While the discussions around the learning needs, methods, and mediators arose naturally within the focus groups, all but one of the semi-structured focus group questions were not specifically tailored to the exploration of these findings (see Appendix B). Therefore, the questions developed for the primary research study were often prioritized over probing questions to further explore needs relative to the secondary analysis. It is important to acknowledge that qualitative data can often be shaped by social, cultural, and political contexts at the time of data collection (Ruggiano & Perry, 2019). These contexts can also change over time, resulting in a potential for being masked to contexts that may have been important to the interpretation and understanding of data, increasing the risk of misinterpreted results (Beck, 2018; Ruggiano & Perry, 2019). To mitigate the potential for misinterpretation of the secondary data analysis, I worked collaboratively with the primary investigator (MYS) of the original study and accessed video recordings of all focus groups. The primary investigator provided essential insight regarding the social and political contexts at the time of data collection, which aided my understanding of the subjective data. Moreover, observing the behaviours and dynamics of focus groups through video recordings enhanced my understanding of the context of conversations within the group setting.

## 5.5 Implications and Future Directions

The working and living conditions of long-term care homes have worsened since the time of data collection due to the COVID-19 pandemic, creating a significant urgency for addressing care provision issues through upskilling the PSW workforce. The COVID-19 pandemic was exceptionally difficult for both PSWs and persons living with dementia in long-term care homes (Gray et al., 2022; Hapsari et al., 2022; Kane et al., 2023). Long-term care homes were the most critically impacted locations for COVID-19 outbreaks

across Canada, representing over 80% of COVID-19-related deaths in 2020 (Lightman, 2022). The profound impact the pandemic had on long-term care homes was attributed to pre-existing deficiencies such as underfunding, overcrowding, inadequate infrastructure, staffing shortages, lack of oversight and accountability for upholding best practices, and recognition of staff (Boamah et al., 2023; Estabrooks et al., 2022; Rossiter & Godderis, 2020; Savundranayagam et al., 2021). As a result of the COVID-19 pandemic, the prevalence of burnout, anxiety, and depression increased significantly among both long-term care residents and staff, causing record-high rates of staff-related challenges, absences, and turnover (Boamah et al., 2023; Clarke, 2021). Vacancy rates for PSWs and nurses reached alarming levels of 8-12%, resulting in approximately 8,000 open positions in Ontario alone (Office of the Auditor General of Ontario, 2023). The compounded effects of poor working conditions and the COVID-19 pandemic compromised the quality of care provided to residents, 63% of whom were individuals living with dementia (Office of the Auditor General of Ontario, 2023). During the first wave of the pandemic in 2020, reports by the Canadian Armed Forces uncovered undignifying, dehumanizing, and unsafe care including the inability to meet the most basic needs (e.g., bathing and using the toilets), restricting resident independence, inadequate nutrition and hydration, inappropriate restraint usage (e.g., removing walking aides), and using degrading and inappropriate language toward residents (Mialkowski, 2020). In the wake of the pandemic's devastation, supporting the well-being of both PSWs and people living with dementia is more critical than ever. Providing PSWs with education that is meaningful to their experiences and roles, addresses their learning needs, and is offered on an ongoing basis can help improve the quality of care provided to people living with dementia (Kary et al., 2020; Rasmussen et al., 2023). Additionally, such education can enhance the well-being of PSWs by improving their competencies and self-efficacy, which can positively impact job satisfaction and retention in PSW roles (Boamah et al., 2023; Chamberlain et al., 2019; Hung et al., 2022; Kane et al., 2023; Zimmerman et al., 2005).

Many of the learning needs identified in this study, such as addressing responsive behaviours, person-centered communication, trauma-informed care, and communication impairments, should be included in the PSW Training Standard. The PSW Training

Standard was updated in 2022 to include more person-centered language and dementia-specific knowledge such as understanding dementia, delirium, and mental health care (Ministry of Colleges and Universities, 2022). For instance, vocational learning outcome 14, performance B, now includes three additional performance objectives relevant to caring for persons living with dementia: 1) observing and identifying changes in behaviour and advocating for revisions to the care plan with an interprofessional team; 2) describe how symptoms and/or presentation can impact clients' behaviour; and 3) identifying irreversible and reversible conditions (Ministry of Training, Colleges and Universities, 2022, p. 47). Indeed, this update reflects positive and timely changes to formal education to better equip PSW students with additional knowledge in person-centered dementia care, compared to the 2014 standard. Yet, it is unclear whether these changes will supply incoming PSWs with sufficient confidence and competencies to meet the needs of persons living with dementia in long-term care settings. Therefore, future research should investigate PSWs' perception of preparedness to provide dementia care and learning needs following education guided by the updated standards. Furthermore, this standard does little to improve the dementia-specific competencies of working PSWs, who represent the majority of the long-term care workforce (Ministry of Long-Term Care, 2020; Sethna, 2013). Therefore, the learning needs identified in the current study remain relevant for PSWs working in long-term care settings and must be addressed to improve dementia care.

This study has the potential to contribute to improving the quality of dementia-specific training programs for PSWs. The findings of this study outline the content (learning needs), delivery methods (learning methods), and mediators required by PSWs to address competency and confidence gaps in dementia care provision. The findings demonstrated that PSWs' dementia-specific learning needs extend well beyond the content and delivery methods offered to them through formal and continuing education programs. Future dementia-specific education programs targeting PSWs should integrate the identified learning needs (understanding dementia, addressing responsive behaviours, person-centered communication and attitudes, and delirium) and methods into the design and delivery, as well as consider the influential mediators.

This study also emphasizes the importance of including PSWs' experiences, perspectives, and needs in the development and improvement of educational programs. Due to the intimate nature of PSW work in long-term care homes, these professionals often spend the most time with persons living with dementia. Compared to other healthcare workers, this uniquely positions them with the opportunities to gather a significant amount of insight regarding daily dementia care capabilities and deficiencies in long-term care homes. Yet, the voices of PSWs and other unregulated healthcare workers have been largely unacknowledged, undervalued, and ignored (Lightman, 2022; Rossiter & Godderis, 2020). Going forward, the perspectives, knowledge, and needs of PSWs must be prioritized to continue to understand approaches to better supporting and promoting optimal dementia care practices in care settings.

## 5.6 Conclusion

As the incidence of dementia increases worldwide, the necessity to effectively equip PSWs with the competencies and confidence to provide optimal, person-centered dementia care becomes increasingly evident. The provision of dementia-specific training can go beyond improving the quality of care provided to people living with dementia, as it can also improve PSWs' well-being and satisfaction within their role. However, this study observed that current formal and continuing education opportunities do not effectively meet the needs of PSWs in long-term care concerning content and delivery methods that are relevant to their roles and promote sustainable learning and application. To ensure the delivery of optimal dementia care, education and training need to be tailored to the unique needs of PSWs working within long-term care homes.

The findings of this study demonstrate a gap in dementia-specific knowledge, skills, and attitudes among PSWs, due to a lack of education opportunities that adequately meet their needs. Education not only needs to teach topics relevant to the context and needs of PSWs in long-term care but also needs to be delivered with supportive and practical learning methods. Topics such as addressing responsive behaviours, using person-centered communication and attitudes, identifying and addressing delirium, and understanding dementia are highlighted as areas requiring greater emphasis in PSW

education. These topics should be delivered within supportive peer learning environments that incorporate experiential methods and opportunities for peer learning and feedback. Continuing education needs to be provided on an ongoing basis for knowledge, behaviour, and attitude changes to be sustained in busy and demanding settings, such as long-term care homes. The addition of learning needs and methods with the progression of Be EPIC suggests that opportunities for dementia-specific continuing education are rarely provided. These findings underscore the importance of providing ongoing, consistent education opportunities informed by the valuable perspectives, experiences, and voices of PSWs.

By highlighting the gaps in formal and continuing dementia-specific education for PSWs, the study findings may help to better inform the development and implementation of dementia-specific education for PSWs in the future. Furthermore, the findings highlight an ongoing and urgent need to acknowledge the value of PSWs' perspectives, opinions, and expertise related to caring for people living with dementia in long-term care settings.



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# Appendices

## Appendix A: Ethics Approval



**Date:** 16 August 2023

**To:** [REDACTED]

**Project ID:** 114354

**Review Reference:** 2023-114354-82760

**Study Title:** Be EPIC: Dementia Training for Mid-Career Workers

**Application Type:** Continuing Ethics Review (CER) Form

**Review Type:** Delegated

**Date Approval Issued:** 16/Aug/2023 15:02

**REB Approval Expiry Date:** 30/Aug/2024

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Dear [REDACTED]

The Western University Research Ethics Board has reviewed the application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

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

Western University REB operates in compliance with, and is constituted in accordance with, the requirements of the Tri-Council 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 REB 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.

**Electronically signed by:**

[REDACTED]

**Reason:** I am approving this document

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

## Appendix B: Semi-Structured Focus Group Questions

### Baseline 1 Session:

1. What would you like to get out of this training program?
  - a. OR: What is one thing you would like to work on with your residents who have dementia?
2. Does being 'mid-career' change your experience working with people living with dementia, compared to when you first started in the PSW role?
3. What makes a good PSW? (impromptu question)
4. How do you communicate with the rest of your team? What are your relationships like in your workplace?

### Baseline 2 Session:

1. Have any of your goals for this training changed or have new ones arose since engaging in the first training session?
2. Has anything changed in the last week in your long-term care home (e.g., changes in shifts, client caseloads, relationships with family members, relationships within the workplace)?
3. How does your interactions with the actors compare to your interactions with your clients living with dementia?
4. Do you find yourself spending too much time with your clients? Or do you not have enough time with them on a daily basis? (impromptu question)
5. Did you feel you had enough time to interact with the actor?
  - a. Probe: Is more than five minutes needed with the actor?
6. How often do you feel you have triggered responsive behaviours from a client due to rushing in the workplace?
7. What brings you joy in your job as a PSW?
8. Do you have any questions?

### Module 1 Session:

- A. What would you like to get out of this training program?
  - a. Probe: Is there something you would like to learn from this program? Is there something you would like to work on with your residents with dementia?
- B. Can you share your experiences of working with people who have dementia?
- C. Does being 'mid-career' change your experience working with people who have dementia?
- D. How do you communicate information about the client with dementia with your co-workers?
  1. Describe your relationship with your clients?
    - a. Probe: What are some positive interactions you've had? What helps create positive interactions with clients?
    - b. Probe: What are some not so positive interactions you've had?

- c. What do you think establishes trust with your clients? (impromptu question)
2. What supports are in place to help you come back to work if you've had a bad day?
  - a. How do you cope with an interaction with a resident or co-workers that does not go as you had hoped?
3. Do you find that your interactions with clients is better when you have more information about them, such as their history? Does it make a difference in your care approach?
4. How do you share information about a client with your co-workers?

#### Modules 2 and 3:

1. How did today's training session go for you?
2. What did you like the most about today's training session and why?
3. What did you learn from today's training session?
  - a. Probe: did you learn something new today?)
4. Did the training session challenge how you would normally interact with a person living with dementia? (impromptu question)
5. Will what you learned from today's training session influence how you are going to provide care in the future?
6. What did you think about giving and receiving feedback? How was the feedback?
7. Did you like giving feedback to your co-workers today?
8. How did it feel to be able to remove yourself from the simulation and ask your co-workers for help?
9. How do you feel about the communication within your groups?
10. Do you feel as if you can speak more freely in the debrief groups compared to the first focus group session?
  - a. Probe: In the smaller groups following a simulation, do you feel comfortable sharing feedback with your peers?
11. Do you enjoy the debriefing as a group?
12. What did you find the most unique about today's session?
13. Do you have any constructive feedback for today's session?
14. Did today's session change any of the beliefs you previously had about persons with dementia?
15. Do you have any questions regarding what you learned during today's session?

#### Module 4 Session:

1. What did you learn from Be EPIC? What did you take away from Be EPIC?
2. Will anything you learned from Be EPIC influence your approaches and interactions with clients living with dementia?
3. How did the simulations affect your learning?
4. Did you feel safe during the simulations?
5. Did feedback from the actors affect your learning?

6. How did you feel about receiving feedback from your co-workers after completing a simulation?
7. In your opinion, what is more important: doing the training with the actors or doing the training with the actors and the feedback?
8. What is the most valuable aspect of Be EPIC? (Probe: What is one strength or advantage of Be EPIC as a training program?)
9. What did you learn about yourself?
10. Do you have any constructive feedback for today's session?
  - a. Probe: Does Be EPIC have enough opportunities to practice what you learned?
  - b. Probe: Do you have any constructive feedback for the facilitator? Do you have any constructive feedback for how the focus groups were held?
  - c. Probe: Do you have any constructive feedback regarding the content you learned?
11. How does Be EPIC support 'mid-career' PSWs?
12. How is Be EPIC different when compared to other dementia-specific training programs?
13. Would you recommend Be EPIC?

#### Three Month Follow-up

1. What did you learn from the Be EPIC program that you've applied in the last three months?
2. How did the simulations affect your learning? How did having the actors portray people living with dementia affect your learning?
3. How did receiving feedback from the actors affect your learning?
4. What have you learned about yourself since completing Be EPIC?
5. How can Be EPIC be improved? How can the Be EPIC facilitators be improved?
9. Has anything changed in the last three months in your long-term care home? (Probe: changes in shifts, client caseloads, relationships with family members, relationships within the workplace)
6. What support have you received (i.e., from co-workers, client families, managers) to enable you to use person-centered communication?
7. How has your communication with colleagues changed since completing Be EPIC?

# Curriculum Vitae

**Name:** Grace Norris

**Post-secondary Education and Degrees:** The University of Western Ontario  
London, Ontario, Canada  
2022-2024 M.Sc.

Carleton University  
Ottawa, Ontario, Canada  
2017-2021 B.HSc. (Hons)

**Honours and Awards:** Master's Student Poster Presentation – 1<sup>st</sup> Place  
Annual Health & Rehabilitation Sciences Graduate Research Conference  
Western University  
2023

Dean's Honour List Scholar  
Carleton University  
2021

Admission Scholarship  
Carleton University  
2017

Health Science Scholarship  
Carleton University  
2017

**Related Work Experience** Graduate Research Assistant  
Sam Katz Community Health and Aging Research Unit  
2022-2024

Knowledge Mobilization Lead  
Sam Katz Community Health and Aging Research Unit  
2022-2024

Be EPIC-VR Facilitator  
Sam Katz Community Health and Aging Research Unit  
2022-2024

Graduate Teaching Assistant  
University of Western Ontario  
2022-2023

Undergraduate Research Placement Student  
Boxing4Health, Ottawa, Ontario  
2020-2021

Clinical Research Assistant  
Children's Hospital of Eastern Ontario (CHEO), Ottawa, Ontario  
2019

**Publications:**

**Norris, G.**, Savundranayagam, MY., Teachman, G., & Vafaei, A. (2024). The representation of personal support workers in dementia-specific learning need assessments: A scoping review. *Educational Gerontology*, 1–19.  
<https://doi.org/10.1080/03601277.2024.2356925>

**Norris, G.**, Savundranayagam, MY., Teachman, G., & Vafaei, A. The continuous learning needs of personal support workers who care for people living with dementia in long-term care. [Manuscript in progress].

Savundranayagam, MY., Chen, A., **Norris, G.**, Schumann, A., Campos, J., & Orange, J. Be EPIC-VR: Translating an In-Person Person-Centered Communication Training Program into Virtual Reality. [Manuscript in progress].

Savundranayagam, MY., Schumann, A., Sagrak, A., **Norris, G.**, Chen, A., Campos, J., & Orange, JB. Organizational Readiness for a Virtual Reality Training Program called Be EPIC-VR in Home Care and Long-term Care Settings. [Manuscript in progress].

**Presentations:**

**Norris, G.**, Savundranayagam, MY., Teachman, G., & Vafaei, A. (accepted June 11, 2024). The continuous learning needs of personal support workers who care for people

living with dementia in long-term care. To be presented at the annual meeting of the Gerontological Society of America.

Savundranayagam, MY., **Norris, G.**, Schumann, A., Campos, J., Sarma, A., & Orange, JB. (accepted June 11, 2024). Acceptability and Preliminary Efficacy of Be EPIC-VR training on Frontline Healthcare Workers. To be presented at the annual meeting of the Gerontological Society of America.

Savundranayagam, MY., **Norris, G.**, Malheiro, G., Schumann, A., Campos, J., & Orange, JB. (accepted June 11, 2024). Implementing Be EPIC-VR in Healthcare: Aligning Virtual Reality Training with Organizational Readiness. To be presented at the annual meeting of the Gerontological Society of America.

**Norris, G.**, Savundranayagam, MY., Teachman, G., & Vafaei, A. (2024, March). The continuous learning needs of personal support workers who care for people living with dementia in long-term care. Presented at the annual Western Research Forum Annual Graduate Conference, University of Western Ontario, London, ON.

**Norris, G.**, Savundranayagam, M.Y., Teachman, G., & Vafaei, A. (2024, February 2). The continuous learning needs of personal support workers who care for people living with dementia in long-term care. Presented at the annual Health & Rehabilitation Sciences Graduate Research Conference, University of Western Ontario, London, ON.

Savundranayagam, MY, Schumann, A., **Norris, G.**, Chen, A., Campos, J., & Orange, JB. (2023, October 28). Organizational Readiness for a Virtual Reality Training Program called Be EPIC-VR in Home Care and Long-Term Care Settings. Presented at the annual meeting of the Canadian Association on Gerontology, Toronto, ON.

Savundranayagam, MY., Chen, A., **Norris, G.**, Schumann, A., Campos, J., & Orange, JB. (2023, October 28). Be EPIC-VR: Translating an In-Person Person-Centered Communication Training Program into Virtual Reality. Presented at the annual meeting of the Canadian Association on Gerontology, Toronto, ON.

**Norris, G.**, Savundranayagam, M.Y., Teachman, G., & Vafaei, A. (2023, October 27). The representation of personal support workers in dementia-specific learning need assessments: a scoping review. Presented at the annual meeting of the Canadian Association on Gerontology, Toronto, ON.

Schumann, A., Savundranayagam, MY., Chen, A., **Norris, G.**, Campos, J., & Orange, JB. (2023, October 18). Implementation Science: Implementing a virtual reality program



in long-term care and home care settings. Presented in Health and Rehabilitation Sciences Health and Aging Graduate Seminar, Western University.

Savundranayagam, MY., **Norris, G.**, Malheiro, G., Chen, A., & Schumann, A. (2023, September). Using implementation science to optimize the research impact of Be EPIC-VR. BrainsCAN Research Impact Day, London, ON.

Savundranayagam, MY., Schumann, A., Sagrak, A., **Norris, G.**, Chen, A., Campos, J., & Orange, JB. (2023, November 10). Organizational Readiness for a Virtual Reality Training Program called Be EPIC-VR in Home Care and Long-term Care Settings. Presented at the annual meeting of the Gerontological Society of America, Tampa, FL.

Savundranayagam, MY, Chen, A., **Norris, G.**, Schumann, A., Jaur, S., Campos, J., & Orange, JB. (2023, November 10). Be EPIC-VR: Translating an In-Person Person-Centered Communication Training Program into Virtual Reality. Presented at the annual meeting of the Gerontological Society of America, Tampa, FL.

**Norris, G.**, & Savundranayagam, M.Y. (2023, February 1). The continuous learning needs of personal support workers working with persons living with dementia in long-term care homes: a rapid review. Presented at the annual Health & Rehabilitation Sciences Graduate Research Conference, University of Western Ontario, London, ON.