THE WAITING PERIOD: CHALLENGES AND OPPORTUNITIES TO SUPPORT CAREGIVERS AND PERSONS WITH DEMENTIA DURING TRANSITIONS TO LONG-TERM CARE

by

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Abstract

Transitions to long-term care are significant and often challenging experiences for older adults with dementia and their caregivers, with waiting lists a common occurrence due to an aging population and a limited supply of long-term care beds. To better understand the complexities related to transitions to long-term care and inform clinical practice, a comprehensive project was undertaken and included an integrative literature review and a gap analysis of local practices in the interior of British Columbia. The literature review and gap analysis findings were analyzed and presented thematically through interrelated themes, including key concepts surrounding the phases of a transition, caregiver coping, and professional support. Four key recommendations arose from this project regarding continuity and coordination of care, discharge planning, post-discharge care, and evaluation. The strengths, limitations, and implications of this project are discussed, including next steps to mobilize knowledge related to the recommendations and influence evidence-informed changes in practice.

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Abbreviations

ADLs	Activities of Daily Living
BC	British Columbia
BCMoH	British Columbia Ministry of Health
CAPs	Clinical Assessment Protocols
CINAHL	Cumulative Index of Nursing and Allied Health Literature
COVID-19	Coronavirus Disease of 2019
DIVERT	Detection of Indicators and Vulnerabilities for Emergency Room Trips
LTC	Long-Term Care
MEDLINE	Medical Literature Analysis and Retrieval System Online
MeSH	Medical Subject Headings
PCP	Primary Care Provider
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PsycINFO	Psychological Information
PWD	Person(s) with Dementia
RAI-HC	Resident Assessment Instrument – Home Care
READI	Readiness Evaluation and Discharge Interventions
RNAO	Registered Nurses' Association of Ontario
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, Research type
SWOT	Strengths, Weaknesses, Opportunities, and Threats

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Dedication

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Chapter 1

Introduction

Transitions in care for persons with dementia (PWD) are significant and stressful events and may include a discharge from hospital or a move to long-term care (LTC). While there is substantial literature surrounding both transitions in care and PWD, less is known about the experience of caregivers when PWD navigate a transition in care, specifically a transition from hospital to home while waiting for LTC admission. Exploring the caregiver experience of a transition and the interactions between caregiving, transitioning from hospital to home, and waiting for LTC admission is needed in order for care to remain person focused, and to inform the development of responsive and evidence-informed clinical practice. Health care professionals, such as nurses, primary care providers (PCPs), and allied health professionals, may find this research helpful in supporting PWD and caregivers undergoing a transition in care, and in identifying and utilizing evidence-informed recommendations. This in turn may aid in improving the experiences of caregivers and PWD, and in creating health systems that can result in reduced costs through increased collaboration, continuity of care, and fewer hospital stays or emergency department visits.

To understand the existing knowledge about caregiver experiences, a comprehensive review of the literature was undertaken guided by the research question: What are the experiences of caregivers in transition when persons with dementia are discharged from hospital to await admission to long-term care? The literature review findings were used to inform a gap analysis of transitional care practices for individuals awaiting LTC within the Central Okanagan local health area of British Columbia (BC). The gap analysis focused on highlighting current strengths and gaps in practice, and potential areas for future quality improvement within a local context. The literature review findings were informative in the development of the gap analysis by providing insight towards potential areas of stakeholder importance and concern, which prompted further attention and exploration of these areas. Exploring caregiver experiences in the literature, followed by a gap analysis, facilitates a process to draw on what is already known, identifies disconnections between evidence and practice, and highlights areas for improvement and further research that can be tailored to local contexts. The following section will present the background concepts relevant to this project, including an overview of dementia, LTC, caregiving, and care transitions. This will be followed by a review of the literature, a gap analysis of transitional care practices, and a discussion of caregivers in transition.

Background

In Canada, over half a million adults are affected by dementia (Chambers et al., 2016; Statistics Canada, 2016), while globally this number is estimated to be 50 million (World Health Organization, 2020). Dementia is a degenerative neurological condition that causes impairments in memory and other cognitive functions severe enough to interfere with daily life (Alzheimer Society of Canada, n.d.). Persons with dementia experience difficulties with memory, language, problem solving, and other cognitive skills, which eventually lead to a loss of independence in performing activities of daily living (ADLs; Alzheimer's Association, 2017). As dementia progresses, the disease leads to increased medical and social costs as complications arise and increased help is needed, while also creating physical, emotional, social, and economic burden for caregivers (Statistics Canada, 2016; World Health Organization, 2017).

Not all PWD have a caregiver able to assist with managing the condition and meeting needs, which can create significant challenges in assuring the care and well-being of these individuals. Caregivers may be formal service providers, such as professional or paid caregivers, or informal caregivers also called family caregivers. This project will discuss informal caregivers, henceforth referred to as caregivers. While situations where PWD do not have a caregiver are undoubtedly difficult and warrant investigation, the focus of this research is caregivers of PWD. This is because caregivers may experience significant burden and distress in their caregiving role, for which health care professional intervention may aid in improving the experiences and outcomes of both caregivers and PWD.

During the course of their illness, many PWD will eventually reside in LTC homes; 75 percent of 80 year olds with dementia reside in LTC, compared with four percent of the general population at the same age (Alzheimer's Association, 2017). Adults affected by dementia are also more likely to require inpatient hospital care than adults without dementia (Canadian Institute for Health Information, n.d.), and for some individuals, this may occur while waiting for LTC admission. These adults are typically discharged home to resume waiting when their acute care needs have resolved, creating an increased level of complexity and concerns regarding safety, as compared to the hospital discharges of other individuals who are not waiting for LTC.

Care transitions are a vulnerable time for patients, whereby fragmentation of care, also referred to as disruptions in coordination and continuity of care, can negatively impact both the person experiencing the transition and their caregivers (Neiterman et al., 2015). Care transitions may also lead to undesirable outcomes for PWD, who may experience hospital readmission, increased mortality, and changes in behaviour or functional status as a result of the complexity of their conditions and an underutilization of caregivers in planning for care transitions (Ray et al., 2015). While substantial research has been conducted to explore the patient experience of transitions in care (Neiterman et al., 2015; O'Neill et al., 2020), less is known about caregiver experiences, particularly during the transition of a PWD from hospital to home while waiting for LTC admission. Long-term care is often the first level of formal care that a PWD may access and includes facilities and units equipped to provide care ranging from standard care to special or complex care, which may be required for persons with specific needs or as dementia progresses.

Caregivers and PWD often encounter challenges and experience burden while managing the illness and coordinating care, with the decision to seek LTC often a last resort. These caregivers have tried to manage the situation to the best of their abilities, yet find themselves struggling and in transition as they begin to explore and seek care options. In order to better understand the challenges and uncertainty that caregivers may experience during a PWD's transition from hospital to home while waiting for LTC, it is necessary to understand how dementia, LTC access policies, and care transitions may bring an additional layer of complexity to the situation. The following section will explore these concepts and illustrate some of the difficulties caregivers may experience as they navigate the diagnosis, management of symptoms, and support services and options available to them and the PWD.

Dementia

Dementia can be defined as a set of "progressive impairments in memory and other cognitive functions" (Chambers et al., 2016, p. 13). Dementia regroups several diseases affecting memory, behaviours, and cognitive abilities, and interferes significantly with a person's ability to maintain their ADLs (World Health Organization, 2017). As the disease progresses, many individuals will be affected by behavioural and psychological symptoms of dementia, which are "psychological reactions, psychiatric symptoms, and behaviors occurring in people with dementia of any etiology" (Finkel et al., 2000, p. 13). Dementia is a terminal condition and in its final stages those affected will be unable to maintain independence with their ADLs, becoming bedbound and requiring 24-hour care (Alzheimer's Association, 2017).

There are several different types of dementia, with Alzheimer's dementia being the most common and comprising 60% to 70% of dementia cases (World Health Organization, 2017). Other varieties include vascular dementia, Lewy body dementia, and frontotemporal dementia, although mixed dementias also occur and distinguishing between the varieties can be challenging (World Health Organization, 2017). Table 1 outlines the definitions and clinical features of all-cause dementia and each of the above subtypes.

Dementia is associated with a broad range of clinical features, including cognitive impairment. Cognitive impairment is a consequence and sign of dementia and is a term that is often confused with or used interchangeably with dementia. Cognitive impairment includes mild cognitive impairment and all-cause dementia (Guidelines and Protocols Advisory Committee, 2016). Mild cognitive impairment refers to "mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends, but do not affect the individual's ability to carry out everyday activities" (Alzheimer's Association, 2017, p. 329). The difference between dementia and mild cognitive impairment relates to the person's ability to perform everyday activities; dementia reduces the person's ability to perform these activities, while cognitive impairment does not (Statistics Canada, 2016). The focus of this research is on PWD and excludes those with cognitive impairment. The rationale for this is that unfavourable outcomes during transitions in care are greatest among those with higher care needs (Ray et al., 2015), and because caregiver stress increases with the intensity of care required (Sinha, 2013).

Table 1

Definitions and Clinical Features of Dementia by Cause

Type	Definition	Clinical Features
All-cause dementia	A degenerative neurological condition due to neuronal changes and cerebral atrophy, creating impairments in memory and other cognitive functions severe enough to interfere with daily life.	Difficulties with memory, language, problem-solving, and other cognitive skills.
Alzheimer's dementia	Dementia due to Alzheimer's disease, a degenerative brain disease with neuronal damage due to the accumulation of amyloid plaques and the formation of tau tangles.	Early clinical features: difficulty remembering new information, apathy, and depression. Later clinical features: impaired communication, disorientation, confusion, poor judgment, behaviour changes, difficulty speaking, swallowing, and walking.
Vascular dementia	Dementia occurring due to vascular lesions, such as infarcts or bleeding in the brain.	Impaired judgment or impaired ability to make decisions, plan or organize. Difficulty with motor function, especially slow gait and poor balance.
Lewy body dementia	Dementia occurring when aggregations of alpha-synuclein (Lewy bodies) develop in the brain cortex.	Early clinical features: sleep disturbances, visual hallucinations, slowness, gait imbalance, or other parkinsonian movement features. May occur in absence of significant memory impairment.
Frontotemporal dementia	Dementia due to marked atrophy of the frontal and temporal lobes of the brain.	Marked changes in personality and behaviour, difficulty producing or comprehending language.
Mixed dementia	Dementia with clinical evidence of two or more causes of dementia.	Varies based on types of dementia present and regions affected.

Note. Adapted from "2017 Alzheimer's Disease Facts and Figures" by Alzheimer's Association, 2017, *Alzheimer's & Dementia,* (https://doi.org/10.1016/j.jalz.2017.02.001).

Pathophysiology

The pathophysiology of dementia is specific to the type of dementia present. In all varieties of dementia, there is a progressive degeneration of neurons, for various reasons, leading to cerebral atrophy (Alzheimer's Association, 2017; Hall et al., 2017; Iadecola, 2013; Wisniewski, 2019). In Alzheimer's dementia, neurodegeneration occurs due to the progressive accumulation of β-amyloid plaques (also called senile plaques) and the formation of neurofibrillary tangles, which are tangles of neuro filaments and tau protein (Hall et al., 2017; Jagust, 2018; Wisniewski, 2019). These changes lead to neuronal dysfunction and loss, hypometabolism, cerebral atrophy, neuroinflammation, cognitive decline, and symptoms of dementia (Hall et al., 2017; Jagust, 2018; Wisniewski, 2019). Vascular dementia is the result of damage to cerebrovascular cells, due to various vascular pathologies (Iadecola, 2013). The most frequent cause of vascular lesions is leukoaraiosis, which are confluent white matter lesions from microvascular alterations, and small lacunar infarcts (Iadecola, 2013). Other causes of vascular dementia include reduced cerebral perfusion, small vessel disease, microinfarcts and microhemorrhages, cerebral amyloid angiopathy (deposits of the protein beta-amyloid in cerebral vessels which is a cause of bleeds and hemorrhages), and mixed lesions (Iadecola, 2013).

Dementias with Lewy bodies can be classified as Lewy body dementia or Parkinson's disease dementia when occurring a year or more after the onset of dementia (Ballard et al., 2013). Lewy bodies are clumps of the protein alpha-synuclein, which develop in areas of the brainstem, diencephalon, basal ganglia, and neocortex, leading to neurodegeneration and dementia (Ballard et al., 2013). Frontotemporal lobe dementia follows neuronal damage in the prefrontal and temporal cortices, resulting in cortical atrophy (Hall et al., 2017).

Risk Factors

Dementia typically develops as the result of multiple factors (Baumgart et al., 2015; Iadecola, 2013; Wisniewski, 2019; World Health Organization, 2017). Certain risk factors are dependent upon the specific etiology of the dementia, although globally distinctions can be made between modifiable and non-modifiable risk factors, as displayed in Table 2. The single greatest risk factor for dementia is age, although developing dementia is not a normal part of aging (Baumgart et al., 2015; Wisniewski, 2019; World Health Organization, 2017).

Diagnostic Criteria

The diagnosis of dementia is primarily made based on signs and symptoms, with input from multiple data sources (Alzheimer's Association, 2017; Chambers et al., 2016; McKhann et al., 2011). British Columbia Clinical Practice Guidelines (Guidelines and Protocols Advisory Committee, 2016) recommend using the diagnostic criteria developed by the National Institute on Aging – Alzheimer's Association workgroups (McKhann et al., 2011), as outlined in Table 3. The criteria require that PWD have significant levels of impairment and functional decline related to two or more cognitive domains, potentially creating dependence and stress upon caregivers. Cognitive testing that may be done to detect and measure impairment includes a mental status examination or neuropsychological testing, such as the Standardized Mini-Mental State Examination, Clock Drawing Test, or the Montreal Cognitive Assessment (Guidelines and Protocols Advisory Committee, 2016). Health care professionals must consider multiple possible causes of the impairment and may arrive at a diagnosis of dementia by exclusion of other conditions. For the purpose of this research, all-cause dementia will be taken into consideration, as functional decline occurs in all types of dementia, creating the caregiving need and complicating transitions in care due to the complex care needs of the PWD.

Table 2

Dementia Risk Factors

Risk Factors	Mechanism
Modifiable	
Cardiovascular disease risk factors	Hypoperfusion, oxidative stress, and inflammation lead to endothelial damage, alterations in the blood-brain barrier, and disruption to vascular and brain cells. [a]
Education	Increased cognitive reserves contribute to fewer cognitive deficits in the expression of the disease. [a]
Social and cognitive engagement	Leisure, social, and cognitive engagement is believed to stimulate nerve growth and survival, and stimulate more brain cell connections, contributing to greater reserves against dementia. [b]
Prevention of traumatic brain injuries	Traumatic brain injuries may lead to disrupted brain function as a result of more active secretase enzymes [c], leading to amyloid deposits. [b]
Non-modifiable	
Age	Increased commonality of cardiovascular disease in older adults [d] and increased spreading of tau tangles in the aging brain. [e]
Family history	Role may be linked to hereditary and/or environmental factors. [b]
Genetic mutation to one of three genes: amyloid precursor protein, presenilin 1, or presenilin 2	Genetic mutations lead to overproduction of β-amyloid and contribute to senile plaques. [a]
Presence of apoliproprotein E e4 gene	Increased and accelerated β-amyloid accumulation and aggregation in the brain. [f]

[a] Iadecola (2013). [b] Woodward et al. (2007). [c] Baumgart et al. (2015). [d] Flier and Scheltens (2005). [e] Wegmann et al. (2019). [f] Liu et al. (2013).

Table 3

Diagnostic Criteria for Dementia

Criteria	
Impairment in at least two cognitive domains:	Memory Language Visuospatial Executive functioning Behaviour
Impairment causes a significant functional decline in usual activities or work	
The impairment is not explained by delirium or other major psychiatric disorder	

Note. Adapted from *Cognitive Impairment—Recognition, Diagnosis and Management in Primary Care—Province of British Columbia*, by Guidelines and Protocols Advisory Committee, 2016 (https://www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/bc-guidelines/cognitive-impairment).

Prognosis and Impacts

Dementia progresses slowly over several years and the average survival is four to eight years following diagnosis of Alzheimer's dementia (Alzheimer's Association, 2017). Likewise, the complex medical and social consequences of dementia give rise to significant caregiver burden, leaving many individuals, caregivers, family, and friends impacted by this terminal condition (Alzheimer's Association, 2017). Challenges related to dementia also include social and economic impacts, including increased medical and social costs, as well as costs related to informal care (World Health Organization, 2017). Dementia affects individuals and families, as the disease can cause significant stress through its physical, emotional, and economic strains (World Health Organization, 2017). An additional challenge noted by the Alzheimer Society of Canada (n.d.) is stigma towards individuals affected, and a focus on the disease and not the person.

Management Strategies

The management of dementia is complex and comprises multiple strategies and interventions. These may include non-pharmacological measures (Guidelines and Protocols Advisory Committee, 2016), pharmacological management, providing support and services, and advanced care planning, which may facilitate preparing for future transitions in care. The goal of non-pharmacological measures is to optimize quality of life and cognitive function (Alzheimer's Association, 2017), and is the recommended initial management strategy (Guidelines and Protocols Advisory Committee, 2016). Strategies include adapting the home environment, ensuring adequate nutrition, socialization, memory training, caregiver support, and exercise (Alzheimer's Association, 2017; Guidelines and Protocols Advisory Committee, 2016). Many of these interventions require the support and coordination of caregivers, who may find the diagnosis and management of dementia distressing and challenging.

Pharmacological Management. Pharmacological management is considered on an individual basis and usage is controversial due to limited known benefits, frequent side effects, and interactions (Guidelines and Protocols Advisory Committee, 2016). Acetylcholinesterase inhibitors (donepezil, galantamine, and rivastigmine) and memantine are approved in Canada for the treatment of Alzheimer's disease dementia, although there is no evidence of benefit when used in mild cognitive impairment (Guidelines and Protocols Advisory Committee, 2016; Russ & Morling, 2012). Pharmacological management does not impede or repair the damage to neurons, but instead increases the amount of neurotransmitters present, resulting in a temporary improvement of symptoms for some affected individuals (Alzheimer's Association, 2017).

Pharmacotherapy, in the form of antipsychotics, may also be added as an adjuvant, when symptoms have increased, or when behavioural or environmental modification strategies have been unsuccessful (Antifeau et al., 2012; Guidelines and Protocols Advisory Committee, 2016). Antipsychotics that may be used include the first generation antipsychotic loxapine, or second generation antipsychotics such as olanzapine, quetiapine, or risperidone (Guidelines and Protocols Advisory Committee, 2016). While there can be benefits from utilizing pharmacological management, many older adults with dementia have other chronic conditions, and polypharmacy is common. This may contribute to pill burden and an increased risk of potential drug interactions and side effects, in turn affecting the quality of life of PWD and their caregivers. Many of the symptoms present in dementia contribute to caregiver burden, with careful consideration needed of the impact and management strategies of the behavioural and psychological symptoms of dementia.

Behavioural and Psychological Symptoms of Dementia. Managing the symptoms that a PWD may experience often falls upon family caregivers, who take on numerous roles: coordinating care, assisting with personal care and medications, managing finances, and providing transportation (Sinha, 2013). As the disease progresses, the PWD becomes increasingly reliant on others, requiring more caregiving hours which can lead to caregiver stress and poor coping (Sinha, 2013). Behavioural and psychological symptoms of dementia are frequently present and have been found to be a contributor to caregiver burden and a predictor to institutionalization in LTC (Feast et al., 2016). Individualized management strategies are required, with input and planning needed by both caregivers and health care professionals (Antifeau et al., 2012).

Support and Services. Community care services can provide assistance in managing care for PWD in their home environment, help caregivers navigate the available resources, and anticipate future care needs, such as the need for LTC as the disease progresses. There are numerous types of community care services available in BC, including publicly subsidized services, such as home support, community nursing, adult day services, caregiver respite, and end of life care, as well as services available from private pay service providers. Community nursing services are provided by a licensed nursing professional and may include wound care, education, care management, and more, while home support is provided by community health workers and may include assistance with ADLs such as mobilization, nutrition, and bathing (British Columbia Ministry of Health [BCMoH], 2012-2020). Not all services are available in all locations; rural caregivers are known to use fewer services and rely more on informal support than urban caregivers (O'Connell et al., 2013).

Caregivers living in rural areas are known to face unique challenges related to accessing and maintaining services, which can include greater travel times, more limited access to health care services, and a stronger reliance on telephone support than urban caregivers (O'Connell et al., 2013; Pong et al., 2011). Although local supports and resources may be limited in rural areas, there has been a growing interest in addressing this gap. For example, an initiative that facilitates the assessment and treatment of older adults with atypical and complex cases of suspected dementia in rural Saskatchewan is available through the Rural Dementia Action Research initiative (University of Saskatchewan, n.d.). Rural and Remote Memory Clinics are able to provide streamlined multidisciplinary assessments and recommendations over one day, which are shared with the patient and caregivers at the end of the day during a care conference, aiming to reduce repeated travel and shorten the time to diagnosis (Morgan et al., 2014; University of Saskatchewan, n.d.).

Publicly subsidized home and community care services are subsidized according to income or may be provided at no cost depending upon the circumstances of the care recipient. When the PWD and their caregiver are well supported in the community, a plan for addressing physical conditions and changes in care needs can be put in place, which may help avoid emergency room visits and acute care stays for social issues, difficulties coping at home, and some health conditions (Godard-Sebillotte et al., 2019). Regardless of the circumstances leading to an emergency department visit or hospital stay for PWD, health care professionals should take the opportunity to assess the situation and connect individuals to the appropriate resources, when an encounter occurs.

Long-Term Care

Long-term care may also be referred to as residential care, care homes, or nursing homes, and is regulated and licensed in BC by the Community Care and Assisted Living Act, or the Hospital Act (Community Care and Assisted Living Act, 2009). A LTC home is defined as “a facility designated by the health authority to provide long-term care services, including short-stay services, and includes licensed community care facilities, private hospitals and extended care hospitals” (BCMoH, 2012-2020, Chapter 6.A, p. 2).

With over 6.4 million Canadians being 65 years of age and above, and estimates that the number will increase to 12.3 - 16.1 million by 2068 (Statistics Canada, 2019), it is anticipated that the demand for LTC will increase substantially. By 2030, as baby boomers begin reaching age 80 (Blomqvist & Busby, 2014), demand for LTC is anticipated to be an all-time high. However, in BC, a decade before this expected rise in demand, the need for publicly funded LTC beds exceeds the current availability. The combination of rapid population aging and a lack of access to LTC represents a critical challenge that has significant policy implications.

Provincial Policies

British Columbia provincial policies describe the regional health authorities' responsibilities in planning and delivering subsidized health care services, including LTC, which is a component of home and community care services. These policies are outlined in the *Home and Community Care Policy Manual* (BCMoH, 2012-2020), which describes who may be admitted to LTC, how the health authorities must coordinate access, and the cost of LTC for residents.

The BCMoH (2012-2020) states that services are intended "to supplement, rather than replace, the efforts of individuals and their caregivers to meet their health needs and make decisions about lifestyle and care" (Chapter 1.A, p. 2), therefore encouraging individuals to manage their own care as able. Criteria for approving LTC services includes the notion that an individual requiring services "has a caregiver living with unacceptable risk to their well-being, no longer able to provide care and support, or there is no caregiver available to the client" (BCMoH, 2012-2020, Chapter 6.C, p. 1). This principle may potentially lead to some individuals finding themselves in the unwanted position of becoming a caregiver, or taking on more than they wish. For example, in a recent study by Jamieson et al. (2016), caregivers reported a sense of being required to provide care to their loved one in hospital and post-discharge due to concerns for safety and expressed frustration and burden related to coordinating care at home. Health care professionals must consider how relevant policies affect individuals, and if some caregivers may end up providing care when they no longer wish to do so.

Long-Term Care Access. The guidelines established by the BCMoH (2012-2020) outline how and when adults can access funded LTC, which typically must occur from home. Waiting lists for LTC admission are common due to the limited number of available beds, with the waiting period ranging from 19 to 191 days (Office of the Seniors Advocate, 2019a). Despite the BCMoH direction for LTC access to occur from home, it is sometimes not feasible or safe for an individual to wait for LTC services in their home. In these situations an exception may occur for LTC admission from hospital or other facilities such as respite or short stay units. A full assessment of the person's capabilities, resources, and consideration of the risk of waiting for LTC from home will aid in determining the urgency of the situation, which may change rapidly as the disease progresses. A PWD who does not have a caregiver may find themselves in a more urgent situation, where they are unable to remain at home as long as other individuals with dementia who have a caregiver, or who require extensive formal supports in order to remain at home.

In 2019, there were 1767 persons on waiting lists for LTC in BC, with median wait times ranging from 19 days in Vancouver Coastal Health to 191 days in Northern Health (Office of the Seniors Advocate, 2019a). Of the 1767 persons on the waiting list for LTC, 418 were in hospital (Office of the Seniors Advocate, 2019a). This waiting period can be a stressful time, especially for older adults with dementia and their caregivers who have experienced a hospital stay, some of whom may return home to wait for a LTC bed to become available. There may be concerns with how the older adult and caregiver will cope, if the situation is safe and difficulty understanding why the older adult is being sent home when the need for LTC has been acknowledged (Office of the Seniors Advocate, 2020). Further understanding transitions in care may yield important insights and help better understand the implications of the policy for caregivers.

Caregiving

A caregiver can be defined as “those aged 15 years and older providing help or care within the past 12 months to either: 1) someone with a long-term health condition or a physical or mental disability, or 2) someone with problems related to aging” (Sinha, 2013, p. 4). Caregiver types include informal caregivers, formal caregivers, and primary caregivers who assume the principal caregiving role when more than one caregiver is involved.

Informal Caregiver Profile

Informal caregivers in Canada are frequently seniors over 65 years, who also spend the most time providing care of all caregiver types (Sinha, 2013). Most of the caregiving is provided to parents (48%), with spouses comprising 8% of the care recipients in Canada (Sinha, 2013). It has been noted that the frequency of caregiving increases when spouses are the care recipient, with an average number of 14 hours of care provided per week (Sinha, 2013). Approximately one quarter of caregivers provide care to their aging parents and while also having children under age 18 at home; these caregivers are often referred to as sandwich generation caregivers due to their competing demands (Alzheimer’s Association, 2017; Sinha, 2013). A slight majority (54%) of Canadian caregivers are female (Sinha, 2013), in contrast to the two thirds cited for American caregivers (Alzheimer’s Association, 2017). Female caregivers typically spend more time caregiving as compared to their male counterparts, and may be at increased risk of burden due to the increased intensity of care activities that females tend to assume (Alzheimer’s Association, 2017; Sinha, 2013).

Recognizing the role that caregiver gender, age, competing demands, and the intensity and frequency of care provided is important when considering the impact and experience that caregiving may have on individuals, along with potential strategies and interventions that may support these caregivers.

Benefits and Challenges

Turcotte (2013) has reported that caregiving benefits include reduced costs in the health and social services sector, as well as increased well-being for the care recipient who may be able to maintain a higher quality of life and remain in their home environment. Caregiving can also be rewarding for caregivers and has been identified as an area of importance for some (Cohen et al., 2002; Lanting et al., 2011). In a Canadian survey of caregivers, 73% of participants were able to find one positive aspect of caregiving, with companionship and fulfillment being the most frequently cited (Cohen et al., 2002). Although there are recognized benefits to caregiving, negative effects such as psychological consequences, health consequences, and financial and professional consequences are also apparent (Turcotte, 2013). Psychological consequences may include caregiver emotional concerns, depression, and mental health issues, with high to very high levels of stress reported by approximately half of caregivers for PWD, in comparison to 35% of caregivers for individuals without dementia (Alzheimer's Association, 2017).

Health consequences of caregiving may include physical strain from caregiving activities, difficulty maintaining general health, sleep disturbances, and consequences related to chronic stress (Alzheimer's Association, 2017). For example, in a phenomenological study examining the experience of caring for a family member with dementia, caregiver participants expressed how the experience was emotionally draining and exhausting, with feelings of stress and frustration that felt never-ending (Butcher et al., 2001). The experience of "enduring stress and frustration" (Butcher et al., 2001, p. 44) is frequently referred to as caregiver burden, which is associated with negative caregiver outcomes (Etters et al., 2008). There is much information concerning caregiving in the literature, however, an area that has not been well explored is the caregiver experience of a transition from hospital to home for PWD while waiting for admission to LTC. Exploring the caregiver experience may help health care professionals better understand what it is like to live a complex and potentially difficult situation: providing assistance to a PWD who requires more care than the caregiver can provide, and experiencing a transition from hospital to home after a hospital stay.

Transitions in Care

A transition in care is often referred to as a movement from one health care setting to another or a discharge home (Coleman & Boult, 2003), although in the Canadian context it may also refer to changes in health care providers or handovers between professionals (Accreditation Canada, 2013). Transitions in care have been recognized as a critical point in a patient's trajectory, with an increased risk of fragmentation of care due to challenges related to care coordination, continuity of care, and communication between settings and providers (Epstein-Lubow & Fulton, 2012). Improving transitions in care has become a focus of various organizations in Canada, including Accreditation Canada (2013) and The Registered Nurses' Association of Ontario (RNAO; 2014).

Transitions in care are recognized as a critical point in an individual's care. Much of the available literature has focused on the health outcomes of individuals, rehospitalization rates, and programs aimed at improving outcomes and reducing rehospitalization after a transition in care (Adams et al., 2014; Coleman et al., 2006; Naylor et al., 2014). Some transitional care interventions have focused on the role of nurse practitioners (Bradway et al., 2012; Mora et al., 2017; Naylor et al., 2014), who undertake essential tasks such as coordinating care, providing education, and monitoring health status. Other key issues discussed in the care transition literature include insufficient hospital discharge planning, fragmentation of care, concern surrounding practical issues once home, and the value of community support services.

Transitional care programs are not frequently offered in Canada, however, nurses in both hospital and community settings frequently support individuals and their caregivers during transitions in care by providing discharge and transition planning, education, psychosocial support, direct care, and case management. Additionally, a wide range of programs and services exist to bridge gaps during transitions in care, including the Quick Response (Dawson & Critchley, 1992; Weir et al., 1999) and Home First programs (Compton et al., 2019; Office of the Seniors Advocate, 2019b), or the recent Personalized Support and Stabilization team (Vancouver Coastal Health, 2019). Regardless of the approach utilized, nurses are well positioned to support individuals during a transition in care due to the ability to consider the whole individual and to take into account the physical, psychosocial, and spiritual components to well-being.

Personal Interest and Context

My personal interest in transitional care has formed through nursing practice experiences, where individual health care professionals and settings often appeared to be working in silos. This observation has been further reinforced in statements from both patients and health care professionals, who have expressed the wish for greater communication and collaboration amongst settings. My previous roles, as both a direct care nurse and patient care coordinator of an acute geriatric medical unit, were informative in contributing to my observation of these challenges in practice, and sparked curiosity to better understand the complexities related to transitions in care.

Despite collaborative initiatives to prevent functional decline in older adults and prepare for transitions from hospital to home, such as the provincial 48/6 care planning strategy (BC Patient Safety & Quality Council, 2012), progress has been slow and many sites continue to use their own care plans with limited collaboration and input from other settings. This highlights the difficulties present in implementing evidence-informed programs and interventions within complex health care organizations with unique local contexts, populations, and resources (Proctor et al., 2009).

Purpose and Significance

Dementia is a widespread condition without a cure, and which significantly impacts those affected by it, their caregivers, and communities. A diagnosis of dementia can be very unsettling for the individual and caregiver, with further challenges experienced as individuals attempt to manage the condition and adapt to changes in relationships, health, and function. Additional difficulties may arise when significant decisions are made surrounding transitions in care, including those related to LTC admission and transitions from hospital to home.

Transitions in care for PWD encompass several issues which have been briefly explored above. In order to fully explicate the experience of caregivers during the transition of a PWD from hospital to home while waiting for LTC, a comprehensive review of the relevant literature will be first undertaken. The review will enable a stronger comprehension of what is currently known about the subject, identify current gaps in knowledge, and will help refine the focus of the gap analysis by illuminating areas of potential relevance or concern to stakeholders, in turn eliciting the most in-depth answers. Following the literature review, a gap analysis will be undertaken to identify potential gaps between evidence-informed guidelines and actual conditions, and to determine existing strengths and opportunities within current transitional care practices.

Through this project, a comprehensive examination of the current evidence of care transitions will be gathered during the literature review, while insights from frontline health care providers and decision makers as they relate to care transitions in the Interior Health Authority will be gained during the gap analysis. Focusing on these evidence and practice insights and gaps will yield valuable data that can be used to inform ongoing practice development and policy change. Furthermore, understanding the experiences of caregivers in transition when a PWD is discharged from hospital to await admission to LTC may help nurses and other health care professionals support these individuals by creating awareness around the areas of significance and importance to caregivers, in addition to the insights gained regarding local practices and recommendations stemming from this project.

Summary

Transitions in care are often challenging times for both caregivers and PWD. The presence of dementia may complicate the transition and necessitates greater caregiver involvement than for persons without dementia. A transition in care may occur among many different settings, including from hospital to home, and from home to LTC. Due to a limited supply of LTC beds, some PWD may be registered on a waiting list during their transition to LTC. During this waiting period, crisis events and health problems for the PWD may occur, leading to a temporary hospital stay and subsequent discharge back home to resume waiting for LTC admission. Understanding the experience of caregivers in transition, while they support PWD after a hospital stay and before LTC admission, will highlight the unique challenges, provide indications of how nurses may best support caregivers and PWD during this time, and inform the development of the gap analysis methodology in order to identify potential areas for improvement in practice. The following chapter will provide a comprehensive overview of the contemporary literature.

Chapter 2

Literature Review

In order to better understand the experiences of caregivers in transition and inform the gap analysis of transitional care practices, an integrative review of the literature was undertaken. The integrative review provides a summary of current knowledge in a topic area and can identify gaps in research and knowledge, in turn creating opportunities to optimize nursing practices and outcomes (Russell, 2005). Integrative reviews are the broadest type of review, allowing the inclusion of diverse methodologies and broad perspectives, therefore providing great potential of contributing to nursing research and practice (Whittemore & Knafl, 2005). These are more inclusive than other forms of knowledge synthesis, including systematic reviews, which are more structured and narrow in focus. Although the combination of diverse methodologies may contribute to a perceived lack of rigour, strategies have been developed to enhance the rigour of integrative reviews (Whittemore & Knafl, 2005), including the use of a robust search strategy. This review is guided by the integrative review methodology of Whittemore and Knafl (2005) and follows four distinct steps:

1. Formation of the literature search question(s)
2. Development of the search strategy
3. Conducting the search
4. Reading and analyzing the research, reporting findings

The ways in which these steps were followed within this project are detailed below.

Formation of the Literature Search Question

The focus of this work is informed by personal practice experiences with older adults with dementia and their caregivers, through which I became aware of the challenges experienced by caregivers when a PWD is discharged from hospital to await LTC admission at home. The research question was formulated with the Sample, Phenomenon of Interest, Design, Evaluation, Research type (SPIDER) tool (Cooke et al., 2012), as displayed in Table 4, and sought to explore both the caregiver experience when a PWD transitions from hospital to home, and while waiting for the PWD to be admitted to LTC. Thus, a focused and integrative review specific to the experience of caregivers in transition when PWD are discharged from hospital to await admission to LTC has been selected.

Table 4

Elaboration of the Research Question Utilizing the SPIDER Tool

SPIDER Component	Component of research question
Sample	Caregivers of adults with dementia
Phenomenon of Interest	Experience of being in transition
Design	Focus groups or interviews
Evaluation	Experience
Research type	Qualitative or mixed methods

Development of the Search Strategy

To conduct the literature review, a comprehensive search strategy was developed, which included the core concepts of interest: dementia, caregiving, transitions from hospital to home, and waiting for LTC. Concept mapping was utilized as a strategy to identify and isolate the individual concepts from the research question, which combined together formed the basis of the search. The aim of the search was to identify sources focused on the concepts of interest, in order to explore how these concepts relate to and influence each other, and included searches for peer-reviewed literature. As part of the process of concept mapping, search terms were identified for each component. The University of Northern British Columbia Health Sciences Librarian, Dr. Trina Fyfe, was consulted during the process to ensure the adequacy and comprehensiveness of the methods, terms, and databases used, as well as to provide a peer review of the search. Appropriate electronic databases were identified and included Cumulative Index of Nursing and Allied Health Literature (CINAHL), Psychological Information Database (PsycINFO), and Medical Literature Analysis and Retrieval System Online (MEDLINE) Ovid databases. The databases were selected to provide the most comprehensive coverage of health-related literature, including the fields of nursing, allied health, psychology, and medicine. Studies searched were not limited by dates, as a preliminary search revealed that there was limited literature available, therefore identifying the need to review both older and more recently published studies.

The search terms included qualitative research methods, in addition to the core concepts of interest, as these methods elicit the exploration of participant experiences. Medical Subject Heading (MeSH) terms were used in CINAHL when possible, and were adapted to each database. The CINAHL specific search terms used are identified in Table 5. The terms within each concept were combined with the Boolean operator *OR*, followed by a combination of the concepts with the Boolean operators *AND/OR* to limit or expand the search as appropriate.

Table 5

CINAHL Search Terms Utilized

Database	Search terms			
	Sample	Phenomenon	Setting	Design
CINAHL	Dementia+ and caregiv*	Transitional care; patient discharge; patient discharge education; early patient discharge; transfer, discharge; discharge planning	Long term care; nursing homes; residential care; waiting lists Keyword: wait N3 (long term care OR nursing home* OR residential care)	Qualitative Studies+; focus groups; interviews; semi-structured interviews; exploratory research; systematic review

Study inclusion and exclusion criteria (see Table 6) were formulated to capture the core concepts of interest and the target population, and were applied during full-text review. To be included, studies had to explore the experiences of caregivers of PWD, and focus on a transition from hospital to home and/or of waiting for LTC. It was initially anticipated that secondary sources, such as systematic reviews, would provide valuable input to the research question, therefore, search terms were inclusive of these sources. However, while reading the literature it became apparent that the scope of the reviews was much broader than the research question guiding this project, rendering isolation of the findings relevant to this research difficult. Second, the search strategy had already identified the relevant primary sources that were presented in the reviews, and which had been selected for inclusion. It was therefore determined that the inclusion of secondary sources did not provide any additional input into the research question, and the article eligibility criteria was modified to include only primary sources. Two primary sources (Caldwell et al., 2014; Shyu, 2000) were included in reviews, yet had not been identified by database searching. These primary sources met the inclusion criteria and were therefore included in the sample.

Table 6

Study Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
Peer-reviewed literature and dissertations	No apparent research methodology
Primary studies	Editorials, letters, opinion pieces
Focus on transitions from hospital to home, including planning for discharge, and/or of waiting for long-term care	Experience of a transition to long-term care that does not include the waiting period at home
Experiences of caregivers of persons with dementia	Transitions from hospital to settings other than home

Conducting the Search

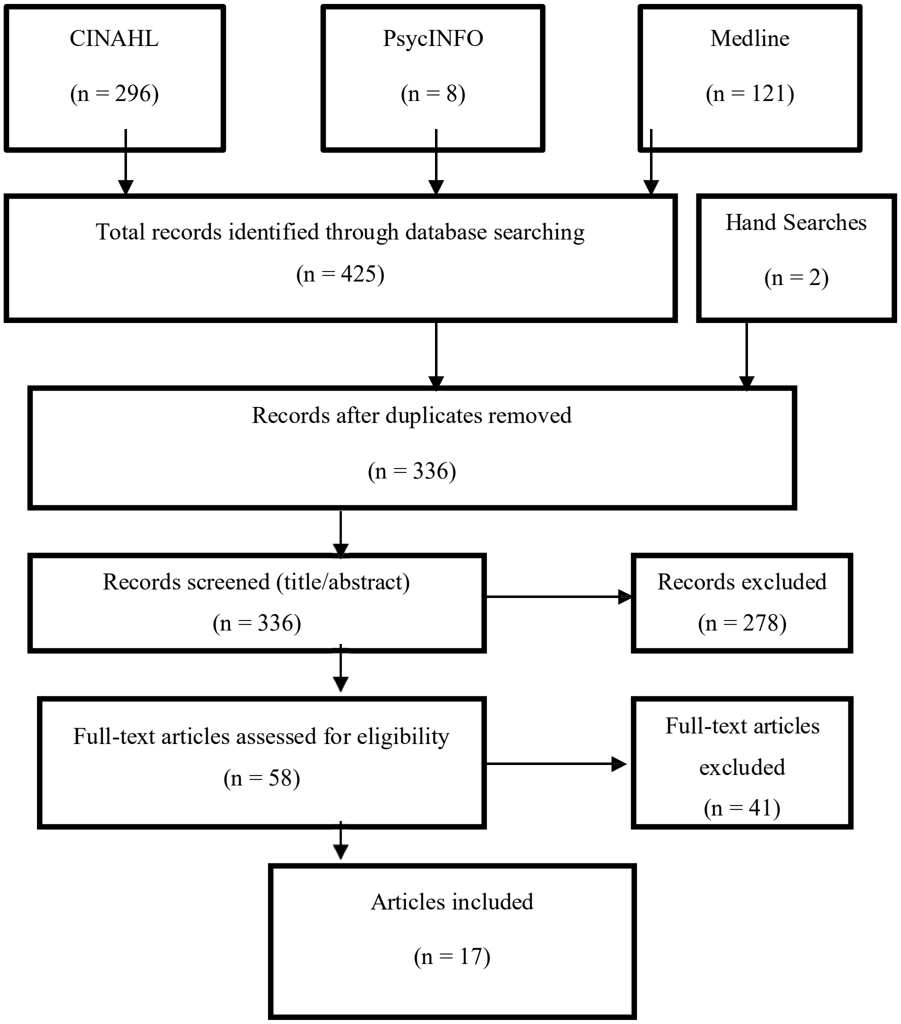
The search was conducted in July 2020 for English language sources only and identified 334 citations. Two additional sources were identified through hand searches of reference lists from key papers related to transitions in care. The specific number of citations per database is detailed in Figure 1, which provides an overview of the search to inclusion. Duplicates were removed and each article title and/or abstract was screened to identify potentially relevant sources. After screening, 58 full text articles were retained for full text review. Following full text review, 41 were removed as they did not meet the eligibility criteria. The remaining 17 articles were critically appraised and analyzed with the findings presented in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart that follows. The search was re-run in March 2021 to ensure all recently published and relevant literature was included. Thirteen additional citations were identified at this time, however, title and abstract screening revealed eligibility criteria was not met and these citations were not included in the PRISMA flow chart.

Data Evaluation and Analysis

The methodological quality of data was carefully considered but was not systematically evaluated with quality scores or a formal process. This reflects the integrative review methodology and the absence of consensus on how to evaluate quality (Whittemore & Knafl, 2005). Additionally, this integrative review included varied types of research design, rendering a consistent approach to quality appraisal difficult (Whittemore & Knafl, 2005). Data evaluation was therefore incorporated into the initial reading and analysis of the sample, through the creation of data extraction tables noting aspects of the study design and methodology. While it was noted that certain studies lacked methodological detail, rendering quality evaluation difficult, findings were generally similar amongst the studies with no outliers identified, a potential indicator for quality (Whittemore & Knafl, 2005). Methodological quality and individual study strengths and weaknesses were therefore considered but did not result in the exclusion of any papers.

Figure 1

PRISMA Flow Chart of Search to Inclusion



The final step of the review, analyzing the research and reporting findings, was guided by the constant comparative method of data analysis described by Whittemore and

Knafl (2005). Patterns and emerging themes were inductively derived through the process of data reduction, data display, data comparison, and conclusion drawing. Detailed notes were kept during this process, recording thoughts, questions, ideas, and processes followed. Data reduction included reading the papers several times in order to get “a sense of whole” (Sandelowski, 1995, p. 373), highlighting key statements and points, and making notes on initial thoughts. Studies were then divided into subgroups, based on the phenomenon of interest: the transition from hospital to home, or the experience of waiting for LTC. A data extraction table was created for each subgroup, and methodological details, study findings, and notes were recorded for each study. See Appendix A for a table of the final cohort of included studies, describing research aim, design, and key findings, organized by subgroup.

The final step of data reduction included identifying the key topics in each paper, which were colour coded in the data extraction table. During this process multiple key topics were identified, and similarities became apparent between some of the topics, which were then combined. Data display included creating a table for each of the two subgroups, and assembling the data around the key topics identified in the previous step (Whittemore & Knafl, 2005). During this step similarities and differences began to be noted between the two subgroups. Data comparison included examining the data displays and noting patterns, themes, and relationships (Whittemore & Knafl, 2005). Conclusion drawing and verification was the final phase of data analysis, and included gradually developing generalizations and continually revising conclusions (Whittemore & Knafl, 2005).

The following section will present the findings to the research question: What are the experiences of caregivers in transition when PWD are discharged from hospital to await admission to LTC?

Findings

Caregiver Role and Experiences

The literature search yielded 17 papers (Figure 1). Despite a comprehensive search, with ongoing support from a health sciences librarian, no articles focusing specifically on a transition from hospital to home while waiting for LTC were discovered. Therefore, articles selected for inclusion focused either on the caregiver experience of a transition from hospital to home for PWD (*n* = 9), or on the caregiver experience of waiting for LTC admission for the PWD (*n* = 8). See Table 7 for details of the sample by country of origin and methodology.

The sample included a broad range of caregiver participants, including spouses, children, friends, siblings, and others. Children were the most prevalent participants. The number of spouses comprising each study's sample varied from unspecified (Jamieson et al., 2016; Macmillan, 2016; Mockford et al., 2017) to a sample composed uniquely of spouses (Kraijo et al., 2015). The majority of studies (*n* = 12) reporting the number of spousal participants had samples where spouses accounted for less than half of all participants (*n* = 9). See Appendix A for complete sample details.

Table 7

Sample by Country of Origin and Methodology (N *= 17*)

Country of origin	Qualitative	Quantitative	Mixed methods	Total papers
Australia	5		1	6
United States	2		1	3
Canada	2			2
The Netherlands	1	1		2
England	2			2
Turkey	1			1
Taiwan	1			1

The studies analyzed in this integrative review discussed the transition experience in various ways, ranging from a clear discussion of the moment a PWD is registered on a waiting list and onwards (Caldwell et al., 2014; Kraijo et al., 2015; Meiland et al., 2001; Strang et al., 2006), to briefer discussions of the time period when caregivers were attempting to find an available LTC facility, within a greater discussion of a transition to LTC (Duncan, 1992; Mamier & Winslow, 2014), or of rural service use (Morgan et al., 2002). Similarly, the discussion of the caregiver experience of a transition from hospital to home emphasized different aspects, from specifically exploring the discharge experience (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011; Fitzgerald et al., 2011), to a broader focus of the discharge and post-hospital adaptation experience (Jamieson et al., 2016; Mockford et al., 2017; Shyu, 2000).

The heterogeneity in individual studies' focus, methodologies, and origins contributed to the inclusion of a diverse sample of experiences, in turn aiding to provide a broad understanding which may be relevant in various contexts. Although the studies comprising the literature sample were focused on discrete experiences, there were similarities, differences, and connections between caregivers in transition within both subgroups, and two processes became apparent. Five common themes were identified to both the caregiver experience of a transition from hospital to home and of waiting for LTC: phases, coping, professional support, relationships, and unpredictability. The theme phases included the subthemes hospital experience and decision-making. Two themes were identified as distinct to the waiting experience, including finances and rural. The findings are presented below by theme, beginning with the five common themes and concluding with the two distinct themes.

Phases

Seven papers within the sample highlighted the different phases that exist during the transition from hospital to home, and of transitions to LTC (Caldwell et al., 2014; Duncan, 1992; Jamieson et al., 2016; Kraijo et al., 2015; Macmillan, 2016; Shyu, 2000; Strang et al., 2006). Exploring the individual components of a transition enables an in-depth examination of the events and processes significant to caregivers, and their impact on the greater transition underway. These included hospital admission and treatment, the discharge process, and settling back at home (Jamieson et al., 2016; Macmillan, 2016), or the phases of role engaging, role negotiating, and role settling (Shyu, 2000) for the transition from hospital to home. Phases of the transition to LTC included the decision-making process, waiting, and the actual move to a LTC facility (Caldwell et al., 2014; Duncan, 1992; Kraijo et al., 2015; Strang et al., 2006). Several papers did not directly explore the various phases of a transition, but focused more specifically on the hospital experience (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011; Fitzgerald et al., 2011; Jamieson et al., 2016; Mockford et al., 2017), or decisions related to LTC admission (Caldwell et al., 2014; Duncan, 1992; Kraijo et al., 2015; Mamier & Winslow, 2014; Strang et al., 2006).

In an insightful Taiwanese study (Shyu, 2000), researchers explored the changing needs of caregivers of frail older adults, including those with cognitive impairment, prior to and at two intervals after hospital discharge. Study participants included 16 family caregivers who were interviewed by research assistants using open-ended questions. Data were analyzed using the constant comparative method, and resulted in the discovery of the core concept of role tuning, where constant adjustments were made by the caregiver and care receiver to adjust to the situation, and which included three phases: role engaging, role negotiating, and role settling.

In this qualitative descriptive study (Shyu, 2000), the phases of the transition from hospital to home were considered in relation to the caregivers' experiences and interactions occurring between the caregiver and care receiver, and not by physical location of where care was provided. The three phases occurred chronologically, beginning with role engaging before the discharge from hospital and reaching the role settling phase when the caregiver and care receiver arrived at a stable pattern of caregiving interactions. Role engaging included the process of preparing for a caregiver-care recipient role and included many informational needs. Role negotiating was identified as a phase where caregivers engaged in providing care but had not yet reached a stable pattern of interactions, and where assistance in managing emotional concerns and conflict was required. The third phase, role settling, was described as the process of reaching a stable pattern of caregiving interactions, and was the phase where caregivers' concerns gradually shifted towards their own needs for support and understanding.

Understanding the different phases of a transition and the processes that caregivers may undergo, such as described by Shyu (2000), provides insight to the experiences of caregivers in transition, highlighting the variations that occur not only by location, but with their relationships and interactions with PWD. While the study explored caregiver needs both before and after hospital discharge, it was not clear if the needs differed between the caregivers of older adults with and without cognitive impairment, which limits comprehension of how needs may differ between caregivers of the two groups.

Another qualitative descriptive study described the caregiver experience when PWD transition from hospital to home (Jamieson et al., 2016). In this Australian study, 30 caregivers of PWD self-selected to participate, via recruitment through care support networks. Data were collected through in-depth telephone interviews, using a semi-structured interview guide. Data analysis was undertaken by thematic content analysis, and findings were validated in a focus group of caregivers who did not participate in the initial interviews. Study findings included three themes: caring while in hospital, being discharged, and being home. The aim of the research was to describe the specific caregiver experience of being at home after hospital discharge, however, all caregivers also described experiences of the care received during hospitalization. This finding highlights how caregivers may focus on their role within the different phases and places of a transition, yet the entire transition experience is viewed as one event, with the hospital experience an integral component of the overall episode of care. Study limitations include the risk of self-selection bias, as participants may have volunteered to participate if they had strong opinions on the topic they wished to share.

The Hospital Experience. Five papers explored the hospital experience as a phase within the transition from hospital to home for PWD and their caregivers (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011; Fitzgerald et al., 2011; Jamieson et al., 2016; Mockford et al., 2017). Four papers reported on two Australian studies (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011; Fitzgerald et al., 2011; Jamieson et al., 2016), and one study was English (Mockford et al., 2017).

In a descriptive qualitative English study, researchers sought to explore the experiences surrounding service provision for persons with memory loss and their caregivers, at and after discharge from hospital, and to develop service user-led recommendations for transitions from hospital to home (Mockford et al., 2017). Thirty-two participants were recruited by non-probability sampling and snowballing, in two acute hospitals. The participants included 15 pairs of caregivers and persons with memory loss, and 17 health and social care staff. Data collection methods included semi-structured interviews, guided by an interview schedule, and caregiver written diary entries. Data were analyzed by framework analysis, with findings validated in focus groups with caregivers, and with health and social care staff providing written feedback. Study findings included four key areas of concern, including challenges in coordinating discharge and care, and the authors provided three key recommendations. These are summarized in Table 8.

This study highlighted the areas of concern during a transition from hospital to home for caregivers and persons with memory loss and identified the influence of the hospital experience on the greater transition home. Although hospital admission and treatment, the discharge process, and settling back at home may appear as individual and distinct processes, caregivers often viewed the transition from hospital to home as a whole, single event, with the experience in hospital exerting a strong influence on caregivers (Mockford et al., 2017).

In other papers that explored the hospital experience within a transition in care, caregivers were noted to frequently discuss the hospital care experience, which was intricately linked to their perception of the quality of transitional care (Bauer, Fitzgerald, & Koch, 2011; Fitzgerald et al., 2011; Jamieson et al., 2016). The hospital experience was often negatively viewed by caregivers, who felt that the low standard of care would impact their ability to manage once back home, due to problems arising in hygiene, continence, and behaviours of the PWD during the hospital stay (Bauer, Fitzgerald, & Koch, 2011). Frustrated with a perceived lack of quality, many caregivers discussed stepping in and providing care, yet feeling that their contribution was not valued (Bauer, Fitzgerald, & Koch, 2011; Jamieson et al., 2016). For example, in an Australian study of caregiver experiences when the PWD transitions from hospital to home, Jamieson et al. (2016) described this phenomenon as the “paradox in hospital” (p. 1116), where caregivers were requested or expected to assist with hygiene, diet, and toileting, yet felt they were ignored by staff in regard to decisions about care. The hospital care experience appeared to set the stage for the upcoming transition experience, and was linked to caregiver views on discharge planning and support (Bauer, Fitzgerald, & Koch, 2011; Jamieson et al., 2016).

Table 8

Key Areas of Concern and Recommendations for Service Provision for Individuals Discharged From Hospital With Memory Loss or Dementia

Four key areas of concern	Three key recommendations
Not being involved in discharge or confusion over what was agreed	Need for a written, mutually agreed and meaningful discharge plan
Too many professionals at home without one person coordinating	Need for a named coordinator who is a point of contact for services and support
Determining when and how to access support	To improve the quality of care provided by care agencies in patients' homes
Considerable caregiver stress due to unreliable and inexperienced care workers	

Note. Adapted from "The Development of Service User-Led Recommendations for Health and Social Care Services on Leaving Hospital with Memory Loss or Dementia - The SHARED Study," by C. Mockford et al., 2017, *Health Expectations, 20*(3) (https://doi.org/10.1111/hex.12477).

In an Australian paper that explored the hospital care experience within a transition from hospital to home, researchers utilized a qualitative constructivist design to understand the family caregiver's experience of hospital discharge planning, preparation, and support (Bauer, Fitzgerald, & Koch, 2011). The sample included 25 principal family caregivers of older adults with a dementia, who were recruited through purposive sampling and interviewed within six weeks of hospital discharge by semi-structured interviews. Member checking occurred during interviews, allowing participants to comment on the emerging analysis and interpretations. Data analysis was conducted using the constant comparative method and three categories were inductively derived to explain caregivers' expectations and needs during hospital discharge: coordination, capability, and consultation. Study participants experienced a lack of consistency in the care provided and a perceived low standard of care. Furthermore, there was a lack of discharge planning and communication, with caregivers feeling frustrated, unsupported, and distressed. The researchers acknowledged the possibility of the views being representative of caregivers wishing to share negative experiences, therefore, it would be worthwhile to know if interview questions included solicitation of any positive experiences related to the discharge planning process.

A lack of discharge planning was echoed in other papers (Bauer, Fitzgerald, Koch, et al., 2011; Fitzgerald et al., 2011; Jamieson et al., 2016), with reports that caregivers were often unaware of a formal discharge plan and feeling uninvolved. Discharge planning was reported as non-existent or ad hoc (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011), and hit and miss (Fitzgerald et al., 2011), without a coordinated team approach amongst professionals and involving caregivers. Within many of the captured studies, caregiver involvement was problematic, with families left out of discharge planning and decision-making (Fitzgerald et al., 2011; Jamieson et al., 2016; Mockford et al., 2017), leaving them feeling uninvolved and unsupported (Bauer, Fitzgerald, & Koch, 2011). Abrupt discharges were frequently reported in the captured studies, with caregivers receiving same day notice of an imminent discharge (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011; Jamieson et al., 2016), or at times arriving at the hospital to discover their loved one had already been discharged (Fitzgerald et al., 2011; Macmillan, 2016).

These findings corroborate those of other research (Jamieson et al., 2016; Mockford et al., 2017), highlighting stressful experiences and the caregiver viewpoint of the transition as a whole. The research by Bauer, Fitzgerald, and Koch (2011) focused on the discharge preparation and experience, yet caregivers discussed many challenges and the hospital care experience from admission to discharge.

Decision-Making. Five qualitative papers explored the significance of the many decisions surrounding LTC in the time leading up to LTC admission (Caldwell et al., 2014; Duncan, 1992; Kraijo et al., 2015; Mamier & Winslow, 2014; Strang et al., 2006). Two papers were American (Duncan, 1992; Mamier & Winslow, 2014), one was Canadian (Strang et al., 2006), one was Australian (Caldwell et al., 2014), and one was Dutch (Kraijo et al., 2015). The decision-making process occurred in phases, including the initial decision to register on a waiting list and the subsequent acceptance or decline of a bed offer (Caldwell et al., 2014; Kraijo et al., 2015).

Although the research question guiding this review was concerned specifically with the waiting period in the transition to LTC, it became apparent that the decision-making process related to LTC planning played an important role in the caregiver experience. Caregivers continually reevaluated their decision to seek LTC, and considered if, when, and where they would accept admission for their loved one (Caldwell et al., 2014; Duncan, 1992; Kraijo et al., 2015; Mamier & Winslow, 2014; Strang et al., 2006). Mamier and Winslow (2014) described this situation as "being stuck in the decision-making process" (p. 15), while Caldwell and colleagues (2014) examined the different stages of decision-making that caregivers were in when applying to a waiting list. The phases did not occur in a linear fashion, with caregivers' reevaluating their decision, and making new ones, based on contributing factors such as how the caregiver was coping, or expectations of family members and the PWD (Caldwell et al., 2014).

Decision-making during the waiting period included determining the appropriate timing for admission, accepting or declining offers, and selecting appropriate care and facilities. Some caregivers considered applying to a waiting list as a commitment and the initial step towards admission, while others deemed that applying to a waiting list was precautionary measure due to long waits and wanting to be prepared, for which a final decision could be made at a later date (Caldwell et al., 2014).

For example, in an Australian qualitative descriptive study of caregivers' decision to apply to a waiting list for LTC, many participants described the decision as the first step towards admission (Caldwell et al., 2014). Although some caregivers were not ready for LTC admission at the time of applying to a waiting list, the anticipation and belief that the PWD's condition would decline and later require LTC prompted the decision. In this study, 27 caregivers of PWD on waiting lists or living in LTC were recruited by purposive sampling and interviewed regarding the circumstances surrounding their decision to apply to a waiting list, and whether an available place would be accepted. The sample included participants of Chinese and English-speaking backgrounds, in areas surrounding Sydney, Australia, and included an examination of the influence of cultural factors on decision-making. Data were collected through face-to-face interviews, with the assistance of an interpreter when needed.

Caldwell and colleagues (2014) analyzed the data thematically, identifying six themes and several subthemes. The six themes included: stages of decision-making when caregivers apply for a waiting list, reasons why caregivers apply, reasons against admission, weighing up the decision, why places are declined, and why places are accepted. The researchers concluded that caregivers apply for LTC when they experience difficulties managing the care needs of their family member and require more skilled care. Although the decision-making process for both cultural groups was similar, some additional difficulties for caregivers of non-English speaking backgrounds were noted. These included concerns of not finding a culturally appropriate facility, children expressing feelings of failing in their duty, fear that parents may feel abandoned, and family disagreements. This study identified many considerations of Chinese-background caregivers when applying to a waiting list for LTC in Australia, however, the findings may be applicable to other populations and settings where language may be a barrier. The findings illustrated the similarity of the decision-making process for both Chinese and English-speaking background cultural groups, and demonstrated the variations in individual experiences that occur.

In the literature overall, numerous factors influenced the decision-making process. When offered a bed in a LTC facility, caregivers assessed their readiness for admission (Strang et al., 2006) and at times would accept the offer due to the perceived urgency of the situation and concern about what could happen if the PWD remained at home (Kraijo et al., 2015). Reasons for declining a bed offer included enjoying the positive aspects of caregiving and family disagreements over admission (Caldwell et al., 2014), or not currently requiring LTC due to still managing the care of the PWD at home (Caldwell et al., 2014; Strang et al., 2006). In selecting an appropriate LTC facility, caregivers placed much importance in finding a convenient location (Duncan, 1992) and culturally appropriate care (Caldwell et al., 2014).

Caregiver Coping and Emotions

Caregivers' ability to cope with the situation at hand was frequently mentioned in the studies of this review, with all of the included papers (*N* = 17) discussing caregiver coping and emotions during a transition in care. Caregiver coping was described as being related to an individual's personal limits and health status (Macmillan, 2016; Mamier & Winslow, 2014; Morgan et al., 2002), and could change due to the behaviours and symptoms of the PWD, or a crisis (Macmillan, 2016; Mamier & Winslow, 2014; Morgan et al., 2002). Caregivers experienced a wide range of emotions that were discussed in much of the literature in relation to coping, including guilt, anxiety, stress, grief, frustration, sadness, and worry. Many authors discussed the considerable stress that caregivers experienced during a transition from hospital to home (Bauer, Fitzgerald, & Koch, 2011; Fitzgerald et al., 2011; Jamieson et al., 2016; Macmillan, 2016; Mockford et al., 2017), or while waiting for LTC (Morgan et al., 2002).

For example, in two papers reporting on an Australian study of the hospital discharge process, caregivers reported feeling stressed, frustrated, and unprepared for their post-discharge caregiving role due to the uncoordinated discharge planning process (Bauer, Fitzgerald, & Koch, 2011; Fitzgerald et al., 2011). Similarly, the confusing experience of having multiple care workers, different services, and late or rushed home visits left caregivers under considerable stress in an English study of caregiver experiences after hospital discharge (Mockford et al., 2017). Stress was not only experienced by caregivers during a transition from hospital to home, but was also a central concern of caregivers who were waiting for the permanent LTC admission of their loved one (Morgan et al., 2002).

Caregiver feelings of guilt and grief were commonly reported in the literature and were found to be particularly distressing while waiting for admission (Caldwell et al., 2014; Chene, 2006; Mamier & Winslow, 2014). Perceived changes in identity and roles were found to contribute to emotional responses, including guilt and ambivalence. For example, Mamier and Winslow (2014) reported that distress was related to the caregiver’s identity as a wife and the perceived need to continue caregiving at home. Other emotions explored in the literature sample included sadness (Chene, 2006; Naylor et al., 2005), anxiety (Caldwell et al., 2014; Macmillan, 2016), and worry (Çelik & Bilik, 2020; Chene, 2006). The described range of emotions and the caregiving situation often left caregivers feeling out of control (Kraijo et al., 2015; Macmillan, 2016; Mamier & Winslow, 2014; Strang et al., 2006), under pressure (Shyu, 2000), at one's personal limits (Mamier & Winslow, 2014), unable to cope, and burdened.

Caregiver burden at the moment of waiting list admission was a frequent concern. In a Dutch study, over half of all participants reported feeling rather heavily burdened at the moment of registration on a waiting list for a LTC facility (Meiland et al., 2001). In this cross-sectional survey of caregivers of PWD, 93 participants from two regions of Amsterdam, Netherlands were recruited by convenience sampling. Data were collected by structured interviews and four measurement scales. Data analysis was completed with descriptive analyses, chi-squared tests, *t*-tests, Spearman's correlations, and multivariate regression analyses, using the Statistical Package for the Social Sciences.

In addition to the frequent incidence of caregiver burden discovered at the moment of registration on a waiting list, variables related to both negative and positive caregiving experiences were presented (Meiland et al., 2001). Negative experiences were found to be related to less severe dementia, lower patient age, and the caregiver provision of more hours of care, while positive experiences were related to lower caregiver income and a perceived favourable quality of relationship with the PWD. Although this study provides valuable insight into caregiver experiences while waiting for LTC, the burden experience of caregivers may be underestimated due to selection bias and study eligibility criteria that excluded PWD hospitalized or in the process of being admitted to LTC due to high need.

The point at which a caregiver reached his or her personal limits was also a frequent theme in the literature exploring the waiting period before LTC admission. This ranged from a gradual process for some to a crisis or turning point for others (Caldwell et al., 2014; Duncan, 1992; Morgan et al., 2002; Strang et al., 2006). A crisis or trigger could activate the need for urgent admission, and was often a health concern or hospitalization of the PWD, or a health concern or complication of the caregiver (Morgan et al., 2002; Strang et al., 2006). For example, in an exploratory Canadian study of the barriers to formal service use in rural dementia caregiving, Morgan and colleagues (2002) identified situations where caregivers were suddenly no longer able to provide care at home, due to a health crisis of their own. These situations were very stressful for caregivers, as the lack of an available LTC bed often led to the PWD being admitted to a temporary respite bed, without a plan in place of where the PWD would go at the end of their respite stay.

In this study of rural Saskatchewan caregiving (Morgan et al., 2002), 34 formal caregivers and 13 family caregivers were recruited by stratified random sampling where feasible, and convenience sampling when random sampling was not possible due to the small number of potential participants. Data were collected by focus groups conducted with a semi-structured interview guide, with data analyzed thematically, using the constant comparative method. Findings included the identification of eight barriers to service use, consequences of low service use, and strategies for greater service use.

In addition to crises, ongoing behaviours of the PWD and the physical aspects of caring were considered challenging within the captured literature, and also contributed to the caregiver's ability to cope with the situation (Chene, 2006; Macmillan, 2016). The transition from hospital to home was experienced as very stressful with feelings of worry, frustration, and sadness, which illustrates how the situation could become a crisis or turning point for some caregivers, who find themselves no longer able to cope and at the point of having reached their personal limits.

Professional Support

Twelve papers explored professional support. These had adopted varied approaches and methods, including qualitative (*n* = 9), mixed methods (*n* = 2), and quantitative methods (*n* = 1). Five papers were from Australia (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011; Chene, 2006; Fitzgerald et al., 2011; Jamieson et al., 2016), three were from the United States (Duncan, 1992; Mamier & Winslow, 2014; Naylor et al., 2005), two were from England (Macmillan, 2016; Mockford et al., 2017), one was from the Netherlands (Meiland et al., 2001), and one was from Canada (Morgan et al., 2002). The theme professional support encompassed caregivers' interactions with health care professionals, and included the advice and support received, formal support services, planning, and collaboration.

In the literature captured in this integrative review, interactions with professionals were often portrayed in a negative light due to limited support, issues surrounding communication, lack of planning for discharge from hospital, and limited collaboration amongst professionals and with caregivers (Bauer, Fitzgerald, & Koch, 2011; Jamieson et al., 2016; Mockford et al., 2017). For example, in an Australian study of caregivers' experience of hospital discharge planning, preparation, and support for PWD, Bauer, Fitzgerald, & Koch (2011) identified three key themes, including caregiver expectations and needs related to discharge: coordination, capability, and consultation. Within the discussion of these three themes, several quotes were provided relating to caregivers' dissatisfaction with the process, and lack of collaboration and communication with health care professionals. Bauer and colleagues (2011) concluded that caregivers “observed a range of responses by health professionals to the management of the person with dementia that they concluded were a demonstration of poor training and ineptitude” (p. 12). Similar findings were also reported by other researchers, with study participants reporting that they often struggled to access information and resources on their own due to a lack of awareness of health care professionals (Mockford et al., 2017).

Despite the often unsatisfactory experiences shared by caregivers with regards to their interactions with health care professionals, some researchers also reported positive experiences (Fitzgerald et al., 2011; Mockford et al., 2017). In an Australian study of caregiver experiences with hospital discharge practices reported in three papers (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011; Fitzgerald et al., 2011), the findings highlighted mainly negative experiences, although one paper reported on the satisfaction expressed by one participant with the hospital discharge planning and information sharing provided (Fitzgerald et al., 2011). Conversely, in an English study of transitional care experiences, Mockford and colleagues (2017) reported that participants shared positive experiences in relation to the kindness and caring attributes of many care workers. In both studies, interviews were conducted using semi-structured questions, although it is not clear if positive experiences were solicited. Additionally, the positive interactions were briefly mentioned, without discussion or adequate participant quotes, rendering consideration of what was helpful and appreciated by caregivers difficult.

Within the literature sample, many caregivers expressed feeling alone (Chene, 2006; Mamier & Winslow, 2014; Naylor et al., 2005) and requiring professional support (Bauer, Fitzgerald, & Koch, 2011; Mockford et al., 2017). For example, in a descriptive case study of the contrasting perspectives in a LTC decision-making experience, Mamier and Winslow (2014) demonstrated how the caregiver felt alone and with limited support in the time leading up to the LTC admission of her spouse, despite having access to a support group leader and a social worker assisting with the transition. In this case study, the caregiver expressed great personal difficulties and drew upon her informal support network during the challenging preadmission phase, while her support group leader was oblivious to the situation unfolding.

Mamier and Winslow's (2014) finding, where professional support is available yet caregivers do not reach out to access it, was similarly reflected in a transitional care study by Mockford et al. (2017), who found that support was available yet caregivers were unsure of when and how to access it, and where to go for help and advice. Feeling alone was further echoed in other studies, with caregivers wishing for a person to talk to and more psychosocial support (Bauer, Fitzgerald, & Koch, 2011), and feeling in the dark and requiring ongoing support (Naylor et al., 2005).

Formal support services appeared highly valued within the captured literature, with Dutch researchers finding that caregivers had less negative experiences while waiting for LTC when more formal home care and social support services were provided (Meiland et al., 2001). Morgan and colleagues (2002) noted that there were consequences of not using support services in a study of rural caregiving for PWD, including a deterioration of the caregiver's health, a crisis situation, or reaching the point where admission in LTC became necessary, yet no beds may be immediately available. Although formal support was considered valuable, it was not always utilized due to difficulties accessing services (Morgan et al., 2002), or limited service availability on discharge from hospital (Macmillan, 2016).

Likewise, Jamieson and colleagues (2016) found that the available services were often not appropriate, and accessing new services or reestablishing existing ones was challenging. Gaps in services left caregivers struggling to manage as best they could, with the burden of care falling on the caregiver (Jamieson et al., 2016).

Morgan and colleagues (2002) reported eight barriers to the use of formal services, including the stigma of dementia and lack of privacy. In this exploratory study it was not only the availability and accessibility of services that proved a barrier, but also the stigma associated with dementia that impacted caregiver service use: Some caregivers were uncomfortable with the behaviours related to dementia and wished to maintain privacy for their family.

Issues surrounding the quality of communication among health care professionals and with caregivers was equally identified as a concern. Many caregivers expressed dissatisfaction with the level of communication provided, not only in respect to discharge and care planning, but also with regards to the medical condition, care, and treatment of the PWD (Bauer, Fitzgerald, & Koch, 2011; Fitzgerald et al., 2011; Naylor et al., 2005). For example, in an American mixed methods study of the experience of a transition from hospital to home for cognitively impaired older adults, researchers described the experience of an emotional caregiver who broke down in tears explaining “Nobody tells me anything. I haven’t talked to a doctor . . . only once … I am in the dark” (as cited in Naylor et al., 2005, p. 57). Bauer and colleagues (2011) reported similar findings, with quotations provided displaying caregivers’ struggles to access medical updates and information surrounding medications.

Bringing a greater understanding to the caregiver perspectives of the professional support received during a care transition will help health care professionals identify potential needs and plan appropriate care and support. This can occur by better comprehending how unsatisfactory experiences affect caregivers and their hesitation or inability to reach out for help.

Relationships, Identity, and Values

Six papers within the sample explored the role of relationships, identity, and values related to the caregiving situation. Two studies were Canadian (Morgan et al., 2002; Strang et al., 2006), two were American (Duncan, 1992; Mamier & Winslow, 2014), and the remaining two were from Australia (Caldwell et al., 2014) and Taiwan (Shyu, 2000). The relationship between the caregiver and the PWD influenced caregiving expectations and decisions, and was central to understanding the caregiver experience of waiting for LTC (Strang et al., 2006). Strang and colleagues (2006) found that caregiving situations could become problematic when the expectations of the PWD and the caregiver were incongruent, as was demonstrated by Caldwell and colleagues (2014) when the PWD refused LTC admission and expected to remain at home.

Duncan (1992) explained that family and personal values, along with each individual’s philosophy, also influenced LTC decisions and the meaning provided to the caregiving situation. Relationships and cultural values within extended families were found to influence care decisions and expectations, such as where and when admission would occur, or if caregiving at home would continue (Caldwell et al., 2014). One’s personal identity was shown to be influential in how and when admission was accepted for one spousal caregiver, whose perceived need to continue caregiving was related to her identity as a wife and caregiver (Mamier & Winslow, 2014).

The role of gender issues in the caregiving experience was further acknowledged by Morgan and colleagues (2002), who argued that gender issues and rural cultural values contributed to social isolation and feelings of guilt in caregivers. Although the majority of captured studies did not specifically explore the role of gender in the caregiver experience, many of the studies' caregiver samples were predominantly female. For example, in a study of the decision-making process to place a PWD on a waiting list for LTC among Chinese and English-speaking background caregivers, researchers found that caregivers experienced guilt, grief, and anxiety when the decision for admission was made (Caldwell et al., 2014). Nineteen of the 27 participants were female, with the role of Chinese cultural values explored in the decision to pursue LTC admission, along with related feelings of spousal obligation. However, exploration of participants experience by gender was not specifically explored or reported.

Interpersonal relationships were also found to be influential to the caregiving experience during a transition from hospital to home for PWD (Caldwell et al., 2014; Shyu, 2000; Strang et al., 2006). Within the process of role tuning (Shyu, 2000) described in the section Phases, conflicts or emotional problems often arose within the caregiver/care receiver relationship, which were challenging for caregivers who were unsure how to respond. Relationships between caregivers and the PWD, along with extended family relationships, and the caregiver's identity and cultural values all appeared to influence the caregiving experience and decision-making processes, with difficulties emerging when conflicts arose. The impact of relationships, identity, and values not only influenced the caregiver experience, but highlight the great diversity of experiences that may occur based on individual circumstances.

Unpredictability

Ten studies within the sample reported instability when describing situations involving a transition from hospital to home for PWD, or while waiting for LTC. The studies explored caregiver perceptions of control, dependence, triggers, and movement of the PWD between settings. Prior to admission the situation of some PWD was characterized by high codependence and comorbidity (Kraijo et al., 2015), with multiple moves prior to being admitted in LTC (Chene, 2006; Duncan, 1992; Morgan et al., 2002). Temporary respite or LTC beds were sometimes used due to waiting lists for LTC facilities (Duncan, 1992; Morgan et al., 2002), with the PWD being moved to a more desirable location when able (Duncan, 1992). For example, Morgan and colleagues (2002) described this situation as revealing feelings of stress, hopelessness, and helplessness, with one participant describing the PWD as a '*yo-yo'*. The instability of these situations was furthermore evidenced by PWD who had traumatic and complex admissions to hospital (Chene, 2006), caregiver perceptions of being out of control (Kraijo et al., 2015; Mamier & Winslow, 2014; Strang et al., 2006), and reaching a crisis point where the need for urgent admission in LTC became apparent (Morgan et al., 2002).

Likewise, Strang and colleagues (2006) identified that a crisis often served as an initiator to the admission process, which caught the attention of caregivers who had not been aware of the extent of the challenges they were facing. Caregivers expressed concern with being able to continue in their caregiving role, with the notion of "looming crises" (Strang et al., 2006, p. 33) ever present while waiting, due to the precarious situation and concern that an incident could occur at any moment.

Situations during a transition from hospital to home for PWD were also unpredictable in nature, with researchers noting that cognitive impairment increased the complexity of care (Çelik & Bilik, 2020; Naylor et al., 2005) and the patient's risk of poor outcomes after a hospital stay (Jamieson et al., 2016; Naylor et al., 2005). Caregivers found themselves in challenging situations at times, where hospital readmission or immediate LTC admission became necessary due to medical complications (Fitzgerald et al., 2011) or the caregiver's inability to cope any longer (Macmillan, 2016; Morgan et al., 2002). In both transition situations, from hospital to home and while waiting for LTC, the situation appeared unpredictable, fragile, and susceptible to change, with outcomes affected by caregiver coping abilities, the PWD's medical and behavioural condition, and potential crises that could modify transition plans. These findings aid in creating an understanding of the many components contributing to the experiences of caregivers in transition, and factors that may influence caregiver coping.

Finances

Finances were briefly explored in four of the included studies, two of which were American (Duncan, 1992; Mamier & Winslow, 2014), one Canadian (Morgan et al., 2002), and one Dutch (Meiland et al., 2001). The role of finances was apparent within the literature studies that discussed the waiting period prior to LTC admission, in relation to hesitation of accepting formal services due to the cost (Mamier & Winslow, 2014; Morgan et al., 2002), or in caregivers' consideration of the financial impact when deciding upon and selecting a LTC facility (Duncan, 1992; Mamier & Winslow, 2014).

Morgan and colleagues (2002) described that the actual cost of services was a financial hardship for some caregivers in rural Saskatchewan, while for other caregivers, concerns about spending money after a life time of hard work left them frugal and apprehensive to spend money. Although the financial aspect of accepting services and admitting a PWD in LTC appeared to complicate the preadmission period, Meiland and colleagues (2001) found that caregivers with lower income encountered more positive experiences in a survey of caregiver experiences while waiting for LTC.

The challenges related to one caregiver's financial situation were further alluded to in a qualitative case study of LTC decision-making, where the spousal caregiver found herself in the difficult middle ground of being "not poor enough and not rich enough" (as cited in Mamier & Winslow, 2014, p. 15) to access LTC for her husband. The caregiver felt that LTC was outside of her financial means, and planned to seek professional assistance in considering her options. Exploring the role of finances in relation to the decisions and experiences of caregivers in transition draws attention to some of the challenges during this time, in turn providing health care professionals with possible avenues to offer assistance and support.

Rural

Few studies have specifically explored rural caregivers' experiences during a transition from hospital to home or while waiting for LTC. However, Morgan and colleagues (2002) provide an informative study of service use in rural dementia home-based caregiving and identified some of the unique challenges faced by rural caregivers, and the need for further research. Although this research focused on formal service use in rural Saskatchewan, many caregiver participants expressed concerns related to the stress experienced while waiting for permanent LTC admission of PWD. Unique challenges that were explored in this study included travel and access to services in rural communities, the distinct demands placed on rural caregivers such as the need to help with farm work, rural cultural values, and concerns surrounding confidentiality and privacy. For example, participants noted that caregivers could be hesitant at times to accept services out of concern whether confidentiality would be respected, when care providers were often close knit community members in rural communities where gossip prevailed. However, a positive aspect reported by Morgan and colleagues (2002) did relate to professional support in rural communities, finding that some caregivers benefitted from their relationship with home care managers who lived in the same community and who were proactive in providing support and coordinating services. In this example, one family caregiver felt their needs were seen and understood as a result of the health care professionals' personal contact with the family.

Based on the available literature, it is difficult to pinpoint the specific differences in the caregiving experience of waiting for LTC between urban and rural caregivers, largely due to the paucity of research studies on this topic and the varying aims and designs of existing research. However, the research by Morgan and colleagues (2002) has illustrated the unique challenges and concerns of caregivers of PWD in rural Saskatchewan, which in turn may inform and aid health care professionals in supporting rural PWD and their caregivers. It is likely that these findings would be transferrable to other rural settings.

Summary of Findings and Gaps in Knowledge

Through the basis of the literature review, the experiences of caregivers in transition have been explored, and themes identified. The seven themes include: phases; caregiver coping and emotions; professional support; relationships, identity, and values; unpredictability; finances; and rural. Caregivers experienced difficulties coping and a range of emotions during the transition, along with a perceived lack of professional support, unpredictable situations, and at times additional challenges related to relationships, finances, and rural settings. The importance of the LTC decision-making process for caregivers was identified (Mamier & Winslow, 2014; Strang et al., 2006), along with the cyclical nature of the process that occurs not only once, but with each bed offer and consideration of admission timing and location (Caldwell et al., 2014; Kraijo et al., 2015).

As highlighted in this review, health care professionals supporting caregivers and PWD during a transition to LTC should be aware of the significance and complexity of the decision-making process, and how their interactions may influence the experience and admission decision. In this integrative literature review, both positive and negative experiences were reported (Chene, 2006; Duncan, 1992; Meiland et al., 2001) and reinforced the need for clear communication and planning (Jamieson et al., 2016; Mockford et al., 2017; Morgan et al., 2002). This may have specific ramifications for nurses, who are often most engaged in the coordination and support of transition processes.

Although nurses are highly engaged, it is not well understood how support can be appropriately tailored to caregivers while they await the LTC admission for a care recipient with dementia, and which interventions and processes may increase interprofessional team coordination and communication. Future research is urgently needed to address these gaps and to support the development and implementation of evidence-informed practices that support caregivers in transition and optimize outcomes for patients.

Transitional Care Recommendations

The literature review findings have illuminated the challenges surrounding transitions in care for caregivers of PWD, revealing practice difficulties and gaps occurring in many of the settings examined by researchers. Furthermore, transitional care recommendations were noted within the literature sample regarding transitions from hospital to home, while no recommendations were found specifically concerning the waiting period prior to LTC admission. However, the themes identified during the review are areas of significance to caregivers that health care professionals must be cognizant of while supporting and interacting with caregivers of PWD in transition. Caregivers may find the situation less stressful if they perceive an adequate level of support is provided, while health care professionals must consider the effect of caregiver relationships, identity, and values in relation to the caregiver's ability to cope. Particular care should be provided in supporting the caregiver's decision-making process, as the literature demonstrated that even after an initial decision to place the PWD in LTC, caregivers revisited the decision and faced many new ones (Caldwell et al., 2014; Duncan, 1992; Kraijo et al., 2015; Mamier & Winslow, 2014).

Much of the literature captured in the review that explored the caregiver experience of a transition from hospital to home also included a discussion of recommendations for transitional care specific to this context. Australian researchers made several recommendations regarding discharge planning (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011; Fitzgerald et al., 2011), while Mockford and colleague's (2017) research with service users led to the elaboration of three final recommendations for transitional care, including community based care. Other authors' research did not result in formal recommendations, but explored the importance of communication, coordination, and involvement with caregivers (Jamieson et al., 2016), and the ongoing need for professional support post-discharge (Naylor et al., 2005).

The transitional care recommendations identified within the literature review were specific to the individual context of each study, encompassing the areas of discharge planning, continuity and coordination, and post-discharge care. These areas warrant further consideration when exploring best practice and evidence-informed recommendations in Canadian settings.

Conclusion

The challenges related to transitions to LTC and the related recommendations are well established in the existing literature, however, gaps and variations in practice are likely to be context specific. Therefore, in order for best practices and quality improvement initiatives to be implemented that could improve caregiver experiences of transitions to LTC for PWD, an analysis of local conditions and practices must be undertaken. The following chapter will present a gap analysis of transitional care practices for individuals waiting for LTC admission in the Central Okanagan region of BC. This will illuminate existing gaps and opportunities in practice and identify where future improvement efforts may be best situated. The review findings were informative in the development of the gap analysis methodology, prompting exploration and discussion of the issues and concerns identified within the literature review.

Chapter 3

Gap Analysis

Background

British Columbia is experiencing challenges related to an increase in chronic and complex diseases, high demand for community health services, and limited availability of LTC beds. Most older adults prefer to remain in their own homes and communities as they age, receiving support as needed to do so (National Institute on Ageing, 2019). However, some older adults eventually require LTC admission, and are often supported to wait at home until an available bed is offered.

In the previous chapter, the analysis of the literature review revealed how difficult and complex the waiting period for LTC can be, with caregivers reporting significant stress during the transition (Meiland et al., 2001; Morgan et al., 2002; Strang et al., 2006), alongside limited access to professional supports (Chene, 2006; Mamier & Winslow, 2014; Morgan et al., 2002). In light of the varied caregiver concerns highlighted in the literature review, a gap analysis of transitional care practices for individuals waiting for LTC admission was conducted. The purpose of the gap analysis was to help uncover areas for improvement within the practice setting, specifically within a large city situated in the Interior Health Authority region where the author is based. Identifying gaps in knowledge and local practices can aid in prioritizing where future quality improvement projects are most needed.

The gap analysis was undertaken in the community of Kelowna, BC, situated in the Central Okanagan local health area within the Interior Health Authority region. The Interior Health Authority is one of seven health authorities in BC, providing public health care services to a population of 762,000, within an area of 215,422 km2 (Interior Health

Authority, 2018a). Within both BC and the Interior Health Authority, improving access to and the quality of seniors care have been recognized as a priority area (BCMoH, 2019; Interior Health Authority, 2012, 2018b).

Within this region, transitional care is provided to individuals within a wide range of settings, accompanying patients through primary care, hospital, community, and LTC settings. The focus of this project is the experience of caregivers in transition when a PWD is discharged from hospital to await LTC admission, which entails a wait in the community. Therefore, a gap analysis of transitional care practices within the community care settings that coordinate LTC admissions within Kelowna, BC was determined to be the most appropriate setting.

Gap Analysis

A gap analysis is a useful tool to define, measure, and analyze problems prior to conducting quality improvement processes (Golden et al., 2017). This process aids in identifying the current state of practice, while comparing it to best practices (Campos & Hamilton, 2019; Davis-Ajami et al., 2014; DeSilets et al., 2013; University of Toronto Faculty of Medicine, 2009). Gap analyses have been utilized in health care to identify practice gaps when performance parameters fall below recognized standards, for example, in relation to patient falls per days of care (Kiyoshi-Teo et al., 2017; Lamb et al., 2020). Gap analyses may also be utilized to provide an understanding of processes in contexts where research is limited and to guide focused improvements, such as exploring clinical handover practices during a transition in care between emergency medical services and trauma teams (Javidan et al., 2020). Analyzing gaps in transitional care practices has the potential to lead to improved experiences for PWD and their caregivers. By highlighting gaps in practice and the unique needs of individuals and organizations, future resource utilization decisions can be contextualized and based on identified gaps and needs (Soriano, 2012). The methods and findings of the gap analysis will be discussed in the following sections.

Methodology

Methodologies to conduct gap analyses are varied and are often adapted to fit local contexts (Golden et al., 2017; Lamb et al., 2020; University of Toronto Faculty of Medicine, 2009). Typically, the process involves the evaluation of the related evidence followed by a review of current practices and gaps.

To conduct the gap analysis of LTC transition in the Interior Health Authority, a process was followed to identify the current state of practice, comparing it to a best practice situation (Campos & Hamilton, 2019; Davis-Ajami et al., 2014; DeSilets et al., 2013; University of Toronto Faculty of Medicine, 2009). The gap analysis followed a four step process: identifying and classifying the problem; identifying and defining best practice; measuring current practice; and strengths, weaknesses, opportunities, and threats (SWOT) analysis (Lamb et al., 2020). The gap analysis process was adapted and continually refined throughout the project as a means of exploring contextual practices and fostering the engagement of diverse stakeholder perspectives, all of which is an integral component of a gap analysis (Davis-Ajami et al., 2014). The four steps are discussed below.

Identifying and Classifying the Problem

In order to identify and classify the problem, consideration was given to define the concern, its scope, and complexity. Classifications of problems include those related to service, practice, or patient outcomes (Davis-Ajami et al., 2014). To determine the classification, concerns were clarified through concept analysis and were considered in conjunction with personal experiences and observations. Key concepts relevant to the focus of this work were identified and briefly explored in the Background section, followed by an in-depth analysis within the literature review. Identifying and classifying the problem brings focus to the concern, provides greater clarity regarding the information needed to inform the gap analysis, and helps guide the process (Davis-Ajami et al., 2014).

Identifying and Defining Best Practice

To identify and define best practice, relevant health care and research evidence and standards were considered, leading to the identification of parameters for the desired level of performance (Davis-Ajami et al., 2014). In preparation for this gap analysis, the integrative literature review sought to understand current knowledge of care transitions based on the experiences of caregivers. The findings reflect the complex nature of care transitions and the broader impacts upon caregivers. Following the review of the literature, key clinical guidelines and practice supports (Accreditation Canada, 2013; BCMoH, 2016; RNAO, 2014) were reviewed in order to explore relevant practice standards and to further inform the development of the gap analysis and its guiding questions. By undertaking a comprehensive review of the available literature and documented best clinical practices, this gap analysis was then crafted to further illuminate practice variation, identify how guidelines are implemented, and to identify strengths, weaknesses, threats, and opportunities as they relate to transitions in care.

Measuring Current Practice

To assess the local transitional care practices affecting individuals waiting for LTC, engagement with varied stakeholders was undertaken. The focus of the engagement was guided by findings of the literature review, specifically to explore how health care professionals can effectively support caregivers during the waiting period prior to LTC admission, and to identify how other themes, including decision-making and unpredictability, are reflected in practice. Continuity of care was considered a significant component of transitional care that was frequently discussed by many of the study authors within the literature review sample, and which was explored within the integrative review theme professional support. Therefore, these concepts were influential in guiding the gap analysis. While conducting the gap analysis, attempts were made to first gather relevant documents, protocols, policies and guidelines, and educational resources supporting transitional care (Golden et al., 2017). From these areas, guiding questions were formulated and these were used to help identify and explore transition practices and gaps with key stakeholder groups. Stakeholders were asked to identify common practices around care transitions, perceived challenges and opportunities, as well as gaps. Two overarching questions concerned with transitional care were asked of health care professionals:

1. What tools/processes/practices guide and assist health care professionals in transition planning and providing support to individuals waiting for LTC, while facilitating continuity of care and promoting safety?
2. How can the support provided to individuals and caregivers waiting for LTC admission be evaluated?

Initial stakeholders were identified and recruited via local knowledge, followed by snowball sampling. Stakeholders were initially contacted by email or fax, and received an introductory letter explaining the project and requesting feedback on transitional care practices. A range of relevant professions and roles were selected, in order to incorporate perspectives from varying angles. These include professionals directly supporting the transition process (e.g., nurses and PCPs), those with system-level expertise in transitional care (e.g., directors or care coordinators), and caregivers with first-hand experience in receiving transitional care. The questions utilized during caregiver stakeholder engagement were modified to the context, with caregivers asked to share their experience of receiving transitional care while waiting for the LTC admission of their loved one, highlighting challenges and successful practices during this time. An informal telephone conversation was scheduled to discuss the relevant practices and gaps. Ten stakeholders provided feedback between January and March 2021. See Table 9 for details of stakeholder participants and snowballing results.

Table 9

Stakeholder Data Collection Summary

Stakeholder role	Date contacted	Identified by
Primary care provider (nurse practitioner)	January 11 2021	Author
Knowledge coordinator	January 13 2021	Author
Registered nurse case manager	January 14 2021	Knowledge coordinator
Registered nurse case manager	January 14 2021	Knowledge coordinator
Registered nurse case manager	January 14 2021	Registered nurse case manager
Community integrated care coordinator	January 15 2021	Author
Director	January 20 2021	Knowledge coordinator
Caregiver	March 6 2021	Author
Caregiver	March 6 2021	Caregiver
Registered nurse case manager	March 8 2021	Author

Despite ongoing effort to include family physician feedback, no primary care physicians responded to requests for input. However, a primary care nurse practitioner provided valuable feedback concerning transitional care practices and the characteristics of longitudinal relationships that developed in practice.

During the stakeholder interviews, the guiding questions were broad and allowed stakeholders to guide the direction of the discussion, provide personal insights, and reveal potential practices and gaps that had not previously emerged. Additional prompting questions were utilized if stakeholders requested clarification or were unsure of how to respond. Detailed notes were recorded during the discussion and snowball sampling techniques were used to identify other individuals who could potentially provide further insight.

The data were read closely and then analyzed thematically. Themes were derived deductively from the data and were explored in relation to the overarching discussion questions and existing transitional care guidelines. Similarities and patterns in the data were identified, coded, and organized by theme (Braun & Clarke, 2006). Reviewing and analyzing the themes were the subsequent steps. Although a deductive approach was utilized, data were analyzed by attempting to interpret what was said and by examining underlying ideas (Braun & Clarke, 2006). The integrative review findings were continuously considered during the gap analysis, prompting further questions and seeking to identify if concerns reported within the captured literature were also noted in practice within the Interior Health Authority.

Strengths, Weaknesses, Opportunities, and Threats

A SWOT analysis was the final step in the gap analysis and is a tool that has been used in a variety of health care settings to identify the internal and external factors that influence organizations, and to guide strategic planning (Demirkol et al., 2020; Swysen et al., 2012; van Wijngaarden et al., 2012). Health care organizations have conducted SWOT analyses in fields such as chronic disease management (Van Durme et al., 2014) and community care for at-risk older adults (Martin et al., 2012), in order to guide program and service development. Researchers have suggested that health care organizations utilize an "organic SWOT" (van Wijngaarden et al., 2012, p. 39) with flexible rules to fit local contexts, as health care organizations frequently operate in networks with other organizations and stakeholders, rendering differentiation between internal and external factors challenging at times. A SWOT analysis may be utilized to guide reflection and discussion of organizational priorities, practices, and results, and is often a social process involving stakeholders with few formal procedures and a flexible analysis. With an organic SWOT analysis, it is important for health care organizations to focus on the stakeholder expectations, resources, and contextual developments that are most important. The gap analysis was conducted between December and March 2021, with the findings presented in the following sections.

Findings

The waiting period prior to LTC admission is a challenging transition for caregivers, who experience stress, burden, emotional challenges, and a perceived lack of professional support (Caldwell et al., 2014; Mamier & Winslow, 2014; Meiland et al., 2001; Morgan et al., 2002). These concerns represent potential gaps in practice, requiring organizational and service delivery perspectives to explore evidence-informed practices and to optimize transitional practices. The following sections will present the current evidence related to best practice transitional care, the actual organizational practices, and will be followed with a SWOT analysis.

Evidence-Informed Practices

To identify potential gaps in transitional care, recommendations from the literature review and evidence-informed practices were considered in order to discern potentials gaps between current and best practices. Although many of the study authors within the literature review sample discussed recommendations for transitions from hospital to home, recommendations for the waiting period prior to LTC admission were notably absent. However, the literature review recommendations include an increased focus on continuity and coordination of care, collaboration, and planning, all of which are likely transferable to other transition contexts. To expand on these recommendations, best practice guidelines for transitional care in the Canadian context were sought. To locate potential best practice guidelines, an internet search along with a review of relevant nursing organizations was undertaken. Following this search, three best practice guidelines were identified and were included in this gap analysis. These included the *RAI-HC Clinical Standards and "Best Practice" Guidelines* (BCMoH, 2016), the *Care Transitions* guidelines (RNAO, 2014), and *Safety in Canadian Health Care Organizations: A Focus on Transitions in Care and Required Organizational Practices* (Accreditation Canada, 2013).

Both the *Care Transitions* guidelines and the required organizational practices (Accreditation Canada, 2013; RNAO, 2014) are for use across many transition settings and are not specific to LTC, while the *RAI-HC Clinical Standards and "Best Practice" Guidelines* (BCMoH, 2016) are related to community care and are not transition specific. However, all of the guidelines recommended collaborative care planning and evaluation, which were also identified as areas of significance within the professional support theme of the integrative review. During the search to identify evidence-informed transitional care practices, an additional resources was located, the health authority standardized process and procedure *Care Management – Access to Long-Term Care Home* (Maxfield & Savard, 2018-2019). This Interior Health Authority document recommends the assessment of individuals and the development of collaborative care plans for individuals in transition, as also recommended within the relevant best practice guidelines (Accreditation Canada, 2013; BCMoH, 2016; RNAO 2014).

Two of the recommendations within the *Care Transitions* (RNAO, 2014) guidelines were recognized as particularly relevant for health care professionals supporting individuals while waiting for LTC admission, as concepts identified within these recommendations were closely related to the themes stemming from the integrative review. These included the concepts of collaboration, interprofessional teams, transition planning, and continuity of care. The two recommendations are:

1. "Collaborate with the client, their family and caregivers and the interprofessional team to develop a transition plan that supports the unique needs of the client while promoting safety and continuity of care" (RNAO, 2014, p. 26), and
2. "Evaluate the effectiveness of transition planning on the client, their family and caregivers before, during and after a transition" (RNAO, 2014, p. 35).

Based on the assessment of the existing literature and a review of relevant best practice guidelines, evidence-informed transitional care for individuals waiting for LTC admission was considered to include the development of a collaborative transition plan that is client specific and inclusive of client, family, and caregiver needs and wishes. Additionally, it is recommended within the guidelines that transition plans promote safety and continuity of care and be regularly evaluated to ensure needs are met (Accreditation Canada, 2013; BCMoH 2016; RNAO, 2014). These recommendations were incorporated into the guiding questions. Transition plans were considered a key element in planning for the LTC admission of a PWD, as the integrative literature review identified concerns surrounding caregiver perceptions of uncoordinated and insufficiently planned transitions in care. These concerns were considered an important element to explore and seek stakeholder feedback regarding.

Current State

The stakeholder engagement process included interviews with a sample of 10 key stakeholders, each of whom hold central roles in the care of older adults awaiting LTC. Following the review of the stakeholder data, four themes were identified. These were related to evidence-informed practices and specifically included the development of collaborative transition plans, coordination of care and safety, evaluation, and education.

Development of Collaborative Transition Plans. Collaborating with individuals, caregivers, and the interdisciplinary team to develop a transition plan is a central recommendation within current best practice guidelines (RNAO, 2014), for which exploration may help address the question of this project. The use and importance of transition plans were explored at length during the stakeholder interviews. Findings from stakeholder interviews related to how collaborative transition plans are developed in practice identified similarities to the literature review findings concerning professional support, caregiver coping, decision-making, and unpredictability. For example, professional support was noted to be highly valued by caregivers in the captured literature (Meiland et al., 2001), which is related to communicating and collaborating with caregivers while planning for LTC admission. In the stakeholder interviews, both caregiver stakeholders who participated commented on the importance of being informed of the complex admission process and the need to be involved in concrete transition planning.

Conversely, one caregiver stakeholder reported difficult emotional responses including frustration and distress when she perceived not being included in the development of a transition plan. Furthermore, this caregiver stakeholder perceived being excluded from the decision-making process related to admission timing and urgency, with a bed offer arising after she verbalized that she had reached the point of no longer being able to cope. These findings echo the themes of professional support, caregiver coping, decision-making, and unpredictability identified in the integrative literature review.

In the stakeholder interviews, varying practices, successes, and challenges in the development of collaborative transition plans were identified. Health care professional stakeholders emphasized the extensive planning, skill, and collaboration employed, with several resources utilized to guide practice and to support the unique needs of individuals waiting for LTC admission and their caregivers. These include policies, standardized processes and procedures, standard work, the Resident Assessment Instrument-HomeCare (RAI-HC), informational resources, professional consultation and collaboration, client and caregiver involvement, and individual professional expertise.

For example, one registered nurse stakeholder emphasized that policies and procedures can be of limited use in clinical practice, while professional judgement and experience were considered extremely valuable in communicating with caregivers and creating appropriate transition plans. However, another stakeholder with system-level expertise as a care coordinator identified the role of existing policies and procedures to support decision-making and reduce unpredictability during the waiting period. Furthermore, this stakeholder identified an existing standardized procedure that prompts steps to take and potential resources to consult when an individual waiting for LTC in the community is admitted to hospital. This complex scenario may relate to the unpredictability of the waiting period described in the literature review findings, with the standardized procedure acting as a tool to support decision-making and continuity of care between settings. Additional policies and procedures related to transitional care are presented below.

Transitional Care Policies and Procedures. The initial development of a transition plan is well established and prompted within many policies and practices, which registered nurse stakeholders noted to be a facilitating factor in care transition planning. The policies begin at the provincial level, with guidelines set out by the BCMoH (2012-2020) regarding access to home and community care services and assessment. The *Home and Community Care Policy* (BCMoH, 2012-2020) includes the requirement to complete a full RAI-HC assessment for individuals with a chronic condition or ongoing needs, to identify the individual's goals, and to develop a collaborative care plan with the client, caregivers, and other interdisciplinary team members. The process is intended to be integrated and collaborative, with information regarding the assessment and care plan developed collaboratively and shared with the client, caregiver, and members of the individual's health care team.

During a stakeholder interview, a registered nurse case manager highlighted the benefit of utilizing existing tools within the RAI-HC assessment, such as outcome scales, to identify needs and tailor the intensity of support offered. For example, individuals recognized as in greatest need during the assessment process could be prioritized to receive closer monitoring and support, which may aid in meeting the caregiver needs regarding professional support identified during the literature review.

After the initial assessment and development of a care plan, the individual awaiting transition and their care plan are to be reassessed at regular intervals and whenever the situation has changed, or as requested by the collaborative team. Three registered nurse stakeholders referred to the provincial guidelines mandating the use of the RAI-HC, which are described within the *RAI-HC Clinical Standards and "Best Practice" Guidelines* (BCMoH, 2016). These guidelines further describe the clinical care planning, ongoing monitoring, and reassessment that must occur. The continued evaluation and reassessment of a PWD is an important component of the nursing process, and is a means of developing responsive, evolving, and person-centred plans of care. However, although evaluation was an important recommendation within all of the identified best practice guidelines (Accreditation Canada, 2013; BCMoH, 2016; RNAO, 2014), stakeholders identified that in practice this was difficult to do due to competing demands.

During the stakeholder interviews, participants also identified a range of tools and resources that assisted them in the care planning process. For example, two case manager stakeholders identified that the *Long Term Care Home Access from Community to do List* (Interior Health Authority, n.d.) was a commonly used practice support tool which prompts health care professionals to partake in collaborative clinical reviews and care planning prior to exploring LTC admission, to ensure that the transition plan is developed in collaboration with the client and caregiver, and in accordance with provincial policies. Furthermore, this tool was reported to facilitate coordinated interdisciplinary care by involving other professionals in the process. One stakeholder specifically described the usefulness of the tool to ensure important aspects were not overlooked, such as providing information and resources to caregivers and communicating with PCPs, and tracking that preparations were in place for a smooth transition.

Once the initial transition plan has been created, the ongoing monitoring and support provided to individuals waiting for admission is not only supported by the above mentioned policies and tools, but by local processes and standard work available within the organization. These resources encourage collaborative, proactive, and client-centred approaches to care planning. A specific example of a practice employed and guided by a stakeholder's contextual knowledge of the challenges surrounding care transitions was provided by the participating PCP stakeholder. This PCP described her specific practice of meeting with caregivers and PWD approximately once every two weeks during the waiting period, due to the vulnerability of the situation and need to ensure adequate support is provided. These findings further echo the challenges surrounding caregiver coping, professional support, and the unpredictability of the waiting period identified in the literature review.

Variations in Practice. Although the policies and resources available for developing collaborative transition plans, such as provincial and health authority policies, the RAI-HC assessment, professional judgement, and encouraging caregiver collaboration are well established, the ease with which the care plan is created and shared among the interdisciplinary team, and the level of support provided to individuals and caregivers, was reported to be highly variable. These variability noted in the gap analysis corroborate the findings of the literature review, which identified caregiver perceptions of both inadequate and sufficient levels of professional support (Morgan et al., 2002). For example, one caregiver within the literature review sample described a situation where health care professionals were proactive and directly involved in communicating with family members and arranging care planning meetings, while within the same study home care staff reported needing to provide more support for caregivers (Morgan et al., 2002). Likewise, in a study of hospital discharge practices included within the integrative review, many caregivers reported negative experiences and insufficient professional support, while another caregiver was satisfied with the communication and information provided by health care professionals (Fitzgerald et al., 2011).

During the gap analysis stakeholder interviews, the practices and concerns identified varied greatly, which may be a reflection of the range of roles and experiences present among stakeholders. Registered nurse case managers were noted to focus on professional experience and assessment skills in the development of transition plans, while a PCP stakeholder focused greatly on the interdisciplinary collaboration that led to the development and adaption of transition plans. For example, one registered nurse stakeholder shared that common sense and professional judgement alerted her to potentially challenging and unsafe situations requiring advocacy on behalf of the caregiver and PWD. In this example, the registered nurse reported voicing her concern and then collaborating with the interdisciplinary team to create an alternative transition plan. A second registered nurse stakeholder reported relying on past experiences of supporting transitions to LTC, and felt this knowledge was helpful and appreciated by caregivers seeking guidance and suggestions. Conversely, a PCP stakeholder commented on the value of communicating frequently with not only caregivers, but other community-based professionals such as case managers, home care nurses, and specialists as needed. These findings reveal that health care professionals may rely on different resources and past experiences while providing professional support to caregivers, which may aid in understanding the variations in both the level of support provided and caregiver experiences noted in the literature review and gap analysis.

During the stakeholder interviews, it was noted that stakeholders without direct involvement in providing transitional care appeared to focus on policies and processes supporting transitional care, and difficulties in facilitating continuity. This finding highlights a potential disconnect in practice, where the concerns related to transitional care of decision makers may not align with those of direct care providers. Furthermore, challenges were noted in identifying which concerns or priorities needed to be addressed first in complex situations, which required and benefitted from an interdisciplinary approach. Caregiver stakeholders who provided feedback had differing experiences and focused on system navigation and advocating for their family member’s best interests. There was great variation in these stakeholders’ description of their participation in the development of plans and level of support received, ranging from very limited to sufficiently involved with frequent communication and input into the plan.

For example, one caregiver stakeholder felt they were not included in the development of a transition plan and was initially unaware of important details and care needs affecting their family member. This caregiver reported reaching out to their personal support network for assistance in learning how to navigate the system and advocate for their loved one, a situation that was repeatedly identified and explored within the captured literature in the integrative review (Mamier & Winslow, 2014). Conversely, another caregiver stakeholder expressed satisfaction with the level of support received and the quality and frequency of communication with the health care professional coordinating the LTC admission process. These examples suggest that although appropriate policies, procedures, and resources are in place to support transitional care, variations in practice remain apparent and directly affect the experiences and outcomes of caregivers and individuals during the waiting period.

Care transitions require individualized planning, support, and approaches, yet the current programs and services offered to PWD and their caregivers offer limited flexibility. An illustration of the challenges and variations apparent in the development of transition plans was provided by a registered nurse during the stakeholder interviews, who described particular difficulty in supporting some caregivers of PWD due to the task-oriented focus of the current home support program. Drawing upon an example of caring for persons with cognitive impairment who remain independent with ADLs, this stakeholder described the challenges of balancing support needs. For example, the stakeholder shared that while these particular clients may have some independence with some activities, frequent supervision throughout the day was still required. These needs were not well balanced with the task-oriented approach to home supports, which proved to be of limited assistance.

This situation described by a stakeholder led to challenges in creating an appropriate transition plan with professional supports during the waiting period, and may have contributed to the caregiver perceiving she was managing well and to subsequently decline a LTC admission when a bed became available. In this case the stakeholder described that a crisis situation followed, requiring the development of a new transition plan, and difficulties in coordinating and providing a sufficient level of support. This situation illustrates not only the unpredictability of transitions as discussed in the literature review, but also the complexities in developing and following transition plans, as individual and caregiver needs may frequently change and require varying levels of support and interdisciplinary involvement at different times. The changing needs of caregivers and PWD may further cause confusion or oversight due to a lack of clarity regarding how to respond and who to inform of the changes.

Interprofessional Collaboration and Continuity of Care. The collaboration that occurs among interdisciplinary teams in preparation for a transition to LTC was frequently discussed during stakeholder engagement. As part of this, numerous challenges related to the current format and utilization of community care plans for individuals waiting for LTC admission were identified. First, many stakeholders reflected that these electronic care plans were often specific to nursing, embedded within current electronic documentation systems, and not shared with PCPs, thereby rendering their utilization by other health care professionals very limited. Second, the care plan is based on the clinical assessment protocols (CAPs) generated from the RAI-HC, which guide further assessment and care planning (BCMoH, 2016). The care plan relies upon a series of clinical assessments and are often undertaken and developed without regular consultation of caregivers and are infrequently shared. Conversely, the development of a transition plan, which includes identifying an individual's priority level for admission, wishes, and the plan for accessing LTC, is frequently the subject of extensive discussion and planning, yet the information is not often recorded on the client care plan. This information is instead recorded in various locations, without a standardized process for all interdisciplinary team members to be informed of and access the transition plan. This raises concerns surrounding both informational and management continuity during the transition period, similarly to the concerns raised by participants within the captured studies of the integrative literature review regarding professional support during transitions in care.

Management continuity is a form of continuity of care, which is the patient's experience of care that is connected, coherent, and consistent with health needs and personal circumstances (Haggerty et al., 2013). More specifically, management continuity refers to the "consistent and coherent management by different clinicians through coordinated and timely delivery of complementary services" (Haggerty et al., 2013, p. 262). During the stakeholder interviews, transition planning was identified as an essential opportunity for collaboration and coordination, with stakeholders noting significant collaboration between different stakeholder groups, clients, and caregivers during their creation. This process includes collaboration between the caregiver, the interdisciplinary team, and PCPs, which may facilitate caregiver perceptions of care that is consistently and coherently managed by different clinicians (Haggerty et al., 2013). Much of the collaboration occurred informally through conversations and meetings, although formal processes, such as standard work and check lists, encourage and prompt communication and collaboration among professionals.

For example, a PCP stakeholder highlighted the important role of the informal communication that occurred with interdisciplinary team members due to the close proximity of their work environment, while a registered nurse stakeholder felt collaboration was facilitated during daily in-person huddles prior to their suspension during the coronavirus disease of 2019 (COVID-19) pandemic. This finding emphasizes the reliance of direct care providers on informal communication with other interdisciplinary team members in order to provide care that is connected and coherent (Haggerty et al., 2013) and to create responsive and need-specific transition plans. Conversely, a decision-maker stakeholder found checklists and standard work helpful in ensuring pertinent information was communicated between different settings, such as when an older adult with community home supports transitioned between hospital and community.

In addition to the stakeholder who reported concerns regarding impeded interdisciplinary collaboration during the COVID-19 pandemic, a second registered nurse stakeholder highlighted another issue related to the pandemic. This stakeholder described the value and benefit of respite and adult day services for some caregivers of PWD, and found it challenging to provide adequate support during the waiting period when these programs were suspended. In this situation, the stakeholder reported struggling to create an appropriate transition plan when the most beneficial supports were no longer available. Likewise, difficulties were noted by this registered nurse when caregivers were hesitant to accept in-person services and supports due to concerns related to the pandemic.

During one stakeholder interview, new initiatives around transitions in care were described, and which are linked to the primary care transformation in BC (BCMoH, 2020). Changes related to this work include widespread transformation across the health system to improve primary and community care, including transitions in home care and home health services. These initiatives include an opportunity to support care transitions through the development of specialized community service programs and collaborative community care plans. This stakeholder described how these care plans are intended to be created with input from the client, caregivers, and members of the interdisciplinary team, and which will replace the current nursing specific care plans in the near future. Health care professionals are encouraged to collaboratively develop the care plan with client-identified goals and to provide a written copy to the client and caregivers. The new approach to care planning is intended to shift the focus from an individual practitioner responsible for care planning, to utilizing a team-based approach.

As a component of the primary care transformation taking place within the Interior Health Authority, motivational interviewing techniques for health care professionals are being promoted as a means of enhancing collaborative care planning skills. Education is currently being delivered to community health care professionals across this region to support these initiatives, which was described by one stakeholder as a promising resource for facilitating greater collaboration. However, other stakeholders expressed frustration and challenges related to heavy workloads and insufficient human health resources to allot time in the day for educational workshops and training. This concern, regarding limitations of time and resources surrounding collaborative practice, was also reported by researchers exploring health care professional perspectives of transitional care for PWD and their caregivers (Kable et al., 2015).

Coordination of Care and Safety. Facilitating the coordination of care between settings and providers, and promoting the health and safety of the individual experiencing the transition is an important component of evidence-informed transitional care (RNAO, 2014). Coordination of care is related to integration of services and is delivered by providers or organizations (Haggerty et al., 2003, 2013). As previously described, authors within the literature review sample recommended coordination of care be improved during care transitions (Fitzgerald et al., 2011; Mockford et al., 2017), which may be facilitated through coordinators of care and services. For example, findings from one of the integrative literature review studies suggested that case management services may aid in improving coordination of care during the transition to LTC, facilitate advocacy for the caregiver and PWD, and lead to an increase in the use of professional supports (Morgan et al., 2002).

Coordinators of care and services may be case managers, PCPs, and caregivers who facilitate coordination of care through their longitudinal relationship with the individual, and role of facilitating communication between settings and providers. During the stakeholder interviews, the importance of these coordination roles was explored, with a specific emphasis on how these roles provide an opportunity for care providers to develop robust and collaborative relationships with PWD and caregivers. For example, case manager and PCP stakeholders discussed the relationships that frequently develop with individuals waiting for LTC and their caregivers, however, challenges were noted to arise when a relationship was not sufficiently developed, often due to staffing difficulties or barriers in accessing care. For example, both caregiver stakeholders who provided feedback reported difficulties related to relational and longitudinal continuity of care. One caregiver stakeholder had limited communication and trust with the coordinating health care professional, which led to feelings of stress and a lack of support and coordination. Another caregiver stakeholder expressed appreciation for the support and coordination of services provided by the health care professional, however, the sudden closure of the family physician's medical practice left the individual waiting for LTC without a physician and facing difficulties in completing required paperwork.

The caregiver stakeholder in this example expressed frustration with their loss of a provider and experienced difficulties in completing requirements of the admission preparation process. In this situation, the coordinating health care professional was essential in the process, however, the overall success of the transition still relied upon ongoing engagement from a PCP and the whole care team. These disconnects in care, described by the caregivers during the stakeholder interviews, mirrored the findings from some of the studies captured in the literature review (Fitzgerald et al., 2011; Mockford et al., 2017; Naylor et al., 2005). For example, a study by Mockford and colleagues (2017) found caregivers desire to have a known professional they can turn to for support and to coordinate care, while individuals may experience distressing emotional responses when they are unsure of what is happening and who to turn to for information (Naylor et al., 2005). These situations highlight the challenges and potential for poorer outcomes when therapeutic relationships have not been established and the whole care team does not work together in a coordinated manner.

In addition to facilitating the coordination of care, ensuring the safety of individuals during a care transition is a component of evidence-informed practice (RNAO, 2014). Within the context of waiting for LTC admission, participants in the stakeholder interviews frequently referred to safety and its importance in guiding care that reflects the best interests of individuals while avoiding harm. For example, one registered nurse stakeholder reported carefully considering the care needs of a PWD when planning to support the transition process. This stakeholder explained that if the care needs or behaviours were greater than what the available community care programs could manage, the situation would potentially be considered unsafe and an alternative transition plan acceptable to the interdisciplinary team would be created.

Considerations surrounding safety were similarly embedded into individual practice, professional judgement, and *Long-Term Care Access Guidelines* (BCMoH, 2019), which includes the notion of determining client prioritization criteria. While developing a transition plan for LTC admission, health care professionals and caregivers collaboratively determine the individual's needs, wishes, and risks of waiting for LTC admission. Provincial guidelines outline prioritization for access to LTC, with individuals assessed as at intolerable risk prioritized (BCMoH, 2019). These individuals often experience challenging situations that lead to the intolerable risk designation, such as by no longer having a caregiver or "living under dangerous conditions, including wandering, that cannot be mitigated" (BCMoH, 2019, p. 5).

As part of this gap analysis, all of the registered nurse stakeholders identified the intolerable risk designation as a necessary measure to facilitate rapid access to LTC in specific and challenging situations. These challenging situations requiring intolerable risk designation echo the theme unpredictability explored in the literature review. Conversely, a caregiver stakeholder who experienced significant challenges in supporting their family member with dementia while waiting for LTC admission and who expressed concerns with safety found the process was expedited only when they reached the point of no longer being able to cope. An additional example of how the safety of the individual awaiting LTC could be ensured was provided by a caregiver stakeholder who explained the challenges encountered when her mother fell and fractured her pelvis. For example, in this case, the older adult was admitted to hospital, but was unable to return home due to a significant decline in mobility. The adult was therefore admitted to a respite bed, prior to accessing LTC. This example highlights the unpredictable situation that unfolded, beginning with a crisis situation and resulting in multiple moves in order to find a temporary safe environment prior to transitioning into a permanent LTC home.

When considering the safety of individuals waiting for LTC, several participants from the stakeholder interviews referred to their assessment and care planning expertise, in conjunction with a thorough exploration of client and caregiver goals, in order to determine the risk designation and waiting list options. Safety plans while waiting for LTC admission were reported to be frequently created through caregiver and health care professional discussions and could be included within the care plan or communicated verbally depending on the unique circumstances and needs.

From the caregiver perspective, it emerged during stakeholder interviews that safety plans were not consistently created and shared with caregivers, which may relate to the unpredictability of transition and caregiver coping. For example, one caregiver stakeholder reported learning about a significant safety issue after an alarming incident occurred. In this case, the PWD was reported to have had an altercation with another resident in the individuals' supportive housing residence, which caused harm and the need for medical care for the other individual. This caregiver stakeholder expressed significant concern that the information had not been shared in a timely manner and was unsure of the exact implications of this event and how it affected the admission process. Furthermore, the caregiver reported being informed by health care professionals that the PWD did not meet criteria for an intolerable risk designation. This led to caregiver feelings of distress while being required to wait for a LTC bed offer in what the caregiver felt was an unsafe situation.

Evaluation. Evaluation of the effectiveness of transition planning was identified to be both a *Care Transitions* best practice guideline (RNAO, 2014), and a provincially mandated process (BCMoH, 2016). Although a review of transition plans are to occur periodically and when a change in condition occurs (BCMoH, 2016), stakeholders noted that evaluation was a challenge and often occurred through informal processes such as unscheduled telephone conversations with caregivers. Three registered nurse stakeholders and one PCP reported developing strong relationships with caregivers, who were instructed to contact the case manager or PCP if problems arose. However, due to time constraints, case manager stakeholders expressed challenges in proactively evaluating the transition plan prior to being contacted by a caregiver experiencing a difficulty. This finding reported by health care professionals was validated by a caregiver stakeholder who waited several months for a routine evaluation, prior to reaching out for assistance when the situation had significantly deteriorated. At this point the caregiver felt they were struggling to cope and was approaching their breaking point. The range of caregiver emotions and the presence of burden during the waiting period have been previously explored in the integrative literature review, with the gap analysis extending these findings and illustrating how evaluations that are not completed in a timely manner may leave caregivers struggling to cope without the professional support they need.

Although evaluation of caregiver coping and the suitability of transition plans were often described by stakeholders as being led by informal processes, one knowledge coordinator stakeholder identified that outcome scales contributed to a greater understanding of client and caregiver health status characteristics (BCMoH, 2016). The scales utilized may include: the Caregiver Strain Index (Sullivan, 2002); Changes in Health, End Stage disease, Signs and Symptoms (CHESS; Ogarek et al., 2018); and the Detection of Indicators and Vulnerabilities for Emergency Room Trips (DIVERT; Costa et al., 2015). This stakeholder reported that the utilization of outcome scales is not mandated provincially or within the Interior Health Authority, although some scales are generated upon completion of a RAI-HC assessment. Furthermore, the stakeholder described that changes in outcome scales over time aid in evaluating evolving situations, however, the familiarity, utilization, and decision-making related to the results of measurement scales is variable, and dependent upon each health care professional's independent practice. For example, the stakeholder shared an example of the Caregiver Strain Index (Sullivan, 2002), which was previously a required component of an application for LTC, and is now utilized based on individual health care professionals' practice.

In summary, evaluations emerged through stakeholder engagement as frequently occurring via informal and unscheduled communication. Although tools, such as outcome scales and the RAI-HC assessment, are available to facilitate thorough evaluations of caregiver coping and the condition of the PWD, they may be infrequently used or not employed during assessments. Furthermore, time constraints were reported by three registered nurse stakeholders as affecting their ability to complete proactive evaluations.

Education. Education emerged during the gap analysis as an important contributor to supporting caregivers and PWD during the transition period and has been examined in gap analyses in other health care settings (Golden et al., 2017; Lamb et al., 2020). Education was explored as both an influence on health care professional practices, and in preparing caregivers and PWD for the transition to LTC.

Educational resources that support transitional care planning were identified by a knowledge coordinator stakeholder and by thoroughly searching the Interior Health Authority intranet. Some educational resources are provided within new hire orientation and RAI-HC training for case managers, with ongoing support and resources further provided through an education department and internal resources found on the health authority intranet. These include presentations, videos, and webinars related to care planning and transitional care. Although care planning education and support is readily available for interested health care professionals, it is not a mandatory component of new hire training or ongoing professional development. Therefore, it is possible that inconsistent transition practices exist as a result of this lack of mandatory training and wide variability in available resources.

The provision of education to support transitions in care was noted to be beneficial to not only health care professionals but also caregivers. Stakeholders reported that providing caregiver education was an integral component of the transition planning process. For example, both case managers and PCPs reported incorporating education into encounters with the individual waiting for LTC and their caregiver, in order to provide resources on how to manage behavioural and psychological symptoms of dementia and to prepare for the actual move to LTC. Specifically, a PCP stakeholder described sharing information regarding the daily routines and care standards of the LTC facility the PWD was waiting for, in order to prepare caregivers, provide an opportunity for questions, and facilitate a smooth transition.

Overall, the insights gained during the stakeholder interviews identified many variations surrounding the development of collaborative transition plans, coordination of care and safety, evaluation, and educational practices and resources. These findings will be further explored in the following section.

Strengths, Weaknesses, Opportunities, and Threats

The aim of the SWOT analysis was to facilitate the development of recommendations and priorities and to guide future strategic decisions (Swysen et al., 2012). The principal findings of the SWOT analysis are presented in Figure 2, and are discussed below.

Strengths. Several strengths related to transitional care practices were discovered during the gap analysis. These include the extensive skill, planning, and collaboration that go into the development of transition plans, appropriate provincial policies and guidelines, health authority standardized processes, and the availability of educational resources and support. For these Kelowna-based stakeholders, these strengths contribute to a culture where collaborative care planning is encouraged, while monitoring the safety and respecting the wishes of the individual and caregiver waiting for LTC admission.

During the gap analysis, it was evident that collaboration occurred among multiple team members, including case managers, clients and caregivers, PCPs, social workers, allied health professionals, and management. These individuals frequently collaborate to develop appropriate transition plans. A culture of communication and team-work prevail, with stakeholders reporting that staff are encouraged and prompted to consult one another, the client, and caregiver, to discuss options and create the transition plan. For the stakeholders, there was a recognized value to working collaboratively to assess and plan for transitions to LTC in complex situations.

The organizational structure contributes to continuity of care, as each individual waiting for LTC has an assigned case manager. The case manager can consult with educators, community integrated care coordinators, managers, PCPs, and others for assistance with transition planning and problem solving. Other resources within the organization, such as educational materials and workshops, further support transitional care planning.

The gap analysis identified many appropriate and comprehensive policies, guidelines, and standardized processes within the Interior Health Authority that encourage the creation of transition plans, with processes available to encourage the safety of the individual waiting for LTC. These processes include the risk determination and waiting list options, with safety plans incorporated into the care plan as needed. Furthermore, all stakeholders recognized the importance of these practices in facilitating patient and family-centred coordinated care.

Weaknesses. Despite many strengths noted during the gap analysis, stakeholders identified some weaknesses related to internal factors presenting challenges to best practice in transitional care. These include the current format and utilization of the care plan, limited evaluation of transition plans, staff workloads and inconsistencies, and variations in individual practices. For example, care plans are not consistently utilized, and do not include a general overview of client and caregiver goals, where the transition plan could be incorporated. Additionally, care plans are currently nursing focused, created from the CAPs generated during the RAI-HC assessment, and are not often shared with the client, caregiver, or other members of the interdisciplinary team.

Although the periodic evaluation of transition plans is mandated, a general reliance on caregivers to contact professionals when difficulties are encountered prevails. This highlights the challenges related to staff workloads and the prioritization of urgent matters, with routine follow up and evaluations often left undone. One caregiver stakeholder alluded to this challenge, stating that an evaluation occurred three months later than mandated, after repeated phone calls and a specific request for follow-up. Staffing challenges also complicate the provision of transitional care, with vacancies in nursing positions creating difficulties in the continuity of care for some clients and caregivers without a regular case manager who is aware of their goals and unique situation.

Opportunities. Factors that are external to the health authority and present opportunities to improve transitional care practices include health care professional investment and the primary care transformation currently occurring within BC. Health care professionals are generally invested in providing holistic care, are empathetic to the challenges faced by clients and caregivers, and desire to provide the support and care these individuals require. This was echoed in the sentiments shared by stakeholders who were attentive to meeting needs, viewed interdisciplinary collaboration as essential, and expressed concern for caregivers in challenging situations.

The primary care transformation occurring in BC facilitates the development of primary care networks or integrated teams, based on the principles of team-based care and comprehensive services through patient medical homes and specialized community service programs (BCMoH, 2017, 2020; General Practice Services Committee, 2017). This transformation presents a unique opportunity to further develop interdisciplinary collaboration and information sharing, particularly between PCPs and other health care professionals supporting transitions to LTC. As a component of the primary care transformation, collaborative community care plans will replace the current nursing-focused care plan, with input and sharing encouraged from all professions involved in the individual's care. Client and caregiver priorities are a mandatory component to the care plan, and are easily located at the beginning of the care plan. Furthermore, health care professionals are encouraged to provide a copy for the client and caregiver. Existing structures for education are currently supporting the upcoming implementation of the collaborative community care plans and motivational interviewing techniques to improve skills in care planning.

Threats. Factors considered threats to best practice in transitional care include challenges related to the COVID-19 pandemic, and individual client and PCP relationships. The COVID-19 pandemic has contributed to client and caregiver concerns surrounding LTC admission and increased contacts that may occur during home visits. As a result, some clients and caregivers elect to decline bed offers and/or home support services. This may create situations where LTC admission is delayed and caregivers receive inadequate or reduced in-person support. Additionally, some services such as facility respite and adult day programs have been suspended throughout the province, resulting in fewer options available to support individuals and caregivers waiting for admission. Another COVID-19 related challenge relates to the remote work conditions of some health care professionals, who as a result experience fewer opportunities for informal communication and information sharing with colleagues.

Finally, a key threat identified during the SWOT analysis is the undeveloped relationship between some individuals waiting for LTC admission and their PCP, whom they see infrequently. Likewise, some older adults are unattached and do not have a PCP. Although PCPs frequently collaborate with case managers supporting transitional care, if the individual waiting for LTC is not well known by their PCP, optimal collaboration and communication is challenging.

Figure 2

Summary of SWOT Analysis

Strengths

- Appropriate policies, guidelines, and standard work
- Educational support and resources
- Collaborative practices
- Organizational structure which facilitates continuity of care through an assigned case manager

Weaknesses

- Format and utilization of care plan
- Limited evaluation of transition plans
- Staff workloads and inconsistencies
- Variations in practices and experiences

SWOT

Opportunities

- Health care professional investment
- Primary care transformation
  - Colaborative community care plans
  - Motivational interviewing

Threats

- COVID-19 pandemic
- Patient and primary care provider relationship

Key Gaps and Limitations

Extensive planning and collaboration occur during the development of a transition plan for an individual waiting for LTC admission. However, the ease and occurrence of how the plan is recorded, communicated, shared, and evaluated is variable. Conversely, relevant policies, guidelines, and processes are strongly focused on provincial mandates, with decisions related to the level and frequency of support provided to clients and caregivers largely dependent on individual health care professionals' judgement, practice, and expertise.

Although careful consideration was given to the methodology and data collection methods for the gap analysis, limitations were noted. Ten stakeholders contributed their perspectives of the transitional care provided to individuals waiting for LTC admission, and although health care professional stakeholder feedback became repetitive, an indicator of reaching saturation, it is possible that a greater number of stakeholders may have revealed further findings. Furthermore, the two caregiver stakeholders who provided feedback had significantly differing experiences receiving transitional care, which highlights the wide range of practices and complexity of individual situations.

Throughout the gap analysis stakeholder perspectives of how transitional care is provided and supported were obtained, yet many health care professionals wished to discuss their experiences of coordinating transitions to LTC and their reliance on professional experience and expertise. The aim of the gap analysis was to explore the current state of transitional care provision, and not health care professional experiences, therefore careful consideration of the practices, policies, structures, and education to support transitional care was prioritized as the focus. Further research and evaluation activities are needed to explore individual and caregiver perspectives of transitional care while waiting for LTC, particularly with regards to what supports are helpful and needed. The following chapter will present a discussion of the literature review and gap analysis findings, bringing forward recommendations for transitional care.

Chapter 4

Discussion

This work focused on the experiences of caregivers in transition, while waiting for the LTC admission of a PWD who experienced a hospital stay. This project included an integrative review of the literature, comprised of a diverse cohort of 17 papers, and a gap analysis to identify local strengths and opportunities for improvement in practices. A discussion of the key findings and recommendations will follow. The integrative review of the literature aimed to develop an in-depth exploration of the caregiver experience during a transition in care and informed the gap analysis methodology by seeking to identify if challenges and concerns reported in the captured literature also prevail within a local context. The review was undertaken by following strategies to enhance rigour, including forming the literature search question: What are the experiences of caregivers in transition when PWD are discharged from hospital to await admission to LTC? Developing the search strategy, conducting the search, and reading, analyzing, and reporting findings were subsequent steps (Whittemore & Knafl, 2005).

The search strategy resulted in a sample of 17 papers, including 14 qualitative, two mixed methods, and one quantitative paper. Seven themes and two subthemes were thoroughly presented in Chapter Two. The themes include phases, coping, professional support, relationships, unpredictability, finances, and rural. The two subthemes, related to phases, are the hospital experience and decision-making.

The analysis of the captured literature illustrated that when PWD transition from hospital to home and wait for LTC admission, their caregivers experience significant stress, burden, a lack of professional support, and unpredictability (Bauer, Fitzgerald, & Koch, 2011; Jamieson et al., 2016; Meiland et al., 2001; Morgan et al., 2002). These findings are discussed below, along with the recurrent theme of the LTC decision-making process and its implication for the interdisciplinary team supporting transitions in care. While the literature review identified a broad range of studies exploring either the caregiver experience of a transition from hospital to home for PWD, or waiting for LTC admission for the PWD, it is likely that caregivers experiencing both phenomena may encounter any combination of the emotions, challenges, and occurrences presented in the review findings. Both caregiver groups found the situation overwhelmingly stressful and burdensome (Fitzgerald et al., 2011; Jamieson et al., 2016; Meiland et al., 2001; Mockford et al., 2017; Morgan et al., 2002), a finding that was validated by Australian health care professionals involved in the transitional care of PWD (Kable et al., 2015). It is possible that caregivers consider these transitions particularly stressful and challenging due to the perceived lack of professional support provided and internal conflict regarding one’s caregiving role stemming from interpersonal relationships, expectations, identity, and values.

Building on the integrative literature review, the gap analysis sought to explore the perspectives of key stakeholders and to identify current practices and gaps. As part of the gap analysis, a convenience and snowball sample of 10 stakeholders were approached to identify how transitional care is provided in the Central Okanagan local health area, within the Interior Health Authority region. The gap analysis was informed by the literature review findings, which identified several concerns and challenges in providing transitional care. Several findings from the captured literature were corroborated by the gap analysis, including concerns surrounding continuity and coordination of care, collaboration with caregivers, and the provision of professional support. In addition to validating these challenges, strengths and opportunities in local transitional care practices were also identified. The literature review and gap analysis findings are integrated and discussed below, based on the key themes identified within the literature review.

Phases

An unexpected finding of the literature review was the importance that caregivers placed on various phases of the transition (Caldwell et al., 2014; Duncan, 1992; Jamieson et al., 2016; Kraijo et al., 2015; Macmillan, 2016; Shyu, 2000; Strang et al., 2006). Two significant phases were identified, the hospital experience and decision-making, which are discussed below.

The Hospital Experience

Caregivers' experience of the care received in hospital by the PWD, along with the related communication and discharge planning, had a profound effect on caregivers and their perceived ability to continue caregiving once back at home. Caregivers within the literature review sample appeared unable to distinguish the care experience in hospital from the transition home (Jamieson et al., 2016). For example, the hospital experience was linked to caregiver perceptions of the quality of transitional care and health care professional inaptitude, along with the caregiver's ability to adequately provide care for the PWD at home (Bauer, Fitzgerald, Koch, et al., 2011; Jamieson et al., 2016). It is possible that failures to maintain the regular routines and function of the PWD in hospital, and to adequately plan for discharge with caregivers, influence the caregiver experience and may increase the effort required to safely care for the PWD once home. The literature review findings related to the effects of the hospital experience were reinforced in a study by Kable and colleagues (2015), with health care professionals who participated in focus groups sharing perspectives on discharge planning and transitional care for PWD and their caregivers. These health care professionals found that failures in the delivery of services to PWD, including the use of physical and chemical restraints in hospital, had a negative impact on the transitional care provided in the community (Kable et al., 2015).

The findings of this study were consistent with the reflections of one of the gap analysis caregiver stakeholders who recalled the stress of expectations around caregiving responsibilities during the waiting period for LTC. For example, this stakeholder considered her mother's hospital admission as a step towards LTC, as opposed to a separate episode of care. When recalling these experiences, this stakeholder participant reported being negatively impacted by the attempts and suggestions of health care professionals to take her mother home with high care and equipment needs.

These observations from both the literature and gap analysis suggest that what may initially appear as a specific phase for some, such as the hospital experience or discharge process, is likely part of a larger transition phase for caregivers who are experiencing varying demands and pressures as their ability to cope and provide care fluctuates over time and with changes in the caregiving situation. Health care professionals supporting individuals prior to and during a transition in care must be aware that their interactions with caregivers and PWD influence not only the perceived quality of care, but also the caregiver's ability to continue providing care at home. Transitions in care are not defined by set episodes of care in specific locations, and as such health care professionals must seek to support and explore the complete journey of care and individual experiences.

Decision-Making

The decision-making process of deciding upon LTC was frequently discussed within the studies captured in the literature review. Within the captured literature, many examples were found that described the uncertainty experienced when considering a transition to LTC (Mamier & Winslow, 2014; Strang et al., 2006), as the process was frequently revisited as caregivers made decisions about whether and when they would accept a bed offer (Caldwell et al., 2014; Kraijo et al., 2015). At this stage, caregivers encountered many decision points during the waiting period and frequently reevaluated their decision to seek LTC admission (Caldwell et al., 2014; Mamier & Winslow, 2014). The decision to seek LTC for a relative has been described as "the most difficult care decision" (Caron et al., 2006, p. 194) for caregivers, who may not feel adequately supported during the decision-making process. This may be due to health care professional assumptions that the decision-making process is linear and uncomplicated. Conversely, the decision-making process was noted to be of utmost importance to caregivers, who frequently doubted or struggled with their decision, and felt stuck in the process (Mamier & Winslow, 2014). The uncertainty described within the literature should be recognized as an integral part of the transition process that professionals may see as linear, yet which does not cease once the initial decision has been made.

The uncertainty of transition was also identified during the gap analysis, with stakeholders explicitly recognizing the challenging nature of the decision-making period. For example, one caregiver stakeholder discussed this challenge during the gap analysis, explaining that it was difficult to make decisions about her preferred facilities without input from the individual who would be transitioning there. This input was challenging to obtain due to the cognitive functioning of the PWD and an inability to visit and view potential LTC facilities during the COVID-19 pandemic, which led to the caregiver making the decision in isolation. Likewise, a case manager stakeholder noted difficulties in supporting caregivers' decision-making process, with some caregivers' initially seeking admission for their family member and then declining the offer when a bed became available. These stakeholder experiences highlight the disconnect in practice, with caregivers and health care professionals potentially believing the decision-making process will be straightforward, only to find that the decision is very difficult with doubts surfacing and challenges apparent in selecting the location and timing of admission.

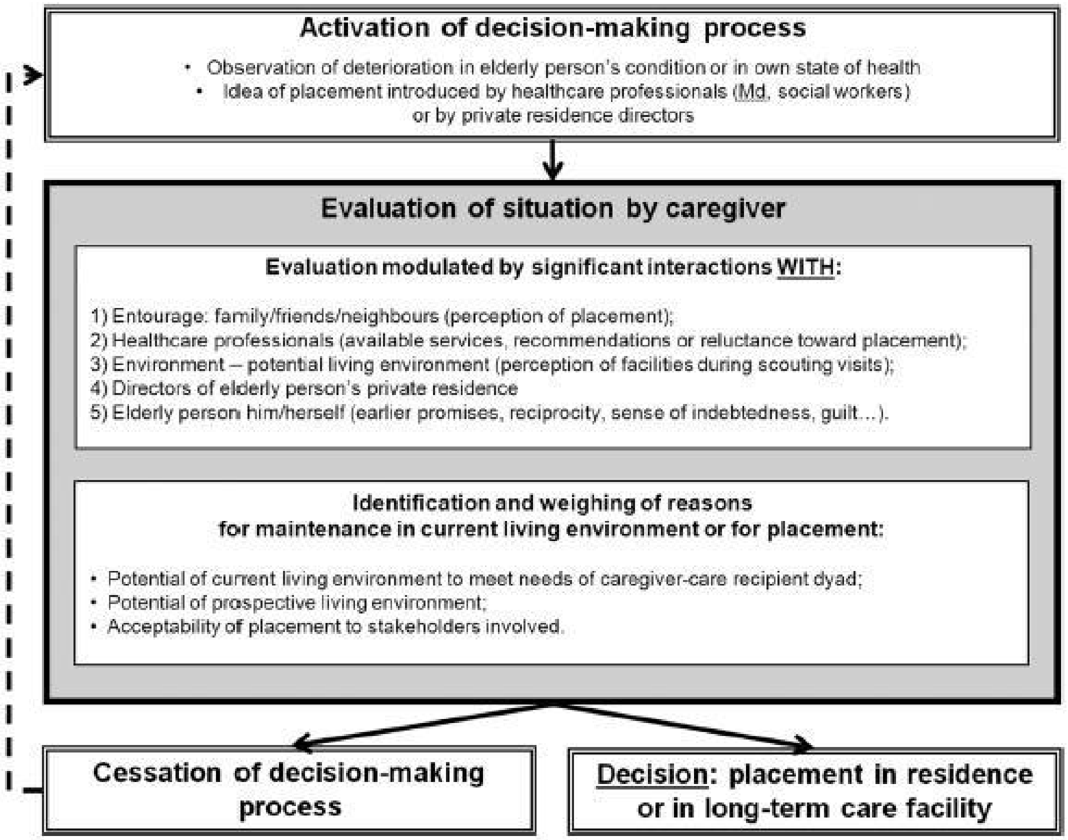
The literature review findings and gap analysis feedback reinforce the need for improved supports during the transition period. An existing model developed by Ducharme and colleagues (2012) explores a component of the transition process and can provide valuable insights on how to advance the support of PWD and their caregivers during this time. This model may be useful in directing care by bringing attention to the influencing factors and complexity of the process, in turn guiding health care professional thinking. The uncertainty and challenges identified in the literature review and gap analysis support the use of a model to highlight the many components of decision-making and to guide health care professional reflection, planning, and support.

Opportunities to support caregivers of cognitively impaired older adults during the LTC decision-making process have been identified and explored by Canadian researchers (Caron et al., 2006; Ducharme et al., 2012). In a grounded theory study, researchers developed a theoretical model based on caregiver experiences, and which explored the decision-making process and the relationships between influencing factors (Ducharme et al., 2012). Once the LTC decision-making process had been activated, researchers discovered that caregivers undertook an evaluation of the situation, influenced by interactions with their entourage, health care professionals, the older adult, the potential new living environment, and directors of the older adult's residence. This theoretical model (see Figure 3) may be beneficial in practice by informing thinking and reflection of how health care professional interactions influence the LTC decision-making process.

In the evaluation of the situation within the theoretical model (Ducharme et al., 2012), consideration was also given by caregivers to the reasons for maintaining the current living environment or for admitting the relative in LTC. This consideration took into account the needs of the PWD and the caregiver, the ability of the proposed living environment to manage the needs of the PWD, and the acceptability of LTC to all those involved. The LTC decision was not necessarily dependent on the number of reasons why the PWD may need the care, or should be admitted, but instead on the relative importance of these reasons and of the acceptability of admission to those involved. The outcome of the decision-making process resulted in cessation of the process, with or without reactivation at a later time, or admission in LTC. Ducharme and colleagues (2012) stated that the process is complex and nonlinear, an observation in accordance with the findings of this review and gap analysis. For example, within the literature review sample, authors explored situations where families struggled with decisions surrounding admission location and timing, or ultimately declined a bed offer when the PWD had been registered on a waiting list (Caldwell et al., 2014). Likewise, during the gap analysis both a caregiver and case manager stakeholder highlighted the challenges of making decisions related to the timing and location of LTC admission.

Figure 3

Theoretical Model of the Decision-Making Process



Note. Theoretical model of the decision-making process of family caregivers regarding placement of a cognitively impaired relative. From "Decision-Making Process of Family Caregivers Regarding Placement of a Cognitively Impaired Elderly Relative," by F. Ducharme, M. Couture, and J. Lamontagne, 2012, *Home Health Care Services Quarterly*, *31*(3), p. 204 (https://doi.org/10.1080/01621424.2012.681572). Copyright 2012 by Taylor & Frances Group. Reprinted with permission.

The theoretical model developed by Ducharme and colleagues (2012) identified and considered the influencing factors when caregivers contemplate LTC admission for a relative with dementia and suggests why the decision-making process may cease or result in admission regardless of the perceived need. For some, admission may simply be perceived as unacceptable, due to caregiver guilt or opposition from the PWD, and the decision-making process may stop due to the importance placed on the acceptability of LTC admission. This model may be utilized to inform health care professionals of the pivotal role they may play in introducing and supporting individuals during the decision-making process. The influencing factors to the decision-making process can be explored with caregivers, to help clearly identify and reflect upon the appropriateness of admission and the importance of the various factors and decisions for caregivers.

Health care professionals' interactions with caregivers during the decision-making process have been found to influence the complex process underway (Caron et al., 2006). Many caregivers have felt unsupported during the decision-making process and during a transition to LTC; health care professionals' knowledge of the complex factors involved in the process and their own influence on the evaluation of the situation may be beneficial and aid in providing support during this transition. In situations where health care professional interactions were considered negative, caregivers were found to be dissatisfied with services, had increased burden, and felt less apt to continue providing care (Caron et al., 2006). These findings were reported by a caregiver stakeholder who waited several months for a routine assessment and found the relationship and communication with the coordinating health care professional challenging. In this situation the caregiver ultimately relied upon their informal network for support and assistance in decision-making, a scenario also reported within one of the literature review studies (Mamier & Winslow, 2014). These individual experiences, where caregivers from both within the literature review sample and gap analysis faced challenging decisions and relied on informal resources for support, suggests that when health care professional interactions are negatively viewed caregivers may strongly rely on informal resources. Health care professionals should be aware of not only how their interactions may influence caregiver reliance on informal resources, but also that neither formal nor informal resources may fully meet caregivers' fluctuating needs.

In contrast to health care professional interactions that caregivers viewed negatively, when the interactions were viewed as positive by caregivers, many felt they had a greater ability to continue caregiving (Caron et al., 2006). Health care professionals' interactions with caregivers during the decision-making process therefore appear to influence the caregiver's coping ability and their evaluation of the situation. Health care professionals can not only introduce the idea of LTC admission that activates the decision-making process, but their interactions with caregivers may influence coping and the evaluation of the situation resulting in admission at a time that is suitable and not arising out of crisis.

The theoretical model developed by Ducharme et al. (2012) may be of use in practice, not only through creating awareness of the factors involved in this complex decision-making process, but also through the:

> development of clinical tools to sensitize health care professionals both to the multiple factors involved in the process that family caregivers go through when deciding whether to place a cognitively impaired relative in a new living environment, and to the key support role that they can play during this difficult process. (p. 215)

Health care professionals have an important role in supporting the decision-making process, yet this appears to be a frequently overlooked component of the transition to LTC. Future tools and processes may aid in bridging the gap and are needed to facilitate decision-making prior to reaching a crisis situation. These may include procedures and/or guidelines to introduce and support the decision-making process in a timely and comprehensive manner. For example, health care professionals could be encouraged to meet with caregivers after a diagnosis of dementia or when coordinating the care and services for PWD in the community in order to discuss future care planning. By proactively discussing and reviewing the current and potential future needs of PWD, caregivers would be aware of the processes related to LTC admission and would begin an early evaluation of the situation, with a health care professional able to provide support and insights.

Caregiver Coping and Emotions

The stress and burden experienced by many caregivers in transition varied by situation, time, and in response to the individual resources available, including financial resources and informal support networks. When examining the captured studies from the integrative literature review, there was a predominance of negative experiences, with frustration and stress being commonly reported. Similarly, one of the gap analysis caregiver stakeholders reported great frustration and difficulties in coping during the transition to LTC. Overall, this suggests that there may be benefits in providing opportunities for caregivers and others to freely express their circumstances and challenges encountered during the transition period. For example, an opportunity exists for health care professionals to enquire about caregiver emotions and experiences during encounters and evaluations. These encounters are an occasion for health care professionals to provide support and consider other programs, interventions, or referrals that may be needed in order to meet caregiver needs. This could include referrals to support groups, encouraging caregivers to connect regularly with their PCP, and connecting with the primary care network's specialized community services programs for frail older adults. These actions may aid in connecting the caregiver with additional supports and resources, and in expanding the interdisciplinary team to individuals with specific expertise in supporting frail community living older adults.

The point when caregivers felt ready to pursue LTC for a PWD was identified within the literature review as being dependent upon their coping abilities, and was often reported to be at a time where caregivers were often faced with triggers, crises, feelings of being out of control, and reaching one's personal limits. If caregiver experiences are not addressed and supported prior to reaching this point, a crisis or precipitating event may occur, which in turn could accentuate guilt, grief, and stress. In addition, if the crisis or factors contributing to limited coping mechanisms subside, the caregiver may doubt the initial LTC decision and experience further emotional struggles related to the changing situation and internal conflict of how to proceed.

The relationship between a caregiver and PWD is complex during transitions and may be further complicated by feelings of codependency. It is well known that PWD may require care and assistance from caregivers, however, less is understood concerning how caregivers rely on PWD and what the influence on caregiver identity may be. The complexity of the relationship and situation may be further accentuated when issues of codependency are not addressed, which can lead to caregiver emotional struggles and hesitation in giving up a direct caregiving role during the transition. Similar experiences have been noted with spouses leaving abusive relationships. For example, women in abusive relationships may hesitate to leave their spouse for what would be an unknown situation and social barriers related to stigmatization and embarrassment over the situation (Haeseler, 2013). As such, considering the complexity of the relationship and emotional impacts of changing health and needs is important.

The challenge of navigating the transition period has also been described in a meta-ethnographic study of caregivers' experiences in relinquishing the care of a PWD to a LTC facility (Graneheim et al., 2014). In this study, researchers compared the process to a crisis, beginning when caregivers reached a turning point and had to make a decision, which led to coping with their choice and adjusting. Furthermore, some caregivers felt ashamed of the decision and lack of their ability to continue caregiving at home, while others distanced themselves from the decision-making process and perceived the LTC decision to have been made by health care professionals. It is possible that this justification may serve as a coping mechanism for caregivers wishing to distance themselves from the stress and guilt involved in determining the turning point for pursuing LTC.

During the gap analysis, stakeholders discussed several concerns surrounding caregiver coping and emotions. For example, health care professional stakeholders identified challenges in completing routine evaluations of caregivers coping and emotional responses, transition plans, and the condition of the PWD in a timely manner, and often relied upon caregivers to reach out when facing challenges. This highlights the significant disconnect in practice surrounding professional support and raises important questions about how caregivers can be proactively supported during transitions in care if evaluations to monitor their emotional responses and coping mechanisms are not completed. Furthermore, one caregiver stakeholder who expressed satisfaction with the quality of communication with the coordinating health care professional reported speaking frequently with the case manager and did not experience significant distress or challenges in coping. These findings suggest that frequent communication with a health care professional who has developed a relationship with the caregiver and PWD may improve caregiver experiences and facilitate an appropriate level of support by frequently evaluating the situation and responding appropriately. Health care professionals who know the caregiver and PWD should create plans for evaluation and frequent communication based on the unique and evolving needs of individuals.

The literature review and gap analysis findings have identified that caregivers often experience significant stress and burden during the transition to LTC. The decision to pursue the LTC admission of a loved one is partially dependent on individual caregiver coping mechanisms, triggers, crises, and feelings of reaching one's personal limits. The complexity of the caregiving relationship may further complicate the transition period, as feelings of codependency may lead to caregiver hesitation to make significant decisions and changes. Further research is needed to identify caregiver experiences and emotions during these challenging transition situations. In light of the multitude of complex situations and range of caregiver emotions identified in the literature review and gap analysis, health care professionals must be cognizant of caregiver distress and the need to regularly evaluate caregiver coping mechanisms, emotional responses, and the suitability of transition plans.

Professional Support

Within the literature captured as part of the integrative review, it was noted that professional support was highly valued by caregivers and was not limited solely to the need for formal supports. Acknowledgement and validation of the caregiver's role appeared to be of significant importance to caregivers, yet many studies focused on the provision of home support services when discussing professional support. Although professional support was identified as inadequate at times in the literature review, researchers have found that health care professionals put forth effort to provide adequate transitional care and support, yet substantial system barriers and pressures often left them struggling to provide the level of support they deemed necessary (Kable et al., 2015). Concerns surrounding the availability and restrictive accessibility criteria of services have also been discussed in the research by Kable and colleagues (2015), who found that long waits and limited service hours left PWD and their caregivers managing on their own much of the time. Without adequate community supports, PWD are at risk of unnecessary or premature LTC admission, while caregivers may provide greater assistance and experience increased distress (National Institute on Ageing, 2019).

In addition to the important role of professional supports during a transition in care, the need for continuity of care was identified within the literature review findings. One study recommended a coordinator of services, such as a family physician, be identified for this purpose (Mockford et al., 2017). Although a PCP may be an ideal coordinator of services due to the longitudinal nature of the patient-provider relationship, many PCPs may not have the required availability and experience with community supports to appropriately coordinate the care. This may lead to fragmented care, a serious issue which can have negative implications for individuals due to discontinuity in communication between hospital and community-based providers (Neiterman et al., 2015). Fragmented care can result in individuals not recognizing when to seek care, community-based providers who are not aware of hospital established treatment and follow-up care requirements, and individuals with limited understanding of “who is doing what” (Neiterman et al., 2015, p. 95).

Collaborating with caregivers during periods of transition is a well-accepted recommendation in the transitional care literature and relevant guidelines (Ray et al., 2015; RNAO, 2014). Of note, the need for partnership in the care process has been previously emphasized. For example, Strang and colleagues (2006) discussed the need for caregivers to be considered true partners in all aspects of care, and not merely helpers. Ensuring that caregivers have the opportunity to share their expertise, insights, contribute to the care plan, and determine the direction of care to be taken may help to create a true partnership between caregivers and clinicians, both before and after admission (Strang et al., 2006). Similarly, one caregiver stakeholder in the gap analysis reflected their desire to be a true partner after feeling left out of the planning process and learning that important information had not been shared by the health care team. This caregiver expressed wanting to be involved in care planning and wished for timely evaluations in order to detect changes in the condition of the PWD.

Health care professionals must therefore be cautious to avoid care planning without caregiver input, strive to frequently communicate with caregivers, and complete evaluations in a timely manner. However, considering caregivers as true partners extends beyond collaborating and care planning with caregivers in individual circumstances. If health care professionals are to strive for partnerships with caregivers and other community members, their input and voices must be incorporated into local program planning and service delivery. One way of facilitating this is by including caregivers and patients in research and engagement activities, with assistance from the Patient Voices Network or BC Support Unit, in order to improve health care in BC (BC Patient Safety & Quality Council, n.d.; BC Support Unit, n.d.).

Gap Analysis Considerations

The use of services, such as home support services to assist with practical care needs, also emerged as a significant component of transitional care in the gap analysis. A noted challenge was the ability to access appropriate and helpful supports for PWD who have limited functional impairments and are able to maintain independence in most ADLs. This was described as a difficulty by one registered nurse stakeholder, who noted that the task-oriented focus of home support services may not meet the needs of some caregivers and PWD. This stakeholder observation corroborates other transitional care research, where caregivers reported struggling to access appropriate services and at times found the care provided did not fit their needs (Jamieson et al., 2016; Mockford et al., 2017).

The challenge of providing individualized supports to meet caregiver and PWD needs was further reported by several stakeholders during the gap analysis. Four registered nurse stakeholders discussed challenges in providing support due to competing demands and a focus on managing crises, similarly to the finding reported by Kable and colleagues (2015) which discussed the system barriers health care professionals face when providing transitional care. These barriers include a pressure to discharge early, inadequate discharge summaries, and problems with medication orders. Although some barriers may be difficult for individual health care professionals to resolve on their own, providing support, acknowledgement, and including caregivers in decision-making are strategies that individual practitioners can employ to meet caregiver and PWD needs. In addition to the ability to influence individual caregiver and PWD experiences through timely and sensitive interactions, health care professionals also have a valuable role to play in influencing the health care system and advocating for evidence-informed practices. Health care professionals must use their voice to participate in committees, working groups, and other initiatives to influence change.

In summary, both the integrative literature review and gap analysis findings identified that professional support is highly valued, although a strong focus remains on support with practical needs despite caregivers wish to be seen, acknowledged, and assisted with the broader issues. Additionally, some caregivers and PWD found that supports were not adapted to their individual requirements. A further issue noted is that health care professionals may face challenges in providing timely and appropriate support due to system barriers and an emphasis on addressing crises and urgent matters prior to routine support and evaluations.

In order to ensure professional support can meet caregiver needs, future research regarding what kind of support is particularly helpful during specific phases of the transition is needed, along with a greater understanding of caregiver perceptions of being seen and emotionally supported by professionals. Health care professionals supporting caregivers in transition must carefully consider not only individual needs and the availability of services, but also their ability to provide support and how to proceed if the available resources are not acceptable or sufficient. This may include encouraging the caregiver to connect with informal support networks, becoming a patient and caregiver advocate, and finding creative solutions to the challenges encountered. For example, if a PWD or caregiver requires a service that is not provided within the *Home and Community Care Policy* (BCMoH, 2012-2020), health care professionals can explore resources outside the health system or exceptions to policy, which can be granted "in client specific circumstances, based on assessed need" (Section 1.A, Exceptions to Policy). Resources outside of the health system may include friendly visitation, volunteer shopping, snow removal, house cleaning, and other services available through the Better at Home program (United Way Southern Interior BC, n.d.), faith groups, and other community organizations.

An important component of transitional care is to recognize the risks of fragmented care and to employ strategies to facilitate a smooth and well supported transition (RNAO, 2014). This includes increasing the communication between hospital, primary care, and community settings (Jamieson et al., 2016), through systems and processes for knowledge and information sharing, coordinators of care and services, and increased caregiver participation. Examples of how information and knowledge may be shared include using audio-visual technology to provide discharge and diagnosis related information to caregivers and facilitating the transfer of information between settings through information technology, person-based, or written methods (Newnham et al., 2017). Newnham and colleagues (2017) have reported that physicians prefer computer-generated discharge summaries due their structured and concise format, which may facilitate the inclusion of relevant information and time efficiency in their completion.

The proposed strategies to increase communication and coordination of care should be incorporated into all transitions, including discharge planning for transitions from hospital to home, by integrating caregivers as true partners and involving interdisciplinary team members such as PCPs and community health care professionals. The primary care transformation currently underway in BC is a promising initiative that will further facilitate interdisciplinary collaboration and continuity of care through its model of team-based care, comprehensive service delivery, and ability to establish relational continuity with health care providers.

Relationships, Identity, and Values

The caregiving relationship, along with the influence of other family members, gender, and cultural values, were identified in the literature review as being influential in the transition experience (Caldwell et al., 2014; Mamier & Winslow, 2014; Strang et al., 2006). For example, Strang and colleagues (2006) described the caregiver-PWD relationship as “fundamental to understanding the caregiver experience of waiting for placement and the final transition to long-term care” (p. 39), while caregivers attempted “to remain in sync” (p. 40) with the PWD. Similarly, Caron and Bowers (2003) described this process as trying to protect the relationship as it was in the past, while managing the physical aspects of caregiving and coming to terms with the transition. Based on the insights generated from the review and gap analysis, this may explain the hesitancy of some caregivers to make decisions related to the LTC admission of their loved one, or reevaluate their initial decision, as they struggle with attempting to protect the relationship and let go of the former caregiving situation.

Within the captured literature as part of the integrative review, it was noted that the majority of caregivers were female, however, the results were not reported by gender or caregiving relationship, such as spouse or child (Caldwell et al., 2014; Meiland et al., 2001; Strang et al., 2006). Likewise, all stakeholders in the gap analysis were female. Graneheim and colleagues (2014) have reported that spouses experience greater challenges in caregiving for PWD in comparison to other caregivers, with an increased risk of grief and loneliness. The caregiving experience may also differ by gender, necessitating gender and relationship focused analyses of caregiver experiences in future research.

During the gap analysis, issues surrounding caregiver experience by gender or role were not raised, however, health care professionals must be aware of the influence of gender and relationships on these individuals’ experiences. Understanding that caregiver burden may be greater among spouses (Graneheim et al., 2014; Meiland et al., 2001), that some caregivers may experience turmoil surrounding their identify as a wife during the transition period (Mamier & Winslow, 2014), and that some children may feel obligated to continuing in their caregiving role (Caldwell et al., 2014) are important considerations for health care professionals to be aware of while supporting caregivers. Appreciating these dynamics through health care professional education, research, and the dissemination of this work may aid in creating awareness that can lead to increased sensitivity and support of the role transitions underway.

Unpredictability

The unpredictable nature of the transition situations were reported within both the literature review and the gap analysis. For example, the integrative literature review findings identified that many PWD experienced multiple moves between hospital, home, and respite prior to LTC admission, along with the notion that a crisis or change in the caregiving situation could become a tipping point where the situation would no longer be tenable (Chene, 2006; Mamier & Winslow, 2014; Morgan et al., 2002). Likewise, both a caregiver and registered nurse stakeholder identified situations during the gap analysis where the PWD was admitted to hospital and a respite facility prior to LTC admission. These admissions were described by the stakeholders as challenging yet necessary due to the decline in condition of the PWD, and highlight the importance of ensuring adequate coordination and continuity of care when multiple transitions occur between settings.

In addition to recognizing the unpredictability of transition situations, it is important to consider how caregivers' coping abilities may influence the outcome of the situation. Based on the insights gained from the literature review and gap analysis, caregivers who are struggling to cope may possibly be at greater risk of unexpected changes in transition plans or outcomes. Health care professionals can utilize their knowledge of transition outcomes and experiences to collaboratively create transition plans with caregivers, while acknowledging the unpredictable nature of the situation and the possibility that plans may need to be adapted dependent upon external factors and coping mechanisms. While many crises and events may not be preventable, health care professionals should prepare caregivers for the possibility that the situation may suddenly change, which may facilitate caregiver coping and reduce distress if such an event occurs.

Finances

The role of finances during a transition in care was briefly explored within the transitional care literature captured in the integrative review. Morgan and colleagues (2002) explained that some individuals in rural Saskatchewan faced financial barriers to accessing services or were reluctant to pay due to frugality, however the effect of this on the caregiving situation and an eventual transition to LTC was not explored. Other research has identified that an individual's financial situation can be a reason for delaying LTC admission (Gaugler et al., 2003), although this finding may not be transferable to settings where LTC is subsidized. The Office of the Seniors Advocate (2019b) explained in the report *Home Support . . . We Can do Better* that home support services are unaffordable for many older adults in BC, which can lead to financially incentivizing LTC in some situations. Although stakeholders did not explore concerns surrounding the role of finances during the gap analysis, attention to the possibility of financial issues may help health care professionals identify caregiver needs and areas requiring support.

A further challenge I have observed in professional practice is situations where caregivers and PWD are hesitant to utilize services or make plans for LTC admission due to the financial contribution required, yet interestingly this phenomenon was not well explored within the captured literature. Likewise, older adults who live with a spouse may experience financial difficulties when their income is divided between paying for subsidized LTC for one spouse, while the other maintains a separate residence. Further research is needed to better understand the role of finances related to the utilization of community services and LTC in BC, and the caregiver experience.

Rural

Within the literature review sample, Morgan and colleagues (2002) reported that rural cultural values contributed to “social isolation and guilt about accepting help with caregiving” (p. 1141). Despite these challenges, other researchers have reported several coping strategies of rural caregivers, with findings identifying a strong reliance on informal social support, self-care strategies, and faith, while also highlighting many positive caregiving aspects (Branger et al., 2016). Although rural caregivers experience challenging situations and barriers to service use (Morgan et al., 2002), it is possible that they may also possess unique strengths and coping strategies related to rural values, such as strong social networks and faith.

Rural caregiving has not been studied as widely as urban caregiving (Branger et al., 2016). Researchers have reported that rural caregivers experience a greater financial impact from caregiving than urban counterparts (Ehrlich et al., 2015), while also receiving less support from informal networks and formal services due to the limited availability of resources in rural communities (Branger et al., 2016). Furthermore, the financial impact of caregiving may be greater for rural caregivers due to lower income in these communities and a predominance of female caregivers, which raises the possibility that financial concerns could also be related to gender issues (Ehrlich et al., 2015).

Concerns related to rural caregiving were not discussed by stakeholders during the gap analysis, however, health care professionals must be aware that not all services discussed in the gap analysis may be available in rural communities. For example, LTC facilities may be situated outside of rural communities, with some individuals required to leave their home community and family to receive the care they need. This may in turn influence decision-making, caregiver role, finances, and continuity of care if providers also change. Indigenous caregivers may also experience an additional layer of complexity in navigating services and agencies, with both a regional health authority and the First Nations Health Authority involved in providing care and service. Furthermore, Indigenous persons may have an increased hesitancy to seek help and interact with the health care system due to concerns of systematic racism and discrimination on behalf of health care professionals (Turpel-Lafond, 2020). These individuals may delay or avoid seeking care for themselves and the PWD, potentially leading to poorer outcomes including increased burden and difficulties coping.

Gap Analysis of Transitional Care Practices

Several of the findings from the gap analysis were discussed in relation to the literature review themes, with additional components explored in the following section. These include the many strengths in current transitional care practices noted within the Interior Health Authority during the gap analysis, along with the challenges that became apparent and which have the potential to contribute to the fragmented care, suboptimal experiences, and poor outcomes that are prevalent in the literature. Principal challenges were noted to be related to continuity of care, recording and sharing of the care and transition plans, and evaluating its effectiveness and caregiver coping. Key barriers to being able to succeed in these areas include the involvement of several different organizations and programs without shared means of communication and documentation, a nursing focused care plan, and workloads resulting in a focus of crisis management.

Ensuring appropriate and timely communication and continuity of care between providers and settings, such as nurses, allied health members, PCPs, and acute care staff can be challenging as individuals travel through the health system and interact with multiple professionals. This is because many settings and professionals may employ different practices and utilize different resources, programs, or processes without established models or processes for information sharing. For example, individuals waiting for LTC admission in the community currently have a nursing specific care plan, and if the individual experiences an acute episode requiring hospitalization, an acute care plan is created. These care plans may also be in addition to other goals or plans created by PCPs and other health and social programs. Although processes for information sharing exist, the fact that individuals may have multiple location-based care plans creates barriers to the continuity of care. Conversely, both case managers and PCPs support individuals during their transition to LTC, however, effective communication and information sharing can be difficult when the care provided spans not only physical settings but also organizations and individuals with differing means and practices.

Research by Haggerty and colleagues (2013) has explored the patient experience of continuity of care when multiple clinicians are seen, revealing that continuity is expressed through feelings of security, confidence, safety, and support. This is in contrast to health care professionals' experience of continuity of care being seamless, smooth, or uninterrupted. Individuals were found to assume that their care was coordinated and providers shared information effectively, unless problems were encountered or individuals experienced feelings of uncertainty and mistrust, which could arise with conflicting messaging or lack of awareness of treatment plans. Haggerty and colleagues also reported that "clinicians' care plans are not patients' care plans" (2013, p. 266), with patients wanting a functional care plan that provides an expected health and personal trajectory, with a plan for issues that may arise. These findings illustrate how care and transition plans that are not individualized and meaningful to the older adult, and effectively shared among all professionals involved, may lead to feelings of uncertainty, insecurity, vulnerability, and mistrust. The present initiative and opportunity to develop meaningful and collaborative community care plans, as identified in the gap analysis, is a promising intervention that may contribute to increased coordination and caregiver support. However, future consideration should be given concerning how the collaborative community care plan can be shared outside of the organization, as the current electronic medical record utilized is organization specific.

An additional challenge revealed during the gap analysis is inconsistencies in how transition plans are evaluated and knowing if the older adult and caregiver are coping during the waiting period prior to LTC admission. Two registered nurse stakeholders providing feedback during the gap analysis reported trusting caregivers' judgment to reach out for assistance if they experienced challenges, while Haggerty and colleagues (2013) reported that individuals are more likely to regularly connect with their clinician when relational continuity has been established. Therefore, it is possible that clinicians who have established strong relationships with individuals and their caregivers do not feel the need to proactively evaluate transition plans, as relational continuity has been established and may aid in promptly identifying and responding to concerns that may arise. Conversely, caregivers who have not established a relationship with a PCP or case manager may be less likely to communicate frequently or reach out for assistance. Health care professionals must be aware of this possibility and strive to frequently evaluate the situation and develop relationships with caregivers and PWD in order to proactively support the transition to LTC and identify and address concerns in a timely manner.

The primary care transformation in BC creates a unique opportunity to enhance continuity of care, through the creation of primary care networks and models of team-based care (General Practice Services Committee, 2017). Within the Central Okanagan local health area, as part of this transformation, home health nursing care plans will be replaced with collaborative community care plans. The new care plans will have client and caregiver goals and priorities embedded within and may be a promising step towards creating a functional, meaningful, and client-specific care plan that can be shared and utilized by the entire interprofessional team. However, variations in individual practice mean that unless barriers to the use of care plans are removed, the transformation may not be successful. Examples of barriers to the use of care plans identified during the gap analysis include the absence of mandatory education, a focus of managing urgent practice issues, and an undermining of preventative measures such as evaluation and care planning. With client and caregiver priorities, and the agreed-upon transition plan clearly formulated within the proposed new care plans, the information may be easily accessed and shared with all team members, in turn contributing to continuity of care and the ensuing feelings of security, confidence, safety, and support as reported by Haggerty et al. (2013).

Recommendations

In light of the challenges identified during the literature review and gap analysis, several recommendations are presented below, and which may contribute to facilitating safe, effective, and well-supported transitions in care with improved caregiver experiences. The recommendations include improving the continuity and coordination of care, discharge planning, post-discharge care, and evaluation. Although guidelines and evidence-informed initiatives, such as the 48/6 model of care (BC Patient Safety & Quality Council, 2012), are present in practice, the implementation and uptake of such initiatives can be challenging. This may be due to insufficient organizational resources, the skills, knowledge needs, and attitudes of professionals, organizational culture, and limited supervision (Gray et al., 2013). Increasing health care professional knowledge and influencing attitudes towards transitional care for individuals waiting for LTC through this research may therefore contribute to facilitating the implementation of evidence-informed practices and recommendations.

Much of the literature captured in the review that explored the caregiver experience of a transition from hospital to home also included a discussion of recommendations for transitional care specific to this context. Australian researchers made several recommendations regarding discharge planning (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011; Fitzgerald et al., 2011), while Mockford and colleagues' (2017) research with service users led to the elaboration of three final recommendations for transitional care, including community based care. Other authors' research did not result in formal recommendations, but explored the importance of communication, coordination, and involvement with caregivers (Jamieson et al., 2016), and the ongoing need for professional support post discharge (Naylor et al., 2005). Both the literature captured within the integrative review and the gap analysis findings were informative in formulating evidence-informed recommendations to support caregivers in transition when a PWD is discharged from hospital to await LTC admission at home, which are presented in the following sections.

Continuity and Coordination

Coordination and continuity of care were identified as being critically important within care transitions and can be facilitated by having a named coordinator who can provide dedicated support to the PWD and caregiver, and "guide them through the health and social care process from discharge back to the community" (Mockford et al., 2017, p. 503). Furthermore, facilitating communication and collaboration among providers and between settings emerged during the gap analysis as a crucial opportunity. This can be done through increased education, greater awareness of the risks of fragmented care, and the integration of processes and tools to facilitate information sharing and collaboration between settings and providers.

The *Care Transitions* guideline (RNAO, 2014)*,* provides evidence based recommendations for nurses supporting individuals undergoing a transition in care, including recommendations for clinical practice, education, organization, and policy. The recommendations are relevant to transitions "within, between or across settings or health-care providers or services" (RNAO, 2014, p. 6), therefore, are relevant and applicable to a wide range of settings and situations. While the recommendations can be utilized in both hospital and community care settings, health care professionals supporting PWD and their caregivers prior to a transition to LTC may find the proposed strategies particularly relevant.

Within the *Care Transitions* best practice guideline, the importance of ensuring continuity of care while planning, implementing, and evaluating care transitions is acknowledged (RNAO, 2014). Strategies that enhance continuity of care were noted to include case management services, liaison nurses to bridge care and services, and primary care follow-up (RNAO, 2014). Health care professionals such as community case managers are well-positioned to assume the role of coordinators of care and should maintain frequent communication and collaboration with PCPs to ensure all providers are working together to optimally support the caregiver and PWD.

Recommendations for practice uncovered in this project reinforce the need for increased continuity and coordination of care during transitions. This can be facilitated through the use of effective communication to share information, by providing education and self-management strategies to the client and caregivers, and by using standardized documentation tools and processes for exchanging information (RNAO, 2014). A further means to improve continuity and coordination of care is to ensure the client and caregiver have been actively involved in the development of the transition plan, which is clearly documented and shared with the interdisciplinary team. In the absence of an electronic medical record that spans organizations, case managers should update the care plan as needed, providing a copy to other team members such as PCPs and hospital-based health care professionals. Likewise, hospital or primary care practice created care plans should be shared with community care providers.

Recommendations for policy related to continuity and coordination of care include creating systems for securely and comprehensively sharing and coordinating information and completing medication reconciliation during care transitions (RNAO, 2014). This can be done through mandated processes, at the local level through organizational policies and guidelines, or provincially through a patient charter. While progress has been made by creating policies for sharing information between settings and providers, the absence of a comprehensive electronic medication record is a pervasive barrier to continuity of care.

Future efforts should explore systems and programs that allow primary care, hospital, community, and LTC settings to view and share information effectively.

Recommendations for research include measuring performance related to continuity and coordination of care, such as by evaluating the impact of coordinators throughout transitions in care, and identifying tools that support the coordination of care. These may include documents for tracking and recording decision-making, appointments, and planning, such as a patient transition passport, and exploring caregiver support programs, including professional, virtual, and peer support options. Measuring client and caregiver experiences of home and community care is equally recommended, and could be undertaken with the use of existing tools, such as the Client and Care Giver Experience Evaluation Survey (Canadian Institute for Health Information, 2017). This survey can measure client involvement with care plan development, quality of communication, and satisfaction (Health Quality Ontario, 2017), and would be beneficial to explore for individuals and caregivers who are waiting for LTC admission.

Discharge Planning

Discharge planning emerged as an important part of the care transition process for individuals experiencing hospitalization. Recommendations related to discharge planning include providing caregivers with a written discharge plan, identifying and including caregivers in discharge planning, having a designated contact person in the hospital for caregivers to liaise with, and having policies in place regarding staff training, discharge notification, and satisfaction surveys (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, et al., 2011; Fitzgerald et al., 2011). These recommendations, noted within the literature review sample and gap analysis stakeholders, encompass the domains of practice, education, and organization and policy noted within the *Care Transitions* best practice guidelines (RNAO, 2014). Many of these recommendations are well accepted in practice, however, individual settings should carefully consider the effectiveness and safety of their current discharge planning practices, identifying areas where gaps in care are apparent and where improvements can be made. This work could be facilitated organization wide with assistance and direction from senior leadership and quality improvement departments, or on individual units through staff initiatives and department specific projects. The scale of the potential quality improvement projects depends on local resources and need, ideally utilizing a methodology to guide the process such as the *Toolkit: Implementation of Best Practice Guidelines* (RNAO, 2012) or SWOT analysis (van Wijngaarden et al., 2012).

A particular area of relevance may be in providing more collaborative discharge planning and education to PWD and their caregivers, as the strongest predictor of readiness for a care transition is the quality of teaching received (RNAO, 2014). Additionally, individuals and their caregivers are better able to accept and adapt to change when their needs, concerns, and goals have been validated and incorporated into the discharge plan (RNAO, 2014). A promising strategy may be to evaluate caregivers' readiness for a transition with an existing tool, such as the Readiness Evaluation and Discharge Interventions (READI) Protocol (Weiss et al., 2019), or with a local questionnaire or tool created to fit specific needs as part of a quality improvement initiative or strategy.

Recommendations for discharge planning related to education include enhancing the knowledge and skills of health care professionals engaged in discharge planning, in order to provide safe, effective, and collaborative care planning (RNAO, 2014). This may be undertaken through initial employee orientation, continuing education workshops, and informal activities such as huddles and team meetings. Education is needed for not only nurses, but other professionals who support discharge planning such as social workers, physiotherapists, occupational therapists, dieticians and others. Nurses frequently coordinate the discharge planning process, however, input and collaboration with other health care professionals is essential, and increasing the education and skills related to discharge planning for all professionals involved is crucial. Additionally, transitional care education should be incorporated into learning programs and education institutions for all professionals supporting transitions in care, including community health workers.

Policy recommendations related to discharge planning include establishing strategic priorities within organizations related to discharge planning, and adopting structures to support the discharge process (RNAO, 2014). Although the provincially mandated 48/6 hospital care planning initiative (BC Patient Safety & Quality Council, 2012) is strongly linked to discharge planning, the variations present within individual practice means the level of planning and collaboration is inconsistent. Allocating sufficient resources and support to ensure the initiative is prioritized and followed, in order to be beneficial to older adults is required. Discharge planning recommendations related to research include evaluating the outcomes of discharge planning, for example, by exploring if the practices utilized meet client and caregiver needs. This could be achieved by routinely adopting patient-reported experience measures, such as the Canadian Patient Experiences Survey – Inpatient Care, the Acute Inpatient Survey (Canadian Institute for Health Information, 2017), or other surveys specifically exploring caregiver experiences. Utilizing a caregiver specific survey may facilitate learning about the experiences of caregivers of PWD, as individuals with cognitive impairment are likely underrepresented in patient surveys due to difficulties in participating.

Regardless of the survey utilized, the results should be shared widely in order to facilitate advancements in practice through quality improvement initiatives and stakeholder engagement activities.

Post-Discharge Care

Service users in an English study of transitional care experiences identified the need to improve the quality of home care provided, specifically in regards to the timing of visits, collaboration with caregivers, and quality of care provided (Mockford et al., 2017). The importance of ensuring appropriate post-discharge care was echoed by Naylor et al. (2005), who noted that caregivers had ongoing needs several weeks post-discharge, and required continued support in managing the PWD's health condition and symptoms. Nurses supporting PWD and their caregivers during a transition from hospital to home while awaiting LTC can be mindful of post-discharge needs by continually assessing the individual and their situation, and collaborating with the PWD and caregivers to develop an appropriate plan tailored to their needs (RNAO, 2014). Further research may be required to examine models of post-discharge support, identifying mechanisms that best meet the support needs of caregivers.

Recommendations for practice related to post-discharge care include assessing evolving care requirements, collaborating with the older adult, caregiver, and interprofessional team to develop and adapt the transition plan, and coaching the older adult and caregiver on self-management strategies (RNAO, 2014). Specifically, the interdisciplinary team must ensure that the older adult will have PCP follow up. This can be facilitated by ensuring the PCP is an integrated member of the team, and who is informed of the hospitalization and discharge in a timely manner. Hospital-based professionals such as hospitalists, nurses, and social workers should encourage individuals to see their PCP promptly after discharge when planning a transition home, and processes should be explored where unit clerks routinely schedule follow-up appointments prior to discharge. Once the individual has returned home, case managers must prioritize routine assessments and monitoring of individuals post-discharge, ensuring they have primary care follow-up planned, completing medication reconciliation, and communicating assessment findings to the PCP.

Recommendations for education include ensuring all professionals who care for individuals after hospital discharge and during a transition in care have the knowledge and experience necessary to provide safe and competent care. This includes not only nurses, but also community health workers, who frequently provide personal care services to individuals after hospital discharge. Ensuring community health workers involved in the care of the older adult have access to the plan of care and understand the significance of care transitions may aid in providing safe and coordinated care. Additionally, community health workers must know how and when to contact a member of the team if they have concerns and how to escalate the situation if they are unable to reach the professional in a timely manner or outside of office hours.

Policy recommendations related to post-discharge care include establishing processes and guidelines to encourage the provision of care that the older adult needs while waiting for LTC. For example, creating guidelines surrounding the frequency of communication and home visits for nurses supporting individuals after a hospital discharge would emphasize the organizational priority of facilitating safe transitions. Additionally, sufficient human health resources must be available to ensure follow-up care is proactively provided by nurses, community health workers, and allied health professionals. Research recommendations include evaluating the impact of the care provided and measuring related services, such as professional visits, the availability and accessibility of home support, and other community programs such as respite or adult day programs. It would be important to have a clear understanding of the current level of post-discharge support provided, by tracking the provision of these services, prior to exploring patient-reported experience measures through post-discharge and community surveys.

Evaluation

The need to ensure that the effectiveness of transition planning and caregiver coping is evaluated emerged during the gap analysis and within the *Care Transitions* guidelines (RNAO, 2014). Recommendations for practice include evaluating the following: how caregivers cope and manage care during a transition, the need for additional resources, and the ongoing support and follow-up care, including by telephone and with PCPs. Policy recommendations include creating structures and conditions where evaluation may become an integral component of transitional care. For example, existing policies, processes, and checklists may be modified in order to prompt and encourage health care professionals to continually evaluate the transition plan and care, after the initial plan has been created. Research recommendations include examining the frequency and occurrence of transitional care evaluation, as well as evaluating individual and caregiver satisfaction with transitional care planning and support.

Implementation Factors

Implementing the multitude of recommendations for transitions in care is a complex process that requires more than creating awareness and ensuring health care professionals have received education on the importance of care transitions (RNAO, 2014). Strategies must be adapted to individual practice settings, taking into account the unique needs of individuals, caregivers, and health care professionals supporting care transitions. Commitment to best practice guidelines is more likely when adequate resources have been allocated to support the process, specific and locally relevant strategies are selected, stakeholders are engaged, and barriers and facilitators to strategy implementation have been considered and addressed (RNAO, 2012, 2014). Although strengths noted during the gap analysis within the Interior Health Authority included significant health care professional expertise and the desire to provide excellent care, challenges related to chronic human health resource challenges, variations in individual practice, and an emphasis on the reactive management of difficulties mean evidence-informed recommendations are not sufficiently implemented. Nurses and other health care professionals wishing to implement best practice guidelines concerning care transitions must ensure sufficient organizational support is provided and may wish to utilize a framework such as the *Toolkit: Implementation of Best Practice Guidelines* to facilitate the process and increase the likelihood of success (RNAO, 2012).

In order to facilitate stakeholder engagement in the implementation of recommendations, it is important to incorporate their perspectives and vision. Therefore, a working group or planning committee comprised of individuals supporting transitions in care and decision makers could provide indications of what changes are most needed and possible to implement. Likewise, buy in from health system leaders would lend further support to such initiatives and would ensure that implemented initiatives are prioritized. Overall, these individuals could help further increase engagement within the organization, provide feedback throughout the process, and determine how to implement evidence-informed recommendations.

Strengths and Limitations

This comprehensive project included a review of the transitional care literature and a gap analysis of related practices within the Interior Health Authority, which was informed by the findings of the captured studies. The integrative review of the literature had many strengths, including the use of a robust search strategy that was peer-reviewed by a health sciences librarian, as well as the inclusion of a heterogeneous sample of 17 papers with diverse aim and methodology of each paper. In addition, the inclusive approach that is characterized by the integrative review methodology allows for the inclusion of a large range of settings and methods, contributing to the ability to inform practice through dissemination of the literature review findings and discussion. The integrative review methodology included steps to enhance rigour, contributing to the accuracy of findings and confidence in a comprehensive search. Following the literature review, a gap analysis of transitional care practices was undertaken, and which corroborated several findings and identified gaps and concerns in practice. These steps led to the development of evidence-informed recommendations, which emerged through the process of the literature review and gap analysis.

Despite many strengths, some limitations exist. First, the literature captured in the integrative review included a generally limited discussion of sampling methods, lack of multisite studies, and limited representation of rural settings. As such, the findings of these studies may not be transferrable to all settings. Likewise, despite repeated attempts to engage a larger and more diverse cohort of stakeholders, the limited scope and number of stakeholders who participated in providing feedback during the gap analysis raise the possibility that important insights may have been overlooked or not explored during the engagement process. Second, many challenging experiences and situations faced by caregivers of PWD were discussed within the literature sample, with positive experiences rarely discussed and where mentioned only briefly explored (Fitzgerald et al., 2011; Mockford et al., 2017). Mixed perspectives were also captured during the gap analysis. It is possible that self-selection bias contributed to the predominance of negative experiences shared, as participants who agreed to partake in the research may have had strong opinions they were compelled to share. In the context of the existing literature, it would be useful to know if the studies not reporting any positive experiences had solicited this information from caregivers, while further development of the positive experiences that were shared would be worthwhile in order to identify which actions and support provided by health care professionals' were appreciated and helpful. Similarly, further research with caregivers should specifically seek to include those that have positive and negative experiences, in order to allow for a more fulsome understanding of the conditions that give rise to caregiver satisfaction during periods of transition.

Next Steps

To disseminate the findings and recommendations of this project, knowledge translation goals, audiences, and strategies must be carefully considered and adapted to individual, practice, and organizational needs (Canadian Institutes of Health Research, 2012). Potential knowledge users of this research include health care professionals, decision makers, researchers, and caregivers. Potential knowledge translation activities are summarized in Table 10, with examples of potential audiences, activities, and goals.

Health Care Professionals

Health care professionals, including PCPs, nurses, community health workers, and allied health professionals may find this research informative in better understanding the complexities of a transition in care and in planning and providing evidence-informed care. The goals of a knowledge translation strategy must be carefully considered, with activities tailored to the specific audience and need (Canadian Institutes of Health Research, 2012). For example, providing interactive and outreach education to health care professionals can be an effective knowledge translation activity to promote change in practice, while traditional education, which lacks active participation, and distribution or dissemination of educational materials may be less effective strategies (Alberta Health Services, 2019). Additionally, educational materials should be appropriate for the audience and must be adapted to the experience and knowledge of the knowledge users (Canadian Institutes of Health Research, 2012).

Table 10

Summary of Knowledge Translation Activities

Knowledge translation goal	Audience	Strategies
Increase knowledge and awareness	Health care professionals	Diffusion of information (presentations, emails, distribution of educational materials, web-based activities)
	Researchers	Peer-reviewed publications Conference presentations
	Caregivers	Plain language summaries Presentations Café scientifique
Promote action	Health care professionals	Interactive presentations and education (café scientifique, town hall, outreach education activities) Engage champion leaders Guidelines Toolkits
	Decision makers	Briefing notes Interactive small group meetings Networking

Note. Adapted from "Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches" by Canadian Institutes of Health Research, 2012 (https://cihr-irsc.gc.ca/e/documents/kt_lm_ktplan-en.pdf) and "Knowledge Translation Strategies for Different Target Audiences" by Alberta Health Services, 2019 (https://www.albertahealthservices.ca/assets/info/res/mhr/if-res-mhr-kt-strategies-for-different-audiences.pdf).

To disseminate the findings of this research to health care professionals and facilitate change, tailored and interactive activities would be most effective. These may include interactive presentations, such as a town hall meeting or presentations provided during professional development workshops and education. Further activities to facilitate the application of research findings include the development or modification of existing policies, guidelines, and toolkits. For example, existing guidelines related to transitions to LTC could be modified to incorporate recommendations related to the waiting period, and a comprehensive toolkit regarding care transitions or LTC could facilitate the access to multiple resources utilized by diverse audiences.

Decision Makers

Decision makers include individuals who may influence organizational change through policy, guidelines, and strategic direction (Canadian Institutes of Health Research, 2012, 2021). They may include administrators, directors, managers, educators, and other stakeholder groups such as external organizations. Appropriate knowledge translation activities for decision makers include briefing notes, interactive small group meetings, and direct networking opportunities (Canadian Institutes of Health Research, 2012).

Researchers

Appropriate knowledge translation activities for researchers include dissemination of findings through peer-reviewed publication and conference presentations (Canadian Institutes of Health Research, 2012). Potential journals for publication would be selected to target individuals in the field of gerontology, for example *Research on Aging* or the *Canadian Journal on Aging*.

Caregivers

Caregivers and other members of the general public interested in the topic may increase their knowledge and awareness related to transitions in care through plain language summaries, infographics, and informal and accessible presentations, such as a café scientifique (Canadian Institutes of Health Research, 2012; Grand, 2014). To successfully diffuse information, the knowledge translation activities would be adapted to the audience, without assuming prior knowledge. Caregivers could be targeted through affixed posters or signs at local support groups, community centres, primary care offices, and LTC facilities, informing interested individuals of upcoming knowledge translation activities. Furthermore, summaries and infographics could be available and distributed through the mentioned community partners and organizations.

Conclusion

Through this comprehensive project, I sought to explore the experiences of caregivers in transition when PWD are discharged from hospital to await LTC admission. Using comprehensive and rigorous search methods, a cohort of 17 papers was selected, which revealed seven themes and two subthemes through inductive analysis. The seven themes included: phases, coping, professional support, relationships, unpredictability, finances, and rural. The theme phases included the subthemes hospital experience and decision-making. The caregiver experience of a PWD's transition from hospital to home while waiting for LTC is a phenomenon that appears to not yet have been explored in the peer-reviewed, English language literature. Studies concerning caregivers' experiences of a transition from hospital to home for the PWD, and caregivers' experiences of waiting for LTC have however identified similarities in the caregiver experience, and areas of unique importance and implication.

Throughout the literature review, caregiver difficulties and challenges were highlighted, with particular importance noted of the caregiver significance of the phases of a transition in care. These phases included the hospital experience, which caregivers frequently reflected upon and were unable to distinguish from the greater transition home. Additionally, caregivers encountered many decision-making points throughout the transition, and often returned to their initial LTC decision-making process to contemplate its ongoing relevance and significance.

The gap analysis of 10 local providers within the Central Okanagan local health area corroborated many of these findings, with both health care professionals and caregivers reporting challenges surrounding the phases of a transition and difficulties in obtaining or providing adequate levels of support. Additional concerns identified through this research include ensuring adequate communication and coordination between providers and services, appropriate follow-up and post-discharge care, and optimal caregiver involvement in care planning and decision-making.

In summary, the evidence related to the experiences of caregivers in transition when a PWD transition from hospital to home to await LTC admission has revealed several areas of particular concern and importance. Gaps in knowledge and practice have been noted related to this particular context, raising questions concerning how health care professionals can best support PWD and their caregivers while waiting for LTC admission. As BC experiences population aging, a limited supply of LTC beds, and the desire to support older adults to remain in their own homes as long as possible, knowledge of caregivers' experiences, evidence-based recommendations for safe and effective care transitions, and future research is needed to ensure nurses and other health care professionals are able to provide truly person-centred care. The key recommendations identified during this comprehensive project include improving the continuity and coordination of care, discharge planning, post discharge care, and evaluation. With continued health care professional investment, primary care transformation, and vital collaboration with caregivers, these evidence-informed recommendations may facilitate improved caregiver experiences and outcomes.

References

Accreditation Canada. (2013). *Safety in Canadian health care organizations: A focus on transitions in care and required organizational practices*. http://www.accreditation.ca/sites/default/files/char-2013-en.pdf

Adams, C. J., Stephens, K., Whiteman, K., Kersteen, H., & Katruska, J. (2014). Implementation of the Re-Engineered Discharge (RED) Toolkit to decrease all-cause readmission rates at a rural community hospital. *Quality Management in Health Care*, *23*(3), 169–177. https://doi.org/10.1097/QMH.0000000000000032

Alberta Health Services. (2019). *Knowledge translation strategies for different target audiences*. https://www.albertahealthservices.ca/assets/info/res/mhr/if-res-mhr-kt-strategies-for-different-audiences.pdf

Alzheimer Society of Canada. (n.d.). *About dementia*. http://www.alzheimer.ca/en/About-dementia

Alzheimer's Association. (2017). 2017 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, *13*(4), 325–373. https://doi.org/10.1016/j.jalz.2017.02.001

Antifeau, E., Cook, H., Drance, E., Felzmann, A., Hazel, M., Janz, T., Long, A., Rose, L., Ward, C., James, P., Higham, B., Bedford, S., & Seller, L. A. (2012). *Best practice guideline for accommodating and managing behavioural and psychological symptoms of dementia in residential care: A person-centered interdisciplinary approach*. British Columbia Ministry of Health. http://www.health.gov.bc.ca/library/publications/year/2012/bpsd-guideline.pdf

Ballard, C., Aarsland, D., Francis, P., & Corbett, A. (2013). Neuropsychiatric symptoms in patients with dementias associated with cortical Lewy bodies: Pathophysiology, clinical features, and pharmacological management. *Drugs & Aging*, *30*(8), 603–611. https://doi.org/10.1007/s40266-013-0092-x

Bauer, M., Fitzgerald, L., & Koch, S. (2011). Hospital discharge as experienced by family carers of people with dementia: A case for quality improvement. *Journal for Healthcare Quality*, *33*(6), 9–16. https://doi.org/10.1111/j.1945-1474.2011.00122.x

Bauer, M., Fitzgerald, L., Koch, S., & King, S. (2011). How family carers view hospital discharge planning for the older person with a dementia. *Dementia*, *10*(3), 317–323. https://doi.org/10.1177/1471301211407790

Baumgart, M., Snyder, H. M., Carrillo, M. C., Fazio, S., Kim, H., & Johns, H. (2015). Summary of the evidence on modifiable risk factors for cognitive decline and dementia: A population-based perspective. *Alzheimer's & Dementia*, *11*(6), 718–726. https://doi.org/10.1016/j.jalz.2015.05.016

BC Patient Safety & Quality Council. (n.d.). *Patient Voices Network*. https://patientvoicesbc.ca/

BC Patient Safety & Quality Council. (2012). *Hospital care for seniors: 48/6 approach*. https://bcpsqc.ca//documents/2012/10/Key-Messages-for-48_6-24Sept2012-1.pdf

BC Support Unit. (n.d.). *BC Support Unit: Advancing patient-oriented research*. https://bcsupportunit.ca/about

Blomqvist, A., & Busby, C. (2014). *Paying for the boomers: Long-term care and intergenerational equity* (Commentary No. 415). CD Howe Institute. https://www.cdhowe.org/sites/default/files/attachments/research_papers/mixed/Commentary_415.pdf

Bradway, C., Trotta, R., Bixby, M. B., McPartland, E., Wollman, M. C., Kapustka, H., McCauley, K., & Naylor, M. D. (2012). A qualitative analysis of an advanced practice nurse–directed transitional care model intervention. *The Gerontologist*, *52*(3), 394–407. https://doi.org/10.1093/geront/gnr078

Branger, C., Burton, R., O'Connell, M. E., Stewart, N., & Morgan, D. (2016). Coping with cognitive impairment and dementia: Rural caregivers' perspectives. *Dementia*, *15*(4), 814–831. https://doi.org/10.1177/1471301214539956

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

British Columbia Ministry of Health. (2012-2020). *Home and community care policy manual*. http://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/accountability/policy-and-standards/home-and-community-care-policy-manual

British Columbia Ministry of Health. (2016). *RAI-HC clinical standards and "best practice" guidelines*. https://www2.gov.bc.ca/assets/gov/health-safety/home-community-care/accountability/pdf/final_rai-hc_guidelines_-_2016.pdf

British Columbia Ministry of Health. (2017). *An action plan to strengthen home and community care for seniors*. https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care

British Columbia Ministry of Health. (2019). *Long-term care access guidelines*. https://www.health.gov.bc.ca/library/publications/year/2019/long-term-care-access-guidelines-2019.pdf

British Columbia Ministry of Health. (2020, September 15). *Transforming primary care in B.C.* https://archive.news.gov.bc.ca/releases/news_releases_2017-2021/2020HLTH0280-001735.htm

Butcher, H. K., Holkup, P. A., & Buckwalter, K. C. (2001). The experience of caring for a family member with Alzheimer's disease. *Western Journal of Nursing Research*, *23*(1), 33–55. https://doi.org/10.1177/019394590102300104

Caldwell, L., Low, L.-F., & Brodaty, H. (2014). Caregivers' experience of the decision-making process for placing a person with dementia into a nursing home: Comparing caregivers from Chinese ethnic minority with those from English-speaking backgrounds. *International Psychogeriatrics*, *26*(3), 413–424. https://doi.org/10.1017/S1041610213002020

Campos, V., & Hamilton, D. (2019). Utilizing a gap analysis to strengthen the strategy of navigation programs. *Journal of Oncology Navigation & Survivorship*, *10*(12), 547–548.

Canadian Institute for Health Information. (n.d.). *Dementia in hospitals*. https://www.cihi.ca/en/dementia-in-canada/dementia-across-the-health-system/dementia-in-hospitals

Canadian Institute for Health Information. (2017). *Patient-centred measurement and reporting in Canada: Launching the discussion toward a future state*. https://www.cihi.ca/sites/default/files/document/visioning-day-paper-en-web.pdf

Canadian Institutes of Health Research. (2012). *Guide to knowledge translation planning at CIHR: Integrated and end-of-grant approaches*. https://cihr-irsc.gc.ca/e/documents/kt_lm_ktplan-en.pdf

Canadian Institutes of Health Research. (2021). *Glossary of funding-related terms*. https://cihr-irsc.gc.ca/e/34190.html#d

Caron, C. D., & Bowers, B. J. (2003). Deciding whether to continue, share, or relinquish caregiving: Caregiver views. *Qualitative Health Research*, *13*(9), 1252–1271. https://doi.org/10.1177/1049732303257236

Caron, C. D., Ducharme, F., & Griffith, J. (2006). Deciding on institutionalization for a relative with dementia: The most difficult decision for caregivers. *Canadian Journal on Aging*, *25*(2), 193–206. https://doi.org/10.1353/cja.2006.0033

Çelik, B., & Bilik, Ö. (2020). The discharge needs of family caregivers of the patients following hip fracture surgery. *Turkiye Klinikleri Hemsirelik Bilimleri*, *12*(2), 173–181. https://doi.org/10.5336/nurses.2019-70706

Chambers, L. W., Bancej, C., & McDowell, I. (2016). *Prevalence and monetary costs of dementia in Canada*. The Alzheimer Society of Canada. http://www.alzheimer.ca/ab/~/media/Files/national/Statistics/PrevalenceandCostsofDementia_EN.pdf

Chene, B. (2006). Dementia and residential placement: A view from the carers' perspective. *Qualitative Social Work*, *5*(2), 187–215. https://doi.org/10.1177/1473325006064257

Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry*, *17*(2), 184–188. https://doi.org/10.1002/gps.561

Coleman, E. A., & Boult, C. (2003). Improving the quality of transitional care for persons with complex care needs. *Journal of the American Geriatrics Society*, *51*(4), 556–557. https://doi.org/10.1046/j.1532-5415.2003.51186.x

Coleman, E. A., Parry, C., Chalmers, S., & Min, S.-J. (2006). The care transitions intervention: Results of a randomized controlled trial. *Archives of Internal Medicine*, *166*(17), 1822–1828. https://doi.org/10.1001/archinte.166.17.1822

Community Care and Assisted Living Act, B.C. Reg. 96/2009 (2009). http://www.bclaws.ca/Recon/document/ID/freeside/96_2009

Compton, R. M., Owilli, A. O., Caine, V., Berendonk, C., Jouan-Tapp, D., Sommerfeldt, S., McPhee, D. J., & Walz, D. (2019). Home First: Exploring the impact of community-based home care for older adults and their family caregivers. *Canadian Journal on Aging*, *39*(3), 432–442. https://doi.org/10.1017/S0714980819000461

Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO: The SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research*, *22*(10), 1435–1443. https://doi.org/10.1177/1049732312452938

Costa, A. P., Hirdes, J. P., Bell, C. M., Bronskill, S. E., Heckman, G. A., Mitchell, L., Poss, J. W., Sinha, S. K., & Stolee, P. (2015). Derivation and validation of the detection of indicators and vulnerabilities for emergency room trips scale for classifying the risk of emergency department use in frail community-dwelling older adults. *Journal of the American Geriatrics Society*, *63*(4), 763–769. https://doi.org/10.1111/jgs.13336

Davis-Ajami, M. L., Costa, L., & Kulik, S. (2014). Gap analysis: Synergies and opportunities for effective nursing leadership. *Nursing Economic$*, *32*(1), 17–25.

Dawson, J. I., & Critchley, L. (1992). Community-hospital partnerships. The Quick Response Team. *The Journal of Nursing Administration*, *22*(11), 33–39.

Demirkol, M. E., Yorgun, S., Esen, H., İmka Şafak, F., Öztürk, B., Baysal, Z., & Orman, H. (2020). An evaluation of hospital practices using SWOT analysis during COVID-19. *Journal of Academic Research in Nursing*, *68*(2), 341–351. https://doi.org/10.5222/jaren.2020.90958

DeSilets, L. D., Dickerson, P. S., & Lavin, S. (2013). More on gap analysis. *Journal of Continuing Education in Nursing*, *44*(10), 433–434. https://doi.org/10.3928/00220124-20130925-17

Ducharme, F., Couture, M., & Lamontagne, J. (2012). Decision-making process of family caregivers regarding placement of a cognitively impaired elderly relative. *Home Health Care Services Quarterly*, *31*(3), 197–218. https://doi.org/10.1080/01621424.2012.681572

Duncan, M. (1992). *Alzheimer's disease caregivers: The transition from home care to formal care* [Doctoral dissertation, Portland State University]. ProQuest Dissertations and Theses Global.

Ehrlich, K., Boström, A.-M., Mazaheri, M., Heikkilä, K., & Emami, A. (2015). Family caregivers' assessments of caring for a relative with dementia: A comparison of urban and rural areas. *International Journal of Older People Nursing*, *10*(1), 27–37. https://doi.org/10.1111/opn.12044

Epstein-Lubow, G., & Fulton, A. T. (2012). Post-hospital transitions for individuals with moderate to severe cognitive impairment. *The Annals of Long-Term Care*, *20*(3), 18–24.

Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*. https://doi.org/10.1111/j.1745-7599.2008.00342.x

Feast, A., Moniz-Cook, E., Stoner, C., Charlesworth, G., & Orrell, M. (2016). A systematic review of the relationship between behavioral and psychological symptoms (BPSD) and caregiver well-being. *International Psychogeriatrics*, *28*(11), 1761–1774. https://doi.org/10.1017/S1041610216000922

Finkel, S. I., Burns, A., & Cohen, G. (2000). Overview. *International Psychogeriatrics*, *12*(S1), 13–18. https://doi.org/10.1017/S1041610200006700

Fitzgerald, L. R., Bauer, M., Koch, S. H., & King, S. J. (2011). Hospital discharge: Recommendations for performance improvement for family carers of people with dementia. *Australian Health Review*, *35*(3), 364. https://doi.org/10.1071/AH09811

Flier, W. M. van der, & Scheltens, P. (2005). Epidemiology and risk factors of dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, *76*(suppl 5), v2–v7. https://doi.org/10.1136/jnnp.2005.082867

Gaugler, J. E., Kane, R. L., Kane, R. A., Clay, T., & Newcomer, R. (2003). Caregiving and institutionalization of cognitively impaired older people: Utilizing dynamic predictors of change. *The Gerontologist*, *43*(2), 219–229. https://doi.org/10.1093/geront/43.2.219

General Practice Services Committee. (2017). *Implementation of the integrated system of primary and community care: Team-based care through primary care networks. Guidance to collaborative services committees*. https://gpscbc.ca/sites/default/files/PMH%20PCN%20CSC%20Guidance%20201712.pdf

Godard-Sebillotte, C., Le Berre, M., Schuster, T., Trottier, M., & Vedel, I. (2019). Impact of health service interventions on acute hospital use in community-dwelling persons with dementia: A systematic literature review and meta-analysis. *PloS One*, *14*(6), e0218426. https://doi.org/10.1371/journal.pone.0218426

Golden, S. H., Hager, D., Gould, L. J., Mathioudakis, N., & Pronovost, P. J. (2017). A gap analysis needs assessment tool to drive a care delivery and research agenda for integration of care and sharing of best practices across a health system. *Joint Commission Journal on Quality & Patient Safety*, *43*(1), 18–28. https://doi.org/10.1016/j.jcjq.2016.10.004

Grand, A. (2014). Café scientifique. *Science Progress*, *97*(3), 275–278. https://doi.org/10.3184/003685014X14098305289149

Graneheim, U. H., Johansson, A., & Lindgren, B.-M. (2014). Family caregivers' experiences of relinquishing the care of a person with dementia to a nursing home: Insights from a meta-ethnographic study. *Scandinavian Journal of Caring Sciences*, *28*(2), 215–224. https://doi.org/10.1111/scs.12046

Gray, M., Joy, E., Plath, D., & Webb, S. A. (2013). Implementing evidence-based practice: A review of the empirical research literature. *Research on Social Work Practice*, *23*(2), 157–166. https://doi.org/10.1177/1049731512467072

Guidelines and Protocols Advisory Committee. (2016). *Cognitive impairment—Recognition, diagnosis and management in primary care—Province of British Columbia*. British Columbia Medical Association.

https://www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/bc-guidelines/cognitive-impairment

Haeseler, L. A. (2013). Women's coping experiences in the spectrum of domestic violence abuse. *Journal of Evidence-Based Social Work*, *10*(1), 33–43. https://doi.org/10.1080/15433714.2013.750551

Haggerty, J. L., Reid, R. J., Freeman, G. K., Starfield, B. H., Adair, C. E., & McKendry, R. (2003). Continuity of care: A multidisciplinary review. *British Medical Journal*, *327*(7425), 1219–1221. https://doi.org/10.1136/bmj.327.7425.1219

Haggerty, J. L., Roberge, D., Freeman, G. K., & Beaulieu, C. (2013). Experienced continuity of care when patients see multiple clinicians: A qualitative metasummary. *The Annals of Family Medicine*, *11*(3), 262–271. https://doi.org/10.1370/afm.1499

Hall, B., Mak, E., Cervenka, S., Aigbirhio, F. I., Rowe, J. B., & O'Brien, J. T. (2017). In vivo tau PET imaging in dementia: Pathophysiology, radiotracer quantification, and a systematic review of clinical findings. *Ageing Research Reviews*, *36*, 50–63. https://doi.org/10.1016/j.arr.2017.03.002

Health Quality Ontario. (2017). *Home care indicator review: Summary report*. https://www.hqontario.ca/Portals/0/documents/system-performance/home-care-indicator-review-report-2017.pdf

Iadecola, C. (2013). The pathobiology of vascular dementia. *Neuron*, *80*(4). https://doi.org/10.1016/j.neuron.2013.10.008

Interior Health Authority. (n.d.). *Long term care home access from community to do list*.

Interior Health Authority. (2012). *Charting the course: Interior Health's planning principles and considerations for change*. https://www.interiorhealth.ca/AboutUs/StrategicDirection/Documents/Charting_the_Course.pdf

Interior Health Authority. (2018a). *Health authority profile: Interior Health*. https://www.interiorhealth.ca/AboutUs/QuickFacts/PopulationLocalAreaProfiles/Documents/Interior%20Health%20Authority%20Profile.pdf

Interior Health Authority. (2018b). *Strategy map*. https://www.interiorhealth.ca/AboutUs/StrategicDirection/Documents/IHStrategyMap.pdf

Jagust, W. (2018). Imaging the evolution and pathophysiology of Alzheimer disease. *Nature Reviews Neuroscience*, *19*(11), 687–700. https://doi.org/10.1038/s41583-018-0067-3

Jamieson, M., Grealish, L., Brown, J.-A., & Draper, B. (2016). Carers: The navigators of the maze of care for people with dementia—A qualitative study. *Dementia: The International Journal of Social Research and Practice*, *15*(5), 1112–1123. https://doi.org/10.1177/1471301214554930

Javidan, A. P., Nathens, A. B., Tien, H., & Luz, L. T. da. (2020). Clinical handover from emergency medical services to the trauma team: A gap analysis. *Canadian Journal of Emergency Medicine*, *22*(S2), S21–S29. https://doi.org/10.1017/cem.2019.438

Kable, A., Chenoweth, L., Pond, D., & Hullick, C. (2015). Health professional perspectives on systems failures in transitional care for patients with dementia and their carers: A qualitative descriptive study. *BMC Health Services Research*, *15*(1). https://doi.org/10.1186/s12913-015-1227-z

Kiyoshi-Teo, H., Carter, N., & Rose, A. (2017). Fall prevention practice gap analysis: Aiming for targeted improvements. *MEDSURG Nursing*, *26*(5), 332–335.

Kraijo, H., Leeuw, R., & Schrijvers, G. (2015). How spouses evaluate nursing home placement of their demented partner: A study about the end of perseverance time. *Scandinavian Journal of Caring Sciences*, *29*(1), 101–109. https://doi.org/10.1111/scs.12137

Lamb, K. V., Ambutas, S. A., Sermersheim, E. R., & Ellsworth, M. J. (2020). Gap analysis: A tool for staff engagement in fall reduction improvement processes. *Nursing Management*, *51*(10), 16–22. https://doi.org/10.1097/01.NUMA.0000698108.86942.f9

Lanting, S., Crossley, M., Morgan, D., & Cammer, A. (2011). Aboriginal experiences of aging and dementia in a context of sociocultural change: Qualitative analysis of key informant group interviews with Aboriginal seniors. *Journal of Cross-Cultural Gerontology*, *26*(1), 103–117. https://doi.org/10.1007/s10823-010-9136-4

Liu, C.-C., Kanekiyo, T., Xu, H., & Bu, G. (2013). Apolipoprotein E and Alzheimer disease: Risk, mechanisms, and therapy. *Nature Reviews Neurology*, *9*(2), 106–118. https://doi.org/10.1038/nrneurol.2012.263

Macmillan, T. H. (2016). Hospital discharge: Lost opportunities to promote or maintain older people's mental health. *Quality in Ageing & Older Adults*, *17*(3), 189–197. https://doi.org/10.1108/QAOA-06-2015-0029

Mamier, I., & Winslow, B. W. (2014). Divergent views of placement decision-making: A qualitative case study. *Issues in Mental Health Nursing*, *35*(1), 13–20. https://doi.org/10.3109/01612840.2013.834014

Martin, D., Kripalani, S., & DuRapau, V. J. (2012). Improving medication management among at-risk older adults. *Journal of Gerontological Nursing*, *38*(6), 24–34. https://doi.org/10.3928/00989134-20120507-50

Maxfield, L., & Savard, A.-M. (2018). *Care management: Access to long-term care home* [Standardized process and procedure]. Interior Health Authority.

McKhann, G. M., Knopman, D. S., Chertkow, H., Hyman, B. T., Jack, C. R., Jr, Kawas, C. H., Klunk, W. E., Koroshetz, W. J., Manly, J. J., Mayeux, R., Mohs, R. C., Morris, J. C., Rossor, M. N., Scheltens, P., Carrillo, M. C., Thies, B., Weintraub, S., & Phelps, C. H. (2011). The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, *7*(3), 263–269. https://doi.org/10.1016/j.jalz.2011.03.005

Meiland, F. J., Danse, J. A., Wendte, J. F., Klazinga, N. S., & Gunning-Schepers, L. J. (2001). Caring for relatives with dementia—Caregiver experiences of relatives of patients on the waiting list for admission to a psychogeriatric nursing home in The Netherlands. *Scandinavian Journal of Public Health*, *29*(2), 113–121.

Mockford, C., Seers, K., Murray, M., Oyebode, J., Clarke, R., Staniszewska, S., Suleman, R., Boex, S., Diment, Y., Grant, R., Leach, J., & Sharma, U. (2017). The development of service user-led recommendations for health and social care services on leaving hospital with memory loss or dementia—The SHARED study. *Health Expectations*, *20*(3), 495–507. https://doi.org/10.1111/hex.12477

Mora, K., Dorrejo, X. M., Carreon, K. M., & Butt, S. (2017). Nurse practitioner-led transitional care interventions: An integrative review. *Journal of the American Association of Nurse Practitioners*, *29*(12), 773–790. https://doi.org/10.1002/2327-6924.12509

Morgan, D. G., Semchuk, K. M., Stewart, N. J., & D'Arcy, C. (2002). Rural families caring for a relative with dementia: Barriers to use of formal services. *Social Science & Medicine*, *55*(7), 1129–1142. https://doi.org/10.1016/s0277-9536(01)00255-6

Morgan, D. G., Walls-Ingram, S., Cammer, A., O'Connell, M. E., Crossley, M., Bello-Haas, V. D., Forbes, D., Innes, A., Kirk, A., & Stewart, N. (2014). Informal caregivers' hopes and expectations of a referral to a memory clinic. *Social Science & Medicine*, *102*, 111–118. https://doi.org/10.1016/j.socscimed.2013.11.023

National Institute on Ageing. (2019). *Enabling the future provision of long-term care in Canada*. https://static1.squarespace.com/static/5c2fa7b03917eed9b5a436d8/t/5d9de15a38dca21e46009548/1570627931078/Enabling+the+Future+Provision+of+Long-Term+Care+in+Canada.pdf

Naylor, M. D., Hirschman, K., Hanlon, A., Bowles, K., Bradway, C., McCauley, K. M., & Pauly, M. V. (2014). Comparison of evidence-based interventions on outcomes of hospitalized, cognitively impaired older adults. *Journal of Comparative Effectiveness Research*, *3*(3), 245–257. https://doi.org/10.2217/cer.14.14

Naylor, M. D., Stephens, C., Bowles, K. H., & Bixby, M. B. (2005). Cognitively impaired older adults: From hospital to home. *American Journal of Nursing*, *105*(2), 52–62. https://doi.org/10.1097/00000446-200502000-00028

Neiterman, E., Wodchis, W. P., & Bourgeault, I. L. (2015). Experiences of older adults in transition from hospital to community. *Canadian Journal on Aging*, *34*(01), 90–99. https://doi.org/10.1017/S0714980814000518

Newnham, H., Barker, A., Ritchie, E., Hitchcock, K., Gibbs, H., & Holton, S. (2017). Discharge communication practices and healthcare provider and patient preferences, satisfaction and comprehension: A systematic review. *International Journal for Quality in Health Care*, *29*(6), 752–768. https://doi.org/10.1093/intqhc/mzx121

O'Connell, M. E., Germaine, N., Burton, R., Stewart, N., & Morgan, D. G. (2013). Degree of rurality is not related to dementia caregiver distress, burden, and coping in a predominantly rural sample. *Journal of Applied Gerontology*, *32*(8), 1015–1029. https://doi.org/10.1177/0733464812450071

Office of the Seniors Advocate. (2019a). *Monitoring seniors services*. https://www.seniorsadvocatebc.ca/monitoring-seniors-services/

Office of the Seniors Advocate. (2019b). *Home support... We can do better*. https://www.seniorsadvocatebc.ca/osa-reports/report-home-support-review/

Office of the Seniors Advocate. (2020). *2019-20 Annual report of the office of the seniors advocate*. https://www.seniorsadvocatebc.ca/annual-report-of-the-office-of-the-seniors-advocate/

Ogarek, J. A., McCreedy, E. M., Thomas, K. S., Teno, J. M., & Gozalo, P. L. (2018). Minimum data set Changes in Health, End-Stage Disease and Symptoms and Signs Scale: A revised measure to predict mortality in nursing home residents. *Journal of the American Geriatrics Society*, *66*(5), 976–981. https://doi.org/10.1111/jgs.15305

O'Neill, M., Ryan, A., Tracey, A., & Laird, L. (2020). The Primacy of 'Home': An exploration of how older adults transition to life in a care home towards the end of the first year. *Health & Social Care in the Community*. https://doi.org/10.1111/hsc.13232

Pong, R. W., DesMeules, M., Heng, D., Lagacé, C., Guernsey, J. R., Kazanjian, A., Manuel, D., Pitblado, J. R., Bollman, R., Koren, I., Dressler, M. P., Wang, F., & Luo, W. (2011). Patterns of health services utilization in rural Canada. *Chronic Diseases and Injuries in Canada*, *31 Suppl 1*, 1–36.

Proctor, E. K., Landsverk, J., Aarons, G., Chambers, D., Glisson, C., & Mittman, B. (2009). Implementation research in mental health services: An emerging science with conceptual, methodological, and training challenges. *Administration and Policy in Mental Health and Mental Health Services Research*, *36*(1), 24–34. https://doi.org/10.1007/s10488-008-0197-4

Ray, C., Ingram, V., & Cohen-Mansfield, J. (2015). Systematic review of planned care transitions for persons with dementia. *Neurodegenerative Disease Management*, *5*(4), 317–331. https://doi.org/10.2217/nmt.15.23

Registered Nurses' Association of Ontario. (2012). *Toolkit: Implementation of best practice guidelines* (Second Edition). https://rnao.ca/bpg/resources/toolkit-implementation-best-practice-guidelines-second-edition

Registered Nurses' Association of Ontario. (2014). *Care transitions* [Clinical Best Practice Guidelines]. http://rnao.ca/bpg/guidelines/care-transitions

Russ, T. C., & Morling, J. R. (2012). Cholinesterase inhibitors for mild cognitive impairment. *The Cochrane Database of Systematic Reviews*, *9*, CD009132. https://doi.org/10.1002/14651858.CD009132.pub2

Russell, C. L. (2005). An overview of the integrative research review. *Progress in Transplantation*, *15*(1), 8–13.

Sandelowski. (1995). Focus on qualitative methods. Qualitative analysis: What it is and how to begin. *Research in Nursing & Health*, *18*(4), 371–375.

Shyu, Y.-I. L. (2000). The needs of family caregivers of frail elders during the transition from hospital to home: A Taiwanese sample. *Journal of Advanced Nursing*, *32*(3), 619–625. https://doi.org/10.1046/j.1365-2648.2000.01519.x

Sinha, M. (2013). *Portrait of caregivers, 2012* (Spotlight on Canadians: Results for the General Social Survey). Statistics Canada. http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm

Soriano, F. I. (2012). *Conducting needs assessments: A multidisciplinary approach* (2 edition). SAGE Publications, Inc.

Statistics Canada. (2016). *Alzheimer's disease and other dementias in Canada*. https://www150.statcan.gc.ca/n1/pub/82-003-x/2016005/article/14613-eng.htm

Statistics Canada. (2019). *Population projections for Canada (2018 to 2068), provinces and territories (2018 to 2043)*. https://www150.statcan.gc.ca/n1/pub/91-520-x/2019001/sect02-eng.htm

Strang, V. R., Koop, P. M., Dupuis-Blanchard, S., Nordstrom, M., & Thompson, B. (2006). Family caregivers and transition to long-term care. *Clinical Nursing Research*, *15*(1), 27–45. https://doi.org/10.1177/1054773805282356

Sullivan, M. T. (2002). Caregiver Strain Index. *Journal of Gerontological Nursing*, *28*(8), 4–5. https://doi.org/10.3928/0098-9134-20020801-03

Swysen, K., Lousbergh, B., Deneckere, S., & Vanhaecht, K. (2012). The use of a SWOT analysis as a strategic management tool in mental health care. *International Journal of Care Pathways*, *16*(4), 146–151. https://doi.org/10.1258/jicp.2012.012009

Turcotte, M. (2013). *Family caregiving: What are the consequences?* Statistics Canada. https://www.statcan.gc.ca/pub/75-006-x/2013001/article/11858-eng.htm

Turpel-Lafond, M. E. (2020). *In plain sight: Addressing Indigenous-specific racism and discrimination in B.C. health care*. https://engage.gov.bc.ca/app/uploads/sites/613/2020/11/In-Plain-Sight-Full-Report.pdf

United Way Southern Interior BC. (n.d.). *Better at Home*. https://unitedwaysibc.com/how-we-help/community/better-at-home/

University of Saskatchewan. (n.d.). *Rural Dementia Action Research*. https://cchsa-ccssma.usask.ca/ruraldementiacare/index.php

University of Toronto Faculty of Medicine. (2009). *Quick tips: Initiating a learning needs assessment—Gap analysis of health care issues*. https://www.cpd.utoronto.ca/newsletter/2009_fall/Quick_Tips_initiating_a_learning_needs_assesment_Gap_Analysis_of_health_care_issues.pdf

Van Durme, T., Macq, J., Anthierens, S., Symons, L., Schmitz, O., Paulus, D., Van den Heede, K., & Remmen, R. (2014). Stakeholders' perception on the organization of chronic care: A SWOT analysis to draft avenues for health care reforms. *BMC Health Services Research*, *14*(1), 179. https://doi.org/10.1186/1472-6963-14-179

van Wijngaarden, J. D., Scholten, G. R., & van Wijk, K. P. (2012). Strategic analysis for health care organizations: The suitability of the SWOT-analysis. *International Journal of Health Planning & Management*, *27*(1), 34–49. https://doi.org/10.1002/hpm.1032

Vancouver Coastal Health. (2019). *Getting seniors safely back home*. http://www.vch.ca/about-us/news/getting-seniors-safely-back-home

Wegmann, S., Bennett, R. E., Delorme, L., Robbins, A. B., Hu, M., McKenzie, D., Kirk, M. J., Schiantarelli, J., Tunio, N., Amaral, A. C., Fan, Z., Nicholls, S., Hudry, E., & Hyman, B. T. (2019). Experimental evidence for the age dependence of tau protein spread in the brain. *Science Advances*, *5*(6), eaaw6404. https://doi.org/10.1126/sciadv.aaw6404

Weir, R., Browne, G., Byrne, C., Roberts, J., Gafni, A., Thompson, A., Walsh, M., & McColl, L. (1999). The quick response initiative in the emergency department: Who benefits? *Health Care Management Science*, *2*(3), 137–148. https://doi.org/10.1023/a:1019035811650

Weiss, M. E., Yakusheva, O., Bobay, K. L., Costa, L., Hughes, R. G., Nuccio, S., Hamilton, M., Bahr, S., Siclovan, D., & Bang, J. (2019). Effect of implementing discharge readiness assessment in adult medical-surgical units on 30-day return to hospital. *JAMA Network Open*, *2*(1). https://doi.org/10.1001/jamanetworkopen.2018.7387

Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, *52*(5), 546–553. https://doi.org/10.1111/j.1365-2648.2005.03621.x

Wisniewski, T. (Ed.). (2019). *Alzheimer's Disease*. Codon Publications. http://www.ncbi.nlm.nih.gov/books/NBK552148/

Woodward, M., Brodaty, H., Budge, M., Byrne, G., Farrow, M., Flicker, L., Hecker, J., & Velandai, S. (2007). *Dementia risk reduction: The evidence*. Alzheimer's Australia. https://www.dementia.org.au/sites/default/files/20100817-Nat-RiskReduction-NumPub-Sept07.pdf

World Health Organization. (2017). *WHO releases new resources on dementia*. http://www.who.int/mental_health/neurology/dementia/en/

World Health Organization. (2020, September 21). *Dementia*. https://www.who.int/news-room/fact-sheets/detail/dementia

Appendix A

Study / Country	Research aim	Design	Participants / Gender / Data collection	Key findings in relation to the present review
Transition from hospital to home				
Bauer, Fitzgerald, and Koch (2011) Australia	To explore family caregivers experience of hospital discharge planning, preparation and support for persons with dementia	Qualitative constructivist	25 principal caregivers (20 females, 9 spouses) of persons with dementia, discharged from hospital within two months Semi-structured interviews	Three themes: 1. Coordination 2. Capability 3. Consultation Participants experienced a lack of consistency in care and a perceived low standard of care. There was a lack of discharge planning and communication, with caregivers feeling frustrated, unsupported and distressed.
Bauer et al. (2011) Australia	To explore caregiver perceptions of discharge planning for persons with dementia, and to determine whether caregiver needs were met	Hospital Qualitative constructivist	25 principal caregivers (20 females, 9 spouses) of persons with dementia Semi-structured interviews	Four caregiver concerns: 1. Discharge planning was ad hoc and sometimes a discharge plan was not apparent 2. Information identified as important to the caregiver role was not provided 3. Inadequate communication regarding the care needs both in hospital and at home 4. Care provided in hospital did not meet expectations and limited caregiver involvement

Study / Country	Research aim	Design	Participants / Gender / Data collection	Key findings in relation to the present review
Çelik and Bilik (2020) Turkey	To reveal the needs of family caregivers of patients having surgery for hip fracture at discharge	Hospital Qualitative description	25 family caregivers (23 females, 24 spouses) Semi-structured, in-depth interviews	Three themes: 1. information needs 2. difficulties encountered in the care of patients with Alzheimer's disease 3. Worry about the patient's recovery and self-sufficiency Caregivers expressed uncertainty in managing at home, worry, and a need for information. Care of patients with Alzheimer's disease was more difficult for caregivers than the care of patients without Alzheimer's disease.
Fitzgerald et al. (2011) Australia	To explore family caregivers experience of hospital discharge planning, preparation and support for persons with dementia	Qualitative constructivist	25 principal caregivers (20 females, 9 spouses) of persons with dementia Semi-structured interviews	Three themes: 1. Insufficient communication 2. Inadequate preparation for discharge 3. Undervaluing the family caregiver as a resource
Jamieson et al. (2016) Australia	To describe the caregiver experience when the person with dementia transitions from hospital to home	Qualitative description	30 caregivers (26 females, number of spouses not specified) of persons with dementia Semi-structured	Three themes: 1. Paradox in hospital 2. Transition home is difficult 3. Social support at home highly valued Caregivers experienced a lack of coordinated

Study / Country	Research aim	Design	Participants / Gender / Data collection	Key findings in relation to the present review
			telephone interviews	discharge planning and difficulties accessing the needed support once home. The hospital experience had a significant impact on the transition experience for caregivers.
Macmillan (2016) England	To explore the mental health implications of the hospital discharge process from the patient and caregiver perspective	Qualitative exploratory	1300 older adults and caregivers in the greater study (gender and number of spouses not specified) 21 Peer-led focus groups, supplemented with written evidence from online surveys, interviews and site visits.	Four themes: 1. The extent that hospital settings can influence mental health 2. Coping being discharged home 3. Implications of discharge for caregiver stress and anxiety 4. Care and involvement of older patients with dementia Caregivers of persons with dementia felt the discharge process was not planned and coordinated, without the needed care arranged at home.
Mockford et al. (2017) England	To explore the experiences of caregivers and people living with memory loss of service provision at and after discharge from hospital To develop service user-led recommendations	Qualitative description	32 participants (gender and number of spouses not specified): 15 pairs of caregiver-patient dyads 17 health and social care staff	Four themes: 1. Not being involved in the discharge or confusion over what was agreed 2. Too many professionals at home without one person coordinating 3. Determining when and how to

Study / Country	Research aim	Design	Participants / Gender / Data collection	Key findings in relation to the present review
	enabling smooth transition for people living with memory loss from hospital to community		Semi-structured interviews and two focus groups	access support at home 4. Considerable caregiver stress due to unreliable and inexperienced care workers Caregivers felt they were not included in the discharge planning and decision-making process, and were unsure of how to access support. The experience of a discharge from hospital to home and settling back at home was experienced as a single event.
Naylor et al. (2005) United States	To explore the needs of cognitively impaired older adults and their caregivers during an episode of illness and after hospitalization To determine the rates of cognitive impairment among older adults hospitalized for acute reasons	Mixed methods: Cross-sectional descriptive and qualitative exploratory	Qualitative component: 5 cognitively impaired older adults (3 females, 1 spouse) and their caregivers (gender not specified) Quantitative component: 145 older adults (gender not specified) In-depth, semi-structured interviews in	Three themes of unmet needs: 1. Managing and negotiating care with multiple providers 2. Managing illness 3. Psychosocial support and coping The care provided to cognitively impaired older adults is more complex than the care provided to cognitively intact older adults. Caregivers felt powerless, frustrated, burdened and *left in the dark.*

Study / Country	Research aim	Design	Participants / Gender / Data collection	Key findings in relation to the present review
			person and by telephone Measurement scales	
Shyu (2020) Taiwan	To explore the changing needs of family caregivers of discharged older adults during the transition from hospital to home	Qualitative description	16 family caregivers (9 females, 5 spouses) of 12 frail older adult (3 older adults with cognitive impairment) In-depth interviews	Three phases of role tuning to achieve a harmonious pattern of caregiving and care receiving: 1. Role engaging 2. Role negotiating 3. Role settling Identified caregiver needs included information, help with mastering caregiving tasks and skills, and emotional support. Caregivers felt under pressure and required support to deal with emotional problems and disagreements.
Waiting				
Caldwell et al. (2014) Australia	To investigate the decision-making process for registering a PWD on a waiting list for LTC To explore why offers are accepted or declined To explore the cultural influence of this decision, in Chinese background and	Qualitative description	27 caregivers (19 females, 3 spouses) of PWD on waiting lists or living in LTC In-person, semi-structured interviews	Six themes and several sub-themes: 1. When caregivers apply for a waiting list 2. Reasons why caregivers apply 3. Reasons against admission 4. Weighing up the decision 5. Why places are declined 6. Why places are accepted Caregivers were at different stages of decision-making when

Study / Country	Research aim	Design	Participants / Gender / Data collection	Key findings in relation to the present review
	English-speaking background people living in Australia			they applied for a waiting list. The decisions were influenced by emotions, expectations, incidents and relationships.
Chene (2006) Australia	To understand how caregivers have experienced caregiving while the person for whom they provide care waits for LTC in aged care units	Mixed methods: Qualitative description Cross-sectional survey	20 caregivers (15 females, 9 spouses) of PWD waiting for LTC Open-ended interviews and surveys	Two themes related to relinquishing care to wait for LTC: 1. Caregiver grief: loss, sadness and resignation 2. Caregiver anxiety: guilt, worry and uncertainty Caregivers felt alone in making a difficult decision and expressed concern surrounding the lack of professional support.
Duncan (1992) United States	To explore the experiences of family caregivers of individuals with Alzheimer's disease as they shift their caregiving from home to formal care settings	Grounded theory	179 caregivers (gender distribution not specified, 76 spouses) Focus groups and in-depth interviews with 12 of the participants (7 females, 6 spouses)	Three themes: 1. Endings-Decisions 2. Placement 3. New beginning The theme endings-decisions explored the caregiver experience of waiting for LTC, including the following sub-themes: event, health care system, relationship, support, options and availability.
Kraijo et al. (2015) The Netherlands	To determine if spouses of PWD found that the LTC admission of their spouse	Grounded theory	14 spouses (6 females) of PWD admitted to LTC	Decisions made in phases over time: 1. Registration on waiting list 2. Actual admission once a

Study / Country	Research aim	Design	Participants / Gender / Data collection	Key findings in relation to the present review
	occurred at the right time		Semi-structured interviews	bed becomes available Spouses experienced admission occurring at the right time, too early, too late, or *out of control.*
Mamier and Winslow (2014) United States	To describe the contrasting perspectives between a family caregiver and the caregiver's professional provider regarding the LTC decision-making experience	Descriptive case study	1 spousal caregiver and 1 health professional (2 females) Three in-depth interviews	Eleven major emerging categories: 1. Process of coming to awareness 2. Triggers for admission 3. Appropriate time for admission 4. Caregiver's readiness for admission 5. Professional's position towards family caregivers 6. Approaches to institutional care 7. Caregiver identity 8. Meaning of admission 9. Coming to terms with the care-receiver's Alzheimer's disease 10. Support group function 11. Caregiver's situation post-admission The caregiver expressed reaching her personal limits for home-based caregiving, yet felt stuck

Study / Country	Research aim	Design	Participants / Gender / Data collection	Key findings in relation to the present review
				in the LTC decision-making process. The caregiver reached a turning point and sought LTC admission, while feeling alone, without reaching out to her professional support network.
Meiland et al. (2001) The Netherlands	To describe the experiences of informal caregivers at the moment of registration of PWD on a waiting list for LTC	Cross sectional survey	93 caregivers (57 females, 16 spouses) Structured interviews including 4 measurement scales	At the moment of waiting list registration, half of the participants were rather heavily burdened or worse. Overall burden at the moment of waiting list registration: -41% somewhat burdened -31% rather heavily burdened -20% very heavily burdened or overburdened The more positive experiences were related to a lower caregiver income and a perceived favorable quality of relationship with the PWD.
Morgan et al. (2002) Canada	To report barriers to use of formal services in rural dementia home based caregiving	Exploratory qualitative	Stakeholder groups including 34 formal caregivers (gender not specified) and 13 family members of PWD (12 females, 3 spouses)	Consequences of low service use Barriers to the use of formal services: -the stigma of dementia -lack of privacy -beliefs and attitudes -lack of awareness -financial barriers -acceptability of services

Study / Country	Research aim	Design	Participants / Gender / Data collection	Key findings in relation to the present review
			7 focus groups	-challenges in service delivery Strategies for greater use of services Families expressed much concern with the stress they experienced while waiting for the permanent admission of their relative with dementia.
Strang et al. (2006) Canada	To explore the experience of family caregivers while they waited for the LTC admission of their family member with dementia and how they coped during this period of waiting and transition	Exploratory qualitative description	29 caregivers (22 females, 8 spouses) at the entry to the LTC wait-list Open ended interviews	Themes related to *the waiting begins:* -Crisis as initiator -Synchronicity -Control -Reciprocity Synchronicity was related to the congruence between caregiver readiness for admission and bed availability. Reciprocity was related to the caregiver and PWD relationship, which was considered fundamental to understanding the waiting experience.